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## A COMPREHENSIVE ASSESSMENT OF CRISIS IN INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND ITS IMPLICATIONS FOR PHYSICAL THERAPY

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A COMPREHENSIVE ASSESSMENT OF CRISIS IN INDIVIDUALS WITH  
INTELLECTUAL DISABILITIES AND ITS IMPLICATIONS FOR PHYSICAL  
THERAPY

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
College of Health Sciences  
at the University of Kentucky

By

Kathleen M. Sutton

Lexington, Kentucky

Co- Directors: Dr. Patrick Kitzman, Professor of Physical Therapy  
and Dr. Jane Kleinert, Professor of Communication Sciences and Disorders

Lexington, Kentucky

2019

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## ABSTRACT OF DISSERTATION

### A COMPREHENSIVE ASSESSMENT OF CRISIS IN INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND ITS IMPLICATIONS FOR PHYSICAL THERAPY

Advancements in medicine, policy, and societal attitudes have improved life expectancy, socialization, and participation for individuals with intellectual and developmental disabilities (IDD). However, inconsistent or a lack of services may drive healthcare utilization toward expensive emergency care services. This can negatively impact health outcomes and disrupt physical therapy treatment plans, limiting their effectiveness and further placing individuals with IDD at risk for crisis episodes. Because of its subjective nature, quantifying crisis is challenging using current definitions. Rehabilitation professionals are often active members of the care team for individuals with IDD, however no evidence currently exists regarding how the profession can positively impact crisis intervention. Because these clinicians often develop long-term relationships with patients and work with them on a consistent basis, they are well-positioned to recognize early signs of crisis and make timely referrals to the appropriate health and social service providers but currently lack resources to guide in this decision-making. A better understanding of characteristics of this population related to crisis is needed in order to develop accessible and useful screening tools and to improve clinical reasoning. The purpose of this dissertation was to identify pertinent risk factors related to crisis for individuals with IDD using a novel, objective crisis definition. Using a mixed methods approach, a revised definition of crisis was developed through surveying of expert clinicians and healthcare administrators at a specialty care clinic for individuals with IDD. The addition of four crisis-related events were included in the definition: (1) unplanned hospital utilization; (2) involvement with the criminal justice system; (3) abuse/victimization; (4) unplanned change in living environment. Using retrospective chart review, these four crisis-related events were further analyzed and validated by comparing their occurrence in patients who did (N=41) and did not (N=144) receive formal crisis intervention services at the clinic between January 1, 2014 and March 1, 2019. The risk for unplanned hospital utilization was 3.4 times higher for crisis patients. The risk for involvement with the police or criminal justice system was 13.86 times higher for crisis patients. The risk for abuse and/or victimization was 6.21 times higher for crisis patients. The risk for unplanned change(s) in living environment was 12.7 times higher for crisis patients. Overall, 90% of crisis patients experienced at least one of the four crisis-related events during the study period, compared to 54.2% of non-crisis patients. Five additional

risk factors were identified that increased crisis risk: hypothyroidism, bipolar disorder, intermittent explosive disorder, personality disorder, and have multiple psychiatric disorders. No statistically significant differences were found between crisis and non-crisis patients for intellectual disability severity level, mobility status, communication status, neurodevelopmental diagnosis, age, race/ethnicity, or living environment. To the best of our knowledge, the identification of hypothyroidism as a potential crisis risk factor was a novel discovery not previously reported in the literature. The findings of this dissertation have multiple implications for clinical practice and add to the body of knowledge regarding crisis experiences for individuals with IDD. First and foremost, over a fifth of our study sample (22%) utilized formal crisis management services during the study period. This suggests that crisis episodes are common in the IDD population. As the majority of individuals with IDD are community-dwelling and life expectancy continues to increase, the likelihood of physical therapists encountering adults with IDD in clinical practice will subsequently increase. However, physical therapists and physical therapy students routinely report feeling unconfident and uncomfortable treating individuals with disabilities, including individuals with IDD. There is a need, then, to improve clinician confidence and skills to ensure that individuals with IDD receive optimal care, especially into adulthood. The findings of these studies provide foundational knowledge and point toward trends in crisis experiences that can help guide physical therapists and other rehabilitation clinicians.

**KEYWORDS:** Individuals with Disabilities, Crisis, Rehabilitation Sciences, Risk Factors

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Kathleen M. Sutton

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11/08/2019

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Date

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## DEDICATION

To the late Dr. Adam Renner and Dr. Dave Pariser. Without their influence I would not be on the journey I am today (or nearly as interesting of a person). May we continue to stand on the shoulders of giants, bear witness, and forge new paths.

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Many of my fellow colleagues and classmates helped keep me motivated, sane, and in good company during this PhD journey, and I can’t possibly list them all. Special thanks to Katie Lucas, my forever tablemate, for making sure that we both survived this journey with most of our wits still intact. Thank you as well to the staff and faculty at UK’s and Bellarmine’s DPT programs for their encouraging words and support throughout this PhD process.



Finally, I cannot extend enough gratitude for my family for their love and support as I, once again, returned to school. Whether it was listening to me rant, think out loud, or question if I was making the right decisions, they always provided a safe haven of support. They also make sure that I was fed and made it out of the house on occasion. And to my devoted and loving fiancé, Bridget, I still cannot believe that I am lucky enough to have you in my life. Thank you again for the sacrifices you've made to support me along the way and the genuine interest and enthusiasm you've shown for my dissertation. I can't wait to see what the future holds.

## TABLE OF CONTENTS

ACKNOWLEDGMENTS .....	iii
LIST OF TABLES .....	viii
LIST OF FIGURES .....	ix
CHAPTER 1 INTRODUCTION.....	1
BACKGROUND .....	1
PROBLEM.....	2
SPECIFIC AIMS.....	3
<i>Specific Aim 1 – Develop a comprehensive definition of crisis</i> .....	4
<i>Specific Aim 2 – Validate and Determine the relationship of crisis-related events</i> .....	4
<i>Specific Aim 3 - Identify risk factors related to crisis</i> .....	5
OPERATIONAL DEFINITIONS .....	5
ASSUMPTIONS .....	7
LIMITATIONS .....	7
DELIMITATIONS.....	7
CHAPTER 2 REVIEW OF LITERATURE.....	9
INTRODUCTION.....	9
IMPACT OF DEINSTITUTIONALIZATION .....	10
CURRENT HEALTHCARE MODELS.....	13
<i>Medicaid and the waiver system</i> .....	13
<i>Healthcare reform</i> .....	14
HEALTHCARE UTILIZATION PATTERNS AND ACCESS TO SERVICES .....	15
<i>Preventative Care and Health Promotion</i> .....	15
<i>Primary Care</i> .....	17
<i>Hospital Utilization</i> .....	18
<i>Reasons for Differences in Utilization and Access</i> .....	19
THE ROLE OF PHYSICAL THERAPY FOR INDIVIDUALS WITH IDD.....	22
<i>Challenges to Service Delivery</i> .....	24
CRISIS IN THE CONTEXT OF IDD .....	25
<i>Challenges with Assessment of Individuals with IDD</i> .....	27
<i>Crisis Behaviors and Risk Factors in Individuals with IDD</i> .....	27
<i>The Effect of Crisis on Individuals with IDD and Caregivers</i> .....	28
<i>Involvement of Physical Therapy in Crisis Screening and Intervention</i> .....	29
CONCLUSION .....	30
CHAPTER 3 DEVELOPING A COMPREHENSIVE DEFINITION OF CRISIS .....	31
BACKGROUND.....	31
METHODS .....	35
<i>Participants</i> .....	35
<i>Materials and Procedures</i> .....	35
<i>Analysis</i> .....	36
RESULTS .....	37

<i>Close-ended Responses</i> .....	37
<i>Open-ended Responses</i> .....	39
<i>Final Proposed Definition</i> .....	41
DISCUSSION.....	41
<i>Limitations</i> .....	43
CONCLUSIONS .....	44

#### CHAPTER 4 VALIDATING A DEFINITION FOR CRISIS USING PROXY

VARIABLES.....	45
BACKGROUND.....	45
METHODS .....	46
<i>Participants</i> .....	47
<i>Materials and Procedures</i> .....	47
<i>Analysis</i> .....	48
RESULTS .....	48
<i>Hospitalization</i> .....	50
<i>Involvement with the Criminal Justice System</i> .....	50
<i>Abuse/Victimization</i> .....	51
<i>Unplanned Change in Living Environment</i> .....	52
<i>Other Crisis-Related Events</i> .....	52
<i>Associated Risk</i> .....	53
DISCUSSION.....	53
<i>Limitations</i> .....	57
CONCLUSIONS .....	58

#### CHAPTER 5 FACTORS RELATED TO CRISIS AND THEIR CLINICAL

RELEVANCE .....	59
BACKGROUND.....	59
METHODS .....	61
<i>Participants</i> .....	61
<i>Materials and Procedures</i> .....	61
<i>Analysis</i> .....	62
RESULTS .....	63
DISCUSSION.....	65
<i>Limitations</i> .....	69
CONCLUSIONS .....	69

#### CHAPTER 6 SUMMARY .....

<i>Hypothesis and Findings for Aim 1</i> .....	70
<i>Hypothesis and Findings for Aim 2</i> .....	70
<i>Hypothesis and Findings for Aim 3</i> .....	70
SYNTHESIS AND APPLICATION OF RESULTS .....	71
FUTURE RESEARCH .....	74

#### APPENDICES .....

APPENDIX A. CRISIS DEFINITION SURVEY QUESTIONNAIRE .....	78
APPENDIX B. DATA ABSTRACTION TEMPLATE.....	85

APPENDIX C. POTENTIAL RISK FACTOR VARIABLES.....	88
REFERENCES .....	90
VITA.....	114

## LIST OF TABLES

Table 2.1 Comparison of Screening Rates .....	17
Table 2.2 Physical Therapy Related Conditions .....	23
Table 3.1 Demographic Data.....	37
Table 4.1 Categorical Variables .....	48
Table 4.2 Demographic Characteristics .....	49
Table 4.3 Neurodevelopmental Diagnoses.....	50
Table 4.4 Unplanned Hospital Utilization.....	50
Table 4.5 Involvement with Criminal Justice System.....	51
Table 4.6 Abuse/Victimization.....	51
Table 4.7 Unplanned Change in Living Environment.....	52
Table 4.8 Crisis-Related Events Risk Table.....	53
Table 5.1 Categorical Variables .....	62
Table 5.2 Demographic Data.....	63
Table 5.3 Logistic Regression Model.....	64
Table 5.4 Final Linear Probability Model .....	64

## LIST OF FIGURES

Figure 2.1 Conceptual Model of Crisis .....	26
Figure 3.1 Overall Definition Agreement .....	38
Figure 3.2 Agreement with Components.....	39

## CHAPTER 1 INTRODUCTION

### Background

Although reports vary, individuals with intellectual and developmental disabilities (IDD) are estimated to comprise approximately 1-3% of the population in the US.<sup>1,2</sup> Prior to the 1970s, such individuals lived primarily in state-run facilities.<sup>3</sup> Investigations and reforms initiated in the 1960s and beyond exposed years of mistreatment, neglect, and abuse. Since that time, a paradigm shift has occurred resulting in increased community-based placement for individuals with IDD.<sup>4</sup> This shift has decreased the number of people placed in large care facilities or state-run hospitals and has helped to foster greater integration into the community and allowed for increased opportunities.<sup>5-7</sup> In order to be successful, this de-centralization of care requires considerable and careful coordination across a variety of support services, particularly for persons with multiple co-morbidities, such as co-existing psychiatric diagnoses, and those with communication difficulties, guardianship or legal issues, or inconsistent living environments.<sup>8-12</sup> This further highlights the need to efficiently and effectively manage care and promote optimal quality of life for this population.

As individuals with IDD are more integrated into community settings, there is a need for greater understanding of their specific needs in order to provide adequate care coordination and support that allows for the greatest quality of life. Without such, individuals with IDD can experience acute episodes of crisis that can interfere with their ability to live safely in the least restrictive settings.<sup>5,13-15</sup> Factors that may influence the ability for individuals with IDD to live successfully in the community include access to adequate healthcare from knowledgeable providers, appropriate support services, safe and

accessible housing, education and employment opportunities, and protection from abuse and victimization.<sup>5,11,16-18</sup> “Crisis” as a construct has been defined variably in the literature. For individuals with IDD, crisis is most often described as it relates to challenging or disruptive behavior, such as physical aggression, property destruction, or intentional self-injury that results in the need for intervention.<sup>16,19,20</sup> The disruptive nature and need for immediate action is well-recognized as a component of “crisis”, but current literature often does not quantify what characteristics specifically constitute a crisis for this population.

When it is more objectively defined, the focus may be on certain factors, such as medical emergencies or psychiatric symptoms, but often lacks a more comprehensive perspective.<sup>16,21-24</sup> Factors beyond an individual’s physiology and specific behaviors have long been recognized as having an impact on overall health and wellbeing.<sup>25,26</sup> These social determinants of health are an important component to take into consideration when healthcare professionals evaluate patients and develop treatment plans.<sup>26,27</sup> Likewise, the multidimensional nature of crisis can have far reaching effects that impact overall health and requires a similar multifactorial approach to evaluation and monitoring.

### **Problem**

Due to the complexity of managing patients with IDD, the signs of potential crisis may present subtly or be difficult to discern until they escalate to acute situations requiring the attention of emergency services or other immediate actions. Because they are disruptive in nature, crisis situations, regardless of their etiology, may interfere with healthcare treatment plans. This can have potentially limiting effects on therapeutic interventions. Physical therapists and other rehabilitation professionals may be well-positioned to identify these early signs of potential crisis in patients due to the nature of care plans that allow for



more frequent interaction with patients than other healthcare providers. However, current definitions in the literature of what constitute crisis are often vague, subjective, or difficult to discern in the absence of in-person, real-time evaluation methods.<sup>23</sup> They also tend to focus on a narrow set of criteria without the incorporation of multiple factors. Current screening and assessment tools are not feasible for physical therapists to administer due to the time needed to complete, leaving clinicians to rely on their own judgment whether or not to intervene. In addition, no comprehensive analysis of risk factors for multidimensional crisis or the extent to which crisis affects individuals currently exists for this population. These limitations can interfere with the ability to evaluate and track potential crisis behaviors or situations over time or develop targeted interventions aimed at reducing crisis episodes.

### **Specific Aims**

The overarching aim of this research was to define and identify a set of risk factors for crisis for individuals with IDD in Kentucky and discuss its relevance to rehabilitation. Doing so may provide more uniform and objective methods for studying crisis in this population that allow for the analysis of crisis across disciplines and settings. Establishing risk across multiple domains may provide a more holistic understanding of how various factors, regardless of etiology, intersect to influence overall health status. By improving the ability to track crisis-related events, this has the potential to help address current challenges in coordinating care for individuals living in community-based settings and improve screening and referral practices. With this overall aim in mind, there were three specific aims.

*Specific Aim 1 – Develop a comprehensive definition of crisis*

Operationalize a comprehensive definition of acute crisis for individuals with IDD using multidisciplinary expert opinion. A mixed-methods survey developed by two healthcare providers was distributed to expert clinicians and other healthcare-related personnel who work with individuals with IDD using a 7-point Likert scale to rank characteristics based on agreeableness that have been previously identified by past studies as constituting an acute crisis. In addition, a qualitative component to the survey solicited responses as to what characteristics, if any, not previously identified may also define an acute crisis. Data from the qualitative component was independently coded for themes by each healthcare provider and then consensus was reached regarding the characteristics to be included in the final definition. It was hypothesized that the previously identified characteristics will have moderate to high agreement (median rank for each subscale  $>5$  and  $IQR \leq 3$ ).

*Specific Aim 2 – Validate and Determine the relationship of crisis-related events*

Using the operationalized crisis definition from Aim 1, the crisis-related events identified in the definition were analyzed in order to investigate if crisis can be specified as a single construct using these proxy variables. Standard descriptive statistics (frequency counts, percentages) and odds ratios with 95% confidence intervals were used to determine the prevalence and significance of these events for patients who are referred for crisis management services. It was hypothesized each of the proxy variables will have  $OR > 2.0$ .

### *Specific Aim 3 - Identify risk factors related to crisis*

A retrospective cross-sectional study was conducted using medical records from a medical home clinic serving adults with IDD to identify potential risk factors for crisis episodes for this population. Binary logistic regression modeling was used to identify pertinent risk factors for crisis. It was hypothesized that the identified crisis cases will have higher exposure to certain variables ( $OR \geq 2.0$ ) than non-crisis cases.

### **Operational Definitions**

Intellectual disability – A disability that arises prior to the age of 18 and involves impairment in both intellectual functioning and adaptive behavior.

Intellectual functioning – General mental capacity, traditionally measured by IQ testing.

Adaptive behavior – The ability to perform conceptual, social, and practical skills.

Developmental disability – A disability that arises prior to the age of 21 and involves significant difficulties in at least three major domains.

Major life domains – Self-care, expressive and receptive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency.

Healthcare provider – Any licensed, registered, certified, or otherwise trained provider of health-related services.

Healthcare administrator – Any individual who has direct input in the day-to-day operation, policy or decision making, or management of healthcare services.

Crisis – A response to stressful life events that may interfere with a person’s ability to manage their daily activities that may result in one or more of the following: emergency department visit or unplanned hospitalization, involvement of law enforcement or the court system, unstable living environment/placement, or victimization or abuse. A crisis may be emotional, physical, medical, behavioral, psychiatric or situational, and carries with it the risk of recurrence of these outcomes if left unresolved.

Crisis-related event – An event or situation external to an individual that occurs at or near the time of and is directly related to one or more crisis behaviors.

Unplanned hospital utilization – Utilization of emergency medical or psychiatric services, with or without inpatient admission, that is unexpected and not a part of an established treatment plan.

Involvement of law enforcement or the court system – Any incident that results in emergency police or judicial intervention including citation, arrest, indictment, conviction, or prosecution.

Victimization or abuse – An act or circumstance that harms or threatens harm to an individual’s well-being and may be physical, emotional, sexual, or financial in nature.

Unstable living environment/placement – An unexpected or sudden disruption in normal living arrangements as the result of abuse/mistreatment, financial issues, loss of support, or the risk to self or others.

### **Assumptions**

It was assumed that:

1. Information available in health records was as complete and accurate as possible.
2. Healthcare providers and administrators answered survey questions honestly regarding their opinions about crisis.
3. Data was abstracted using a standardized protocol to reduce error and bias as much as possible.

### **Limitations**

1. As data is abstracted retrospectively, missing or incomplete data points may be present.
2. The use of health records is a standard source of data for studies analyzing health conditions and outcomes, however the information collected in them is subject to human error and reliant on patient and caregiver input.
3. The healthcare professional abstracting the data was unblinded to crisis status during chart review and abstraction.

### **Delimitations**

1. Participants for Specific Aims 2 and 3 are restricted to adults over the age of 18. The focus of this dissertation was on adults, as adults with IDD are studied less and their experiences differ from those of children.

2. The study designs for Specific Aims 2 and 3 are retrospective. The use of health records was chosen as the most accessible and reliable data source for the study population. Patients are often accompanied to the clinic with direct support staff that may or may not be familiar with the patient. Only legal guardians are able to provide consent, and as many patients have state-appointed guardians who do not routinely accompany them to clinic appointments, it would be very difficult to gain informed consent from a significant portion of the clinic population.

## CHAPTER 2 REVIEW OF LITERATURE

### Introduction

Encompassing a diverse array of individuals, persons with intellectual and developmental disabilities (IDD) constitute between 1-3% of the population.<sup>1</sup> An intellectual disability arises prior to the age of 18 and is “characterized by significant limitations both in intellectual functioning and in adaptive behavior.”<sup>28</sup> This encompasses not just IQ level (the standard measure for intellectual functioning) but also incorporates the ability to perform conceptual, social, and perceptual skills.

Developmental disability is a broader term that can include intellectual disability. As defined in the Developmental Disabilities Assistance and Bill of Rights Act, a developmental disability is a “severe, chronic disability that originated at birth or during childhood (prior to age 22), is expected to continue indefinitely, and substantially restricts the individual's functioning in at least 3 major life activities.”<sup>29</sup> As they are often correlated with one another and share similarities in terms of experiences and characteristics, intellectual and developmental disabilities are generally paired together in research, academic and professional discourse, policy, and intervention.<sup>30</sup>

There are numerous conditions and genetic factors that can be associated with IDD, which may be acquired during birth or adolescence or inherited from genetic or chromosomal abnormalities. The most common conditions associated with IDD include fragile X syndrome, trisomy 21 (Down syndrome), autism spectrum disorder, cerebral palsy, and fetal alcohol syndrome.<sup>31</sup> Individuals with IDD tend to have complex health needs and experience many disparities in health outcomes and service provision compared to the general population, leaving them vulnerable to experience crisis.<sup>32,33</sup> Addressing

these disparities requires having an in-depth understanding of the multitude of factors that influence health outcomes for this population and the specific considerations that are needed to make interventions successful and sustainable. Therefore, the purpose of this review is to examine the supports and barriers to long-term health and healthcare for persons with IDD and how crisis is experienced in this population. Specifically, this paper aims to address (1) the implications of transitioning from institutionalization to community-based placement; (2) current healthcare system utilization patterns and access to services; (3) crisis theory and its applications to individuals with IDD; and (4) the current role of physical therapy for individuals with IDD and its potential role for those in crisis.

### **Impact of Deinstitutionalization**

Prior the Industrial Revolution, individuals with IDD were cared for by family or surrounding community members and were largely incorporated into existing social structures. However, starting in the mid-19<sup>th</sup> century and persisting through the latter half of the 20<sup>th</sup> century, the majority of individuals with IDD lived in large-scale, mostly publicly-operated institutions.<sup>4</sup> While officially these institutions were labeled as “schools” or “hospitals,” they often provided little to no educational opportunities and delivered substandard medical care. Attitudes and beliefs about individuals with disabilities regarding their supposed “inferiority” and potential negative influence on society, such as those endorsed by proponents of eugenics and Social Darwinism, meant that institutions often served as a means of isolation and segregation rather than growth and opportunity.<sup>34,35</sup> Limited funding and overcrowding were common problems, which contributed to unsanitary living conditions and the easy spread of disease. Residents were



especially vulnerable to abuse, neglect, and exploitation due to the isolated conditions in which they lived.<sup>35</sup>

Efforts starting in the 1960s and 1970s led to increased awareness of the deplorable conditions at many of these facilities. This sparked a substantial shift away from centralized institutionalization and toward community-based placement, where individuals live in either family homes, small staffed residences in the community, or independently with support. The Developmental Disability Act of 1970 created independent state IDD councils involved in reforms and planning. The transfer of institutions – now known as Intermediate Care Facilities for individuals with intellectual disability (ICF/ID) – to Medicaid in 1972 created new federal funding sources and incentives to support community living, and subsequent policy reforms set new federal standards of care.<sup>36,37</sup> As a result, between 1977 and 2010, the number of persons with IDD living in institutions in the United States (defined as facilities serving greater than 15 residents) decreased by 72.6%.<sup>3</sup>

In the decades since, changes in health status and related outcomes for individuals with IDD have been largely positive, although some results have been mixed.<sup>4,38</sup> Individuals still residing in centralized residential centers, such as ICF/IDs, are more likely to be older, have more severe levels of intellectual disability, and have more chronic health conditions than those individuals who are in community-based placement or living with family.<sup>39</sup> However, analyses of healthcare utilization patterns among adults with IDD suggest gaps in service provision for those in community-based placement. Individuals with IDD in large care centers are more likely to have received an annual physical examination, dental examination, eye examination, flu and pneumonia vaccination, and screenings for cervical, breast, prostate, and colon cancer than individuals living with

family members.<sup>40</sup> Individuals in community-based settings have been observed to experience greater rates of unexpected weight gain and weight loss and have higher prevalence of obesity than those individuals in institutional facilities.<sup>41,42</sup> This may be due to increased opportunity and self-determination, as community-dwelling individuals are more likely to have fewer restrictions placed on dietary and activity options and thus have greater freedom to make potentially unhealthy choices.<sup>43</sup>

Other metrics point toward positive quality of life outcomes for individuals with IDD who have transitioned to the community. In a review of studies examining behavioral outcomes among US adults with IDD who transitioned from institutions to community-based placement, Larson and Lakin found improvements in adaptive behavior including academic, self-care, community living, and social skills attainment.<sup>4</sup> This is echoed by Felce, who also notes overall improvements in social interaction, self-determination, and familial contact for individuals with IDD living in the community, but cautions that “it is quite probable that the general superiority of community services owes more to the initial poor quality within the institutions than their widespread excellence.”<sup>38</sup>

At the heart of any successful living situation is the availability of adequate support services to address the needs of and provide opportunities for individuals with IDD. For community-based placement, this requires considerable care coordination. This might include managing direct support personnel who provide care and assist with a variety of daily activities, transportation assistance, educational support, vocational training, case management, financial planning, insurance and waiver systems, home modification and assistive technology services, guardianship, and numerous healthcare providers.<sup>44</sup> However, the availability of these services does not always meet the demand. As of 2016,

there were greater than 400,000 children and adults with IDD on state waiting lists to receive community-based services, with an average waiting period of 48 months.<sup>45</sup> Low wages and demanding workloads often lead to burnout and high turnover of direct support personnel, which can disrupt care and have a negative effect on the well-being of individuals with IDD.<sup>9</sup> While funding, such as the Medicaid Home and Community-Based Services waiver system (discussed in greater detail later in this review) provides for support services, individuals with IDD and their family members report increased responsibility and burden for coordinating these services and difficulties in balancing numerous schedules and competing demands.<sup>46</sup>

### **Current Healthcare Models**

The deinstitutionalization movement has changed not only behavioral outcomes and opportunities for individuals with IDD but has also impacted how health-related services and systems operate for this population. Rather than the centralized delivery model of the past, where healthcare services were provided in institutions, today the majority of individuals with IDD utilize services in community settings.

#### *Medicaid and the waiver system*

Created along with Medicare in 1965, Medicaid is the largest publicly-funded health insurance program in the United States and serves as the primary payer source for healthcare and related support services for individuals with IDD.<sup>47</sup> States exercise wide control over how funding is allocated, and states are increasingly shifting away from fee-for-service and toward managed care plans for Medicaid enrollees as a way of containing costs and incentivizing healthcare providers and organizations to improve healthcare

delivery. Research findings have been mixed regarding the true cost savings of these measures and their impact on care delivery and utilization.<sup>48,49</sup>

In addition to traditional healthcare costs covered by Medicaid services, Medicaid's Home and Community-Based Services (HCBS) 1915(c) Waiver program provides a financial incentive for states to provide community-based services and is an important component for supporting health and healthcare for individuals with IDD. Created in 1981 to provide an alternative to institutionalization for vulnerable populations, there are currently 115 waivers supporting approximately 630,000 children and adults with IDD in the United States.<sup>50</sup> These waiver programs are controlled by individual states and as a result, there is great variability in their scope and eligibility criteria. The average spending per waiver participant was \$37,583 in 2013, but the range among all waiver programs was \$1,752 to \$143,000.<sup>51</sup>

### *Healthcare reform*

Medicaid may be the primary healthcare payer for individuals with IDD, but other sources, such as Medicare and private insurance, are also utilized. The implementation of the Patient Protection and Affordable Care Act (ACA) in 2010 created specific reforms and changes to the healthcare system that impact individuals with IDD. Most notably, it prohibits insurance companies from placing lifetime and annual expenditure limits on insurance policies, creates standards for minimal essential healthcare benefits, and prevents insurance companies from charging clients higher premiums for pre-existing conditions.<sup>52</sup> It also provided funding and support to allow states the option to expand Medicaid services as well as HCBS waiver programs, allowing for individuals who had previously been

ineligible for Medicaid but not able to access private insurance a means for gaining health insurance.

### **Healthcare Utilization Patterns and Access to Services**

Changes in living environment and evolving healthcare system models have great influence on the utilization patterns and access to health services for individuals with IDD. Access to services and providers is variable across care settings, impacting health outcomes and utilization patterns.

#### *Preventative Care and Health Promotion*

Over the last half century, longevity has improved for individuals with IDD, although life expectancy still lags behind the general population by an average of 20 years.<sup>53</sup> With increasing age comes increasing risk for chronic disease, and persons with IDD experience similar or higher rates of chronic conditions such as obesity, heart disease, hypertension, and diabetes when compared to the general population.<sup>6</sup> Van de Loew et al. found overall similar rates of hypertension prevalence in a Dutch sample of adults with IDD compared to the general Dutch population, but advancing age and more severe intellectual disability was associated with higher prevalence in the IDD sample.<sup>54</sup> A Scottish sample of individuals with IDD ranging in age from 16 to 83 years reported that obesity was the most prevalent health condition, with 47% of study participants being classified as obese.<sup>55</sup> In addition, the average number of co-morbid conditions per participant was 11.04 (SD 4.7, range 0-28) and 98.7% had at least 2 health conditions. Havercamp et al. found that adults with IDD were more likely to be sedentary (defined as participating in no physical activity in the last month) than those without disabilities

(45.1% vs. 10.0%, respectively) and more likely to be obese (31.1% vs. 23.8% prevalence, respectively).<sup>56</sup>

While genetic and other physiological factors related to specific conditions certainly contribute to some of these disparities, access to preventative healthcare services and wellness programs can also greatly influence these outcomes. In a review of published studies of physical fitness and nutrition programs specifically targeting individuals with IDD, Heller et al. found improvements in weight reduction, adaptive behaviors, life satisfaction, and a decrease in maladaptive behavior.<sup>57</sup> However, physical fitness and wellness programs are often inaccessible for persons with IDD or do not address their specific needs, particularly for individuals with co-occurring mental health conditions.<sup>25,58</sup> Individuals with IDD have demonstrated the ability to understand general concepts regarding health behavior and wellness but report barriers to participating in wellness initiatives and maintaining good health.<sup>59,60</sup> These barriers include inadequate support and opportunity, differences in risk perception, stress, lack of transportation and physical accommodation, and varying levels of motivation and self-efficacy.<sup>60</sup>

Disparities in participation in secondary preventative services are also evident, with consistently reported lower rates of screening for certain types of cancer (see Table 2.1 for examples). However, with targeted intervention, these rates improve. Brown et al., in an analysis of the secondary screening patterns of a cohort of community-based adults with IDD in Washington D.C., found that adults with IDD received screenings for colon, breast, and cervical cancer at similar or even higher rates than the general population with the implementation of a strategic plan to specifically target individuals with IDD.<sup>61</sup> Improved rates of vision and hearing screening, cancer screening, and immunizations were also

observed by Lennox et al. when a comprehensive health assessment protocol was introduced in general practice clinics.<sup>62</sup>

Table 2.1 Comparison of Screening Rates

Study	N	Screening Prevalence (%)					
		Mammography*		Pap Smear*		Colorectal Screen	
		IDD	No IDD	IDD	No IDD	IDD	No IDD
Ouellette-Kuntz et al. <sup>63</sup>	IDD = 66,484 No IDD = 2,760,670	52.2	70.7	33.7	66.7	32	47.2
Havercamp et al. <sup>56</sup>	IDD = 20,395 No IDD = 312,144	56.6	76.6	50.2	82.3	-	-
Iacono and Sutherland <sup>64</sup>	IDD = 659 No IDD = sample size not reported	19	57	12	64	-	-
Cobigo et al. <sup>65</sup>	IDD = 17,777* No IDD = 1,440,962*	41.6	59.9	34.3	66.8	-	-
Reichard et al. <sup>66</sup>	IDD = 1880 No IDD = 16,215	63	76	62.6	85	-	-

Percentage of adults with IDD receiving cancer screenings compared to adults without IDD. \*data for women only

### Primary Care

Despite disparities in health status, life expectancy, and participation in wellness and preventative care, research indicates that persons with IDD often utilize primary healthcare at similar or higher rates than the general public, although variance exists as to the reasons for those encounters.<sup>67,68</sup> In an analysis of NCI and Behavioral Risk Factor Surveillance System data, Havercamp et al. found that adults with IDD were more likely to have a routine physical exam in the last year than adults without IDD (86.2% vs. 66.8%, respectively).<sup>56</sup> Tyler et al. also reported higher utilization of primary care services by individuals with IDD compared to age- and sex-matched non-IDD peers, with individuals with IDD utilizing primary care at 54% higher rates.<sup>69</sup> Visits to specialty care, however,

were lower among individuals with IDD, suggesting differential access to these services. Weise et al. reported that despite similar frequency rates of primary care visits between adults with and without IDD in a large representative Australian sample, those with IDD were seen more often for administrative reasons, such as to have disability-related forms completed, rather than for specific health concerns.<sup>67</sup>

### *Hospital Utilization*

When compared to the general population, individuals with IDD experience higher hospitalization rates across the age continuum. This is particularly true for unplanned admissions deemed as “ambulatory care-sensitive conditions” (ACSC). ACSCs are designated as those conditions that with appropriate outpatient management should not result in an emergency department visit or hospitalization.<sup>70</sup> ACSCs are used as a metric to measure the overall quality of primary healthcare systems and are often utilized in health services research to provide a consistent standard for measurement and comparison.<sup>71</sup> Common ACSCs experienced by persons with IDD include epilepsy, respiratory complications, urinary tract infections, diabetes, dehydration, and cardiovascular complications.<sup>72,73</sup> Admissions for injuries and psychiatric crises are also common for this population.<sup>74,75</sup>

When comparing unplanned hospital admission rates between Canadian adults with and without IDD, Balogh et al. found that the overall adjusted rate ratio was 6.1 (95% CI 5.6, 6.7).<sup>76</sup> This rate was even higher when comparing younger adults. Persons with IDD between the ages of 30 and 39 years were 13 times more likely to be admitted than their similarly aged non-IDD peers (RR 13.09; 95% CI 10.59, 16.19). In a follow-up study



focusing on ACSCs, Balogh et al. found higher admission rates for individuals with IDD compared to those without IDD, including those for epilepsy (RR 54.13, 95% CI 43.14, 67.92), schizophrenia (RR 14.75, 95% CI 11.49, 18.94), asthma (RR 2.05, 95% CI 1.35, 3.11), and diabetes (RR 4.72, 95% CI 3.50, 6.36).<sup>73</sup> Similarly, Hosking et al. reported increased rates of emergency hospital admissions in the United Kingdom for adults with IDD compared to age- and sex-matched adults without IDD even after adjusting for comorbidities, smoking, and socioeconomic status (IRR = 2.16; 95% CI 2.02, 2.30). When looking specifically at ACSCs, this rate increased to 3.6 (95% CI 3.25, 3.99).<sup>77</sup>

#### *Reasons for Differences in Utilization and Access*

Many factors are at play that influence utilization and access to health services for individuals with IDD. Consistently reported across care settings are difficulties in finding knowledgeable healthcare providers with experience working with individuals with IDD, particularly adults. No longer isolated in institutionalized settings, the need for knowledgeable providers across disciplines is in great demand but finding such care can be challenging. As a result, some individuals with IDD choose to stay with their pediatricians well into adulthood due to a lack of adult-focused practitioners who are knowledgeable and willing to work with them.<sup>18</sup> Individuals with IDD and their caregivers have also reported experiencing delays in care due to a lack of specialists willing and able to provide care, as well as long waiting lists for primary and specialty care practices that do provide comprehensive care for individuals with IDD.<sup>18</sup> An analysis of Ohio Medicaid recipients demonstrated no statistically significant differences between adults with developmental disabilities and those without disabilities in regards to routine primary care

utilization, but adults with developmental disabilities were more likely to report difficulties in getting needed care, in experiencing delays in treatment, and in accessing specialty care. They were also more likely to have unmet health needs and rate their overall health as either fair or poor.<sup>68</sup> Thus, being able to schedule a face-to-face encounter with a healthcare provider does not ensure that the encounter will result in adequate and equitable service. If outpatient care is insufficient or delayed, individuals are vulnerable to having those unmet needs escalate into crisis situations, and this may be a contributing factor to the high hospital utilization rates seen in the IDD population.<sup>78</sup>

Healthcare professional education is likely attributable to some of the inequities experienced by individuals with IDD in the healthcare system. Despite an often high willingness to work with patients with IDD, healthcare students in multiple disciplines report limited didactic or clinical preparation with working with individuals with disabilities.<sup>6</sup> Medical students have been shown to order routine tests more often for patients without disabilities than those with disabilities in standardized patient scenarios.<sup>79</sup> This corresponds to findings that indicate medical and dental school curriculum often does not prioritize disability-related content, and less than half of medical and dental students report feeling adequately prepared to care for individuals with disabilities.<sup>80</sup> This lack of preparation and experience with treating the complex needs of persons with IDD may lead to delays in treatment, a tendency to misattribute symptoms to the intellectual disability itself instead of exploring other underlying causes, and decreased screening and monitoring of certain health conditions.<sup>18,58</sup>

The structure and operating procedures of healthcare systems can also impact care delivery and outcomes. Busy offices with high patient volumes may mean that individuals

with IDD are not able to spend enough time with healthcare providers to have their needs adequately addressed.<sup>18</sup> For individual with sensory impairments or who are unable to read, navigating clinics or hospitals can be frustrating and confusing without appropriate accommodations.<sup>81</sup> Likewise, individuals with IDD are often unable to undergo certain diagnostic exams or medical procedures because the equipment is not accessible or the procedures needed to make them accessible are not implemented or available.<sup>82</sup> For example, dental offices that are not equipped or authorized to carry out sedation procedures limit the ability for some individuals with IDD to access routine dental care and may therefore increase non-emergent hospitalization in order to have these needs met.<sup>83</sup> Informal caregivers are also often heavily relied on to act as medical liaisons and even assist with care during inpatient hospital stays. A study of Australian adults with developmental disabilities who had experienced a recent emergency department visit or hospital admission found a positive association between having an informal caregiver stay during the admission and getting enough to eat and drink and spending an adequate amount of time out of bed.<sup>84</sup>

Communication deficits can also create substantial barriers, particularly for individuals who do not use verbal language. Persons with disabilities are six times more likely to experience communication barriers while using healthcare services than those without disabilities.<sup>85</sup> In the same study of Australian adults with IDD experiencing a recent hospitalization, 60% of participants reported difficulties with communicating with staff at least some of the time during their hospital stay.<sup>84</sup> Lack of familiarity or confidence with assistive technology or alternative forms of communication on the part of care providers can lead to communication breakdowns, and the needs of individuals with IDD

are therefore more likely to be ignored or misinterpreted.<sup>18</sup> Amor-Salamanca and Menchon reported that adults with profound intellectual disabilities who presented to the emergency department in Spain were less likely to have consultation for somatic pain conditions and more likely to be discharged for non-specific diagnoses than those without disabilities.<sup>86</sup> The lack of accessible pain evaluation tools for persons with more severe intellectual impairments, particularly those who use non-verbal communication, may contribute to these treatment discrepancies.<sup>87</sup> These findings are similar to those by Findlay et al. who found that British adults with IDD reported difficulty with describing pain to caregivers as well as with receiving attention and care when they do.<sup>88</sup>

Social and environmental factors that influence healthcare access and outcomes have been well described and cannot be overlooked.<sup>89</sup> Disparities in access to care exist between urban and rural communities, with rural residents less likely to receive primary care services and therefore driven to utilize emergency departments and hospitals at greater rates.<sup>90</sup> These patterns also appear to hold true for individuals with IDD.<sup>91</sup> Lack of transportation, isolation, and high rates of poverty contribute to these rural-urban disparities, and individuals with IDD are more likely to be of lower socioeconomic status and experience unemployment than those without disabilities.<sup>6,25,92</sup> A lack of social agency and stigmatization also further marginalize individuals with IDD, making them vulnerable to exclusion and decreasing the social and political capital needed to advocate for their rights and needs.<sup>93</sup>

### **The Role of Physical Therapy for Individuals with IDD**

Physical therapy has traditionally played an important role throughout the lifespan in promoting and sustaining health and function for individuals with IDD through

interventions aimed at improving mobility, strength, balance, and coordination.<sup>94</sup> Individuals with IDD have high prevalence rates of many common conditions encountered by physical therapists (see Table 2.2 for examples). While exact counts differ by setting and location, rehabilitation utilization rates continue to generally trend upward globally.<sup>95,96</sup> This increase in utilization paired with increase in longevity, means physical therapists across settings will likely encounter individuals with IDD in their practice.<sup>97</sup>

Table 2.2 Physical Therapy Related Conditions

Study	N	Prevalence (%)			
		Ataxia/Gait Disorders	Musculoskeletal Conditions*	Falls	Obesity
Chiba et al. <sup>98</sup>	144	20.8	-	28.5	-
Cox et al. <sup>99</sup>	114	14.2	-	34	52.2
Finlayson et al. <sup>100</sup>	511	22.5	24.5	12.3	-
Kinnear et al. <sup>55</sup>	1032	29.9	48.2	-	40.6
Traci et al. <sup>101</sup>	119	50.9	31.6	-	47.9
Tyler et al. <sup>102</sup>	1267	-	29.8	-	18.3
van Timmeren et al. <sup>103</sup>	162	76	72	-	-

Prevalence of common conditions treated by physical therapy.

\*includes osteoarthritis, myalgias, weakness, bone/joint deformity, osteoporosis

The majority of research involving physical therapy interventions for individuals with IDD has been conducted in pediatric populations, with limited investigation into how individuals transition into adulthood and utilize services outside of pediatric clinical settings.<sup>94,104</sup> Furthermore, interventions tend to be focused on physiological and functional outcomes without exploration of how physical therapy interventions impact other areas including quality of life, participation, and healthcare utilization. Therefore, limited evidence currently exists regarding the most effective physical therapy interventions and treatment models for improving overall health and well-being for individuals with IDD.

### *Challenges to Service Delivery*

There are multiple unique challenges involved in service delivery for individuals with IDD. Similar to other healthcare settings, finding knowledgeable and competent providers can be a considerable issue.<sup>97,104</sup> Physical therapists and physical therapy students consistently report feeling underprepared to work with individuals with disabilities, particularly those with IDD.<sup>80,105,106</sup> This can make even routine, non-disability related concerns a challenge to treat in the face of low clinician confidence and the risk of diagnostic overshadowing. Recognizing these challenges, the American Physical Therapy Association House of Delegates passed resolution RC34-05 in 2005, creating the Continuum of Care for Lifelong Disability task force to improve the transition to adulthood and foster better collaboration and communication between pediatric and adult oriented clinicians.<sup>94</sup>

While improving clinician knowledge and confidence is key to improving service provision, additional challenges exist for individuals with IDD to access quality physical therapy. Traditional reimbursement models that rely on progression of functional status as a qualifier for service reimbursement can be difficult for individuals with IDD, who may make inconsistent or slow progress due to the chronicity of their health conditions but still benefit from long-term involvement in physical therapy. Long waiting periods for waiver services that cover physical therapy services also routinely impede access.<sup>107</sup>

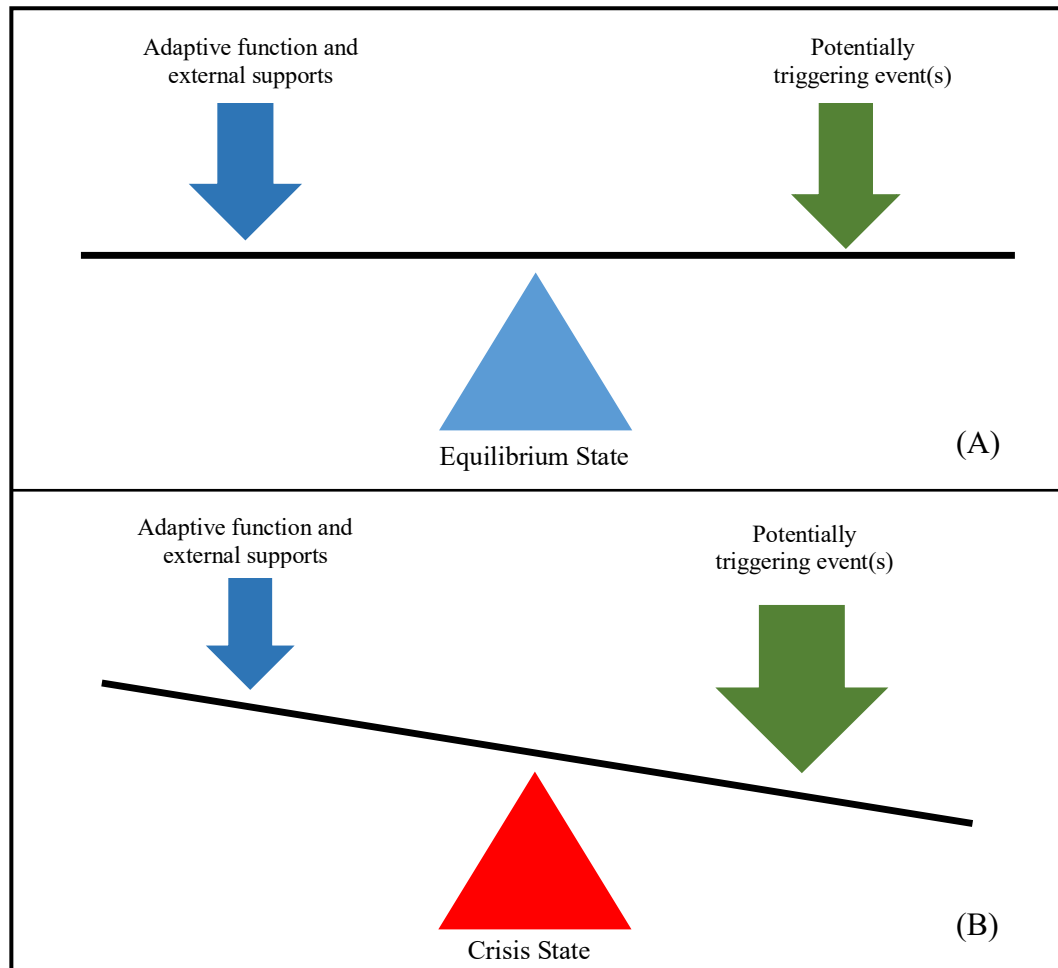
Additionally, social and environmental supports are vital components of successful participation in physical therapy and goal attainment. Caregiver involvement can heavily influence adherence to treatment plans, and individuals with IDD often require assistance

for therapy-related care including scheduling, transportation, and completing home exercise programs.<sup>108</sup> Adding to this complexity is the fact that there are often multiple caregivers involved in an individual's life. This increases the amount of communication and coordination required to maintain adherence to and continuity of treatment plans, and high turnover of staff and staffing ratios can impact successful implementation.<sup>109,110</sup>

### **Crisis in the Context of IDD**

With high prevalence rates of chronic disease, psychiatric and behavioral diagnoses, and challenges related to healthcare access, individuals with IDD are often vulnerable to experiencing episodes of acute stress and crisis.<sup>111,112</sup> Broadly defined as a response to a stressful event(s) that temporarily overwhelms an individual's coping mechanisms and adaptive function, "crisis" is contextual and subjective (see Figure 2.1). It is a perception that an individual cannot cope with a given situation that is the true hallmark of a crisis. This makes the concept of "crisis" a latent construct, and therefore evaluation and intervention can prove challenging, particularly for individuals with IDD.<sup>23</sup>

Figure 2.1 Conceptual Model of Crisis



Conceptual model of crisis adapted from Caplan and Roberts. When adaptive function and support are adequate, then potential triggering events are attenuated and emotional equilibrium is maintained (panel A). However, when those triggering events overwhelm an individual's ability to adapt to and overcome them, this creates a dysfunctional crisis state (panel B).

While the conceptualization of crisis dates back millennia, modern crisis theory and intervention originate in the turn of 20<sup>th</sup> century, alongside the growth and modernization of the field of psychology. After a massive fire in Massachusetts in 1942 killed over 800 people, Eric Lindemann observed that survivors processed grief in seemingly consistent and distinct stages.<sup>113</sup> This laid the foundation for the development of community-based interventions to address grief, developed by Lindemann and colleague Gerald Caplan.



Caplan advanced this concept through the study and focus on an individual's capacity to withstand stress, face reality, and employ effective coping mechanisms. Much of modern crisis intervention is derived from Albert Roberts's work studying suicidality and crisis hotline organizations, with a focus on rapid assessment, support, and problem-solving strategies.<sup>114</sup>

### *Challenges with Assessment of Individuals with IDD*

Evaluating individuals with IDD who may be in crisis poses several difficulties. As many assessment tools rely on semi-structured interviews, individuals with IDD with communication impairments may not be able to provide adequate information using traditional assessment techniques.<sup>115</sup> A limited number of checklist assessments have been developed to decrease time and improve feasibility, but their psychometric properties have not been thoroughly investigated.<sup>19,115,116</sup> Gaining informed consent from a proxy is one strategy to improve assessment feasibility, but given that an individual with IDD can have numerous family members, care attendants, and other support personnel, finding the most appropriate person to act as a proxy respondent can be a considerable obstacle.<sup>117</sup>

### *Crisis Behaviors and Risk Factors in Individuals with IDD*

Despite its high prevalence, limited research exists regarding crisis behaviors and risk factors. Perhaps related to the heterogeneity of assessment tools, as well as the subjective nature of crisis, studies of individuals with IDD who experience crisis episodes have varied results. Stark et al. found that the most commonly reported triggers leading to acute psychiatric admission in adolescents with autism spectrum disorder were unexpected

changes or transitions and altered goals or expectations; physical and verbal aggression constituted the most commonly observed behaviors.<sup>19</sup> Physical aggression was also the most commonly reported crisis behavior in a study by Weiss and Lunsky of adults with ID residing with family, although it was not predictive of utilizing the emergency department during a crisis episode.<sup>118</sup> Kalb et al. found that severity of ID was inversely related to crisis-related hospitalization, with individuals with mild ID being hospitalized at a higher rate than those with moderate or severe ID.<sup>14</sup> The presence of one or more psychiatric diagnoses and not receiving waiver services were also significant predictors. In contrast, Tint and Lunsky found that individuals with moderate or severe ID were more likely than individuals with mild ID to have psychiatric consultation and admission in a study of individuals with ID presenting to the emergency department for crisis stabilization.<sup>119</sup> Heterogeneity of study populations also likely contributes these mixed results. More research is greatly needed to gain a better understanding of how individuals with IDD experience and respond to crisis episodes and how healthcare providers can effectively intervene.

### *The Effect of Crisis on Individuals with IDD and Caregivers*

Crisis, by its nature, is disruptive. While exposure to certain stressors can improve coping strategies, the negative effects of crisis experiences can also persist long after acute stabilization.<sup>10,112</sup> Hypervigilance, exhaustion, family dysfunction, financial strain, and isolation have been reported by individuals with IDD and their caregivers following crisis experiences.<sup>112</sup> This can impact quality of life and interfere with an individual's ability to function and participate in their environment, leaving them vulnerable to future crisis

episodes.<sup>10</sup> These negative consequences are compounded by a perceived lack of support services and resources that force many individuals and caregivers to rely on emergency services such as the police and emergency department, which can be costly and time consuming.<sup>112,120</sup>

### *Involvement of Physical Therapy in Crisis Screening and Intervention*

To the best of the author's knowledge, there is currently no published literature regarding the role of physical therapy in either crisis screening/referral or interventions for preventing or mitigating crisis episodes for individuals with IDD. However, physical therapists are well-positioned to become valuable assets in crisis prevention and management. As treatment plans tend to be on-going, physical therapists often build relationships over time with clients and their caregivers. Individuals with IDD and their caregivers may also have greater interaction with physical therapy and other rehab professionals as they are typically scheduled for weekly appointments, potentially allowing for more frequent screening and monitoring than other healthcare providers. Early recognition of impending crisis may lead to early referral and better outcomes.

Additionally, when interprofessional training and engagement with individuals with ID is included as a part of physical therapy curriculum and continuing professional education, it increases knowledge attainment and perceived readiness to provide competent care.<sup>32,121</sup> Improving physical therapist knowledge of crisis behaviors in individuals with IDD may also lead to appropriate modifications of treatment plans to better serve clients and reduce additional stress. In order to achieve these objectives, however, crisis screening tools need to be adapted to make them feasible and relevant for physical therapists.

## **Conclusion**

The future of long-term health and healthcare for individuals with IDD involves numerous challenges. The complexity involved in providing comprehensive and effective care for this population requires that any intervention or plan be holistic in its approach and take into consideration the numerous factors that influence health and health outcomes. Decreased adaptive functioning, high rates of chronic disease and psychopathology, and difficulties with care coordination and access leave many vulnerable to experience crisis episodes. One way of decreasing this risk may be through operationalizing and validating a more objective definition of crisis for individuals with IDD in order to better understand crisis and its related events. This may also improve tracking of outcomes over time and provide a framework from which to develop relevant screening tools and interventions for physical therapists and other healthcare providers.

## CHAPTER 3 DEVELOPING A COMPREHENSIVE DEFINITION OF CRISIS

### Background

Although reports vary, persons with intellectual and developmental disabilities are estimated to comprise around 1% of the population.<sup>1</sup> Prior to the 1970s, such individuals lived primarily in state-run facilities.<sup>3</sup> Investigations and reforms initiated in the 1960s and beyond exposed years of mistreatment, neglect, and abuse. Since that time, a paradigm shift has occurred resulting in increased community-based placement for persons with intellectual and developmental disabilities (IDD).<sup>4</sup>

This shift has decreased the number of people placed in large care facilities or state-run hospitals and has helped to foster greater integration into the community and allowed for increased opportunities for persons with IDD.<sup>5-7</sup> In order to be successful, this decentralization of care requires considerable and careful coordination across a variety of support services. This is particularly important for persons with multiple co-morbidities, such as co-existing psychiatric diagnoses, and those with communication difficulties, guardianship or legal issues, or inconsistent living environments.<sup>8-12</sup>

As persons with IDD are more integrated into community settings, there is a need for greater understanding of their specific needs in order to provide adequate care coordination and support that allows for the greatest quality of life. Without this coordination, persons with IDD can experience acute episodes of crisis that can interfere with their ability to live safely in the least restrictive settings.<sup>5,13-15</sup> Factors that may influence the ability for persons with IDD to live successfully in the community include access to adequate healthcare from knowledgeable providers, appropriate support services,

safe and accessible housing, education and employment opportunities, and protection from abuse and victimization.<sup>5,11,16-18</sup>

“Crisis” as a construct, has been defined variably in the literature. For persons with IDD, crisis is most often described as it relates to challenging or disruptive behavior, such as physical aggression, property destruction, or intentional self-injury that results in the need for intervention.<sup>16,19,20</sup> The disruptive nature and need for immediate action is well-recognized as a component of “crisis”, but current literature often does not quantify what characteristics specifically constitute a crisis for this population. When it is more objectively defined, the focus may be on certain factors, such as medical emergencies, psychiatric symptoms, or criminal justice issues, but often lacks a more comprehensive perspective.<sup>16,21-24</sup>

The lack of clear consensus on what constitutes a crisis for this population is also influenced by the dearth of available assessment tools that are appropriate for use for individuals with IDD.<sup>115</sup> The most common methods for rapid assessment of crisis involve semi-structured interviewing in which individuals with IDD may not be able to fully participate due to cognitive or communication barriers. Likewise, individuals with IDD may lack the autonomy to seek help in crisis situations and rely on caregivers or other support staff to advocate on their behalf.<sup>122</sup> This may, therefore, lead to underreporting and underutilization of crisis management services. While there have been efforts to validate needs assessments for individuals with IDD who experience crisis, such as those utilizing inpatient mental health services,<sup>19,116</sup> there remains few validated and accessible screening or assessment tools, and no tools are currently aimed at healthcare providers such as physical therapists.

Factors beyond an individual's physiology and specific behaviors have long been recognized as having an impact on overall health and wellbeing.<sup>25,26</sup> These social determinants of health are an important component to take into consideration when healthcare professionals evaluate patients and develop treatment plans.<sup>26,27</sup> Likewise, the multidimensional nature of crisis can have far reaching effects that impact overall health and requires a similar multifactorial approach to evaluation and monitoring.<sup>119</sup> Crisis situations, regardless of their etiology, may therefore interfere with healthcare treatment plans, potentially limiting the effects of therapeutic interventions.

Ultimately, crisis is personal and contextual. What constitutes a crisis for one person in one situation may not do the same for another person. This makes it a difficult construct to accurately define and study, as situations may require evaluation on a case-by-case basis and potential causes for crisis may be so numerous that it is not feasible to try to create an exhaustive list. However, past research does point toward common experiences that are relevant to individuals with IDD and may be crisis-related. The use of emergency services, through the police or hospital or both, is consistently reported to occur during or as a result of crisis episodes.<sup>14,19,112,118,123,124</sup> Outcomes related to utilization of emergency medical and police services, unplanned hospital admissions, and interaction with the court system can be measured and tracked objectively. Individuals with IDD are also highly susceptible to victimization and abuse.<sup>125-127</sup> Reports and open investigations made to agencies such as adult protective services and other indicators (e.g. the involuntary revocation of custodial guardianship) can be used to approximate crisis-related abuse and victimization. Unplanned or unwanted changes in living environments are also frequently reported as contributing factors to crisis behaviors.<sup>112,123,128</sup> These can be tracked by self-

report and may include expulsion from residence, placement in emergency respite care, loss of residence due to financial reasons, and unplanned involuntary admission to a higher level of care (i.e. institutionalization).

While these events are supported by past research, it is currently unknown if they are appropriate proxy variables for crisis in individuals with IDD. Therefore, we sought to operationalize a definition for crisis that was specific to adults with IDD by first using expert opinion from a multidisciplinary team. Using current available literature and clinical expertise, we hypothesized four possible events that are commonly experienced by individuals with IDD: (1) unplanned hospitalization or emergency department visit;<sup>68</sup> (2) involvement with the criminal justice or legal system;<sup>129</sup> (3) unstable living environment;<sup>16</sup> (4) victimization or abuse.<sup>125</sup>

The purpose of this study was to identify and describe a comprehensive definition of crisis for individuals with IDD as defined by multidisciplinary expert opinion. This study aimed to address the following objectives:

1. Identify specific components of crisis episodes for individuals with IDD from multidisciplinary team members
2. Determine the most frequently cited specific components of crisis for individuals with IDD from multidisciplinary team members
3. Formulate a tentative definition of “crisis” for individuals with IDD



## Methods

Documentation of informed consent was waived for this study and approval for this study was granted by the Institutional Review Boards at the University of Kentucky and the Kentucky Cabinet for Health and Family Services.

### *Participants*

Participants were recruited from a state-operated comprehensive care clinic providing interdisciplinary outpatient care to adolescents and adults with intellectual and developmental disabilities. As children and adults experience differences in terms of access to medical and social services, we were primarily interested in the experiences of adults with IDD. Inclusion criteria included individuals who were between the ages of 21-85, male or female, of any ethnic/racial background, English-speaking, who possessed at least 1 year of experience working with individuals with IDD in the following areas: medicine, dentistry, rehabilitation, psychiatry, nursing, behavioral analysis, crisis intervention, or administration. Administrators included those individuals whose day-to-day work involved direct input into the operation, policy or decision making, or management of healthcare services for individuals with IDD. Exclusion criteria were age of less than 21 years, non-English-speaking, or having less than 1 year of experience working with adults with IDD.

### *Materials and Procedures*

This study consisted of an anonymous online questionnaire survey created by the investigators and administered through Qualtrics Survey Software, utilizing both open-ended and close-ended questions. The proposed crisis definition was developed by the authors using a modified version of a definition first created by a crisis intervention

specialist and former colleague of one of the authors (RB). The proposed definition includes objective criteria to quantify crisis in order to improve its usefulness for assessment and intervention purposes. Participants were asked to rate their agreeableness to the following definition for acute crisis on a 7-point Likert scale: “A response to stressful life events that may interfere with a person’s ability to manage their daily activities that result in one or more of the following: emergency department visit or unplanned hospitalization, involvement of law enforcement or the court system, unstable living environment/placement, or victimization or abuse. A crisis may be emotional, physical, medical, behavioral, psychiatric or situational.” Participants were then asked to separately rate the components of the proposed definition on additional 7-point Likert scales. These components were (1) emergency department visit or unplanned hospitalization, (2) involvement of law enforcement or the court system, (3) unstable living environment/placement, and (4) victimization or abuse. Demographic data regarding gender, job type, and years of experience were also collected, which are further detailed in Table 1. An open-ended question then asked participants to provide comments regarding other situations they believed should be included in the definition of “crisis” for the target population.

### *Analysis*

Likert scale data was analyzed for agreeableness using median rank and interquartile ranges for each subscale. Trustworthiness and credibility for the qualitative data was ensured through dual coding of the comments. Open-ended responses were first individually coded by two of the investigators for themes and frequency counts. Then the

two investigators compared and discussed themes. Finally, once 100% agreement on themes and additional characteristics was reached between the investigators, the data from the closed-ended and open-ended responses was combined and a final operationalized definition was proposed.

## **Results**

A total of 45 potential participants were sent email invitations to take part in this study, with 18 participants completing surveys during the study period (see Table 3.1). Job title information was included as an optional response, of which 13 responses were collected. Participants included physicians, nurses, dentists, a dental assistant, rehabilitation professionals, psychiatrists, crisis intervention specialist, and administrators.

Table 3.1 Demographic Data

<b><i>Gender</i></b>	
Male	3
Female	14
No Answer	1
<b><i>Job Description</i></b>	
Clinical	10
Administrative	7
Other	1
<b><i>Years of Experience</i></b>	
1-2 years	3
3-5 years	4
6-10 years	2
11-15 years	4
>15 years	5

### *Close-ended Responses*

Median rank of agreement on a 7-point Likert scale was calculated for the overall proposed definition and for each of the four proposed outcome components, with a score

of 1 indicating strong disagreement and a score of 7 indicating strong agreement. An interquartile range (IQR) was also calculated for the overall proposed definition and for each of the four proposed outcome components. The median rank for the overall proposed definition was 6.5. For the individual components, the median ranks for “emergency department visit or unplanned hospitalization” and for “involvement of law enforcement or the court system” were both 6. The median ranks for “unstable living environment” and “victimization/abuse” were both 7. The overall proposed definition and the individual components each had an IQR of 1. Responses are further illustrated in Figures 3.1 and 3.2.

Figure 3.1 Overall Definition Agreement

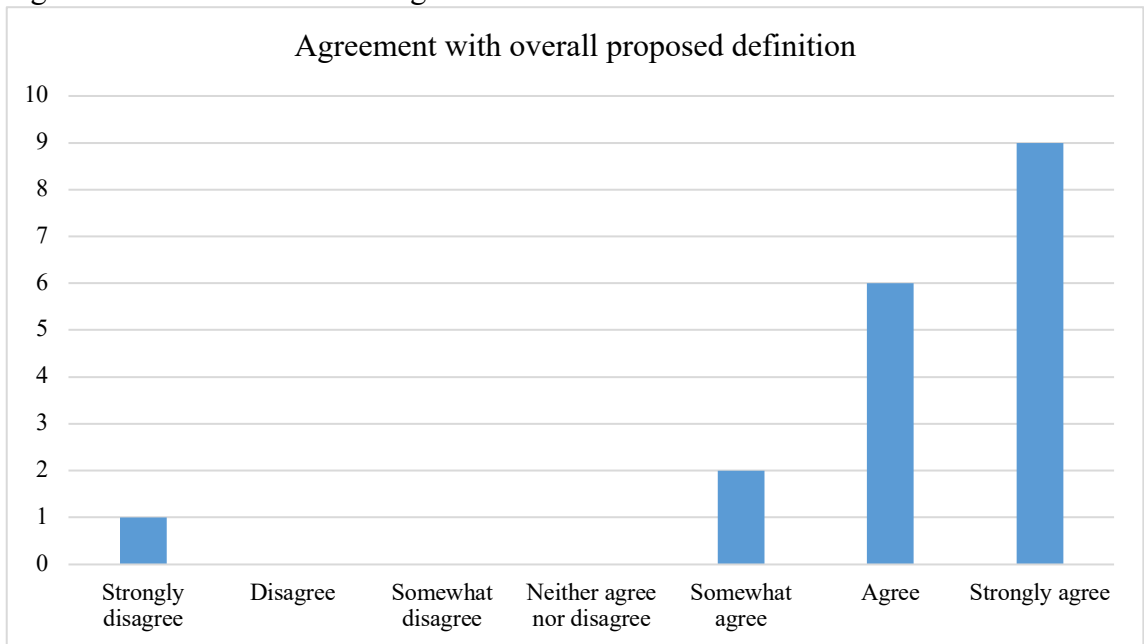
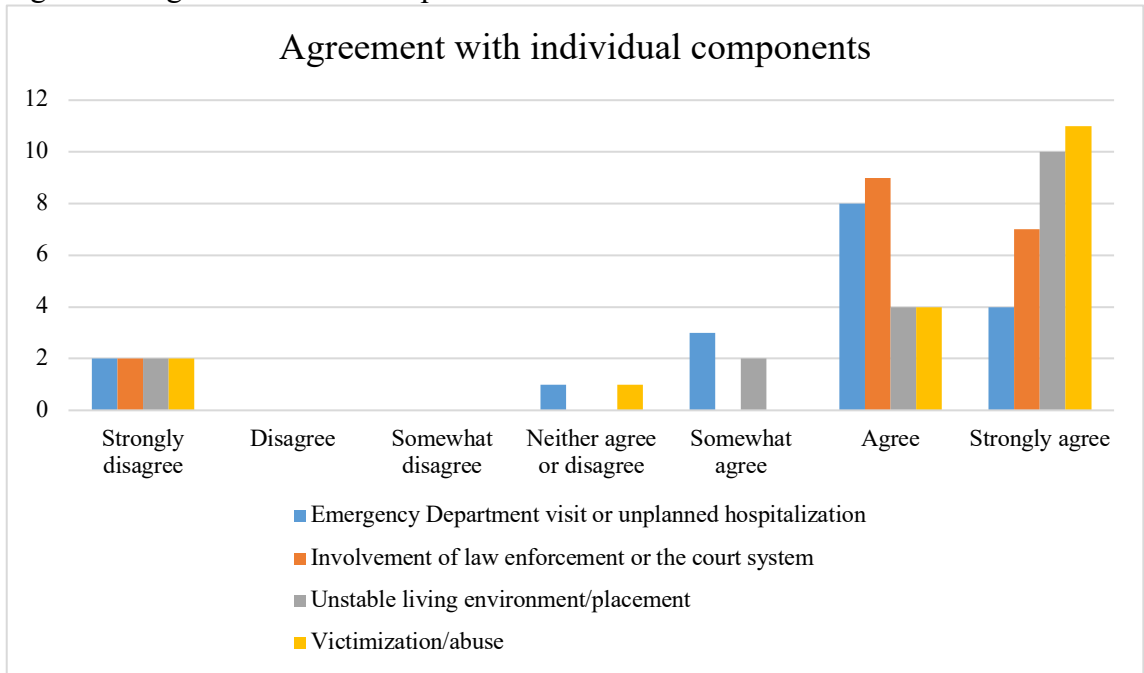


Figure 3.2 Agreement with Components



### *Open-ended Responses*

An open-ended question asked participants to comment on additional components, if any, that they felt should also be considered in the overall definition. A total of 8 responses were recorded. After discussion, 100% agreement was reached on themes as well as on the overall final proposed definition. Five themes emerged from the open-ended responses.

- (1) *Access*. Three respondents cited issues related to access to care or resources as contributing to crisis.

*Many crisis issues stem from the socioeconomic problems such as; access to care, delays in receiving care, medication, provision of care and barriers to additional resources. I often hear providers discuss solutions to crisis,*

*without taking into account financial resources a patient/family may have to implement their plan of care.*

(2) *Training/education.* Two respondents commented on a lack of training or knowledge on the part of providers.

*Frequently, a patient may have support providers or lack thereof who are adequately trained or compassionate towards individuals with IDD. I find so often in crisis situations if there is a trained individual who is able de-escalate the situation with either the caregiver, patient, etc the crisis may be resolved in a more peaceful setting.*

(3) *Personal factors.* Two respondents listed personal factors, such as inability to communicate and aggressive behavior.

*Significant behavioral issues like severe aggression or destructive behavior towards items or self injurious behaviors or behaviors toward others.*

(4) *Prognosis/risk.* One respondent commented on the threat of recurrence as a distinguishing factor.

*For me, the important missing piece of information in the definition is that, for the person in crisis, the consequences are \*likely to happen again in the near future\*. Without the threat of recurrence, I would not necessarily consider a single isolated incident of the above consequences to constitute a crisis.*

(5) *Life events*. One respondent listed life events, such as loss of a loved one/caregiver.

*Loss of a family member/valuable person in patients life; Change of plans that essentially throw off a persons regularly scheduled routine.*

### *Final Proposed Definition*

After combining the data from the closed- and opened-ended responses, a final definition for crisis was reach by the authors: “A response to stressful life events that interferes with a person’s ability to manage their daily activities and may result in one or more of the following outcomes: emergency department visit or unplanned hospitalization, involvement of law enforcement or the court system, unstable living environment/placement, or victimization or abuse. A crisis may be emotional, physical, medical, behavioral, psychiatric or situational and carries with it the risk of recurrence of these outcomes if left unresolved.”

### **Discussion**

To the best of our knowledge, this is the first study to assess crisis in a comprehensive manner using our proposed proxy variables. The overall definition and each of the proposed outcome components had high overall agreement among our participants, as indicated by the high median ranks and narrow interquartile ranges resulting from the survey responses. This provides evidence that the definition was acceptable among our sample of multidisciplinary experts. It also gives preliminary support to the idea that a comprehensive definition that takes into account a wide array of related event scenarios

may be an acceptable approach for screening or research purposes. We propose that when real-time evaluation methods are unavailable or infeasible, using our operationalized definition may provide other avenues for studying crisis by helping to reduce the ambiguity that may be involved in identifying individual crisis episodes and tracking their relevant outcomes. Additionally, by more objectively defining crisis for this population, our definition may lay the foundation for the development of screening and referral tools that are appropriate for healthcare providers who are not routinely involved in the management of crisis situations but who may otherwise encounter patients experience crisis.

The comments identified important factors related to crisis for persons with IDD and also highlighted the complexity of operationalizing this construct for this population. The two most frequently cited themes related to access and training/education. This corresponds to previous studies that indicate significant disparities in access to care and other support services for persons with IDD in comparison to the general population.<sup>6,68,130</sup> Additionally, it recognizes that for individuals with IDD, crisis experiences are often related to the competency of support personnel and caregivers.<sup>118,128</sup> Inadequate support or training to de-escalate situations, such as managing challenging behaviors, can lead to the need for emergency services, potentially triggering the crisis cycle.<sup>111</sup> The range of comments covering social, environment, and personal factors also point toward the need to take a broader approach to “crisis” and lends support to the inclusion of non-healthcare related outcomes in our final definition.

Overall, while the survey comments provided meaningful insight into the experience of crisis for persons with IDD, we felt that all but one of the comments described situations that could result in one of the four proposed components rather than



being distinct separate crisis-related events. Therefore, 7 of the 8 comments were not included in the final definition. This may have been due to the structure of the survey, which did not provide additional examples of what would constitute a crisis-related event so as not to bias participants. This may have introduced ambiguity into the questions and influenced the answers we received. For example, multiple comments mentioned a lack of training or education on the part of care givers that can exacerbate crisis situations. While this may certainly be a contributing factor, it did not represent a distinct crisis-related event that could be quantified and tracked, which was the primary objective of our definition. This again highlights the difficulty in adequately describing a latent construct, such as “crisis.”

We did include one additional component to our proposed definition. One comment cited the likelihood of recurrence as a feature of crisis. After discussion, we decided to incorporate this in the final definition, as we felt it captured the seriousness and risk associated with crisis that our initial definition did not provide. As the perceived inability to manage the stress of a situation is a key component of crisis, we felt that the risk of recurrence of our crisis-related events was an important distinguishing factor and would emphasize the cyclical nature of the construct.

### *Limitations*

As with all research, there are limitations to this study. This is a pilot study with a small sample size and all of the participants were recruited from the same specialty care clinic. The limited availability of the survey due to scheduling constraints may have influenced the small response rate. The agreeableness of the participants with the proposed

definition may be reflective of the clinic practices and culture, and therefore the results from the study may not be generalizable beyond our study sample. Future research is needed to validate our proposed definition as well as explore the construct of “crisis” from additional perspectives, such as those of individuals with IDD and their caregivers and from care providers of other disciplines and care settings. Future studies should assess the experiences of individuals with IDD who utilize formal crisis management services to exam if our proxy variables are indeed associated with crisis situations.

### **Conclusions**

“Crisis” can be a difficult construct to define as it can be highly circumstantial and personal. However, this study demonstrates promising evidence that agreement on a definition can be achieved from a multidisciplinary perspective using a range of events that can result from a crisis situation. It is hoped that by further operationalizing crisis using these proxy variables, tracking and studying its occurrence can be done in a more systematic and comprehensive manner. This may lead to a better understanding of its scope and impact, leading to the development of innovative and effective strategies to address it.

## CHAPTER 4 VALIDATING A DEFINITION FOR CRISIS USING PROXY VARIABLES

### Background

Crisis is broadly defined as any stressful situation that acutely overwhelms an individual's capacity to adapt and overcome such stressors.<sup>114</sup> As individuals with intellectual and developmental disabilities (IDD) by definition have deficits in adaptive functioning, they are particularly susceptible to experiencing periods of crisis.<sup>19</sup> These crisis episodes can directly interfere with healthcare management as they may disrupt treatment plans, increase injury risk, and trigger the need for higher levels of care.<sup>111</sup> Healthcare expenditures may also increase as a result.<sup>131</sup> It is imperative, therefore, to improve understanding of the experience and impact of crisis for individuals with IDD in order to create more robust screening and intervention strategies to reduce and prevent episodes.

Despite being at high risk, the impact of crisis on this population is not well understood. As crisis is based on personal perception, it is difficult to measure and track over time.<sup>23,115</sup> Because crisis is a latent construct, the use of proxy variables to create a model that provides measurable outcomes may provide a way to quantify the impact of crisis on this population, as well as better capture crisis as a singular construct. Proxy variables act as "stand ins" that approximate an unmeasurable construct.<sup>132</sup> The use of proxy variables for latent trait modeling has been used numerous times in healthcare research and practice to quantify constructs such as self-efficacy,<sup>133,134</sup> pain,<sup>135</sup> depression,<sup>136</sup> and quality of life.<sup>137</sup> The use of proxy variables to approximate crisis for individuals with IDD would therefore be reasonably acceptable and feasible in healthcare settings.<sup>138</sup>

Much of the focus on the experience of crisis in individuals with IDD, particularly adults, has been on precipitating factors that lead to a crisis episode. These may include external factors, such as previous experiences of trauma or life changes (e.g. death of a loved one).<sup>10,14,119,139</sup> Internal factors have also been identified, such as the presence of psychiatric or behavioral disorders.<sup>14,119,123</sup> For individuals with IDD, the use of formal crisis management services can help to quickly stabilize and then address the factors that are contributing to the crisis state.<sup>122,128,140</sup> However, little research has focused on the events surrounding the crisis episode that often trigger the use of these services. If certain crisis-related events are common occurrences among individuals in crisis, then these events may serve to better quantify crisis for this population. Therefore, the purpose of this study was to quantitatively assess the four previously identified crisis-related events from Chapter 3 as potential proxy variables for a crisis construct. The four variables under investigation were (1) unplanned hospitalization or emergency department visit; (2) involvement with the criminal justice or legal system; (3) unstable living environment; and (4) victimization or abuse. As we also added the concept of risk of recurrence to the definition, we also assessed the frequency of crisis-related events.

## **Methods**

Documentation of informed consent was waived for this study and approval for this study was granted by the Institutional Review Boards at the University of Kentucky and at the Kentucky Cabinet for Health and Family Services.

### *Participants*

This retrospective cross-sectional study utilized health record data from an interdisciplinary specialty care clinic serving adolescents and adults with intellectual and developmental disabilities in Kentucky. Participants were included if they were at least 18 years old as of January 1, 2015; had an intellectual and/or developmental disability; were a patient of record for at least one consecutive year between January 1, 2015 and March 1, 2019; and had attended at least 5 visits. The representation of adults with IDD in scientific literature is scarce, and the experiences of adults differ than those of children for this population. As we were primarily interested in the clinical implications of adults who experience or are at risk for crisis, we limited our study sample to exclude minors under the age of 18.

### *Materials and Procedures*

Data abstraction and coding were completed using a standardized abstraction template by a research physical therapist familiar with the clinic's health record system. Information abstracted from the health record included age, gender, race/ethnicity, severity of intellectual disability, neurodevelopmental diagnosis, health conditions, waiver enrollment, living environment, communication level, mobility level, clinic services received, hospital utilization, and any report of abuse/victimization, involvement with the police, or changes in living environment (see Table 4.1 for details). Data collection was performed between March and May 2019. Health records were pulled by hand using a random number generator and reviewed until 185 participants meeting inclusion criteria were collected. A sample size calculation, accounting for the expected large variance in

our study population, estimated a sample of 185 to detect a minimum odds ratio (OR) of 2.0.

Table 4.1 Categorical Variables

<b>Category</b>	<b>Stratification</b>
Neurodevelopmental Diagnosis	Perinatal Trauma; Down Syndrome; TBI in Childhood; Fragile X Syndrome; Other; Unknown
Mobility Status	Ambulatory; Non-ambulatory
Communication Status	Verbal; Limited/Non-verbal
Living Environment	Independent; With Family; With Unpaid Roommate; Family Home Provider; Staffed Residence; ICF/ID
Guardianship Status	Own Guardian; Family Member Guardian; State Appointed Guardian
Comorbidities	Individual Somatic and Behavioral/Psychiatric Diagnoses
Waiver Enrollment	None; ABI; SCL; Michelle P.; Other

Categorical variables with their stratification levels. TBI = traumatic brain injury; ICF/ID = Intermediate Care Facility for Intellectual Disability; ABI = Acute Brain Injury Trust; SCL = Supports for Community Living waiver

### *Analysis*

Descriptive statistics were used for frequency counts and proportions of demographic data for crisis and non-crisis patients. Chi-square analysis was conducted to analyze between group differences and calculate odds ratios and 95% confidence intervals for each crisis-related event. A Spearman’s rho correlation coefficient was calculated to assess relationships between crisis-related events. All data analysis was conducted using IBM SPSS Statistics, version 25.

## **Results**

A total of 197 health records were reviewed with 185 meeting all inclusion criteria. Of those, 41 patients received crisis services during the study period. There were no

significant differences found for age, gender, race/ethnicity, or severity of intellectual disability between the two groups. A detailed description of patients is presented in Table 4.2.

Table 4.2 Demographic Characteristics

		<b>Non-Crisis Patients (N = 144)</b>	<b>Crisis Patients (N = 41)</b>	<b>p-value*</b>
<b>Age (Mean ± SD)</b>		34.92 ± 13.25 years	30.37 ± 11.20 years	0.30
<b>Gender (% Male)</b>		70.1	65.9	0.60
<b>Race/Ethnicity (%)</b>	<b>White/Caucasian</b>	66.7	75.6	0.46
	<b>Black/African-American</b>	23.6	19.5	
	<b>Asian</b>	2.1	4.9	
	<b>Latino/Hispanic</b>	2.8	-	
	<b>Other/Unknown</b>	4.8	-	
<b>Intellectual Disability Severity (%)</b>	<b>Mild</b>	31.9	34.1	0.31
	<b>Moderate</b>	31.3	39.0	
	<b>Severe</b>	29.9	26.8	
	<b>Profound</b>	16.9	-	

**Table 4.2** Demographic characteristics of crisis and non-crisis patients. \*Chi-square p-value with significance at p<0.05

Of those who had an identifiable neurodevelopmental diagnosis, the most commonly reported diagnosis was trauma occurring immediately before or following the first few weeks of birth (e.g. infection, hypoxia, cerebral palsy), followed by Trisomy 21, traumatic brain injury (TBI) occurring after the perinatal period but prior to age 21, and Fragile X syndrome (see Table 4.2). Additional diagnoses included rare genetic disorders and/or chromosomal differences known or strongly suspected to contribute to intellectual disability. No significant differences were found between crisis and non-crisis patients in regard to neurodevelopmental diagnosis ( $\chi^2=5.054$ , p=0.409).

Table 4.3 Neurodevelopmental Diagnoses

<b>Diagnosis</b>	<b>N (%)</b>
Perinatal trauma/infection	45 (24.3)
Trisomy 21 (Down syndrome)	13 (7.0)
TBI in childhood	9 (4.9)
Fragile X syndrome	4 (2.2)
Other	25 (13.5)
Unknown	88 (47.6)

Distribution of neurodevelopmental diagnoses among patients; TBI = traumatic brain injury

### *Hospitalization*

During the study period, 105 of the 185 patients experienced at least one recorded unplanned hospitalization or emergency department (ED) visit, totaling 311 identified encounters (see Table 4.4). Psychiatric and behavioral encounters accounted for 42.4% of visits in the entire study sample. Seizures, pneumonia, and urinary tract infections were the most commonly reported reasons for somatic visits.

Table 4.4 Unplanned Hospital Utilization

	<b>Non-Crisis Patients (N=144)</b>	<b>Crisis Patients (N=41)</b>
Any unplanned hospital/ED visit (%)	73 (50.7)	32 (78.0)
Mean $\pm$ SD of encounters per patient	1.1 $\pm$ 1.5	4.3 $\pm$ 4.0
Range	0-6	0-14

Hospitalization and ED visits for crisis and non-crisis patients. SD = standard deviation

### *Involvement with the Criminal Justice System*

During the study period, 24 patients experienced at least one recorded instance of police or criminal justice involvement, with crisis patients accounting for 70.8% of incidents. (see Table 4.5 for details). Reasons for encounters with police were variable and



included assault or attempted assault, property destruction, elopement, self-injurious behavior, and theft.

Table 4.5 Involvement with Criminal Justice System

	<b>Non-Crisis Patients (N=144)</b>	<b>Crisis Patients (N=41)</b>
Any involvement with criminal justice system (%)	7 (4.9)	17 (41.5)
Mean $\pm$ SD of encounters per patient	0.06 $\pm$ 0.26	1.23 $\pm$ 1.94
Range	0-2	0-7

Encounters with criminal justice system for crisis and non-crisis patients; SD= standard deviation

*Abuse/Victimization*

During the study period, 21 patients experienced a recorded instance of abuse and/or victimization, with crisis patients accounting for 57.1% of all incidents (see Table 4.6). Reasons for reports included involuntary loss of guardianship due to neglect, abuse, or exploitation and/or being the victim of physical violence or sexual abuse from a caregiver, roommate, or peer.

Table 4.6 Abuse/Victimization

	<b>Non-Crisis Patients (N=144)</b>	<b>Crisis Patients (N=41)</b>
Any report of abuse/victimization (%)	9 (6.3)	12 (29.3)
Mean $\pm$ SD of encounters per patient	0.08 $\pm$ 0.30	0.4 $\pm$ 0.67
Range	0-2	0-2

Reported incidents of abuse and/or victimization for crisis and non-crisis patients; SD = standard deviation.

### *Unplanned Change in Living Environment*

During the study period, 32 patients experienced at least one unplanned change in living environment, with crisis patients accounting for 79.1% of the 67 individual incidents (see Table 4.7 for details). The most common reported reason was due to expulsion/involuntary removal due to difficult behaviors. Other reasons for unplanned changes in living environment included loss of home due to financial circumstances and removal from living situation due to suspected abuse or neglect.

Table 4.7 Unplanned Change in Living Environment

	<b>Non-Crisis Patients (N=144)</b>	<b>Crisis Patients (N=41)</b>
Any report of living environment change (%)	11 (7.6)	21 (51.2)
Mean $\pm$ SD of encounters per patient	0.10 $\pm$ 0.34	1.33 $\pm$ 1.07
Range	0-2	0-10

Reported incidents of unplanned changes in living environment for crisis and non-crisis patients; SD = standard deviation.

### *Other Crisis-Related Events*

In addition to the four crisis-related events that we selected a priori, additional events were reported by crisis patients and their caregivers. Four crisis patients did not have any of the four crisis-related events. Of those four patients, three had lost support services (e.g. day habitation, home health aides) due to either being expelled from those services or from aging out of services. The remaining crisis patient came to crisis services by internal referral due to an unexplained onset of aggressive behavior during therapy sessions.

### *Associated Risk*

Ninety percent of crisis patients experienced at least one of the four crisis-related events under investigation, with 58.5% experiencing two or more events during the study period. For non-crisis patients, 54.2% experienced at least one of the four crisis-related events, and 12.5% experienced at least two events. All four crisis-related events demonstrated statistically significant differences between crisis and non-crisis patients, with involvement with the criminal justice system showing the highest associated risk (see Table 4.8).

Table 4.8 Crisis-Related Events Risk Table

<b>Crisis-related Event</b>	<b>Odds Ratio</b>	<b>95% CI</b>	<b>p-value*</b>
Unplanned hospitalization/ED use	3.40	1.52-7.66	0.002
Involvement with criminal justice system	13.86	5.2-36.98	<0.001
Abuse/victimization	6.21	2.39-16.10	<0.001
Unplanned change in living environment	12.70	5.33-30.24	<0.001

Associated risk of each crisis-related event; \*Chi-square p-value with significance at  $p < 0.05$

### **Discussion**

While crisis is a complex and difficult construct to adequately quantify, our results provide preliminary support for using proxy variables to better capture crisis and its impact on individuals with IDD. Consistent with previous research,<sup>77,141</sup> our study sample experienced high rates of unplanned hospitalization and ED use. The patients in crisis management, however, had a greater percentage of individuals who utilize hospital services overall, as well as higher frequencies of the number of encounters. Crisis patients were nearly three and a half times more likely to be hospitalized during the study period. Visits related to psychiatric or behavioral issues occurred in just over half of the crisis patients

(53.7%) and were more prevalent than non-crisis patients. Somatic encounters occurred in about the same number of crisis patients (51.2%). However, the frequency of encounters was much higher for psychiatric visits than somatic for crisis patients, with 100 individual psychiatric visits occurring during the study period vs. 51 individual somatic visits. This suggests that while somatic hospitalization should not be ignored, psychiatric or behavioral issues may be more prevalent with individuals experiencing crisis. The higher average number of encounters of any kind for individuals in crisis management compared to those not in crisis management lends strength to the concept of recurrence of events as a distinguishing factor of crisis as suggested in Chapter 3.

Involvement with the police or criminal justice system was experienced in much greater frequency by crisis patients and was correlated with unplanned hospital use. Per the health records reviewed, police were most often called to stabilize and then transport individuals following acute episodes of challenging behavior, which usually involved treatment and/or admission through the ED for injuries or psychiatric evaluation. Challenging behavior is generally defined as “aggressive, self-injurious, destructive and ‘other’ difficult, disruptive or socially unacceptable behavior” (Emerson et al., p.80). These behaviors place individuals at risk of being excluded from or limited in participation in usual community services and facilities.<sup>142</sup> Prevalence rates of challenging behaviors are difficult to estimate due to the broad definition of what constitutes such behavior as well as heterogeneity of study samples, but are estimated to occur in 10-15% of individuals with IDD and increase in prevalence with increasing severity of intellectual disability.<sup>142,143</sup> Challenging behavior is also associated with communication disorders, as an inability to effectively communicate needs or process complex situations can evoke aggressive or

destructive responses.<sup>144</sup> However, while the crisis patient records reported high rates of challenging behavior, our study sample did not show a statistically significant relationship between intellectual severity level and receiving crisis management services. This may be due to the distribution of severity levels in our sample, as less than a third were diagnosed in the severe or profound range, so we may have been underpowered to detect a smaller difference. Severity level of intellectual disability was sometimes reported as a borderline status (e.g. mild/moderate or moderate/severe). To maintain consistency during data collection, the more severe level was recorded, but this may have introduced confounding into our analysis.

Abuse and victimization had the lowest number of reported occurrences out of the four crisis-related events, with 28 reported incidents across 21 patients. Crisis patients, however, were 6.1 times more likely to have a report of abuse or victimization. Individuals with IDD are highly susceptible to abuse and victimization due to deficits in adaptive behavior, communication deficits that make reporting abuse difficult, and decreased social agency.<sup>125,145</sup> We only used reports of adult protective service involvement with substantiated abuse or victimization claims as indicators for our variable, as well as involuntary revocation of legal guardianship due to abuse or neglect. As abuse is widely underreported, the actual rate of occurrence may be higher than what our study findings indicate.<sup>125</sup> Because healthcare providers are mandatory reporters of suspected abuse or neglect, awareness of potential abuse risk and its apparent relationship to crisis is important for all providers who come into contact with patients with IDD.

Similar to unplanned hospital utilization, unplanned changes in living environment were also significantly correlated with involvement of the police or criminal justice system.

This is likely due to the numerous reports indicated in the health records of individuals being removed or expelled from their living situation due to challenging behavior, which often occurred after multiple interactions with the police. Consistent and adequate support measures are needed for individuals with IDD to live successfully in community-based settings.<sup>146,147</sup> However, factors such as frequent care staff turnover and the high prevalence of challenging behaviors among residents can increase the risk of failed community placement.<sup>38,148</sup> Inadequate training and knowledge in how to effectively communicate and de-escalate situations is also often reported during interactions with support staff and police officers, which can further exacerbate crisis behavior.<sup>149,150</sup> The other most common reason for an unplanned change in living environment was emergency removal from residence due to neglect or abuse. The risk of recurrence that we proposed in our original definition is also evident in this variable, as only one of the 11 non-crisis patients who changed living environments experienced multiple incidents, but 11 of 21 the crisis patients with living changes experienced two or more occurrences.

While each of our proposed crisis-related events have challenges regarding their ability to be accurately measured, our study demonstrates that they were highly prevalent among the crisis patients, which supports our proposed crisis definition from Chapter 3. These findings have implications for both research and clinical practice. The availability of this information that we found in the existing health records provides supporting evidence that collecting information regarding these potentially sensitive topics is feasible for community-based healthcare settings. By standardizing the collection process and streamlining the methods for obtaining this information, even more reliable data can be

captured. This would also decrease the administrative burden of tracking such data, improving its potential clinical utility.

These crisis-related events may serve as appropriate proxy variables to track crisis over time in this population. Improved surveillance may also lead to better early identification of individuals in crisis or at high risk for worsening crisis episodes. Additionally, using measurable outcomes can allow for the evaluation and impact of crisis services and other referral interventions to see if these crisis-related events are attenuated through screening and intervention strategies.

### *Limitations*

The findings of this present study should be interpreted with caution. As the data was abstracted retrospectively from health records, our identified crisis-related events were self-reported, and therefore missing variables or errors may have been present which could confound the findings. The use of a single clinic may also only reflect the experiences of those patients and not be generalizable to a larger IDD population. However, the comprehensive nature of the clinic adds strength to our findings, as health-related information was available across multiple disciplines. Future research is needed for further validation of these proxy variables, ideally with prospective data collection using standardized protocols. Future research should also investigate if there are any additional variables that are common to crisis experiences for the IDD population, as the current study was limited to only the four variables identified by our survey data.

## **Conclusions**

Crisis is a complex experience, particularly for adults with IDD. However, our findings support the use of four proxy variables to better quantify and measure crisis in this population: (1) unplanned hospitalization or emergency department visit; (2) involvement with the criminal justice or legal system; (3) unstable living environment; and (4) victimization or abuse. An improved definition of crisis that is specific to individuals with IDD may lay the foundation for further examination of the most effective and clinically relevant methods for identifying and tracking crisis-related events. It may also inform targeted interventions to allow for early referral and treatment for individuals with IDD experience crisis, thus reducing disruption of care plans.



## CHAPTER 5 FACTORS RELATED TO CRISIS AND THEIR CLINICAL RELEVANCE

### Background

Life expectancy for individuals with intellectual and developmental disabilities (IDD) continues to increase, and the majority of these individuals are expected to be long-term community dwellers.<sup>151,152</sup> This increases the likelihood that rehabilitation professionals, such as physical therapists, will encounter adults with IDD in clinical settings.<sup>94</sup> While rehabilitation clinicians, such as physical therapists, are not routinely involved in crisis management, they are likely to encounter patients who are at risk of or actively experiencing crisis. As such, they need access to resources for appropriate and prompt referral for crisis management.

Awareness of potential crisis episodes is not without precedence in current physical therapy practice. As consumer knowledge about direct access improves, more and more physical therapists will encounter self-referred patients in outpatient clinical settings. Many systemic diseases can mask themselves as musculoskeletal symptoms.<sup>153,154</sup> Thus, screening and referral practices have increased in importance and sophistication as direct access legislation has increased across the United States.<sup>155</sup> Likewise, there has been increasing attention on the influence of psychosocial factors on PT-related functional outcomes.<sup>156,157</sup> These include extrinsic factors such as socioeconomic status, environmental supports and barriers, and policies and regulation.<sup>158,159</sup> They also include intrinsic factors such as health literacy, health beliefs, self-efficacy, and fear-avoidance.<sup>160-</sup>

162

Screening and treatment modifications for depression provide an example for how such practices could apply to crisis screening and intervention. Depression has been shown

to influence multiple functional outcomes across patient populations and settings. Patients with stroke and co-morbid depression perform worse on mobility and functional tasks and report increased need for assistance than those patients without depression.<sup>163</sup> Depression is also highly correlated with chronic pain conditions and is predictive of return-to-work potential. While treating depression is not a part of PT scope of practice, depression can greatly affect a PT treatment plan and outcomes. Thus, it is important for PTs to have an awareness of patients with depression and to make appropriate referrals and adapt treatment plans as necessary. Screening tools for depression are available for PTs that are quick and easy to administer and are often a required component of documentation systems in some settings.<sup>164</sup>

Chapter 4 identified four crisis-related events to include in a comprehensive crisis definition that may improve surveillance, screening, and outcome measurement of crisis for adults with IDD. In order to develop effective crisis screening tools that would be useful in PT clinical settings, the predisposing or precipitating factors that influence crisis need to be examined in greater detail. Previous studies on crisis-related factors have produced variable results, depending on the setting and demographic characteristics of their study samples. These studies have tended to focus on behavioral and psychiatric factors or on major life events.<sup>10,19,112</sup> Little research exists regarding the influence of other factors on crisis, such as multiple co-morbidities, mobility status, communication status, or living environment, particularly for adults living in community-based settings. Therefore, the purpose of this study was to assess additional factors that are related to crisis episodes for adults with IDD and exam their relevance to PT practice.

## Methods

Documentation of informed consent was waived for this study and approval for this study was granted by the Institutional Review Boards at the University of Kentucky and at the Kentucky Cabinet for Health and Family Services.

### *Participants*

This retrospective cross-sectional study utilized health record data from an interdisciplinary specialty care clinic serving adolescents and adults with intellectual and developmental disabilities Kentucky. Participants were included if they were at least 18 years old as of January 1, 2015; had an intellectual and/or developmental disability; were a patient of record for at least one consecutive year between January 1, 2015 and March 1, 2019; and had attended at least 5 visits. As we were primarily interested in the clinical implications of adults who experience or are at risk for crisis, we limited our study sample to exclude minors under the age of 18.

### *Materials and Procedures*

Data abstraction and coding were completed using a standardized abstraction template by a research physical therapist familiar with the clinic's health record system. Information abstracted from the health record included age, gender, race/ethnicity, severity of intellectual disability, neurodevelopmental diagnosis, health conditions, waiver enrollment, living environment, communication level, mobility level, clinic services received, hospital utilization, and any report of abuse/victimization, involvement with the police, or unplanned changes in living environment. Data collection was performed between March and May 2019. Health records were pulled by hand using a random number

generator and reviewed until 185 participants meeting inclusion criteria were collected. A sample size calculation, accounting for the expected large variance in our study population, estimated a sample of 185 to detect a minimum odds ratio (OR) of 2.0.

*Analysis*

As this study was exploratory in nature, both binary logistic regression modeling and linear probability modeling were performed using a forward stepwise process to develop a model for crisis prediction in our study population. Potential variables considered for our model included type of neurodevelopmental diagnosis, mobility status, communication status, living environment, guardianship status, and comorbidities (see Table 5.1 for details). These variables have not been studied in detail as they relate to crisis, and they each are relevant to clinical practice. Each potential variable was first analyzed univariately using a Chi-square test, and those with statistical significance ( $p < 0.05$ ) were entered into the logistic regression analysis. As no significant differences with respect to age, gender, race/ethnicity, and intellectual disability level were found between crisis and non-crisis patients in Chapter 4, these were not considered as variables in our model.

Table 5.1 Categorical Variables

<b>Category</b>	<b>Stratification</b>
Neurodevelopmental Diagnosis	Perinatal Trauma; Down Syndrome; TBI in Childhood; Fragile X Syndrome; Other; Unknown
Mobility Status	Ambulatory; Non-ambulatory
Communication Status	Verbal; Limited/Non-verbal
Living Environment	Independent; With Family; With Unpaid Roommate; Family Home Provider; Staffed Residence; ICF/ID
Guardianship Status	Own Guardian; Family Member Guardian; State Appointed Guardian
Comorbidities	Individual Somatic and Behavioral/Psychiatric Diagnoses

Categorical variables with description of their stratification levels; TBI = traumatic brain injury; ICF/ID = intermediate care facility for individuals with intellectual disability

## Results

A total of 197 health records were reviewed with 185 meeting all inclusion criteria. Of those, 41 patients received crisis services during the study period. Demographic data is described in detail in Chapter 4. Additional information regarding mobility status, communication status, guardianship, living environment, and co-morbidity status is presented in Table 5.2.

Table 5.2 Demographic Data

Variable	Non-Crisis Patients (N=144)	Crisis Patients (N=41)
Mobility Status N(%)	Independent	111 (77)
	Ambulates with assistance	14 (9.7)
	Household ambulator	1 (0.7)
	Primarily non-ambulatory	18 (12.5)
Communication Status N(%)	Verbal	82 (57)
	Limited/Non-Verbal	62 (43)
Living Environment N(%)	Independent	4 (2.8)
	With roommate	1 (0.7)
	With family	57 (39.6)
	Family home provider	41 (28.5)
	Staffed residence	34 (23.6)
	ICF/ID	7 (4.9)
Guardianship N(%)	Own guardian	22 (15.3)
	Family guardian	89 (61.8)
	State guardian	32 (22.2)
Co-morbidities	Mean(SD)	8.51(3.52)
	Range	1-18

Distribution frequency of select variables between crisis and non-crisis patients with the corresponding percentage in parentheses. Both groups were majority independently ambulatory and fully verbal.

After univariate analyses of 61 possible variables, 14 were considered for the logistic regression model, and five are included in the final model (see Appendix A for

details). The logistic regression model was statistically significant,  $\chi^2(5) = 33.272$ ,  $p < 0.001$  (see Table 5.3). Hypothyroidism, bipolar disorder, personality disorder, intermittent explosive disorder, and the presence of more than one psychiatric disorder were all significantly associated with an increased risk for receiving crisis management services. Further analysis for near-perfect prediction was completed, which prompted the use of linear probability modeling. This model supported hypothyroidism, bipolar disorder, personality disorder, and having multiple psychiatric diagnoses as previously identified in the logistic regression. It also identified obesity as a significant discriminating factor (see Table 5.4).

Table 5.3 Logistic Regression Model

Factor	B	S.E.	Wald	df	Sig.	Exp(B)	95% CI
Hypothyroidism	1.013	0.438	5.349	1	0.021	2.754	1.167-6.500
Bipolar Disorder	1.081	0.539	4.024	1	0.045	2.946	1.025-8.469
Personality Disorder	1.731	0.756	5.241	1	0.022	5.644	1.283-24.832
Intermittent Explosive Disorder	1.705	0.850	4.022	1	0.045	5.500	1.039-29.101
Multiple Psychiatric Disorders	1.402	0.644	4.731	1	0.030	4.062	1.149-14.364
Constant	-3.047	0.616	24.499	1	-	0.048	-

Final logistic regression model with associated risk of crisis for each of the five factors. Having a personality disorder demonstrated the highest risk, as individuals with one were 5.6 times more likely to have been a crisis patient.

Table 5.4 Final Linear Probability Model

Factor	Coefficient	S.E.	t	Sig.	95% CI
Hypothyroidism	0.161	0.070	2.290	0.023	0.022-0.300
Bipolar Disorder	0.216	0.092	2.344	0.020	0.043-0.399
Personality Disorder	0.331	0.130	2.545	0.012	0.074-0.587
Obesity	0.119	0.058	2.045	0.042	0.004-0.233
Multiple Psychiatric Disorders	0.131	0.066	1.987	0.048	0.001-0.261
Constant	-0.007	0.058	-	-	-

Final linear probability model, which indicates that obesity may be a potential discriminating factor and replaces intermittent explosive disorder.

## Discussion

Our study both corroborated and contrasted previous studies that examined similar variables in relation to crisis. Kalb et al. examined 11 factors and their relation to psychiatric hospitalization for adults with IDD referred to a community-based crisis early intervention program. Similar to our study, they found that the presence of multiple psychiatric disorders was associated with higher risk of psychiatric hospitalization.<sup>14</sup> However, the investigators also reported increased risk associated with younger age, African-American/Black race, and less severe levels of intellectual disability, which were not significant risk factors in our study sample. Weiss et al. also found that individuals with mild or borderline intellectual disability went to the emergency department for crisis stabilization more often than those with moderate or severe intellectual disability.<sup>118</sup> In a study comparing individuals who were and were not admitted for emergency inpatient psychiatric care, Painter et al. found significant differences in scores on a standardized risk assessment tool<sup>116</sup> for individuals with psychiatric and behavioral diagnoses, similar to our study findings.<sup>123</sup> In contrast to our findings, however, they also found that communication problems and living environment were significantly different in individuals who were hospitalized compared to those who were not. As each of these studies used hospitalization as an outcome rather than the crisis episode itself, they do not provide a direct comparison with our study, which may explain some of the variance in the findings.

As demonstrated, previous studies on factors related to crisis have produced mixed results. One of the reasons is most likely due to the heterogeneity of the IDD population. Although they are often grouped together in research, individuals with IDD incorporate a wide range of diagnoses with even more variability within those diagnostic categories. In our study sample, there were 31 separate neurodevelopmental diagnoses, not including

those who did not have an identified diagnosis. Our sample also differed from other studies in regard to the distribution of intellectual disability severity, with greater balance across categories, while previous studies have tended to be biased toward one end of the spectrum. Therefore, if study samples are highly variable across factors such as intellectual disability severity, age, neurodevelopmental diagnoses, or living environment, they may not be comparable populations.

Mobility and communication status were two of the variables of high interest for consideration in our model due to their high relevance to clinical practice. Mobility status has been correlated with health outcomes, and mobility deficits are routinely treated by physical therapy.<sup>165</sup> However, there is no standard for classifying mobility levels for research related to individuals with IDD.<sup>166</sup> Therefore, we classified mobility status as both a binary (ambulatory vs. non-ambulatory) and categorical (independently ambulatory, ambulates with assistant, household ambulator, primarily non-ambulatory) variable. Neither classification yielded statistical significance, however the categorical classification with four stratification levels did approach significance ( $\chi^2=7.267$ ,  $p=0.064$ ). This may have been due to our study being underpowered, as the majority (81%) of the study participants were independently ambulatory, likely due to the primarily community-based nature of our study population. Individuals with more complex health needs, which correlates to ambulatory status, are more likely to be institutionalized and therefore may have been underrepresented in our sample.<sup>151</sup> Future research is needed to investigate the effects of mobility status on risk for crisis, along with more standardized methods for classification.



Likewise, we were interested in assessing the impact of communication status on risk of crisis. Deficits in verbal communication have been shown to negatively influence health and quality of care.<sup>84,167</sup> Challenging behavior is also correlated with communication deficits, as challenging behavior can be the result of frustration from an inability to effectively communicate needs.<sup>142</sup> However, communication status was not found to be statistically associated with crisis in our sample ( $\chi^2=0.213$ ,  $p=0.645$ ) and the prevalence of communication deficits was similar in crisis (39%) and non-crisis (43%) patients. Communication disorders have been reported to be more prevalent in individuals with greater severity of intellectual disability.<sup>168,169</sup> Individuals with severe or profound intellectual disability represented less than one third of our study sample, therefore, we may have been underpowered to detect small differences between the two groups.

Communication is also complex. We used a binary designation (fully verbal vs. limited/non-verbal) due to the fact that not every patient received speech therapy services so the level of detail in the health records regarding speech and language development was variable. The categorization of communication status may need further refinement, and stratification by specific speech and language components (e.g. receptive language, articulation, social communication, access to alternative and augmentative communication, etc.) may more effectively elucidate a relationship between communication status and crisis risk. Other non-psychiatric factors of clinical relevance (e.g. obesity and diabetes mellitus) also came close to reaching statistical significance, but ultimately fell out of our final model. Like mobility and communication status, future research with a larger sample size may provide sufficient power to detect potentially smaller risk differences.

It is also important to note that while our classification of communication status needs further refinement, we were unable to collect any data regarding the communication competence and strategies of caregivers, providers, or emergency response personnel that are involved during situations that can escalate to crisis episodes. Poor communication and the lack of knowledge about de-escalation techniques on the part of caregivers and care providers can make stressful situations worse or create an environment that is ripe for crisis behavior.<sup>119,120</sup> These factors may influence crisis experiences and need to be further explored.

Perhaps the most significant finding of our study was the identification of hypothyroidism as a risk factor for crisis. To the best of our knowledge, our study is the first to demonstrate a relationship between crisis risk and hypothyroidism for adults with IDD. Neuropsychological deficits have been well documented in individuals with impaired thyroid function, including issues with executive function, memory, attention, concentration, mood, and expressive language.<sup>170,171</sup> It is reasonable to suggest that these deficits can all interfere with adaptive functioning and the ability to handle potentially stressful situations, thus leading to crisis episodes.<sup>19,112,140</sup> These symptoms are largely observed to be reversible with appropriate treatment to bring thyroid hormone levels to normal ranges.<sup>171,172</sup> However, individuals with IDD can have altered metabolism that can affect pharmacological treatment effectiveness.<sup>173</sup> Medication adherence is also a concern, which can impact the maintenance of therapeutic hormone levels.<sup>174-176</sup> While our data is preliminary, it does suggest that close monitoring of thyroid function and awareness of the symptoms of hypothyroidism may play an important role in reducing crisis risk.

### *Limitations*

There are limitations to consider when interpreting the results of this study. Using data from health records are subject to missing variables or errors, which could confound the findings. The use of a single clinic may also only reflect the experiences of those patients and not be generalizable to a larger IDD population. However, the comprehensive nature of the clinic adds strength to our findings, as health-related information was available across multiple disciplines. As previously noted, our study may have been underpowered to detect small differences between the two groups, and the classification of some of the study variables may have affected the results. As this study was exploratory in nature, additional significant factors may be missing from our final model.

### **Conclusions**

Managing the health of individuals with IDD is complex and multifactorial. Although physical therapists are not routinely involved in crisis management, they are likely to encounter patients who are at risk for experiencing crisis episodes. Early identification and referral may help mitigate the effects of crisis on treatment plans. Our study found that hypothyroidism, bipolar disorder, personality disorder, intermittent explosive disorder, and having multiple psychiatric diagnoses all increased the likelihood of experiencing crisis for adults with IDD. Future research with individuals with IDD is needed to develop quick, feasible screening tools for physical therapists and other rehabilitation clinicians to use to identify and refer patients experiencing crisis.

## CHAPTER 6 SUMMARY

This dissertation had three main purposes. The first purpose was to operationalize a comprehensive definition of acute crisis for individuals with IDD using expert opinion from a multidisciplinary team. The next purpose was to assess the crisis-related events identified in the operational definition for their appropriateness as proxy variables for crisis. The third purpose of this dissertation was to identify additional potential risk factors for crisis episodes for individuals with IDD.

### *Hypothesis and Findings for Aim 1*

Hypothesis 1: It is hypothesized that the proposed crisis-related events and the proposed full definition will have moderate to high agreement (median rank for each subscale  $>5$  and  $IQR \leq 3$ ) among experts across disciplines.

Finding: The hypothesis was accepted, as median rank for the overall definition and each component were 6 or greater and IQR was  $<3$ .

### *Hypothesis and Findings for Aim 2*

Hypothesis 2: The crisis-related events identified in Aim 1 will have  $OR >2.0$ .

Finding: The hypothesis was accepted. Each of the four crisis-related events reached statistical significance, with ORs between 3.4 and 13.86.

### *Hypothesis and Findings for Aim 3*

Hypothesis 3: The identified crisis cases will have higher exposure to certain variables ( $OR \geq 2.0$ ) than non-crisis cases.

Finding: The hypothesis was accepted. Five significant risk factors for crisis were identified: hypothyroidism, personality disorder, bipolar disorder, intermittent explosive disorder, and having more than one psychiatric disorder.

### **Synthesis and Application of Results**

The overall purpose of this dissertation was to define a comprehensive definition of crisis for individuals with IDD and then identify clinically relevant risk factors to ultimately improve screening and referral practices of physical therapists and other rehabilitation professionals. First, an operationalized definition of crisis specific to this population needed to be determined. We added four objectively measurable components to a standard definition that we hypothesized were common crisis-related events experienced by adults with IDD: (1) unplanned hospital utilization, (2) involvement with the police or criminal justice system, (3) unplanned changes in living environment, and (4) abuse/victimization. This definition was developed through surveying expert clinicians and administrators who work with individuals with IDD:

“A response to stressful life events that interferes with a person’s ability to manage their daily activities and may result in one or more of the following outcomes: emergency department visit or unplanned hospitalization, involvement of law enforcement or the court system, unstable living environment/placement, or victimization or abuse. A crisis may be emotional, physical, medical, behavioral, psychiatric or situational and carries with it the risk of recurrence of these outcomes if left unresolved.”

The definition and its components all had high agreeability among our survey participants. The concept of recurrence was added to the definition based on the input provided by the

participants. We felt that it captured the risk and cyclic nature of crisis and helped to differentiate it from isolated, non-crisis incidents.

At that point, while we had an agreed-upon crisis definition, we did not know if the crisis-related events that we added actually occurred in patients receiving crisis management services. Therefore, the definition that was developed using multidisciplinary expert input in Specific Aim 1 was assessed for validity using health records from a metropolitan specialty care clinic. A total of 185 patient records were analyzed, which included 41 patients who received crisis management services and 144 patients who did not. The four crisis-related events identified in the new definition were found to occur significantly more often for crisis patients than for non-crisis patients, thus supporting our hypothesis. The risk for unplanned hospital utilization was 3.4 times higher for crisis patients. The risk for involvement with the police or criminal justice system was 13.86 times higher for crisis patients. The risk for abuse and/or victimization was 6.21 times higher for crisis patients. The risk for unplanned change(s) in living environment was 12.7 times higher for crisis patients. Overall, 90% of crisis patients experienced at least one of the four crisis-related events during the study period, compared to 54.2% of non-crisis patients. These events not only occurred more frequently for crisis patients, but the average number of occurrences was also higher for crisis patients, supporting our addition of risk of recurrence to the final definition.

Finally, having validated our new crisis definition, we were also interested in examining any additional risk factors for crisis for adults with IDD that may have clinical relevance for physical therapists and other rehabilitation clinicians. These were assessed using the same sample of 185 specialty care clinic patients. Five risk factors were identified

that increased crisis risk: hypothyroidism, bipolar disorder, intermittent explosive disorder, personality disorder, and have multiple psychiatric disorders. Additional analysis using linear probability modeling also indicated obesity as a potential discriminating factor. No statistically significant differences were found between crisis and non-crisis patients for intellectual disability severity level, mobility status, communication status, age, race/ethnicity, or living environment. To the best of our knowledge, the identification of hypothyroidism as a potential crisis risk factor was a novel discovery not previously reported in the literature.

The findings of this dissertation have multiple implications for clinical practice and add to the body of knowledge regarding crisis experiences for individuals with IDD. First and foremost, over a fifth of our study sample (22%) utilized formal crisis management services during the study period. This suggests that crisis episodes are common in the IDD population. As the majority of individuals with IDD are community-dwelling and life expectancy continues to increase, the likelihood of physical therapists encountering adults with IDD in clinical practice will subsequently increase.<sup>151,152,177</sup> However, physical therapists and physical therapy students routinely report feeling unconfident and uncomfortable treating individuals with disabilities, including individuals with IDD.<sup>105,106</sup> There is a need, then, to improve clinician confidence and skills to ensure that individuals with IDD receive optimal care, especially into adulthood. The findings of these studies provide foundational knowledge and point toward trends in crisis experiences that can help guide physical therapists and other rehabilitation clinicians in their clinical decision-making when patients display concerning, atypical behavior.

## **Future Research**

The studies conducted were exploratory in nature, as little previous research and literature existed with regards to crisis experiences, outcomes, and risk factors for individuals with IDD, especially with regard to physical therapy and rehabilitation in general. The findings of this dissertation, therefore, provide a foundation from which multiple research questions can be asked. The use of retrospective health records was justified for this dissertation given the constraints, but future research would benefit from a prospective design with standardized protocols for collecting and recording risk factor and crisis information. This could be accomplished as a part of a clinic policy procedure or quality improvement project, and data could be routinely collected during normal appointments.

The findings of this dissertation point toward three main focus areas for future research: (1) surveillance, (2) screening, and (3) intervention. Surveillance efforts could be greatly improved with the addition of our four crisis-related events. Tracking their occurrences can point toward trends over time, as well as provide another way of measuring the effectiveness of crisis interventions to see if these occurrences reduce as a result. Economic analyses of cost benefit and effectiveness could also be made to gauge the overall impact of crisis and intervention strategies.

The second focus area for future research is in improving screening methods. There currently exist no short, simple screening tools for crisis risk that would be feasible and accessible for physical therapists and other rehabilitation clinicians to use in day-to-day clinical care. By establishing a preliminary set of risk factors, this dissertation provides a starting point to develop quick screening assessments or clinical decision-making tools that could alert therapists to increased risk for crisis in their patients. By increasing awareness,



it would hopefully improve early referral to essential services (e.g. case management, psychiatric/behavioral, etc.) and decrease crisis risk. This would also potentially improve treatment outcomes as it may lead to fewer disruptions in care and allow patients and their caregivers to focus on treatment goals instead of allocating time and resources toward managing crisis situations. Providing useful screening tools for therapists may also improve confidence and skill in treating adults with IDD, as it would help manage some of the complexity involved in providing care.

The third focus area for future research is in developing therapy-specific interventions to improve crisis outcomes and reduce crisis incidents. Currently, no studies exist that exam the relationship between therapeutic intervention and crisis-related factors. Physical, occupational, and speech therapy can all help strengthen adaptive function, provide environmental modification, improve communication, and increase physical activity to provide a positive outlet for stress. These could be important components to reduce crisis risk for this population. This would also provide much-needed understanding of the effect therapeutic intervention has on more distal outcomes as opposed to proximal effects such as strength, balance, and function.

Future research would also greatly benefit by mixed-methods approaches that incorporate the perspectives of individuals with IDD, their caregivers, support staff, and other healthcare providers and administrators. The crisis experience is complex, and quantitative data can only provide so much information. The data that was abstracted from the medical records for this dissertation provided a wealth of valuable information, but qualitative data would have provided even richer context and strength to the quantitative data we found. For example, while we quantified the frequency of hospitalizations,

gathering information about those hospital visits from individuals with IDD and their caregivers and healthcare providers can provide useful information about the efficiency and effectiveness of the care received or whether individuals were treated respectfully and appropriately.

Ultimately my goal is to improve screening and intervention for individuals with disabilities and to expand understanding of how psychosocial factors can affect and be affected by physical therapy and other therapeutic interventions. This dissertation provides a strong foundation from which to continue to explore the complexity of health and healthcare for a population of high need that is often overlooked.

## APPENDICES

## **APPENDIX A. CRISIS DEFINITION SURVEY QUESTIONNAIRE**

### **Defining Acute Crisis for Persons with IDD**

#### **Consent Statement**

Q1 To Participant: You are being invited to take part in a research study about determining a comprehensive definition of acute crisis as it pertains to adults with intellectual and developmental disabilities. You are being invited to take part in this research study because of your expertise in working with persons with intellectual and developmental disabilities. Although you will not get personal benefit from taking part in this research study, your responses may help us understand more about understanding of the needs of persons with intellectual and developmental disabilities (IDD) who experience episodes of crisis. In addition, the results of the study may help to inform future research as well as improve interventions tailored to persons with IDD. We hope to receive completed questionnaires from about 20-30 people, so your answers are important to us. Of course, you have a choice about whether or not to complete the survey/questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time. The survey/questionnaire will take about 15 minutes to complete. You will not be paid to participate in this research study. There are no known risks to participating in this study. Your response to the survey is anonymous which means no names will appear or be used on research documents, or be used in presentations or publications. The research team will not know that any information you provided came from you, nor even whether you participated in the study. Please be aware, while we make every effort to safeguard your data once received from the online

survey/data gathering company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company's servers, or while en route to either them or us. It is also possible the raw data collected for research purposes may be used for marketing or reporting purposes by the survey/data gathering company after the research is concluded, depending on the company's Terms of Service and Privacy policies.

If you have questions about the study, please feel free to ask; my contact information is given below. If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428.

Thank you in advance for your assistance with this important project.

Sincerely,  
Kathleen Sutton  
Department of Rehabilitation Sciences  
College of Health Sciences  
University of Kentucky  
PHONE: 859-218-0580  
E-MAIL: kathleen.sutton@uky.edu

---

Q2 Do you consent to participating in this survey?

- Yes
- No, I do not wish to participate

## Demographic Information

Q3 Are you 21 years old or older?

Yes

No

---

Q4 What is your gender?

Male

Female

Prefer no to answer

---

Q5 What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
  - High school graduate (high school diploma or equivalent including GED)
  - Some college but no degree
  - Associate degree in college (2-year)
  - Bachelor's degree in college (4-year)
  - Master's degree
  - Doctoral degree
  - Professional degree (JD, MD)
- 

Q6 Which of the following best describes your job title:

- Clinical
  - Administrative
  - Other
- 

Q7 What is your job title? (Optional)

---

Q8 How many years of experience do you have working with persons with intellectual and developmental disabilities (IDD)?

- <1 year
- 1-2 years
- 3-5 years
- 6-10 years
- 11-15 years
- 15+ years

End of Block

---

## **Crisis Definition**

Q9 Current research on crisis in persons with IDD often relies on ad hoc or vague definitions of what constitutes a crisis situation. This study aims to more objectively define acute crisis in order to improve assessment, surveillance, and intervention methods for persons with IDD who may be at risk for crisis. By "acute crisis" we aim to define those situations which represent the "worst case scenarios" that result from such an event.



---

Q10 Acute crisis is defined as “a response to stressful life events that may interfere with a person’s ability to manage their daily activities that result in one or more of the following: emergency department visit or unplanned hospitalization, involvement of law enforcement or the court system, unstable living environment/placement, or victimization or abuse. A crisis may be emotional, physical, medical, behavioral, psychiatric or situational.” How strongly do you agree with this definition?

- Strongly disagree
  - Disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Agree
  - Strongly agree
-

Q11 Based on the definition above, how strongly do you agree that the following situations describe acute crisis for persons with IDD?

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly Agree
Emergency Department visit or unplanned hospitalization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Involvement of law enforcement or the court system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unstable living environment/placement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Victimization/abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q12 Are there other situations not previously mentioned that you believe to be related to an acute crisis for persons with IDD? Please list any/all of these situations:

---



---



---

**APPENDIX B. DATA ABSTRACTION TEMPLATE**

**Subject #:** \_\_\_\_\_

**Age:** \_\_\_\_\_

**Gender:**

- Male
- Female
- Unable to determine or missing

**Race/Ethnicity:**

- Non-Hispanic White/Caucasian
- Black/African-American
- Asian
- Native American/Pacific Islander
- Hispanic/Latino
- More than one race/ethnicity
- Missing or unable to determine

**Neurodevelopmental Diagnosis:** \_\_\_\_\_

**Co-morbid Diagnoses:**

Neurological

- Epilepsy
- Ataxia/Movement disorder
- Parkinson’s Disease
- Dementia/Alzheimer’s
- Sensory Processing Disorder
- Chronic pain
- Chronic fatigue

Cardiovascular

- Hypertension
- COPD
- Asthma
- CHF
- Anemia

Endocrine/Metabolic

- Diabetes
- Dyslipidemia
- Hyponatremia
- Hypokalemia
- Obesity

Psychiatric/Behavioral

- Bipolar
- Borderline Personality Disorder
- Anxiety
- Depression
- Schizophrenia
- Conduct Disorder
- ADHD
- Impulse Control Disorder
- Autism

- Uninsured

**Other Systems**

- Chronic kidney disease
- Liver disease
- GERD
- Other GI disease
- Cancer
- Integumentary disorder
- Osteoporosis
- Osteopenia
- Arthritis
- Other:

**Living Environment:**

- Independent
- With family
- Roommate/Spouse (not staffed residence)
- Group home/FHP (staffed residence)
- ICF/ID
- Guardian:

**Waiver Status:**

- None
- Michelle P.
- SCL

**Insurance:**

- Medicaid
- Medicare
- Private

**Unplanned Hospitalization:**

- No
- Yes – Date(s): \_\_\_\_\_

Description:

**Involvement with Police/Justice System**

- No
- Yes – Date(s): \_\_\_\_\_

Description:

**Communication Status:**

- Verbal
- Non-verbal
- Communication device
- Description:

**Severity of Intellectual Disability:**

- Mild
- Moderate
- Severe
- Profound

**Mobility Status:**

- Primarily non-ambulatory
- Household ambulator
- Ambulates with assistance
- Ambulates independently

**Services**

- Dentistry
- General Medicine
- Neurology
- Behavior Analysis
- PT
- OT
- Speech
- Psychology
- Psychiatry
- Podiatry
- Nutrition
- Audiology
- Endocrinology
- Crisis

**Abuse/Neglect/Victimization**

No

Yes – Date(s): \_\_\_\_\_

Description:

**Unplanned Changes in Living Environment**

No

Yes – Date(s): \_\_\_\_\_

Description:

## APPENDIX C. POTENTIAL RISK FACTOR VARIABLES

Variable	Chi-square	df	p-value
Seizure Disorder	1.796	1	0.180
Ataxia/Movement Disorder	0.660	1	0.416
Parkinson's Disease	0.019	1	0.890
Dementia	0.449	1	0.503
Sensory Processing Disorder	0.007	1	0.934
Chronic Pain	0.498	1	0.480
Chronic Fatigue	2.071	1	0.150
Diabetes Mellitus	5.404	1	0.020*
Dyslipidemia	0.424	1	0.515
Hyponatremia	1.766	1	0.184
Hyperprolactinemia	0.906	1	0.341
Obesity	8.596	1	0.003*
Vitamin D Deficiency	2.856	1	0.091
Hypothyroidism	7.611	1	0.006*
Hypertension	1.294	1	0.225
COPD	0.177	1	0.674
Asthma	5.087	1	0.024*
Sleep Apnea	0.361	1	0.548
Congestive Heart Failure	1.837	1	0.175
Anemia	0.361	1	0.548
Arrythmia(s)	0.082	1	0.775
Bipolar Disorder	8.899	1	0.003*
Personality Disorder	14.024	1	<0.001*
Anxiety	0.052	1	0.820
Depression	0.017	1	0.896
Schizophrenia	0.181	1	0.671
Conduct Disorder	4.762	1	0.029*
ADHD	1.343	1	0.247
Impulse Control Disorder	7.260	1	0.007*
Autism Spectrum Disorder	0.257	1	0.612
PTSD	2.389	1	0.122
OCD	0.034	1	0.853
Psychogenic Polydipsia	0.262	1	0.609
Chronic Kidney Disease	0.109	1	0.742
Liver Disease	1.423	1	0.233
GERD	2.237	1	0.135
Other GI Disease	0.636	1	0.425
Dysphagia	0.044	1	0.833
Cancer	1.463	1	0.226
Integumentary Disorder(s)	0.235	1	0.628

Osteoporosis	0.545	1	0.460
Osteopenia	0.118	1	0.731
Arthritis	3.505	1	0.061
Chronic Constipation	0.033	1	0.856
Allergic Rhinitis	0.660	1	0.416
Tobacco Abuse	0.839	1	0.360
Living Environment	2.482	5	0.779
Guardianship Status	0.641	3	0.887
Insurance	6.347	5	0.274
Neurodevelopmental Diagnosis	5.054	5	0.409
Visual/Hearing Impairment	4.492	1	0.034*
Intermittent Explosive Disorder	5.161	1	0.023*
ODD	1.164	1	0.281
Sleep Disorder	0.019	1	0.890
Genitourinary Disorder(s)	2.723	1	0.099
Mobility Status	0.037	1	0.847
Communication Status	0.213	1	0.645
Any Psychiatric Disorder	4.158	1	0.041*
Multiple Psychiatric Disorders	10.375	1	0.001*
More than 3 Psychiatric Disorders	9.294	1	0.002*
10 or More Comorbidities	5.289	1	0.021*

\*p<0.05, factor considered for final regression model

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## VITA

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### **Education**

#### **University of Kentucky**

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#### **University of South Florida**

Master of Public Health – August 2014

#### **Bellarmine University**

Doctor of Physical Therapy – May 2010

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### **Academic Experience**

#### **University of Kentucky**

Course Assistant – Department of Physical Therapy  
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#### **Bellarmine University**

Adjunct Professor – Department of Physical Therapy  
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### **Additional Professional Experience**

Frazier Rehabilitation Institute

Bardstown, KY

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Florida Hospital Tampa

Tampa, FL

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Brandon Regional Hospital

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Taylor Regional Hospital

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### **Professional Publications**

**Sutton K**, Kitzman P, Hunter E, Hudson K, Wallace C, Sylvia V, Brock J. Engaging individuals with neurological conditions and caregivers in rural communities in a health research team. *Progress in Community Health Partnerships*. 2019;13(2):129-139.

**Sutton K**, Kitzman P, Hunter E, Logsdon B, Santella B. The role of physical therapy in addressing modifiable risk factors in stroke survivors: a scoping review. *Journal of Geriatric Physical Therapy* (in press)

Kitzman P, **Sutton K**, Wolfe M, Bellamy L, Dobbs M. The prevalence of multiple comorbidities in stroke survivors in rural Appalachia and the clinical care implications. *Stroke* (in press)