A Dissertation by

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Submitted to the Department of Psychology
and the faculty of the Graduate School of
Wichita State University
in partial fulfillment of
the requirements for the degree of
Doctor of Philosophy

May 2019
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To my wonderful family, Jacob, Diana, and Jerry.
ACKNOWLEDGEMENTS

I would like to thank my truly inspirational and unforgettable mentor and advisor, Dr. Rhonda Kay Lewis, for her guidance, encouragement, and continued belief in my abilities. Thank you to my friends and colleagues who I met at CEI, for all the support and encouragement to pursue this dream and the extra push to continue on this journey. Thank you to my boss, colleague, and mentor Tara Gregory for being supportive, patient and kind throughout this process and always believing that in me. Thank you to all of my family members— Jacob, Mom, Dad, Katie, and Maranda—I love you all so, so much. I could not have done this without you.
ABSTRACT

Trauma is a public health epidemic. Adverse Childhood Experiences are extremely common throughout the general population and trauma incident reports jump from 25% to 80% when comparing the general population to the I/DD community. Trauma is also common throughout many different provider populations, including the helping professions. However, there has not been much research outside of child welfare and social workers. This study examined the expression of trauma on the individual and organizational levels and how that impacted the I/DD system. The purpose of this dissertation is to examine how trauma expresses itself at the individual and organizational level of persons and systems that interact and work with persons with Intellectual and Developmentally Disabilities (I/DD). It is also intended to examine if and/ or how trauma impacts the I/DD system as a whole.

A review of persons with I/DD’s records was conducted as well as focus groups with parents/ guardians, and providers, and an organizational assessment using the ProQoL. To provide context, interviews with the researchers who conducted the original studies were also conducted. Concurring with previous research, there was a high rate of trauma present in persons with I/DD and also within the I/DD providers. An unexpected finding was that the I/DD system impacted both persons with I/DD, parents/ guardians, and providers within the system. Results were consistent with the limited previous research on the I/DD community. Future research should further examine the impact trauma has on the IDD community and determine system-wide changes to reduce that trauma that is occurring.
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Glossary

ACES- Adverse Childhood Experiences
APA- American Psychiatric Association
BH- Behavioral Health
CARE- Center for Applied Research and Evaluation
CDC- Centers for Disease Control
CDDDO- County Developmental Disability Organization
CEI- The Community Engagement Institute
CODC- Center for Organizational Development and Collaboration
DM-ID- Diagnostic Manual- Intellectual Disabilities
HCBS- Home and Community Based Services
I/DD- Intellectual/ Developmental Disabilities
IRB- Institutional Review Board
MRNs- Medical Record Numbers
PROQOL- Professional Quality of Life
PTSD- Post Traumatic Stress Disorder
SAMHSA- Substance Abuse and Mental Health Services
SCDDO- Sedgwick County Developmental Disability Organization
SPMI- Serious and Persistent Mental Illness
SSN- Social Security Number
STS- Secondary Traumatic Stress
TIC- Trauma Informed Care
CHAPTER 1

INTRODUCTION

Trauma is a serious public health issue in the United States. Trauma occurs in the home, school, the workplace and other places too. According to Fischer and Riedesser (1999) trauma is defined as “the experience of vital discrepancy between threatening factors in a situation and individual coping abilities.” Trauma can, and for some does, begin in childhood. When that occurs, a person is said to have experienced an Adverse Childhood Experience. These Adverse Childhood Experiences (ACES) have a high reporting rate with over 25% of people reporting one ACE before the age of eighteen with the reports including one incident (CDC, 2016). Within the Intellectual and Developmental Disability Community (I/DD) community, the reporting rate for abuse and neglect jumps up to 80%, with each ACE report including three or more different incidents (Hulbert-Williams et al., 2008). The purpose of this dissertation is to examine how trauma expresses itself at the individual and organizational level of persons and systems that interact and work with persons with Intellectual and Developmentally Disabilities (I/DD). It is also intended to examine if and/or how trauma impacts the I/DD system as a whole.

I’m going to first address the definition of and research on trauma, followed by similar discussions of issues closely related to secondary trauma for I/DD providers, including burn out, compassion fatigue, STS, PTSD, individual risk and protective factors, the ecological framework of trauma, organizational risk and protective factors, and finally provide information about the partnering organization utilized in this dissertation. All of these elements are important in understanding the processes that contribute to the secondary trauma indicated within the individuals, organizations, and systems in this study.
Trauma

Trauma is a public health epidemic (Magruder, McLaughlin, & Borbon, 2017). It is an experience that is not only subjective to a person but also can be viewed objectively from outsiders in a given situation. We cannot think of trauma as just situational; it is, in fact, a psychological process that has long lasting effects on a person. This includes, but is not limited to: affecting a persons’ coping abilities, health outcomes, risk of pregnancy, and likelihood of substance abuse (CDC, 2016). Trauma occurs at all stages of life. When it occurs before the age of 18 it is known as an Adverse Childhood Experience (ACE).

Adverse Childhood Experiences (ACEs)

From 1995 to 1997 the Centers for Disease Control and Prevention (CDC) and Kaiser Permanente conducted a landmark study on Adverse Childhood Experiences (ACEs). This study looked at how experiencing identified childhood traumas impacted participants later in life (CDC, 2016). There were over 17,000 participants and the study was conducted in two waves. The ACE Study included only the ten most frequently mentioned childhood traumas from a sample of about 300 participants in the Kaiser-Permanente study. Each of these experiences was also well studied individually within the research literature (CDC, 2016). Researchers defined adverse childhood experiences as stressful or traumatic events that occur in childhood (before the age of 18). See Appendix A for the list of ACEs that were identified through this study.

The ACEs study found that ACEs are common. There was a high rate of reporting from participants for physical (28%) and sexual abuse (21%), for example. Approximately 23% of participants also reported having a parent with a mental and/or substance use disorder and 24.5% stated they were living in a home with divorced/separated parents (CDC, 2016). ACEs tend to
cluster, meaning if someone has one ACE they are most likely going to have another similar ACE. Over 60% of the surveyed population in the Kaiser-Permanente study (N=>17000) reported one or more ACE. “Nearly 40% of the Kaiser sample reported two or more ACEs and 12.5% experienced four or more” (SAMHSA, 2018).

While ACEs are a concern in themselves, as the number of ACEs increase, the risk for the following increases as well:

- Alcoholism and alcohol abuse and illicit drug use
- Chronic obstructive pulmonary disease, ischemic heart disease, & liver disease
- Depression, suicide attempts, poor work/academic performance, & financial stress,
- Fetal death, unintended pregnancies, STDs, and adolescent pregnancy,
- Health-related quality of life, early initiation of smoking, and smoking,

Knowing that these health problems are more likely to be related in persons with ACES, research has been done on the actual development of these risk factors as well. ACEs have a dose-response relationship with many health problems (SAMHSA, 2018). The literature shows that a person’s cumulative ACEs score had a strong relationship to numerous health and behavioral problems throughout their life; many of these problems tend to be comorbid or co-occurring (SAMHSA, 2018). This includes the previously listed risk factors and more. (CDC, 2016). See Appendix B for a visual representation.

Adverse Childhood Experiences play a role in how, as adults, trauma is expressed and dealt with. Unresolved or unrecognized trauma can affect clients, staff, organizations, and system structures. Unresolved trauma or consistent re-traumatization can impact everyday life as well.
Re-traumatization is not necessarily experiencing the same trauma over and over again but rather experiencing events that are traumatizing, which can feel similar and have the same effects as a previous traumatic incident (SAMHSA, 2018). In work, it could turn into burnout or secondary traumatic stress which can bleed into personal life. One of the more common forms of ACEs and trauma in a workplace is staff burnout.

**Burnout**

Burnout is a prominent issue throughout the helping professions and may directly affect the mental health and public health of individuals, organizations, and systems. Staff burnout is defined as "emotional exhaustion, depersonalization, and reduced personal accomplishment . . ." [occurring in response to] "...the chronic emotional strain of dealing extensively with other human beings, particularly when they are troubled or having problems" (Maslach 1982). Simply put, it is when people who love/like their job no longer feel any joy whatsoever in it. They are exhausted, disconnected, and constantly drained when they go to work; they are burnt out.

The Center for Victims of Torture (2016) defines burnout as an element of compassion fatigue and that it is associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. They state that these feelings have a gradual onset. That is, a person does not just suddenly burnout but rather, there is a build-up of incidents and experiences that cause a person to feel the effects of burnout. It is hypothesized to be associated with a high-case load or a non-supportive work environment (Center for Victims of Torture, 2016).

Staff burnout can also be conceptualized as an organizational outcome. Scott and Shortell (1988) state that the impact that the organization’s processes and features have on their outcomes
can present as an issue of effectiveness for that organization. That is, higher levels of burnout can mean a lower rate of effectiveness for an organization. There are many theories that attempt to examine this type of impact. Theories such as the population ecology model described by Hannan & Freeman (1977), which explores the rise and fall of different organizations within a set population, attempt to explain staff burnout by positing the notion that an individual organization (A) could have a different branch of the same organization (A1) and that branch (A1) can be absorbed or taken over by the main organization (A). This could result in a redefined main organization that has taken on more cases per staff member, staff from the branch organization (A1), and possibly more funding issues while they attempt to absorb new staff and an increased clientele. In I/DD staffing, the absorption of another branch of an organization or an associated organization can mean that workers are handed more cases (more difficult cases), working longer, and/ or not receiving any extra benefits including increased pay.

When looking at staff burnout, both direct and indirect factors influence work satisfaction. Direct influences are things like the severity of the client’s case. Indirect influences include organizational policies that impact the number of cases a person has and the amount of time a staff member has away from their job (Schaufeli et al. 1996). This can be seen in professions such as those serving persons with serious and persistent mental illness (SPMI) or those serving persons with intellectual/ developmental disabilities (I/DD) (Schaufeli et al. 1996). Research also shows that staff burnout can be attributed to other personal factors. It has most often been attributed to the interpersonal relationships that caregivers/ staff members develop with those they serve. These relationships tend to be emotionally demanding and unbalanced in nature (Schaufeli et al. 1996). Throughout human service organizations, burnout has been shown to be especially severe.
There is a large body of literature that examines burnout within a variety of professions including social workers and child welfare workers. However, not a lot of research has been conducted with persons who work with the I/DD community. According to Horwitz (2006), there is a clear indication that helping professions such as child welfare workers are exposed to a variety of workplace events that could negatively impact the worker. These persons listen as clients describe facts and feelings that are related to emotions such as depression, anger and loss. Specifically, child welfare workers work in clients’ homes, schools and communities and have a frontline view of the deprivation and abuse that permeate their clients’ lives (Horwitz, 2006). The devastation that occurs when child welfare workers are unable to provide services that their clients clearly need is prominent throughout the system (Horwitz, 2006). Similar effects could be occurring with staff members who work with the I/DD community. These staff members also tend to experience loss, observe abusive situations, and/or are stuck in a system that does not allow them to provide all the services their clients might need. With these similarities, it would not be a far stretch to assume that staff members of the I/DD community experience similar feelings of burnout as child welfare workers.

Adams et al. (2006) conducted a study with social workers who worked in trauma recovery with victims post 9/11 looking at the burnout rate of these social workers. They looked at several factors to determine if they would protect against burnout. The factors were marriage, years of professional counseling, and having a supportive environment. Only having a supportive environment was significant. It was also found that the social workers were at a high risk of burnout due to higher case load and interacting with traumatized populations from 9/11 (Adams, 2006).
The 9/11 research study was the first of its kind in this population and appears to support the theory that mental health professionals are more at risk for compassion fatigue, which is closely tied to burnout (Adams, 2006). The Center for Victims of Torture defines compassion fatigue as a combination of burnout and secondary traumatic stress. This means that a person would feel depersonalized, stretched too thin, over worked, and experience a sense of second-hand trauma that contributes to a person not finding joy with their work. Adams suggests that mental health professionals are not the only persons that can experience burnout or even secondary traumatic stress. Instead, they are stating that the important variables in predicting compassion fatigue may include the degree of exposure to a trauma or secondary trauma, a person’s history, their social support, and environmental factors (Adams, 2006). These are predictor variables that may likely have an effect amongst lay caregivers as well (Adams, 2006). Overall, burnout is a complex concept on both an individual and organizational level but it is a vital determinant in retaining staff in the helping professions. Thus, more research is needed to determine the sorts of components that will be helpful to individuals and organizations.

**Secondary Traumatic Stress**

Secondary traumatic stress is similar to burnout. Where burnout is related to job stress and emotional exhaustion, secondary traumatic stress is more related to the exposure to stressful events and what affects that has on the person. Secondary Traumatic Stress (STS) is a component of compassion fatigue (a disinterest, lack of joy in one’s job) and is related to vicarious trauma (repeatedly listening to traumatic events). Within the I/DD system, a direct care provider having to report and handle neglect and abuse cases for clients that use I/DD services is an example of
possible STS. The repeated trauma that clients share with direct service providers could possibly build up and create some level of STS for the provider.

While the exact percentage of persons living with STS is not known, it is assumed to be high both within the general population and subpopulations such as social workers. This is because exposure to trauma is 40-81% overall, with 60.7% of men and 51.2% of women being exposed to one or more traumas and 19.7% of men and 11.4% women being exposed to three or more traumas (Kessler, Sonnega, Bromet, & Nelson, 1996). While the national prevalence rate is high, it is higher in subpopulations such as psychiatric patients. Davidson & Smith (1990) found that 94% of outpatient mental health consumers reported a history of trauma with 31-42% fitting the PTSD criteria.

Professionals who work with traumatized populations can display a lot of the same symptoms as the people they serve. The length and severity of the professional’s STS varies person by person. If a professional has had personal trauma in their lives, they are more likely to experience STS symptoms than if they did not have their own trauma experience. There is also a difference based on sex; women are more likely to exhibit symptoms than males (Beaton & Murphy, 1995)

Some of the most common symptoms experienced by helping professions after being exposed to STS situations include: sleep, anger, fear, suppression of emotions, nightmares, flashbacks, irritability, anxiety, alienation, feelings of insanity, loss of control, and suicidal thoughts (Beaton & Murphy, 1995). While the severity and length of STS symptoms vary by person, researchers have found a positive correlation between length and severity of STS symptoms and longevity of career, large caseloads, increased contact with clients, and long work hours (Dunning & Silva, 1980). Ultimately meaning, the more symptoms experienced the shorter
the career of the professional. This supports the notion that persons in the helping professions have a higher risk of succumbing to some level of STS. Another concern helping professionals have is STS combined with Post Traumatic Stress Disorder (PTSD). In the general population, PTSD affects approximately 6.8% of people at some point in their lives (APA, 1994). STS symptoms are very similar to those of post-traumatic stress disorder with certain forms of PTSD manifesting as STS. Thus, distinguishing the two can be very difficult. Research also shows that helping professions have a high risk of experiencing PTSD themselves (Dunning & Silva, 1980). PTSD combined with STS may also lead to higher rates of burnout.

People who are closest to the person who experience direct trauma are most at risk for PTSD or STS (American Psychiatric Association [APA], 1994). A person can be traumatized simply by learning about a traumatic incident resulting in PTSD and/or STS (Stamm, 1995). While everyone can be said to be at risk of being traumatized, those most at risk for being traumatized are the significant others of the primary victim. This includes family, friends, neighbors, work colleagues, and helping professionals who assist the primary victim (Figley & Kleber, 1995). A good example of this is social workers and the environment they work in.

A quantitative study conducted by Bride (2007) sampled 600 master’s level social work students to look at the prevalence of STS individual symptoms and if/ how frequently PTSD criteria is met. Individually they found that intrusive thoughts were the most frequently reported (Bride, 2007). This is consistent with the literature within helping professions. What is also interesting is that approximately a quarter of the respondents indicated having arousal and/ or sleep difficulty (Bride, 2007). Bride (2007) found that 45% of persons did not meet any criteria for PTSD. However, 55% met one criterion (a stressor, intrusion symptoms, avoidance, negative alterations in cognitions and mood, alterations in arousal and reactivity, duration, functional
significance, and exclusion), 20% met two criterions, and 15% meet all three core criterion (stressor, intrusion symptoms, and avoidance). It is important to note that this measure did not include all criteria for PTSD and is not meant to diagnose PTSD in participants. These findings are consistent with the literature in helping professions and is something that all providers must be wary of. Since PTSD and STS can be masked as one another it is important to address both to ensure that staff are minimizing their risk for burnout and further traumatization. This research indicates that over half of the sample met PTSD criterion suggesting that this is an organizational problem.

A meta-analysis conducted by Baird & Kracen (2006) reviewed the evidence on secondary traumatic stress. Each finding was categorized into one of three categories:  

“**Persuasive evidence** or evidence that was the most supportive of the findings– hypothesis is supported by a statistically significant finding in at least three-five studies. **Reasonable evidence** or evidence that was able to make a case for the findings but was not as strong as the previous category – hypothesis is supported by a statistically significant finding in at least two-seven studies. **Some evidence** where some evidence was present to support the findings but more evidence is needed to make a strong case for those findings– hypothesis is supported by a statistically significant finding in at least one-three studies.” For each topic examined, the results were mixed. They found some evidence that a personal history is linked to the likelihood of having vicarious trauma and of developing STS. There was also some evidence that it is NOT linked to developing STS. Baird & Kracen (2006) also found some evidence that exposure to traumatic client material is linked to vicarious trauma and persuasive evidence that it is linked to STS. There was also some evidence that perceived coping ability is a protective factor for STS (Baird & Kracen, 2006). Overall, the literature is mixed when it comes to STS but it is
acknowledged that helping professionals all experience some level of secondary traumatic stress. Those working in the I/DD community are no exception.

While the I/DD community is no exception to experiencing trauma, there is a gap in the literature showing this experience. In the previously cited studies, helping professions are grouped together but oftentimes refer to just mental health professionals (social workers) or medical professionals (nurses). There are minimal, if any, studies conducted specifically within the I/DD community that are directly related to secondary traumatic stress on an individual, organizational, and/or systemic level.

**Individual Risk Factors**

In a previous section, the risk and protective factors for children under eighteen who experience ACEs were addressed. For those over eighteen, risk factors for PTSD and for experiencing traumatic events are similar, if not the same. When looking at the literature, most note an overlap in the factors for both. Some risk factors for experiencing trauma include low socioeconomic status, minimal or lack of education, a low IQ, minimal or no social support, and a high level of life stress (Brewin, Andrews, & Valentine, 2000; Ozer & Weiss, 2004).

A meta-analysis of over 23 articles, most of which were about military personnel, concluded that the most common PTSD risk factors were: younger age, being of low SES, lack of education, having low intelligence, being a minority, having a psychiatric history, experiencing childhood abuse, family psychiatric history, the trauma’s severity, and lack of social support (Brewin, Andrews, & Valentine, 2000). When comparing the risk factors from the ACEs study to the PTSD risk factors, they overlap significantly.
The literature is lacking in the I/DD focus area related to trauma but it is growing slowly (Hulbert-Williams et al., 2008). From the research that is available, it shows that these risk factors tend to be particularly high within the I/DD community (Hulbert-Williams et al., 2008). Persons with I/DD report more instances of abuse and neglect than the non-I/DD population (Hulbert-Williams et al., 2008). Research shows persons with ACEs (such as abuse and neglect) are experiencing the risk factors noted above resulting in a higher rate of traumatic experiences (Hulbert-Williams et al., 2008).

Members of the I/DD community also face a unique set of challenges in mental health settings. This includes the use of mechanisms of restraint and ways to prevent violent behavior (Hulbert-Williams et al., 2008). When the use of physical and mechanical restraints are still a best practice with I/DD individuals, this produces an atmosphere to produce traumatic experiences and responses (Hulbert-Williams et al., 2008).

Providers also tend to fail to screen persons for traumatic experiences when doing assessments (Center for Substance Abuse Treatment, 2014). By not asking if a person has experienced trauma in the past, providers are missing the mark. However, once a screening is done and assessment is decided to be pursued, some providers only assess for symptomology. That is, what are the current symptoms that a person is experiencing that are related to trauma (i.e., nightmares, shaking, hyper-alertness) versus what and/or how trauma is impacting the person (i.e., substance abuse, poorer health outcomes) (Center for Substance Abuse Treatment, 2014). By assessing for trauma symptomology only, a dependency on traditional interventions, such as behavior management, occurs. This automatically excludes trauma informed care and other methods that may get to the root of the problem and address risk factors such as previous trauma in a nontraditional manner (Center for Substance Abuse Treatment, 2014). The traditional
methodology does not address the trauma-related behaviors the individual is experiencing nor meet their needs (Scotti et al., 2012). By not addressing the potential risk factors that come with a previously experienced trauma, re-traumatization can occur (Magruder, McLaughlin, & Borbon, 2017). Overall, within the I/DD community, risk factors are not adequately being addressed to prevent unnecessary trauma.

**Individual Protective Factors**

The main protective factor against trauma and PTSD/STS is level of resiliency. Resiliency can be defined as a “complex repertoire of behavioral tendencies” that are used to adapt to a person’s life events (Wilson and Agaibi, in press). Research states that resilience characterizes a style of behavior in which identifiable patterns of thinking, perceiving, and decision making varies across a variety of different types of situations. Level of resiliency can be thought of as a strength that protects persons from trauma. The higher the level of resiliency that a person has, the less likely that traumatic events will have a significant impact on them (Wilson and Agaibi, in press). Factors that lead to a high resiliency are higher intelligence, social support networks, impulse control, positive coping mechanisms, and higher levels of education (Fraser, 1997). There is much literature on both ACEs and in trauma/PTSD that show the importance of resiliency. Suggesting that while trauma may not be able to be completely prevented, its impact on a person can be. Where the literature lacks is in the specific area of I/DD, which this dissertation intends to attempt to address.
Intellectual/ Developmental Disabilities (I/DD)

The American Psychiatric Association (APA) defines I/DD as “a disorder in which impairments of general mental abilities that impact adaptive functioning in three domains, or areas.” Intellectual/ Developmental Disabilities (I/DD) affect approximately 1-10% of the population (APA, 2013). It is most accurately diagnosed in the early school years and developmental delay is the term often used in preschool years (WHO, 2015). There is also a biological link to I/DD on the X chromosome for some of the I/DD and a difference in sex ratio of 1.5:1, M: F (WHO, 2015). Each of these domains determine how well a person will cope with everyday tasks. The domains include a conceptual domain (language skills, math, reasoning, memory, etc.), the practical domain (self-management in personal care, money management, work tasks, etc.), and the social domain (empathy, ability to make and retain friendships, social judgements, etc.) (APA, 2013).

The American Psychiatric Association has also updated its diagnostic criteria for I/DD and it is listed in Appendix E.

Within the overall classification of I/DD, there is a breakdown of levels of severity of the disorder: Mild, Moderate, Severe, and Profound. With mild I/DD the IQ range is from 50-55 to 70, and approximately 85% of the I/DD community fall into this classification. These persons can live independently with minimum levels of support. The next level of severity is moderate I/DD with the IQ range of 35-40 to 50-55, and approximately 10% of the I/DD community fall into this classification. For these persons, independent living may be achieved with moderate levels of support- i.e. group homes. Next, there is severe I/DD with an IQ range of 20-25 to 35-40, and about 3.5% of the community is categorized here. These persons require daily assistance with self-care activities and safety supervision. Finally, the last classification is profound I/DD.
These persons have an IQ below 20-25, and only 1.5% of the community falls into this percentile. These persons require 24-hour care (WHO, 1968; NIH, 2015).
Trauma within the I/DD Community

Trauma is intertwined within mental health conditions and is directly related to PTSD symptoms as noted in the previous chapter. Within the I/DD community, this type of relationship with trauma is especially common. (Fletcher, Loschen, Stavrakaki, & First, 2007). The failure of providers to recognize and consider the major implications of trauma presented in the I/DD population is one of our greatest public health failures (Mitchell & Clegg, 2005). There has been much evidence that has linked negative life events to later presenting psychological issues (Hulbert-Williams et al., 2008) and their trauma responses (Wigham, Taylor, & Hatton, 2011) in the I/DD population (See Appendix F). There are no truly reliable prevalence rates for trauma in this population, presenting a large gap within the literature and research (Wigham, Hatton & Taylor, 2011). There has been, however, research done that links risk of traumatic events to the I/DD population.

Cross-cultural research has suggested the I/DD population is actually at a greater risk of exposure to negative and traumatic life events than the average population. They are 3-6 times more likely to be abused or neglected than non-disabled populations (Hulbert-Williams et al., 2008). Scotti et al. (2012) reported that at least 79% of persons within the I/DD community have been exposed to approximately three traumatic events in their lifetime. These events can include institutionalization, being physically restrained, and having to be completely dependent on caregivers, some of which can be abusive or neglectful (Hulbert-Williams et al., 2008; Wigham et al., 2011).
Ecological Model

Both researchers and clinicians have studied and adapted the ecological model from community psychology and applied it to trauma survivor research. This perspective supports the perspective that an individual’s reactions are best understood within the context of their community values, skills, behaviors, and community cultures (Kelly, 1968 & 1986). Within community psychology itself, it is the understanding of the interrelationship of individuals and their community where they draw their identity, meaning, and sense of belongingness (Koss & Harvey, 1991).

When this model is applied to trauma, the ecological model posits that violent and traumatic events are ecological threats to the adaptive abilities of individuals but also to the ability for the community to foster health and resiliency for affected community members who may need it (Koss & Harvey, 1991). Thus, abuse and neglect within the I/DD community can be viewed as a plague that overwhelms services that are provided by organizations such as Developmental Disability Organizations.

While violent events can harm a community, values, traditions, and beliefs of the community can help heal as well (Harvey, 1996). These can support both community and individual resiliency. If abuse and neglect can be viewed as a plague, familial support and access to services can be seen as an ecological protective factor. One model of ecological framework applied to trauma is the: Person x Event x Environmental Influences on the "Trauma Response" (Harvey, 1996). These factors are separate from one another but interact with one another; each factor is explained in more detail below.
**Personal Factors**

Many personal factors may influence an individual’s STS response and their recovery. In this framework, it is important to consider the factors that impact the quality and dynamics of the individual-community relationship (Harvey, 1996). Some important personal factors are: age, initial distress level, developmental stage, personality, intelligence, coping capabilities, presence of prior trauma, and relationship to the offender (Harvey, 1996). For persons with I/DD, a lot of these are risk factors. Low intelligence, delayed developmental stages, higher risk for distress levels, and prior traumas are all more common in this population than the general public (Harvey, 1996).

**Event Factors**

“Event factors describe salient attributes of one or a series of traumatic events” (Harvey, 1996). Important dynamics that may influence the STS response may include, for example, the frequency, severity and duration of the event/s experienced, the degree of physical violence, the extent of the abuse that occurred, and if the trauma was experienced alone or around others (Harvey, 1996). Also relevant in this model is any significance that the community or individual places on these types of events. For example, if a person with I/DD is abused in any way and is attached to a staff member of a particular facility, shame, re-traumatization, and rejection from that person may occur with any other staff member of the same facility. This is because the significance placed on that particular staff member was high and the abuse will be associated with any other person who holds a similar significance in the life of the person served (Harvey, 1996).
Environmental Factors

Environmental factors are the largest group that influence STS response and recovery. They include many ecological descriptors such as the home, workplace, provider offices, etc., and even some of the salient attributes of the person's natural support system (Harvey, 1996). They also include the system’s ability to foster an adaptive vs. a maladaptive coping environment and the degree to which safety and control is afforded post-trauma (Harvey, 1996). After the trauma occurs, the attitudes and behaviors of first respondents and the actions of family, friends, and other significant individuals/ groups are vital factors of the person’s recovery environment (Harvey, 1996).

Environmental factors of particular importance in an ecological understanding include, overall community attitudes and values, cultural dimensions of race and gender, and the quality, quantity, accessibility and cultural relevance of the community's post-trauma care and advocacy resources (Harvey, 1996). The person who has been assaulted by a staff member may face ridicule, humiliation, and lack of believability when reporting abuse to other staff. This will be a challenge if there is a lack of resources, cultural relevance to reporting, or a negative attitude about reporting abuse by staff members. Harvey then poses outcomes of recovery based on the personal, event, and environmental factors.

Recovery Outcomes

Harvey (1996) proposes that there are four possible outcomes of recovery for persons who experience trauma.

1) Trauma victims who have received clinical care and have psychologically recovered from their experience. This is a typical clinical outcome when traditional therapy is applied and
is successful for the person. They are “recovered” from their trauma and are able to live a normal life.

2) Trauma victims who have received clinical care but have not benefitted and have not recovered. Therapy can be premature or poorly paced and can destabilize and retraumatize a person seeking help (Herman, 1992). Treatment approaches that are fundamentally insensitive to the cultural heritages of persons who have experienced trauma or are ill-informed about the role of community beliefs, values and resources are also likely to do more harm to the person than good (Harvey, 1996).

3) Trauma survivors who have recovered without benefit of clinical intervention. These are persons that are able to access and make use of both inner and outer resources in times of crisis and distress (Harvey, 1996). This includes personal resiliency, natural supports, and protective factors.

4) Trauma victims who have not received clinical care and have not recovered. These persons are and remain traumatized by their past experiences. They may live in relative isolation from others within their community, and they may be reliant on maladaptive coping skills (Harvey, 1996). There is very little, if any, help seeking behavior from these individuals (Harvey, 1996).

Organizational Risk Factors

According to the limited research available surrounding I/DD organizational risk factors for trauma, many organizations are at risk in the same way that individuals are (Harvey, 1996). In the presented model, traumatic experiences are influenced by personal factors, event factors, and environmental factors. Thus, personal risk factors such as if staff have ACEs and the level at
which they have ACEs, help determine an organization’s risk of trauma. Burnout and the prevalence of STS are also organizational risk factors (Agaibi & Wilson, 2005). With a high prevalence of either, an organization’s efficiency decreases and staff leave. Thus, a cycle is created with not enough staff, too many cases, and, as discussed earlier, burnout and STS have a positive correlation. Other factors like maladaptive coping environments and settings in which traumatic events occur for a longer duration of time are also organizational risk factors (Harvey, 1996).

**Organizational Protective Factors**

The literature is not much clearer with organizational protective factors. Harvey (1996) has identified an adaptive coping environment, community attitudes, values, culture, quality, quantity, accessibility, and cultural relevance of post-trauma care, and advocacy resources as some protective factors for organizations dealing with trauma. With these in place, a community or organization is in a place to respond to previous trauma and set up community supports to prevent future trauma. Another practice that is identified in the literature as a protective factor is that of trauma-informed care practices.

**Trauma Informed Care Practices (TIC)**

Trauma informed care can be defined as an organizational commitment to a culture that is based on principles of choice, empowerment, collaboration, safety and trustworthiness (Butler, Critelli, & Rinfrette, 2011). These principles are sensitive to the needs of the population that is being served and the traumas that they have experienced. It is throughout the entire organization from the front desk to the executive office (Butler, Critelli, & Rinfrette, 2011). It does not intend
to treat trauma symptomology but it does identify experiences that are traumatic that are central
to a person’s identity and this practice urges sensitivity toward potential causes associated with
the prior traumatic experiences that are now affecting their current state of being (Butler, Critelli,
& Rinfrette, 2011)

When an organization makes a shift to becoming trauma-informed it must go through a
cultural shift. Literature has suggested about 5-10 years for this shift to actually become
embedded into the organization (Butler, Critelli, & Rinfrette, 2011). This framework also
acknowledges the likelihood of trauma occurring in the lives of the persons who are receiving
services and those who are providing the services (Butler, Critelli, & Rinfrette, 2011). With
nearly 80% of persons living with I/DD experiencing some form of traumatic event, trauma-
informed care is more important than ever. There is also emerging research showing similar need
in caregivers (Scotti et al., 2012).

Outside the I/DD population, trauma informed care has been shown to be associated with
increased client satisfaction and a decrease in the implementation of restraints and seclusion with
youth in psychiatric treatment facilities (Azeem, Aujla, Rammerth, Binsfield, & Jones, 2011). It
has also been shown to improve the consistency in staff’s approach with individuals and it has
been shown to decrease aggressive acts between clients and staff (Azeem, Aujla, Rammerth,
Binsfield, & Jones, 2011). With staff in child congregate care facilities, training in TIC has been
associated with increased knowledge and self-reported behavior that was favorable to TIC
(Azeem, Aujla, Rammerth, Binsfield, & Jones, 2011). In another study, after staff participated in
TIC training, staff members in both the public and private sectors reported improvement in their
ability to support clients with their past traumas (Giller, Vermilyea, & Steele, 2006). While these
are not directly related to I/DD services, these studies show that TIC can improve the way providers and clients interact with one another.

**Current I/DD Services and TIC**

Since deinstitutionalization for persons with I/DD, community-based organizations have significantly increased. From 1977 to 2009 the number of persons receiving residential services has risen from 247,782 to 439,515 (Larson, Lakin, Salmi, & Webster, 2011). There have also been other increases as Braddock et al. (2013) noted an increasing number of individuals residing in supervised settings (i.e., from 368,989 individuals in 1994 to 613,184 individuals in 2011). There are also noted increases in those persons receiving day/work and supported employment services (i.e., from 256,656 individuals in 1988 to 571,664 individuals in 2011). With these increases, there is more of a fiscal strain on organizations, potentially resulting in lower pay grades and less staff.

I/DD organizations are mostly guided by the person-centered planning approach and focus on quality of life (Claes, Van Hove, Candevelde, van Loon, & Schalock, 2010). TIC focuses on the same guidelines. It sets a standard of care that fosters the well-being of the persons being served with their interests at the core of how and what support is given to them. Trauma informed care takes things a step further than the person-centered care and quality of life lenses. TIC requires that these principles are applied both to the persons being served and to the staff members (Scotti et al., 2012).

Most human service organizations do implicitly follow TIC principles but they tend to fail to integrate them into policies and procedures for staff (Wolf, Green, Nochajski, Mendel, & Kusmaul, 2014). Trauma informed care reflects the philosophy that behaviors may appear
maladaptive but may be identified as attempts at self-regulation and coping that was learned from responding to a trauma and are still being used. “Furthermore, the identification of behavioral triggers and the reduction of (re-)traumatization are given priority” (Butler et al., 2011). Direct service providers often do not get much training on trauma. Staff employed in I/DD organizations tend to receive about 40 hours of classroom-based training similar to the basic training used in institutions on topics such as “emergency procedures, introduction to developmental disabilities, and first aid” (Hewitt & Larson, 2007, p. 181). There is a major gap in knowledge with direct service providers surrounding trauma, trauma informed care, and how those interact within the I/DD population.

**TIC Principles and I/DD Services**

**Choice**

“Choice is a fundamental component of trauma informed care. Encouraging and providing opportunities for choice are vital for persons in the I/DD community. To ensure that individuals in this community are able to make well-informed choices, sensitivity and thoroughness are required. This can be achieved by going above and beyond to ensure that they have the simple opportunity to make a choice. It is important to clearly delineate individuals’ rights and responsibilities, as to ensure that there is a framework for choice-making” (Scotti et al., 2012)

**Collaboration**

“While power is shared between management, staff, and individuals, it is important that there is a clear and known balance between the three. Staff have a profound impact on the lives of individuals and that is acknowledged. The value of their ongoing contact with individuals is
also acknowledged. The Individual is known and respected as the expert on their lives and care. They are also provided ample opportunity to participate in service planning” (Scotti et al., 2012).

**Empowerment**

“Empowering both staff and individuals to make choices in care is vital. Creating an atmosphere in which there is the fostering of personal growth through training and opportunities is crucial. Through the recognition of staff and individual abilities, they can be encouraged to use such strengths when experiencing difficult situations or reliving traumatic experiences” (Scotti et al., 2012). Persons with I/DD having a sense of self could lead to more independence and a possibility of removing themselves from a traumatic situation.

**Safety**

““Safety” refers to both the physical and emotional safety of the staff and individual being served. Having transparent policies, adequate training and staffing patterns, and supervision fosters safety for staff. Additional considerations for individuals with IDD also include sensitivity in residential placement, respecting privacy, and supporting individuals in developing coping skills” (Scotti et al., 2012).

**Trustworthiness**

“This is primarily established through the relationships between management, staff and individuals. Trust is influenced by clarity of responsibilities and explanations of procedures, and the maintenance of confidentiality. Trust is earned slowly and hard to come by with those who have a history of trauma. Since persons with I/DD have a reporting rate of some type of trauma around 80% trust is not often taken lightly nor does it come by quickly. They may be hesitant to trust others, including staff, so being patient is key (Scotti, Stevens, Jacoby, Bracken, Freed, & Schmidt, 2012).
This research study was conducted in a collaborative community partnership with the Sedgwick County Developmental Disability Organization (SCDDO). The website for the SCDDO says the following about their mission and services: “SCDDO is the agency that ensures services and supports are available for children and adults with intellectual and/or developmental disabilities (I/DD). At the SCDDO, we are a one-stop resource and a point of entry for the services available to individuals and families in need of I/DD services.” (SCDDO, 2019)

“Although SCDDO is not a service provider, we do contract with the State of Kansas to ensure services are available locally. We have affiliate relationships with Community Service Providers (CSP) in Sedgwick County to ensure a wide range of essential services are available to all eligible individuals (SCDDO, 2019).

The SCDDO, acts as a central point of application and information for families exploring services, determines eligibility for the Intellectual and Developmental Disability (I/DD) system and program funding, maintains a network of service providers, reviews requests for service funding, manages local and state funding, monitors services for quality assurance purposes, and provides public awareness of developmental disability issues.” (SCDDO, 2019).

Purpose of the Research

The goal of this study is to assess trauma by answering the following research questions:

1) How does trauma express itself at an individual level;

2) How does trauma express itself at an organizational level;

3) If trauma is expressed at an organizational and at an individual level, what impact does that have on the IDD system?
On the individual level this dissertation aims to determine if individual clients were experiencing any type of trauma in their lives, if caregivers were experiencing trauma by taking care of their loved one or through navigating the system, and to see if staff were experiencing any type of burnout symptomology or secondary traumatic stress symptomology and how that impacted each group and/or their work.

On an organizational level this dissertation aims to determine if trauma was expressed through various affiliate direct service provider staff and if that trauma impacted the organization’s functionality in any manner. Also, to see if those affiliate staff are experiencing compassion satisfaction, burnout, and secondary traumatic stress and how that might impact their work and the organization.

On a systemic level this dissertation plans to combine the above findings to determine the impact both individual and organizational trauma have on the I/DD system as a whole. Overall, the main goal of this dissertation is to determine if trauma is expressed on the individual and/or organizational levels, determine its impact, and to determine whether the combination of individual trauma and organizational trauma has an impact on the I/DD system.
CHAPTER 3

METHODOLOGY

This dissertation examined three levels of data: the individual level (research question 1), the organizational level (research question 2), and the systemic level (research question 3). To answer the first research question, a quantitative approach was taken when conducting a secondary analysis on the client records from the SCDDO and a secondary analysis using qualitative grounded theory approach was taken with all the focus groups conducted. In answering the second research question, quantitative analysis was conducted on the ProQoL and the same secondary analysis using qualitative grounded theory approach was taken with all the focus groups. Finally, to answer the third research question, a qualitative interpretation of the combination of the focus groups and the interviews were used. See Figure 1 for a visual representation of how the data was used.

Data Usage

Procedure Study #1 Client Record Review- Individual Level

This project was conducted by researchers other than the author and used in this dissertation for a means of secondary analysis. Data used in this study were from 250 client records from the Sedgwick County Developmental Disability Organization (SCDDO) as part of a
larger project of the Center for Applied Research and Evaluation (CARE). The project was approved by Wichita State University’s Institutional Review Board (IRB) through a full review due to the sensitivity of information (client records) and was found to comply with all federal and university regulations surrounding human subjects. Data were de-identified before they were given to CARE for analysis. The purpose of the project was to better describe trauma for I/DD population, including the definitions of trauma (using literature and the record review), the levels of trauma, the prevalence of trauma, and the relationship of trauma to outcomes/behaviors. CARE, in place of a traditional informed consent and to comply with HIPAA regulations, sent all SCDDO clients and/or legal guardians a letter that explained in very simple language the goals of the research and that they could be excluded from the pool of potential clients' records.

Two weeks after estimated delivery of this letter by mail, the medical record numbers (MRNs) of those who did not opt out were listed and a random sample of 250 MRNs were identified and assigned a new ID number to further distance the coded data from identifying information. Researchers (who had gone through HIPAA training provided by the SCDDO) pulled and reviewed the medical and SCDDO assessment records for the identified sample and coded the needed data in an Excel spreadsheet.

**Record Review Protocol and Process**

The record review protocol and process were developed by the primary researcher (Hannah White, PhD) on the original project. For the purpose of this dissertation, the original protocol is listed but was adapted for secondary analysis.
Upon logging into the computer system onsite at SCDDO, the researcher inputted one of the identified MRNs into PsychConsult to retrieve a social security number\(^1\) that can be used in OnBase to retrieve the documents for review.

Once the collected documents associated with the selected MRN were accessed in OnBase, the review began with an examination of two assessments.

- Initial functional assessment was reviewed and variables collected
- Most recent updated functional assessment was reviewed and updated behavior variables were only collected

After reviewing the functional assessment documents, qualitative review of additional consumer file documents commenced. Where each document type exists, it was scanned for evidence of trauma. The researchers hypothesized that clients with less or no evidence of trauma in the record had fewer types of documents to review.

- Documents the researcher reviewed can be found in Appendix H
  1. Psychological Evaluation
  2. Critical Incident Reports (All)
  3. Child in Custody documents and/or Child In Need of Care Petition(s)
  4. Medical Report and/or Discharge Summary
  5. Funding Request
  6. Waiting List Exception Request
  7. Crisis Request
  8. Contract Exception Request

\(^1\) At no time is the SSN collected. It is used only for the purpose of locating the documents and is never written down or captured in any way.
• Framework for indications of trauma—First, Adverse Childhood Events (ACEs) were used as a framework to estimate whether an event/situation described in a report could be traumatic. Even though ACEs are inherently considered traumatic for children, they were used as a foundation for understanding trauma among this population, including events that occurred after the individual turned 18. Additionally, behavioral evidence of trauma described in the DM-ID as a standard for trauma was used. See Appendix H for breakout of variables.

• Information captured from Consumer Files (see comprehensive list above)
  o Documents located in the consumer files in order (see order above) were reviewed. Up to 10 specific trauma types/incidents were recorded. (NOTE: If a consumer has 10 different episodes of trauma events/situations reported in the Psychological Evaluation, those events/situations were recorded, and then reviewed additional documents in order noting any issues.)
  o Understanding that the existence of any trauma supports the implementation of Trauma Informed Systems of Care (TISC), 1 recorded incident is sufficient to establish need. Additional traumatic incidents (up to 10) indicate degree of trauma experienced. After 10, saturation is reached with respect to the goals of this research, given the literature showing the connection between negative outcomes and only 3 to 4 incidences (i.e. providing empirical evidence that trauma in the IDD population exists, that TISC should be implemented with IDD clients, and that additional trauma training for practitioners is needed).
In order to provide more context to how the client record review impacted outside persons, an interview with the primary researcher was conducted. Below, in table 1, are the questions that were asked in her interview.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Client Record Review Interview Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk about your experiences working on this project</td>
<td></td>
</tr>
<tr>
<td>What lined up with your expectations? What was different?</td>
<td></td>
</tr>
<tr>
<td>How did working on the record review affect you?</td>
<td></td>
</tr>
<tr>
<td>Talk about your experiences compared to this one</td>
<td></td>
</tr>
<tr>
<td>Would you say that you experienced trauma from working on this project? If so, please explain.</td>
<td></td>
</tr>
<tr>
<td>What would you change about how this project was set up?</td>
<td></td>
</tr>
</tbody>
</table>

**Participants**

This study is based on data from client records who met the following inclusion criteria:

- The person is a current client being served by the SCDDO.
- Researcher who reviewed the client records

A random sample of this population was determined; therefore, exclusion was randomly assigned. There are approximately 2500 active case files out of which the 250 were randomly selected.

The final sample meeting the criteria for this study included 250 clients and the researcher who conducted the record review. Fifty-eight percent of clients were male. Seventy percent of clients were White/ non-Latino. Approximately 35% of clients reported having a psychiatric disorder as well as a disability. See table two for more detailed demographics.
<table>
<thead>
<tr>
<th>Table 2</th>
<th>Descriptive Statistics - Individual Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>104</td>
</tr>
<tr>
<td>M</td>
<td>146</td>
</tr>
<tr>
<td>Psychiatric Diagnosis</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>158</td>
</tr>
<tr>
<td>Yes</td>
<td>88</td>
</tr>
<tr>
<td>N/A</td>
<td>3</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>African American/ Black</td>
<td>32</td>
</tr>
<tr>
<td>American Indian/ Alaskan Native</td>
<td>5</td>
</tr>
<tr>
<td>Asian/ Pacific Islander</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>Reporting 2 or more</td>
<td>3</td>
</tr>
<tr>
<td>White Hispanic</td>
<td>26</td>
</tr>
<tr>
<td>White Non-Hispanic</td>
<td>176</td>
</tr>
</tbody>
</table>
Procedure Study #2 Focus Groups- Individual, Organizational, and Systemic Levels

Data used in this study were from 36 mental health professionals, I/DD professionals, and parent/guardians of persons with disabilities recruited through the Sedgwick County Developmental Disability Organization (SCDDO) as part of a larger project of the Center for Applied Research and Evaluation (CARE) and the Center for Organizational Development and Collaboration (CODC). This project was conducted by researchers other than the author (Tara Gregory, PhD & Nicole Freund, PhD) and used in this dissertation for a means of secondary analysis.

The project was approved by Wichita State University’s Institutional Review Board (IRB) through expedited review under the category which states focus group research that does not cause more than minimal discomfort can be reviewed in an expedited manner.

The purpose of the project was to better describe co-occurring disorders and gaps in services through the lens of professional and the guardians of persons with disabilities. Before the groups were conducted, a recruitment letter went out to parents/guardians associated with SCDDO, mental health case managers who work with the I/DD population, and I/DD staff associated with SCDDO and their partners. The letters stated when the groups would occur, where they would take place, and who would be leading them. Copies of these letters can be found in Appendix J. CARE obtained consent from each participant through traditional consent forms tailored to each population. Only an “X” was required as to not collect names to ensure confidentiality. Each focus group was scheduled for 1.5 hours with leniency if the group wanted to continue past the scheduled time. There was no compensation offered for this study, and there were two female facilitators conducting each group.
Participants

This study is based on data from participants of focus groups who met the following inclusion criteria:

- The person is a current guardian of a person being served by the SCDDO or one of the affiliates.
- The person is a current mental health case manager.
- The person is a current I/DD targeted case manager.
- Researcher who conducted focus group

The sample was self-selected as each participant had opted-in to participating in the focus groups. The final sample meeting the criteria for this study included 9 parents/guardians, 16 behavioral health case managers, and 11 I/DD providers. No other demographics were collected at the time of the focus groups therefore, gender, age, race, etc. are unknown. With these focus groups both primary researchers who conducted them were also interviewed. They were both female, white, and college educated.

Focus Group Questions

Each focus group was asked similar questions however, they were tailored to be specific to each group. Below, in tables three- five, are samples of the focus group questions that were asked for each group.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>MH Case Managers Focus Group Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. For someone working in your field generally, what would be their perception of the need for or likely success of treating someone with IDD?</td>
<td></td>
</tr>
</tbody>
</table>
Table 3 (continued)

<table>
<thead>
<tr>
<th>2.</th>
<th>What’s your experience with de-escalation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.</td>
<td>Talk about your biggest successes in treating people with co-occurring disorders.</td>
</tr>
<tr>
<td>4.</td>
<td>In terms of coordination of care, please share some experiences with the separation of IDD and BH services.</td>
</tr>
<tr>
<td>5.</td>
<td>In a perfect world, what would the system look like – how would it work?</td>
</tr>
</tbody>
</table>

Table 4  
**IDD TCMs and Behavior Specialists Focus Group Questions**

<table>
<thead>
<tr>
<th>1.</th>
<th>For someone working in your field generally, what would be their perception of the need for or likely success of behavioral health treatment for someone with IDD?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>What’s your experience with de-escalation?</td>
</tr>
<tr>
<td>3.</td>
<td>Talk about your biggest successes in treating people with co-occurring disorders.</td>
</tr>
<tr>
<td>4.</td>
<td>For someone working in your field generally, what would be their perception of the need for or likely success of behavioral health treatment for someone with IDD?</td>
</tr>
<tr>
<td>5.</td>
<td>In terms of coordination of care, please share some experiences with the separation of IDD and BH services.</td>
</tr>
</tbody>
</table>

Table 5  
**Parents/Guardians Focus Group Questions**

<table>
<thead>
<tr>
<th>1.</th>
<th>Talk about your experience in accessing behavioral health services</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>How well do you feel your needs have been met by the providers you’ve worked with?</td>
</tr>
<tr>
<td>3.</td>
<td>Who here has been on the IDD waitlist (How long)?</td>
</tr>
</tbody>
</table>
Table 5 (continued)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>Please explain your experience with how BH services are impacted during that waitlist time?</td>
</tr>
<tr>
<td>5.</td>
<td>Talk about your expectations for receiving services once you started seeking them.</td>
</tr>
<tr>
<td></td>
<td>a. Where do you want to receive them?</td>
</tr>
<tr>
<td>6.</td>
<td>What techniques or approaches to either IDD or BH services provided do you particularly appreciate or not appreciate?</td>
</tr>
</tbody>
</table>

**Interview Questions- Researchers**

In order to provide more context as to how trauma impacts individuals, organizations, and the system the two primary researchers on the original project were interviewed. One researcher was interviewed in person and the other, to ensure completion of the project, was given the interview questions to answer on their own. Sample questions are in table six.

Table 6  
Researchers Interview Questions

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Talk about your expectations for the focus groups.</td>
</tr>
<tr>
<td>2.</td>
<td>How did conducting these focus groups affect you?</td>
</tr>
<tr>
<td></td>
<td>a. Talk about your experiences with other focus groups compared to this one.</td>
</tr>
<tr>
<td>3.</td>
<td>Would you say that you experienced trauma from conducting these groups? If so, please explain.</td>
</tr>
<tr>
<td>4.</td>
<td>What you would change about how these groups were set up or conducted?</td>
</tr>
</tbody>
</table>
Procedure Study #3- ProQoL- Organizational Level

Data used in this study were from 154 staff persons from the Sedgwick County Developmental Disability Organization (SCDDO) and their affiliates. The project was approved by Wichita State University’s Institutional Review Board (IRB) at an exempt level under category 2 which states that survey data that will not have an identifiable data attached qualifies for exempt status. The purpose of the project was to better describe trauma for staff that works with the I/DD population, including levels of trauma, the prevalence of trauma, and the type of trauma experienced by staff (STS, Burnout, Compassion Fatigue). The survey was distributed to direct support professionals and targeted case managers. No other demographic information was collected. Designated organizational leaders and supervisors were responsible for handing out and collecting the surveys. Once the staff had the survey, each person recorded their responses anonymously. Paper surveys were sealed in an envelope by the respondent and then those sealed envelopes were collected by the designated staff person to be mailed back to the research team for analysis. Respondents could also respond online through an anonymous link to the survey.

In addition to the ProQoL, staff were asked 5 additional scaled questions based on the SAMHSA Trauma-informed System of Care Guiding Principles and also to provide any other comments and/or concerns after taking the ProQoL. These responses were collected both from the paper and online versions of the survey. The open-ended responses were then themed into groups of similar responses and broken down into categories. Two trained CARE staff, including the author, conducted the analysis of the ProQoL data. Once analysis was completed, the resulting scores were separated by cut-off points listed in the ProQoL. This allowed researchers to interpret staff results. Cut-offs are listed below in table seven.
### Table 7  
**Quartile Cut-Off Points**

<table>
<thead>
<tr>
<th></th>
<th>Compassion Satisfaction</th>
<th>Burnout</th>
<th>Secondary Traumatic Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below Average Quartile</td>
<td>44 (Least Healthy)</td>
<td>43 (Most Healthy)</td>
<td>42 (Most Healthy)</td>
</tr>
<tr>
<td>(25th percentile)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average (50th percentile)</td>
<td>50</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Above Average Quartile</td>
<td>57 (Most Healthy)</td>
<td>56 (Least Healthy)</td>
<td>56 (Least Healthy)</td>
</tr>
<tr>
<td>(75th Percentile)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Validity**

The ProQoL has good construct validity with 200+ published papers using the measure. Compassion Fatigue, secondary traumatic stress, and vicarious traumatization have 100 published papers and of that, nearly half have used the ProQoL or one of the earlier versions of the measures. There are three separate scales and they all measure something separate. The Compassion Fatigue scale is distinct. “The inter-scale correlations show 2% shared variance (r=-.23; co-σ = 5%; n=1187) with Secondary Traumatic Stress and 5% shared variance (r=-.14; co-σ = 2%; n=1187) with Burnout. While there is shared variance between Burnout and Secondary Traumatic Stress the two scales measure different constructs with the shared variance likely reflecting the distress that is common to both conditions. The shared variance between these two scales is 34% (r=.58; co-σ = 34%; n=1187). The scales both measure negative affect but are clearly different; the BO scale does not address fear while the STS scale does” (center for victims of torture, 2019).

**Scoring**

Behaviors were rated on a scale of 1 to 5. A score of 1 indicates a never has a person experienced that thought or feeling in the past 30 days and a score of 5 means they have
experienced that very often. It is important to keep in mind that these thoughts and feelings are only in the past 30 days and are scored based on subscales of the ProQoL.

There are three steps to scoring the ProQoL. The first step is to reverse some of the items on the scale. The second step is to sum the items by each subscale: Compassion Satisfaction, Burnout, Secondary Traumatic Stress. Lastly, the third step is to convert the raw score to a t-score. Once the score is a T-score one can use the cut off chart to indicate what percentile a person will fall into. See Table 8.
### Table 8: Quartile Cut-offs for ProQoL

<table>
<thead>
<tr>
<th>Quartile Cut-offs</th>
<th>Compassion Satisfaction</th>
<th>Burnout</th>
<th>Secondary Traumatic Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below Average Quartile (25th percentile)</td>
<td>44 (Least Healthy)</td>
<td>43 (Most Healthy)</td>
<td>42 (Most Healthy)</td>
</tr>
<tr>
<td>Average (50th percentile)</td>
<td>50</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Above Average Quartile (75th Percentile)</td>
<td>57 (Most Healthy)</td>
<td>56 (Least Healthy)</td>
<td>56 (Least Healthy)</td>
</tr>
</tbody>
</table>

### Plan of Analysis

This study intended to examine the impact of trauma on the client, organizational, and systemic levels. For the Client Record Review all data was cleaned and screened for missing items that could prove cause to eliminate that particular case. With this data, cases have a different standard of inclusion when compared to the data from the ProQoL. This is due to the nature of the actual data (looking at records knowing reporting varies and no two are alike vs. reporting scores on a validated scale). The client record review data had frequencies and central tendency measures run in order to show the frequency of trauma, abuse, and other factors occurring in these reports. For the client record review, a regression model was used. This outlined which reported factors predicted behavior incidents. Also, this data helped answer the research question: How does trauma express itself on a client level?

With the ProQoL, the data was cleaned and screened for missing items that could prove cause to eliminate that particular case. The ProQoL data had frequencies and central tendency measures determined in order to show the frequency of secondary traumatic stress, compassion satisfaction, and burnout. The ProQoL was scored and used as it is outlined in its manual. That is, converted into T scores and grouped into cut-off points. The ProQoL helped answer the second research question: how does trauma express itself on the organizational level?
For the focus group data and both sets of interviews, a grounded theory approach was taken. It was used in a manner to see if the focus groups supported the ACEs framework rather than create a new theory/ framework. Grounded Theory is a qualitative analysis approach that takes data and codes the responses (with memos, codes, multiple rounds of coding) into categories for interpretation. Depending on the which perspective is chosen, the responses that are coded, either as themes or theoretical contexts, are used to determine if a theory has emerged from the data or if the data supports a preselected theory (Kenny & Fourie, 2015). Grounded theory is broken into three main philosophies: Classic, Straussian, and Constructivist Grounded Theory. This analysis will focus on the constructivist grounded theory perspective. A former student of Glaser and Strauss, the original creators of classic grounded theory, developed a much more adaptable approach to coding that allows the researcher more flexibility when interpreting responses. It begins with initial or open coding where a person analyst codes for actions and potential theoretical cues. This is followed by re-focused coding, which identifies the codes that are recurring or particularly significant within the area being studied (Charmaz, 2008). This coding procedure is more interpretative, intuitive, and impressionistic than the Classic or Straussian Grounded Theory (Charmaz, 2006).

Initial themes were determined in the focus groups already therefore another round of theming according to the selected grounded theory approach was conducted. Once the themes were identified (4+ mentions) they were grouped according to prominent topics that have emerged. These topics were compared to the initial themes found in the original project. They were used to answer all three research questions by providing context and additional information that was not gathered initially in the quantitative phase of data collection. A similar process was used for the interviews. Since this will be primary analysis, an additional round of coding and the
creation of a code book took place. Once this was completed another round of theming and topic grouping occurred. These interviews helped answer the final research question: how does trauma express itself within the I/DD system?
CHAPTER 4

RESULTS

Client Record Review

Research questions #1: *How does trauma express itself on an individual level*, a simple linear regression was performed. This sample consisted of N= 250 randomly selected client MRNs, 58.4% of the sample was male, 43.2% had multiple disabilities (i.e., developmental delay, intellectual deficits, developmental delays, etc.), and 35.2% of persons were also diagnosed with a mental health condition. See table nine for demographics. The number of reported trauma incidents within the client records were captured through basic frequencies. Frequencies showed that 79.6% of clients had a minimum of one report of any type of trauma in their records with the average being 4.7. Of the sample, approximately 65% of persons had a report of one or more ACE and approximately 70% of the sample had one or more reports of a non-ACE trauma. These results clearly show that trauma is apparent within persons with I/DD.
<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>104</td>
<td>41.6</td>
</tr>
<tr>
<td>M</td>
<td>146</td>
<td>58.4</td>
</tr>
<tr>
<td><strong>Psychiatric Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>158</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>88</td>
<td>35.2</td>
</tr>
<tr>
<td>N/A</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>I/DD Disabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>142</td>
<td>56.8</td>
</tr>
<tr>
<td>Multiple</td>
<td>108</td>
<td>43.2</td>
</tr>
</tbody>
</table>
A simple linear regression was calculated to predict the number of recent behavior incidents based on number of ACEs reported. Dummy variables for total amount of ACEs and total amount of behavior incidents were created in order to run the regression model. A statistically significant regression equation was found ($F(1,247)= 14.19, p< .000$) with an $R^2$ of .054. Participants predicted recent behavior incidents is equal to $22.244+ 1.562$ (number of ACEs reported) number of recent behavior incidents when number of ACEs is measured in reported occurrences. Number of recent behavior incidents increased 1.562 for each occurrence of an ACE. See Figure 2 for a graph of these results.

The regression model was used to predict factors that impact client level trauma which indicates that the number of traumatic experiences that a person has, increases the number of behavioral incidents a person had later in life. This included things such as negative personal behaviors (i.e. self-harm), criminal behaviors (i.e. physically assaulting someone), and the need for strict staff intervention (i.e. carefully structured environment).

**Linear Regression Model for Number of ACEs and Recent Behavior Scores**

![Figure 2](image-url)
Overall, from the client records, 65% of clients reported one or more ACEs and ACEs were able to predict poor outcomes in the I/DD population.

**ProQoL**

Research question #2: *How does trauma express itself on an organizational level,* an analysis of the ProQoL was conducted to determine where organizational staff scored on the Compassion Satisfaction, Burnout, and Secondary Traumatic Stress scales. The staff was composed of Direct Support Professionals (DSPs) and Targeted Case Managers (TCMs). With these scores, the expression of trauma across the organization is apparent throughout staff responses. Overall, the majority of direct support professionals and affiliated staff were at higher than average or average level scores for all three categories: Compassion Satisfaction, Burnout, and Secondary Traumatic Stress. There was a total of N=154 responses to the survey excluding four surveys that were not clearly written or incomplete and therefore were not able to be included in this analysis.

**Compassion Satisfaction**

Average or above average scores for compassion satisfaction indicate staff experience a high level of job satisfaction. Overall, 57% (n=88) of staff reported above average levels of compassion satisfaction, 20% (n=31) reported average levels, and 23% (n=35) reported below average levels of compassion satisfaction. (See Figure 3)
This suggests that the majority of the direct support staff are satisfied with the way their work unfolds most days in the environment and with the staff currently in place. The open-ended responses indicated two themes that correspond with compassion satisfaction. These themes were:

1. Supportive Staff/Management/Environment – Expressing the ways in which teams feel valued and appreciated
2. Feeling Fulfilled by the Work – Finding meaning, value, and joy in helping persons served

By feeling fulfilled with their work direct support staff are finding meaning, value, and joy in helping persons served. Examples include:

“Overall, I love my job. I love the clients, my co-workers. I love the fact that I am able to add value to someone else's life...”

“I work with a group of amazing people who really care about our clients...”
Additionally, 80% of respondents reported feeling generally safe at work, 69% reported they felt supported, and 61% felt their individuality and uniqueness were valued.

**Burnout**

Average or above average scores for burnout indicate a greater feeling of hopelessness, job stress, and that they are no longer making a difference. Overall, 27%, (n=41) of staff had average levels of burnout, 23.3%, (n=36) had below average scores, and 50%, (n=77) had above average burnout scores. (See Figure 4)

![Burnout Chart]

*Figure 4: Percentage of Scores Falling in Each Category for Burnout*

This suggests that the majority of the affiliated support professionals are experiencing above average or average levels of stress, lack of motivation, and feeling burnout within their work environment. The open-ended responses indicated four themes that correspond with burnout. These themes were:

1. **Non-Supportive Staff/Management/Environment – Expressing ways in which DSPs/TCMs feel abandoned in their work or underappreciated**
2. Inappropriate Behavior of Staff/Management – Some described observations that felt inappropriate with the clients or with the DSP him/herself

3. Compensation Issues – Expressions about feeling their pay is inadequate

4. Evidence of Burnout/STS – Descriptions of DSPs and TCMs own behavior that imply feelings of burnout or Secondary Traumatic Stress

The first theme consisted of expressions in which direct service providers felt abandoned in their work or underappreciated in what they provide to clients. One example includes:

“New ideas are not usually supported. ‘We tried that years ago’ or "senior management won't approve" are the most common reasons to dismiss an idea or different approach.

Under the theme of Inappropriate Behavior of Staff/Management, respondents indicated they observed instances in which inappropriate behavior of staff/management occurred:

“We have leads that are doing inappropriate joking that can be mistaken for harassment in a sexual manner. Horse playing in front of parents, instead of acting in a mature manner.”

Compensation Issues included feelings about not being compensated fairly for their time/work. Finally, DSPs and TCMs mentioned that they felt burnt out and showed evidence of secondary traumatic stress. Several respondents reported similar sentiments to:

“...DSP's do hard work and can easily become bogged down from the number of persons served that we are caring for all at one time. It is common to be understaffed, and the workload can seem impossible at times (especially with aggressive outbursts taking place).”

All of these responses communicate a sense of frustration and exhaustion common to burnout.
While in general staff responded positively to the questions about their work from the Guiding Principles, two items had relatively higher levels of disagreement than the others:

- My skills and experience are recognized and valued (22% disagreed) and
- My employer tells me everything about the company that I need to know (23% disagreed)

These suggest that even simple recognition of value through communication may not be present in sufficient quantities and might fairly easily be improved. This also supports the comments surrounding burnout as staff do not appear to be receiving what they need in order to do their job properly.

Secondary Traumatic Stress

Average or above average scores for STS indicate a high level of professional traumatic stress or experiences of secondary trauma. Overall, 19.5%, (n=30) of staff had average levels of STS, 33%, (n=51) had below average scores, and 47.4%, (n=73) had above average STS scores. (See Figure 5)

![Secondary Traumatic Stress](image)

Figure 5: Percentage of Scores Falling in Each Category for Secondary Traumatic Stress

These results suggest that the direct support professionals and targeted case managers are experiencing above average and average STS which is a sign that a majority of staff are being
subjected to some level of secondary trauma. The open-ended responses produced one major theme for this category:

1. Evidence of Burnout/STS – Descriptions of DSPs and TCMs own behavior that imply feelings of burnout or Secondary Traumatic Stress

Many respondents reported having feelings that could be attributed to STS.

“When at home and on weekends I limit social activities, do not care to be around people much. All the time I have to correct myself that I am not a fixer of all problems with personal family and friends. [. . .] I often feel helpless to respond to the needs of my clients.”

Many similar responses suggest that many direct support professionals are feeling overwhelmed and experiencing some form of second-hand trauma in their line of work. This also suggests that burnout and STS are not just individual problems but rather spread across the organization. With that in mind, it may be fair to say that trauma is in fact expressing itself at the organizational level through staff members.

Overall, this survey provides an assessment of the level of professional quality of life for DSPs and TMCs working for SCDDO affiliates. Staff are overall feeling satisfied with their working environment, however, there are above average levels of burnout and secondary traumatic stress occurring in approximately 50% of their staff members. The majority of staff in this sample have higher levels of professional trauma that suggest organizations should address this issue at an organizational level as well as an individual level. It is important to note this is a snap shot of the SCDDO affiliates and the expressed level of trauma in staff members and within organizations could vary at any given moment.
Focus Groups

In answering all three posed research questions, *how does trauma express itself at an individual level; how does trauma express itself at an organizational level; and if trauma is expressed at an organizational and at an individual level, what impact does that have on the IDD system*, three focus groups that were conducted by CARE staff were analyzed. There was one focus group for each of the following groups: parents and guardians of persons with co-occurring disorders, mental health case managers, and I/DD targeted case managers and behavior specialists. The questions for each focus group were similar and can be found in the Methods chapter with mental health case managers and I/DD TCMs and behavior specialists having questions focused on perceptions of co-occurring disorders and experiences in their positions, while parents and guardians were asked questions that were more specific to their experiences in accessing and receiving services.

Overall, the responses from all groups reflected some similar themes. This included frustrations with wait-lists, inconsistency of providers and policies, difficulty navigating the system, and concerns over people not receiving needed services. Considering these persons are navigating and/or working within both the mental health system and the I/DD system, responses indicated that the I/DD system was seen as the primary place for services for persons with co-occurring disorders. This suggests that the mental health system is unable to and/or does not meet the needs of persons with co-occurring disorders. Even with this, participants largely recognized that the I/DD system does not have the resources to meet every need of this population and is not equipped to provide intensive behavioral health services. This also suggests that the I/DD system is also not meeting behavioral health needs, often leaving persons with

53
behavioral health problems with nowhere to go to receive adequate services. The findings from the focus groups are described below.

Parent- Guardian Focus Group

Nine (9) parents/guardians participated in this focus group. Questions were worded to elicit both strengths/positives and challenges/negatives however, from the collected responses, it appears the participants largely focused on the challenges of both systems. Additionally, because their answers across questions tended to be similar, their responses were themed regardless of the question asked as they were in the original analysis. After several rounds of coding four themes emerged. Those were: difficulties in funding/keeping well-trained or “good providers,” lack of cross system communication, system-wide failures, and training. Below are the themes found.

1. **Difficulties in finding and keeping well trained and/or “good” providers**

   Participants in this group expressed that oftentimes they would find providers that made them feel understood, that understood their child, and also offered quality services. Responses also showed that these providers had often stopped providing services for their child. There was much frustration expressed in having to constantly search for new providers that understood their children and treated them appropriately. Some of the issues participants shared with finding new providers for their children were, too few providers understood co-occurring disorders, having to deal with a high staff turnover rate, and issues with funding for services. One participant stated,

   “If it’s not written down, it doesn’t exist, even when [it’s] written down, sometimes [it’s] ignored”

when asked about working with providers.
Working with providers that are not understanding can be traumatizing/retraumatizing for both the clients and parents/guardians of persons with co-occurring disorders. Going through the process of repeating services, being denied treatments, or getting kicked off of waivers because someone is doing “well enough” in one area may lead to provider cycling, frustration with the system, and fear of when the next service is denied or when the next provider change is coming. One person noted, that

“People have no services, case manager may ignore [the problem]”

when in the process of changing providers. The consistent need to fight a battle between systems, with providers who are not listening, and just to receive services may lead to burnout in this subpopulation.

2. Lack of cross-system communication

Participants frequently mentioned a need for better communication across systems, particularly between I/DD and behavioral health providers. One parent said,

“The minute you get CDDO services, behavioral health services stop – you’re on your own”

because the systems are not designed to work with one another. They noted care plans as being of particular concern in that they appear to not be consistent, are not accessed when needed, or they lack the appropriate information. As one person said it’s like “trying to find your way in the dark during a crisis” because the needed information is either not available or ignored. They also noted that other systems need better communication with the I/DD system as well, such as the police department. One person noted that someone is
“supposed to contact case manager if [the] police arrest someone on CDDO lists

[however, it] still leaves gaps if CDDO doesn’t [have] everything done then [the] jail doesn’t know”

what is happening with that person. These responses show that not only are I/DD organizations traumatizing both clients and parents/guardians of persons with I/DD but also that the I/DD and other systems are perpetuating trauma as well. Without clear and precise communication, it is possible that clients are not having their needs met across the system (such as in jails) and may not even be receiving correct services because the correct information is not there.

3. System-wide Failures

Responses continuously reflected participants’ feelings about the system in general not working in an integrated manner across providers, waivers, and time. Lack of funding for services was specifically mentioned in how it severely impacts quality of life for persons with co-occurring disorders. When talking about transitioning through services a parent said, that their “Funding promised for transition never materialized” and that reportedly is not uncommon. There was also the issue of the “chain of funding” and who actually pays for services and how they are funded in general. With lack of funding available, services become unattainable for most persons. While there is an option to pay out of pocket, most parent and guardians cannot afford to do so. As one parent stated,

“[you] have to pay for everything- cannot afford [to do so].”

Another issue specifically mentioned was the long wait-list that persons with co-occurring disorders have to be placed on when there is either no funding for their services or a spot is not available for them. One parent stated there are about

“3500 [people] waiting for HCBS” with an average of “7-8 years” of wait time.
Another parent stated,

“while on the waitlist there are no day/ residential services” available.

This meant that the parents and guardians now had to juggle taking care of their loved one and trying to afford basic cost of living. Someone also shared that

“everyone is on the waitlist at some point”

furthering the frustration of the participants with the system itself.

The combination of both of these system-failures produces a chain reaction of clients not receiving services they need, a loss of progress, and eventually a regression in clients sets in.

There was a lot of frustration expressed with the lack of resources that were available to persons with co-occurring disorders and their families. One person called-out the system as “asininely stupid” while another parent feared that her child “would outlive her and be incapable of advocating for himself.” Through these responses it is clear that trauma is occurring for both persons with co-occurring disorders and their parents/ guardians. As parents noted, the struggle to afford services themselves and the fear that their children will not be able to navigate the system themselves could be classified as either primary trauma (clients) or STS (parents and guardians). From frustration with funding and waitlists to being denied services due to the 7-8-year long waitlist, the system is traumatizing.

4. Training

There was much concern surrounding the training, or lack thereof, amongst professionals and across systems that interact with the co-occurring (MH and I/DD) population. Concerns surrounding multiple agencies abilities to understand, work with, and provide for persons with co-occurring disorders arose. One parent stated that,

“CDDO side needs more BH training or BH needs more CDDO access”
because neither system is working together for persons with co-occurring disorders. This concern was also expressed toward the training police receive. It was stated that,

“police [need to be] trained for behavioral outreach.”

Without both systems being trained in one another’s services or system structure, traumatic experiences may occur for all involved through lack of communication between poorly trained professionals or through one system not understanding the others services, rules, and procedures.

Overall, parents/guardians were not happy with the system, identifying multiple frustrations and failures throughout. They spoke of the exhaustion and tiresome battle of finding well trained professionals and maintaining those professionals. The lack of funding and cross system training creating fear and navigating problems for their children. Finally, they spoke about wait-lists and lack of services when their child is deemed to be making progress towards therapeutic goals. From these responses it was concluded that the system itself is traumatizing to these parents/guardians and clients and does not always meet their needs.

**Mental Health Case Managers Focus Group**

Sixteen (16) behavioral health case managers participated in this focus group. Many of the themes reflected in their responses were similar to the other focus groups. As professionals who try to serve persons with co-occurring disorders, they primarily expressed frustration at issues such as the I/DD wait list, lack of communication and training, and system-wide failures. These professionals also expressed a sense of frustration with the lack of adequate services for those with co-occurring disorders. After coding their responses two themes emerged: lack of communication and training and system-wide failures.
1. *Lack of Communication and Training*

Participants in this group also expressed a lack of shared understanding and practices between the I/DD and behavioral health systems regarding how to deal with persons with co-occurring disorders. One participant noted a sense of

“*hopelessness*” when serving persons with co-occurring disorders in the sense of

“*providing services*” and “*not knowing how to communicate with both systems*”. The idea of “not knowing the timing to provide services” also came up and “not being on both waivers at the same time” makes providing and communicating treatment plans even more difficult.

Participants also noted such issues as treatment levels not matching between the two systems, and having different goals for the client as a clear sign of miscommunication between both systems. It was stated that

“*mental health [professionals] have the goal to rehabilitate the mental health [issue] while I/DD has different goals.*”

There was also mention of lack of coordination of goals, and families being told different things by the different providers which can lead to many issues moving forward with services. This creates a tiresome work environment that may lead to staff having increased levels of burnout.

Participants also stated that they have difficulty within the system because they are not trained to provide services to persons with I/DD. As one person stated,

“*mental health case management is not the same as CDDO management*” and “[they] are trained to work with mental health [cases] but not with I/DD; [not even] the I/DD specialists.”
This lack of training promotes a sense of “hopelessness” and feelings of “constantly being let down” when their clients are not doing as well as they perceive they should be. This may lead to burnout in staff and could reflect both organizational and system-wide policy failures. The feelings of hopelessness that staff are experiencing may eventually lead, if they have not already, to STS as they are experiencing a secondary trauma through the lack of success in clients and their inability to change that. They also recognize the lack of understanding of I/DD makes it difficult to diagnose mental health issues and impedes their ability to deal with escalated situations. One participant said it’s

“hard to qualify people for mental health services because [the] diagnosis is difficult.”

Further, one participant commented that

“one of the worst feelings is knowing the mental health system isn’t qualified”

to help someone with I/DD.

2. System-Wide Failures

Participants mentioned the issues inherent in trying to serve lower functioning adults (e.g., they are taken advantage of by those who are higher functioning) and the basic difficulty in trying to apply treatment models with which they are most familiar. One participant stated,

“normal tools to de-escalate won’t work for I/DD”

and it was stated that the familiar treatment models that they have used have the same difficulty.

Additionally, they expressed concern that many people fall through policy-related cracks because they do not meet criteria for services or clients cannot be on two waivers at once. It was stated that

“families want kids on mental health services because [of the] waitlist”.
One participant noted that clients do not just fall through cracks; they fall off a cliff because of policies that limit the services they can receive. Another participant related an experience in which she tried to help a client access I/DD services due to there no longer being a need for mental health services. This person was denied simply because she (the mental health care provider) was proof that they were still receiving mental health services. Not only is this traumatizing to families and persons with co-occurring disorders but it can affect providers STS levels as well since they are experiencing the same difficulties through the client they are seeing.

The mental health providers recognize the wait-list as a significant issue for persons who need I/DD services as well. However, there is an added layer of complexity for them. Due to the long wait time, many clients and their caregivers want to hang on to other services, including mental health, as long as possible to avoid a gap. The way the mental health system is set up is that mental health providers cannot prolong services if the client is meeting therapeutic goals. Also, the I/DD system will not allow a person to receive services if on the mental health waiver. With this, mental health professionals are left in a position of terminating services to persons who may see them as the only option for receiving any sort of helpful intervention and clients and families are left in a transition period where they may not be receiving services at all. This not only impacts clients and families in a traumatic way but the guilt and hopelessness that providers feel also impacts organizations and their ability to continue to provide services.

Overall, MH providers feel as if they are stuck. That is, they are wanting to help persons with I/DD diagnosis but either do not have the training to do so or the system is working against them. These providers expressed that following a simple care plan is even difficult because the I/DD and MH systems just do not communicate with one another. These providers felt for the parents/guardians and clients trying to hang on to whatever services they have but recognized
that the system is flawed and have to discharge these persons when they are meeting their goals, leaving persons with I/DD diagnoses on their own. This breeds a sense of hopelessness and feelings of burnout amongst staff.

**I/DD Provider Focus Group**

Eleven (11) I/DD providers participated in the final focus group. Again, their responses were similar to those of participants across other groups in identifying frustration at barriers in the system that make it difficult for clients to make or maintain progress. This group had four main themes emerge from responses. They echoed the themes of lack of communication and training, as well as had additional concerns surrounding lack of resources and support, and stigma for clients with co-occurring disorders.

1. **Lack of resources and support**

Participants in this focus group mentioned the lack of resources to adequately serve persons with co-occurring disorders. They mentioned that this could be attributed to the field’s skepticism about whether behavioral health treatment can be successful for someone with I/DD. A concern about clients not receiving mental health services while in crisis was also expressed.

"**Hospitals [tend to say] sorry we can’t help!**" or "**you have to go to several places**" when a client is in a crisis because "**they won’t take them because of I/DD.**"

One participant expressed that

"**[hospitals] think I/DD is the problem when it’s not**"

when someone is in a mental health crisis.
Additionally, they noted that the lack of resources forces some out of services prematurely and causes people who are not qualified to act as “counselor” for those who need mental health support. One person shared that

“I/DD can be for life but ComCare can only be for a max of five years.”

Not having a place to land while in crisis and/ or being pushed out of services is a very traumatic event. It can instill hopelessness in both families and clients but also in providers in such a way that they don’t feel like anything they do will matter. This may increase STS and burnout at both an individual level and organizational level.

Lack of support was also specifically called out surrounding issues with providers and clients receiving the support they need to be successful. They called out lack of support by parents and guardians specifically. One person stated,

“parents challenge providers choices” and that “trust comes slow[ly].”

Providers report not being supported in following through on plans of care which can lead to difficulties for clients and an appearance that services do not work. This is challenging and is an example of the stress that providers are under that can lead to burnout. Without support of the parents/ guardians in what they are doing those feelings of not making a difference may arise.

2. Stigma

Whereas other groups didn’t discuss stigma to a significant extent, I/DD providers provided a number of examples of how stigma affects services for persons with co-occurring disorders. They mentioned issues with persons in health care and law enforcement viewing persons with I/DD as problems or not a priority. Someone shared,

“police don’t find I/DD calls important” and that “decide to jail based on I/DD and resources.”
They also believe the general community has a negative view and expectations of persons with co-occurring disorders, (“They don’t hear the good things, they only hear the really bad parts”), which reinforces poor self-image and challenging behaviors on the part of clients.

One participant stated,

“It seems like they shouldn’t be in the community at all”
due to all the stigma and resistance. Another person states,

“clients are often keenly aware of how they are perceived” and “people don’t always hide their negative ideas of the group”.

According to some participants this may lead to persons beginning to act like the perceptions they hear all the time which could lead to criminal behavior or even jail. Stigma can be one of the most traumatizing experiences a person with a co-occurring disorder could go through; it can also be exhausting for staff. If clients are acting out in the way they hear people perceive them, it can put strain on the organizations serving them and possibly increase STS levels in staff or create higher levels of burnout. This may create higher turnover rates and affect the organizations and systems intended on providing services for persons with co-occurring disorders.

3. Lack of communication and training

Participants in this group also shared the mindset that those with co-occurring disorders would be better off if there were better communication among providers and systems. Specifically, communication around plans of care and care coordination is considered critical to shared understanding and delivery of the most appropriate services for each client. One participant shared,

“[there is] no communication between [I/DD] and mental health/ hospitals”
making it difficult to follow plans of care. Another person shared, 

“*reading a behavior plan and following it are different*” and that “*psychiatrists help varies*”.

Overall, there was an expression of lack of communication and help from the mental health system.

There was also mention of the need for and current lack of professionals who fully understand the unique issues of persons with co-occurring disorders. They identified specific issues with the following: police not understanding the limits of what providers can do for the client (“decide if a person goes to jail based on I/DD and resources” not based on what providers can actually do), doctors asking for information that I/DD staff are not trained to provide (e.g., assessing suicidality), and failure of providers to follow plans. Another issue brought up was inability of staff to de-escalate. One person shared,

“*staff may hesitate because they might not get the backup needed*”; also, that they’re

“*not trained in mental health problems*”

so de-escalation may not be something they are able to provide due to lack of knowledge and training. Finally, the participants expressed a frustration with mental health providers not understanding the impact of certain actions on behaviors (e.g., taking clients off meds). Someone stated,

“*mental health environment changes things [with patients, especially taking them off meds] that don’t work outside [their] environment.*”

4. **System-Wide Failures**

Participants indicated system-wide failures less than other groups. One frustration mentioned was being more focused on defensive measures versus preventative. Staff are so
overwhelmed that there is no time or staff person available to progress to preventative measures. One participant mentioned,

“[there’s] not enough staff for preventative measures due to the necessity of defensive measures”

to make sure clients and staff are safe. Also, briefly mentioned was difficulty in placing an I/DD client in the mental health system and not managing transitions between systems or environments well. This was referenced in other themes throughout this group where participants did not think that mental health staff were following treatment plans and taking a person off their meds (and other activities) were not being thought through carefully because of their unawareness to how it impacts I/DD behaviors.

Finally, high turnover among staff and not providing adequate breaks to staff after an incident were mentioned by participants. One person shared,

“there are no breaks after incidents [due to understaffing]”.

Overall, staff mentioned being burnt out (understaffing, no breaks) and not having enough staff to handle incidents with persons with co-occurring disorders. This can lead to multiple STS incidents on the same staff members.

This group reiterated the difficulties that the system and lack of cross system coordination have on an organization. They shared that burnout and high turnover were frequent throughout their agencies. These participants also shared concern and frustration over the stigma that persons with I/DD experience and felt as if the community sets them up to fail and that there is not much they can do to help correct that image. Staff were tired from fighting with parents/guardians about each care plan change and mentioned the exhaustion that comes from working with co-occurring disorder when they are not trained to handle mental health cases. This group
overall, expressed a lot of concern for clients but also a lot of frustration with the system and lack of training to help persons with co-occurring disorders.

**Interviews**

Only two out of the three interviews were completed. The interview with the researcher who conducted the client record review is not included as of now due to deadlines. Of the two interviews included, both researchers expressed that the focus groups went as planned but the level of frustration and pain from both parents/guardians and providers was more than expected.

“The degree of frustration that was ultimately expressed was probably more intense than I could have expected since I didn’t have much experience with the system at that time.”

The researchers said that other focus groups have affected them but not in the same way. That these focus groups were touching on a more serious topic and the pain of all the participants really resonated with them. One stated that “the questions didn’t matter” in these groups because they served more as a platform for the participants to express themselves.

These focus groups also affected the researchers in different ways. For one, they still stay with her until this day and they make her sad thinking back. The levels of pain and frustration are something that she reflects on from time to time. For the other researcher, she stated that she instantly knew that these focus groups were more draining and were very difficult. She shared,

“I came away with a different sense of empathy for those who care for family with I/DD issues”

and that her daily frustrations could not compare to those who have operate within the I/DD system.
As for experiencing trauma, each researcher had a different take on their experiences. One stated that while it doesn’t influence her on a daily basis, she probably did experience some STS.

“[It was probably] good trauma- [it created] more empathy for these persons and now know more about [co-occurring disorders]”

While the other researcher who was interviewed stated that she did not have any lingering symptoms from conducting the groups and therefore did not think that she had experienced any STS. However, she did state that she was affected by the groups.

Overall, the focus groups did go as expected but were filled with unexpected pain and frustration. These researchers were impacted by the groups although in different ways. One experiencing STS and the other being impacted on a more subtle level. These interviews show that the system has a way of impacting persons completely detached from it.
CHAPTER 5
DISCUSSION

The purpose of this study was to investigate the expression of trauma on the individual, organizational, and systemic levels within the I/DD community. This is an important topic, because the majority of trauma-related research has been conducted with other helping professions (i.e. social welfare workers, social workers, nurses, etc.) and may not provide a completely accurate picture of what is occurring within the I/DD community. Approximately 80% of the I/DD community reports instances of abuse or neglect (Hulbert-Williams et al., 2008) and it is known that there is a significant risk of burnout and secondary traumatic stress within the helping professions (Horwitz, 2006). There is room for improvement for the system itself and the first step is to focus on prevention and effective trauma reduction policies, practice, and procedures (Butler, Critelli, & Rinfrette, 2011).

Thus, it is imperative that trauma is recognized within the community and addressed through trauma informed organizations and systems within the I/DD community. The overall body of literature does not include many, if any, findings specific to trauma within the I/DD community. This study contributes to the literature because it provides an in-depth examination of how trauma is expressed on multiple levels within the I/DD system.

This study helps to provide clarity on the lack of literature regarding trauma within the I/DD community. The more we know about trauma on the individual, organizational, system levels and how it effects these systems, the better equipped we will be to make informed decisions regarding best practices for developing trauma informed care interventions for persons dealing with trauma in the I/DD community.
Relevance to Previous Research

There are no real reliable prevalence rates for incidents of trauma in the I/DD population thus, showing a large gap within the literature and research (Wigham, Hatton & Taylor, 2011). However, research has suggested the I/DD population is at a greater risk of exposure to negative and traumatic life events than the average population. They are in fact 3-6 times more likely to be abused or neglected than non-disabled populations. (Hulbert-Williams et al., 2008). This study showed that there was approximately an 80% reporting rate of some type of trauma within the records. ACEs also tend to cluster suggesting, that if someone has one ACE they are most likely going to have another that is similar (think physical abuse and sexual abuse). With over 60% of the surveyed population within the Kaiser-Permanente reporting one or more ACE (SAMHSA, 2018), similar results were found in this study as there was an average of 1.79 ACEs per client record reported.

ACEs have a dose-response relationship with many health problems (SAMHSA, 2018). The literature shows that a person’s cumulative ACEs score had a strong relationship to numerous health and behavioral problems throughout their life; many of these problems tend to be comorbid or co-occurring (SAMHSA, 2018). This dissertation also found that the number of ACEs that a person had predicted the number of recent behavior incidents that were reported within the records confirming what the literature has previously stated.

These findings can also be interpreted in light of research on traumas impact on organizations. SCDOO and affiliates had higher than average scores on burnout and STS in approximately 50% of their staff. These findings are both interesting and consistent with trauma research in other helping professions (Bride, 2007). In professions such as social workers and child welfare workers, levels of burnout tend to be higher than other non-helping professions
(Bride, 2007). Specifically, child welfare workers work in clients’ homes, schools and communities and have a frontline view of the deprivation and abuse that permeate their clients’ lives (Horwitz, 2006). The devastation that occurs when child welfare workers are unable to provide services that their clients clearly need is prominent throughout the system (Horwitz, 2006). These results suggest that similar effects on I/DD staff are occurring. With reports of “feeling helpless” and having feelings of “hopelessness” due to the constraints the I/DD and Mental Health system places upon them, I/DD professionals are experiencing some of the same frustrations that other helping professions, such as child welfare workers.

While the exact percentage of persons living with STS is not known, it is assumed to be high both within the general population and subpopulations such as social workers. This is because exposure to trauma is 40-81% in the general population. (Kessler, Sonnega, Bromet, & Nelson, 1996). While the national prevalence rate is high, it is higher in subpopulations such as helping professions (Davidson & Smith, 1990). While the severity and length of STS symptoms vary by person, researchers have found a positive correlation between length and severity of STS symptoms and longevity of career, large caseloads, increased contact with clients, and long work hours (Dunning & Silva, 1980). Reports from I/DD providers suggest that this is what is occurring at the organizational level. With the results showing a higher than average level of STS for approximately 50% of their staff and having self-reports of STS experiences this study can contribute to the literature as a way to show that I/DD professionals are experiencing similar levels and effects of STS as other helping professionals.

**Key Findings**

A client record review, three sets of focus groups, an organizational assessment, and two interviews were conducted on the individual and organizational levels of the I/DD system to
determine if and/or how much trauma was being expressed at each level and if that could help inform the creation of new trauma-informed policies, practices, and procedures. The results indicate that trauma is, in fact, being expressed at the individual and organizational levels and suggest that the system (I/DD) itself impacts the levels of trauma that both individuals and organizations experience.

Frequencies showed that 79.6% of clients had a minimum of one report of any type of trauma (ACE and non-ACE) in their records with the average being 4.7. Of the sample, approximately 65% of persons have a report of one or more ACE and approximately 70% of the sample had one or more reports of a non-ACE trauma. These results clearly show that trauma is apparent within persons with I/DD. The regression model used to determine factors that impact client level trauma indicates that the number of traumatic experiences that a person has increased the number of behavioral incidents a person has later in life. This included things such as negative personal behaviors (i.e. self-harm), criminal behaviors (i.e. physically assaulting someone), and the need for strict staff intervention (i.e. carefully structured environment). The regression models also showed that I/DD do not predict if someone will experience trauma.

The ProQoL assessment used at the organizational level to assess levels of Burnout, STS, and Compassion Satisfaction determined that while the majority of staff members had high rates of Compassion Satisfaction (57% higher than average) there were also high rates of Burnout (50% higher than average) and high rates of STS (47.4% higher than average). Themes of burnout and secondary traumatic stress also appeared throughout the gathered responses. Other themes that appeared were: 1) non-supportive staff/management/environment, 2) inappropriate behavior of staff/management, 3) compensation issues, 4) a supportive staff/management environment, and 5) feeling fulfilled by the work.
The focus groups and interviews conducted revealed that STS and burnout were apparent in caregivers, clients, and both behavioral health staff working with the I/DD population and I/DD staff. The focus groups revealed that system-wide failures, lack of communication and training in staff and across systems, access to well trained and “good” providers, stigma, and lack of support are the main contributors to feelings of burnout and STS in all three groups. The interviews further highlighted the feelings of STS were carried over to those researchers who conducted the focus groups and client record review.

**Research Question #1: How does trauma express itself at an individual level?**

The client record review and focus groups were used to look at trauma on the individual level and to determine if and/or how many instances of trauma were present. These instances were calculated through a previous extensive review of the content within the provided MRNs. Through this review, both ACEs and non-ACE incidents were identified within the MRNs and each trauma identified was marked and calculated to a total. The record review showed that of the random 250 persons samples, 79.6% of clients had a minimum of one report of trauma in their records with the average being 4.7 incidents reported. This is higher than the national average of two to three incidents of trauma reported within the I/DD community (Hulbert-Williams et al., 2008). This was further broken down into reports of ACE related trauma and reports of non-ACE trauma. Of the sample, approximately 65% of persons had a report of one or more ACE and approximately 70% of the sample had one or more reports of a non-ACE trauma. These results clearly show that trauma is apparent within persons with I/DD.

The regression model used to determine factors that predict client level trauma indicates that the number of traumatic experiences that a person has increases the number of behavioral
incidents a person has later in life. With an average recent behavior incident score of 35.4 it shows that trauma is still affecting clients even after receiving services. The results show that trauma, on a very basic level, is expressed on an individual level in clients with an I/DD diagnosis.

Through the focus groups parents/guardians and providers shared frustrations that the system-wide failures place them under leading to possible STS. I/DD service providers also shared the stigma that persons in the I/DD community undergo. They shared that this can have a direct effect on a person with co-occurring disorders and may be one of the causes for criminal behavior. There were also mentions of burnout from providers which can set the stage for secondary traumatic stress.

From these reports, it is clear that trauma is expressed at the individual level but, what does that mean? It shows that ACEs are common within the I/DD population. It also shows that trauma incidents are occurring at a higher rate with clients served through affiliates of the CDDO compared to the national average for the I/DD community. Trauma is a major issue for the I/DD community. With this, there is a definite need for trauma informed policies, practices, and procedures to help combat the trauma that is experienced by persons with I/DD. More training surrounding how to reduce traumatic experiences and awareness about the prevalence of trauma also needs to become a part of community-wide discussions. Overall, trauma is expressed at the individual level and trauma informed care initiatives need to be implemented community-wide.

**Research Question #2: How does trauma express itself at an organizational level?**

The second research question determined if trauma was present at the organizational level. For staff, there were high levels of burnout and STS (50%, 47.4% higher than average) suggesting trauma manifesting itself in the majority of staff. Reports from the open-ended
questions also provided insight into exactly how the staff felt about working for their organization. Results showed self-identified feelings of burnout and STS along with identified issues that could result in both burnout and STS. These included frustrations with compensation, high turnover rates for staff, and non-supportive staff/management. These results were simply a snapshot of a set of organizations staff and should be used with caution. It is recognized that feelings of burnout and STS can vary and that this information may change over the course of time.

The focus groups conducted with mental health and I/DD providers shared reports of “hopelessness” and defeat when talking about how to serve clients with co-occurring disorders. I/DD professionals self-identified trends of burnout amongst staff and cited that the lack of system-wide communication hindered their ability to do their jobs to the fullest. Both sets of professionals also identified that there is a lack of training within both systems (mental health and I/DD) which can put a strain on staff, clients, and parents/guardians. Without the proper training staff are forced to implement treatment plans that are not coordinated, cope with plans of care not being followed, and attempt to de-escalate situations they are not trained for.

This places staff members and organizations in a position to be retraumatized, as the clients are, every time they have a client with co-occurring disorders. Combined with the ProQoL results, the focus groups helped determine that trauma is indeed being expressed at an organizational level. Through staff reports of their own burnout and STS experiences and through what are seen as system-wide failures, there are plenty of reports that show trauma is occurring throughout the system and that is impacting the organizations that serve the I/DD community.
To further support this conclusion, researchers who worked on each of these projects were interviewed. It was stated multiple times that these focus groups resonated with trauma that “stuck with” the researcher to this day. These researchers came from a separate organization and have had some organizational experience working with the I/DD population but no personal experience with the I/DD system itself and the level of trauma the providers and parents/guardians were experiencing still affected them. With the researcher’s STS experiences from just conducting the groups, the claim that trauma is being expressed at the organizational level is strengthened.

It is clear that burnout and STS are a problem at an organizational level and that trauma informed practices and policies need to be implemented in order to reduce both of these phenomena. While it is unclear whether these issues are persistent or just a current state of mind, there are system structures that are impacting providers abilities to feel fulfilled and competent in their work. This is an issue that is seen in the literature with other helping professions and is not surprising to find within the I/DD community (Bride, 2007).

**Research Question #3: If trauma is expressed at an organizational and at an individual level, what impact does that have on the IDD system?**

The final research question sought to determine if trauma was expressed at the individual and organizational level, what impact that has on the I/DD system. Results of the three focus groups conducted indicated that providers had an impact on how the system is able to deliver services. Also found was that the system also impacted the individual parent/ guardians as well as the providers at the organizational level.
Reports of not enough cross training between the behavioral health system and I/DD system were stated to affect one’s ability to help a person with co-occurring mental health and I/DD diagnosis. The lack of knowledge surrounding how to de-escalate a client, where to send a client when they are in a crisis, and the unlikelihood of both types of providers to follow a simple care plan were mentioned as system-wide barriers to provide effective services. Reports of “hopelessness” and defeat surrounding these issues were also made. Parents/guardians shared their fear surrounding their children having to navigate the system without them one day possibly resulting in a future lack of help-seeking behavior. The trauma and burnout that providers are experiencing with their lack of experience in treating co-occurring disorders is resulting in providers leaving the field. This suggests that there will be fewer providers in the future thus, impacting the system’s ability to provide adequate services to all persons within the I/DD community.

Both parents/guardians and providers shared experiences with the seven to eight year long wait-list for services and the lack of effective communication within the I/DD and behavioral health systems as a source of frustration. They identified that they go to great lengths to retain some type of service (even if it’s not appropriate for the client’s needs) so that there is not a gap in service delivery. This fear, frustration, and ultimately exhaustion may lead to burnout in staff and traumatic experiences for both clients and families. This suggests that the system is perpetuating trauma among the persons utilizing it.

The interviews conducted with the researchers who collected the focus group data and client record review also suggest that these parents/guardians and providers were experiencing trauma. Reports that the focus groups had more trauma revealed than first expected and that personal accounts of struggles with the system provides support for the conclusion that the
system can and is often traumatizing to navigate through. Researchers shared that these studies had resonated with them because of the content of discussions and some even stated that they experienced some type of STS when looking back. These results further the claim that the system can impact an organization and individuals.

Overall, it is clear that there are major system-wide barriers that are impacting persons with I/DD diagnoses, their parents/guardians, and providers. These results show that there are major gaps in implementing trauma-informed policies, practices, and procedures throughout the system. These results also suggest that the system impacts outside individuals as well and that systemic trauma is a much bigger problem than originally thought.

Like other studies examining trauma at multiple levels within the I/DD system, the results of this study led to more questions than answers. What is the long-term impact of trauma on the I/DD system? Are there differences in levels of trauma between geographic locations, between different types of organizations that serve I/DD populations? Since I/DD is not a predictive factor for trauma, what preventative methods could be put into place to reduce traumatic experiences for organizations and individuals? These are all questions that could not be answered by the present study, and should be considered in future research.

Implications

Trauma is a public health issue and awareness surrounding prevalence within communities is steadily rising. As the acknowledgement and awareness of trauma increases, we must consider subpopulations such as the I/DD community when examining trauma due to the high reporting rates of particular ACEs. In order to ensure maximum effectiveness, we must
learn as much as we can about how trauma is expressed and how it impacts this community and system along with how it may vary compared to the majority population.

Results of this study suggest that trauma is expressed at the individual and organizational level and that the I/DD system impacts this expression. This study found that approximately 80% of client records contained at least one report of trauma. 60% of the population sampled reported 1 or more ACE and approximately 70% of the sample reported one or more non-ACE related trauma. A linear regression found that the number of ACEs a person reports predicts the number of recent behavior incidents after receiving some services. At the organizational level, burnout and STS were found to be at higher than average levels for nearly 50% of the staff. Reports of burnout, STS, and traumatic experiences for both providers and parents/guardians of persons with I/DD supported the results of the client record review and the ProQoL suggesting that trauma is occurring and both the individual and organizational levels. Researchers and I/DD professionals should consider the dynamics of trauma when working with persons with I/DD their families, and other I/DD professionals. They should also be mindful that the I/DD system itself impacts levels of trauma for all persons working within it.

Cross-training throughout schooling and in professional job development is a practical solution to the under trained providers that work within the I/DD system. Inclusion of legislatures and health insurance companies in discussions of how to improve the I/DD system should begin immediately in order to create a more trauma-informed atmosphere for providers, parents/guardians, and persons living with I/DD. Providers should also be offered sabbaticals, not unlike academics, and have a reduction in their caseloads in order to help prevent burnout and keep them working in the system. These solutions need to start from the top-down beginning with systemic changes that will help create opportunities for change within service organizations.
The structure of the I/DD system is struggling to meet the needs of both clients and families as well as the providers that are working within it. With reports of system-wide failures and lack of training for professionals these populations struggle just to receive and deliver basic services. Perhaps it would be beneficial to conduct a system-wide review of policies, practices, and procedures that inhibit and retraumatize persons within the system. Although this would be more resource-intensive, a system-wide assessment with a variety of providers, organizations, clients, and families would provide a more complete picture of the expression of trauma within each assessed level.

**Strengths and Limitations**

The strengths of this study include the diversity of types of respondents in the sample, multiple methods of data collection, and the richness of the gathered qualitative data. There are also several limitations that should be mentioned. First, this study lacked information surrounding individuals that are not currently or have not sought services through the partnering organizations. Furthermore, excluding persons that may not have resources to utilize services leaves a gap in knowledge as it cannot be assumed that persons not using services are not experiencing trauma since 80% of persons with I/DD are reporting two-three instances of abuse (Hulbert-Williams et al., 2008). Another limitation is that this study was not geographically diverse. Although, trauma was found within Sedgwick County there was no exploration past that county. Other factors may contribute to both protective factors and higher risk factors in other areas of the state such as being located in more rural areas with limited access to I/DD services. Having information on persons with I/DD in different communities, their parents/guardians,
and, other organizations outside this geographic location would allow for a more accurate estimation of the occurrence of trauma within the I/DD system as a whole.

Utilizing a limited amount of records from one set of organizations along with a point in time measure could potentially limit findings to a moment in time and to only persons who have actively sought out services. For example, perhaps there was an extremely hard six months at the surveyed organizations but it was not that way all the time. This would spike the burnout and STS scores of staff since that is the time period they are being asked about - not their entire career. Also, there might be more clients that have more/less reported trauma that do not have access to services. These persons were not included and may shift perceptions of trauma expression on the individual level.

This research also neglected to include the higher-level administrators of each organization. That is, it focused mostly on those who receive I/DD services and those who provide direct services to persons living with I/DD. This gap of understanding the higher administrators view point is something that should be addressed in future studies. Change must come from the top down and by neglecting the view-points of those persons, we fail to see how trauma is impacting the decision makers and the constraints they are under when forming policy.

Another limitation was that only two out of the three intended interviews were conducted. Because of this, the experience of the researcher who conducted the original client record review was excluded. In future research this interview should be conducted along with any other researchers who helped on these projects. While, the results were not impacted by the one missing interview, in the future the qualitative richness from multiple more interviews would add value.
A final limitation was the ProQoL is a snap-shot in time measure. Researchers should gather more information by utilizing multiple administrations of the ProQoL. This study was only able to determine point in time levels of burnout and STS of staff members. While this allows for the assumption that trauma is being expressed at an organizational level, it is limited in manner that the conclusion can only be applied to the past few months of staff person’s job, not necessarily to their overall career within the organization. Results should be interpreted in light of these limitations.
Future Research

A more in-depth quantitative approach that includes other organizations and different demographics is needed to provide a clearer picture of the data. Further, either a non-time constricted measure or multiple administrations of the ProQoL approach should be conducted to determine if the trauma reported was situational or is throughout the duration of a staff member's career at a CCDO. Future research should also assess the community impact systemic trauma has on the I/DD community (i.e. stakeholders, organizations not related to direct services, housing, etc.) in order to better inform policy makers. Finally, future research should explore potential solutions to reducing trauma in the I/DD community. While there is research showing the protective and risk factors for trauma, research is limited in how to actually implement community wide changes to help reduce the occurrence of trauma and re-traumatization for persons with I/DD and their families. It is important to conduct qualitative and quantitative research studies with all stakeholders, policy makers, and administrators to assess the level of trauma at all levels of the organization. It is possible that trauma is happening at all levels and is trickling down to the clients.

Conclusion

It is important to recognize and assess trauma within the I/DD community and those who work within the I/DD system. It appears that trauma is present within individuals and at the organizational level; both affecting the system and the system affecting individuals and organizations. In the present study, trauma was identified along with how system structures can impact those levels and how those levels impact the system. Given this information, tailored interventions and community-wide system changes can begin to be developed. Key stakeholders
can use this information to inform funding decisions and determine if policies, practices, and procedures at the system and organizational levels need to be changed and re-developed to reduce trauma. For example, it is similar to understanding the human brain, this is the first step in a long, complicated process in reducing trauma for the I/DD community and the present study contributes incrementally to our understanding of the nuances of trauma within one of the most vulnerable populations we have.
REFERENCES
REFERENCES


APPENDIX
APPENDIX A

*Adverse Childhood Experiences*

<table>
<thead>
<tr>
<th>Abuse</th>
<th>Neglect</th>
<th>Violence</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Abuse</td>
<td>Physical Neglect</td>
<td>Intimate partner violence</td>
<td>Substance misuse within household</td>
</tr>
<tr>
<td>Emotional Abuse</td>
<td>Emotional Neglect</td>
<td>Mother treated violently</td>
<td>Household mental illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Parental separation or divorce</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Incarcerated household member</td>
</tr>
</tbody>
</table>

Source: (CDC, 2016)
APPENDIX B

*Adverse Childhood Experiences Pyramid*

Source: (SAMHSA, 2018)
APPENDIX C

ACE Prevalence for CDC-Kaiser ACE Study Participants by Sex, Waves 1 and 2.

<table>
<thead>
<tr>
<th>ACE Category</th>
<th>Women</th>
<th>Men</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent (N = 9,367)</td>
<td>Percent (N = 7,970)</td>
<td>Percent (N = 17,337)</td>
</tr>
<tr>
<td>ABUSE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Abuse</td>
<td>13.1%</td>
<td>7.6%</td>
<td>10.6%</td>
</tr>
<tr>
<td>Physical Abuse</td>
<td>27%</td>
<td>29.9%</td>
<td>28.3%</td>
</tr>
<tr>
<td>Sexual Abuse</td>
<td>24.7%</td>
<td>16%</td>
<td>20.7%</td>
</tr>
<tr>
<td>HOUSEHOLD CHALLENGES</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother Treated Violently</td>
<td>13.7%</td>
<td>11.5%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Household Substance Abuse</td>
<td>29.5%</td>
<td>23.8%</td>
<td>26.9%</td>
</tr>
<tr>
<td>Household Mental Illness</td>
<td>23.3%</td>
<td>14.8%</td>
<td>19.4%</td>
</tr>
<tr>
<td>Parental Separation or Divorce</td>
<td>24.5%</td>
<td>21.8%</td>
<td>23.3%</td>
</tr>
<tr>
<td>Incarcerated Household Member</td>
<td>5.2%</td>
<td>4.1%</td>
<td>4.7%</td>
</tr>
<tr>
<td>NEGLECT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Neglect(^3)</td>
<td>16.7%</td>
<td>12.4%</td>
<td>14.8%</td>
</tr>
<tr>
<td>Physical Neglect(^3)</td>
<td>9.2%</td>
<td>10.7%</td>
<td>9.9%</td>
</tr>
</tbody>
</table>

Note: \(^3\)Collected during Wave 2 only (N=8,629). Research papers that use Wave 1 and/or Wave 2 data may contain slightly different prevalence estimates. (n=17,337)

Source: Centers for Disease Control and Prevention, Kaiser Permanente.
APPENDIX D

ACE Prevalence for CDC-Kaiser ACE Study Participants by Sex, Waves 1 and 2.

<table>
<thead>
<tr>
<th>Number of Adverse Childhood Experiences (ACE Score)</th>
<th>Women Percent (N = 9,367)</th>
<th>Men Percent (N = 7,970)</th>
<th>Total Percent (N = 17,337)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>34.5%</td>
<td>38.0%</td>
<td>36.1%</td>
</tr>
<tr>
<td>1</td>
<td>24.5%</td>
<td>27.9%</td>
<td>26.0%</td>
</tr>
<tr>
<td>2</td>
<td>15.5%</td>
<td>16.4%</td>
<td>15.9%</td>
</tr>
<tr>
<td>3</td>
<td>10.3%</td>
<td>8.5%</td>
<td>9.5%</td>
</tr>
<tr>
<td>4 or more</td>
<td>15.2%</td>
<td>9.2%</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

Note: Research papers that use Wave 1 and/or Wave 2 data may contain slightly different prevalence estimates. (n=17,337)

Source: Centers for Disease Control and Prevention, Kaiser Permanente.
### I/DD CRITERIA

<table>
<thead>
<tr>
<th>Deficits in Intellectual Functioning</th>
<th>Various mental abilities: Reasoning; Problem Solving; Planning; Abstract thinking; Academic learning (ability to learn in school via traditional teaching methods); Experiential learning (the ability to learn through experience, trial and error, and observation).</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Deficits or Impairments in Adaptive Functioning</th>
<th>Various skills are needed for daily living:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>Communication</strong>: The ability to share information person to person while expressing themselves through words and/or actions and the ability to understand others.</td>
<td></td>
</tr>
<tr>
<td>• <strong>Social skills</strong>: A person’s ability to effectively interact with others. This includes the ability to understand and comply with social rules, customs, and standards of public behavior. People are able to process figurative language and detect unspoken cues such as body language with this skill.</td>
<td></td>
</tr>
<tr>
<td>• <strong>Personal independence at home or in community settings</strong>: With this skill, people are able to take care of themselves. It also includes the ability to safely complete day-to-day tasks without guidance and people are able to complete routine activities in the community.</td>
<td></td>
</tr>
<tr>
<td>• <strong>School or work functioning</strong>: With this skill, people are able to conform to the social standards at work or school. They are able to learn new knowledge, skills, and abilities. Being able to apply this information in a practical, adaptive manner; without excessive direction or guidance is key.</td>
<td></td>
</tr>
</tbody>
</table>
These limitations occur during the developmental period—before 18. This means problems with intellectual or adaptive functioning were evident during childhood or adolescence.” (APA, 2013).

Source: (American Psychiatric Association, 2013)
APPENDIX F

Person X Event X Environment Model

Traumatic Life Event

- Specific stressor dimensions (e.g., duration, severity, degree of threat, etc.)
- Subjective experience of traumatic stressors (e.g., degree of affect dysregulation)
- Types of stressor (single, multiple, complex, etc.)
- Level of stressor impact (e.g., threat, injury, exposure, etc.)
- Type of allostatic load (e.g., repetitive system failure, etc.)
- Level of affect dysregulation (i.e., negative or positive affect balance)

Impact to Personality, Self-Structure & Ego-Processes Caused by

- Structure of Personality Characteristics (e.g., five factor model)
- Ego-States: (1) static, (2) fluctuating, (3) regressed, (4) accelerated
- Identity configuration: fragmented vs. integrated
- Bases of self-worth, ego-strength and ego-resiliency
- Sense of vulnerability to master anxiety situations and cope competently
- Ego defenses against injury and vulnerability
- Changes in ideology, beliefs and world view
- Cognitive schemas in self, others and reality
- Dissociative & peri-dissociative processes

Activation of Allostatic Stress Response

<table>
<thead>
<tr>
<th>Personality Characteristics</th>
<th>Affect Modulation</th>
<th>Ego Defenses Style</th>
<th>Coping</th>
<th>Mobilization &amp; Utilization of Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td>(b)</td>
<td>(c)</td>
<td>(d)</td>
<td>(e)</td>
</tr>
</tbody>
</table>

Continuum of Adaptation & Resilience

Low Resilience | Normal Range of Coping | Optimal Coping

- Minimal Coping
- Normal Range of Coping
- Optimal Coping

Avoidance /Non-focused Emotional Coping

Acute & Long Term

“At Risk” for PTSD & Psychopathology

Source: (Agaibi & Wilson, 2005)
APPENDIX G

Ecology of Trauma in the I/DD Population

Created for dissertation by: Brittany Brest, 2019
APPENDIX H

*Documents Reviewed in Client Record Review*

<table>
<thead>
<tr>
<th>ACEs (with evidence experience happened prior to client turning 18)</th>
<th>Physical Abuse, Sexual Abuse, Emotional Abuse, Presence of mentally ill member of household, Alcohol or drug abuse in household, Incarcerated member of household, Violence between adults in household, Parental divorce or separation.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral evidence as described in DM-ID</td>
<td>Including: Behavioral changes related to aggression, self-injury, and agitation, Non-compliance behavior and resistance, Behavior that might be described as re-enacting a trauma, Triggered outbursts</td>
</tr>
<tr>
<td>Variables captured from Basis Assessment</td>
<td>DOB, Veteran, Spouse of Vet, Gender, Ethnicity, Race, ID/Disability (Single/Multiple), Primary Disability, Listed Disorders, Child in Custody, Psychiatric Diagnosis, Intellectual Assess, Taking Psych Meds, Init_Assess_Data Entry Date, Most_Recent_Assess_Data Entry Date, Behavior Frequency</td>
</tr>
<tr>
<td>Results of Behaviors</td>
<td>Beh Prevents Lower Restrictions_Initial AND Most Recent, Has Beh. Intervention, Plan_Initial AND Most Recent, Carefully Structured Environ_Initial AND Most Recent, Staff Intervenes Physically_Initial AND Most Recent, Time-Out Needed 1x Week_Initial AND Most Recent, Requires 1-1 Supervis. Initial AND Most Recent</td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
APPENDIX I

Client Notification Letter

Dear XXX,

The Sedgwick County Developmental Disability Organization (SCDDO) is always working to serve its clients better. One way to do that is to continue to learn and research what affects clients significantly so that we can improve partnerships with service providers. This kind of research is what we are trying to do right now, and as part of this project we have asked some researchers from Wichita State University’s Community Engagement Institute to review some of our client records.

Approximately 250 records will be randomly selected for review, which means your records may or may not be included. The researchers will keep everything completely confidential, according to HIPAA rules, and they will do the entire review in the SCDDO offices.

If you do not wish your records to be available for this review, all you have to do is call us at the SCDDO and tell us to take your records out of consideration. The phone number to call is: XXX-XXXX. There is absolutely no penalty for removing your records from this research and your relationship with your providers and the SCDDO will not change.

No action is required by you as long as you do not want to remove your records from the review. If we do not hear from you, we will assume that it is okay with you to include your records in the review. Again, everything will remain confidential regardless.
If you have any questions, please contact XXX at XXXX

Thank you,

Dee Staudt, Director

Sedgwick County Developmental Disability Organization
APPENDIX J

Focus Group Recruitment Letters

SUBJECT: Tell Us What You Think!

Have you received services for co-occurring disorders (i.e., intellectual/developmental disability AND behavioral health issues such as mental illness or substance use)?

Are you a family member or caregiver of someone who’s received services for co-occurring disorders?

If you said “yes” to either question, you’re invited to a special focus group, sponsored by the Sedgwick County Developmental Disability Organization, to discuss what’s good about services for persons with co-occurring disorders, what’s not so good, and what can be done to improve these services.

Details about the focus group:

- It’ll be from 5:30 to 7 p.m. on XX, XX at the Sedgwick County Developmental Disability Organization office at 615 N. Main in Wichita.
- Dinner will be provided.
- About 10-15 people who either receive services themselves for co-occurring disorders or who are family members/caregivers are expected to attend.
- This group is only open to people who are 18 years old or older.
• You’ll be asked about your experiences in finding services for co-occurring disorders, what’s been good about them, what doesn’t work so well, and any suggestions for improvement.
• There are no right or wrong answers during a focus group – you can say whatever you want and it will not have a negative impact on the services you receive or relationships with providers.

The SCDDO has asked staff of Wichita State University’s Center for Applied Research and Evaluation (CARE) to lead these focus groups. CARE staff will not ask or record your names and they won’t ask for personal or uncomfortable information. And no SCDDO or other agency staff will be in the room for this group. So you can be completely honest with CARE staff in answering their questions.

Participating in this focus group is completely voluntary. You may decide not to attend, not answer any questions, or even leave before it’s done. But we hope you’ll come and give your opinions about services for co-occurring disorders so we can help make the system even better.

MH Case Managers
The Sedgwick County Developmental Disability Organization (SCDDO) would like to know your opinions about services for persons with co-occurring intellectual/developmental disabilities (I/DD) and behavioral health concerns. For this reason, SCDDO has asked Wichita State University’s Center for Applied Research and Evaluation (CARE) to lead a focus group for Mental Health Case Managers on this topic. The focus group will take place at 11:30 a.m. on
XX, XX at the SCDDO office (615 N. Main, Wichita, Kansas). The focus group will last about 1½ hours and lunch will be provided. About 8 – 15 Mental Health Case Managers from various agencies are expected to attend.

During the group, representatives of WSU’s CARE will ask you a series of questions about your experiences with services for co-occurring disorders, including what seems to be working well, what doesn’t work so well, and other issues related to helping persons with co-occurring disorders access and receive helpful services. There are no right or wrong answers and nothing you say will impact your relationship with the SCDDO or other providers. Your comments will help the SCDDO and other providers understand services for those who have co-occurring disorders and what can be done to make them more helpful. No one will collect your name or other identifying information during the group so your answers will remain anonymous. This group is only open to persons who are 18 years or older.

Your participation in this group is purely voluntary and, if you decide to participate, you can stop or leave at any time. But we hope you’ll attend and provide the SCDDO with your feedback about services for co-occurring disorders.

I/DD Targeted Case Managers and Behavior Specialists

The Sedgwick County Developmental Disability Organization (SCDDO) would like to know your opinions about services for persons with co-occurring intellectual/developmental disabilities (I/DD) and behavioral health concerns. For this reason, SCDDO has asked Wichita
State University’s Center for Applied Research and Evaluation (CARE) to lead a focus group for I/DD Targeted Case Managers and Behavior Specialists on this topic. The focus group will take place at 3:30 p.m. on XX, XX at the SCDDO office (615 N. Main, Wichita, Kansas). The focus group will last about 1 ½ hours and snacks will be provided. About 8 – 15 Targeted Case Managers and Behavior Specialists from various agencies are expected to attend.

During the group, representatives of WSU’s CARE will ask you a series of questions about your experiences with services for co-occurring disorders, including what seems to be working well, what doesn’t work so well, and other issues related to helping persons with co-occurring disorders access and receive helpful services. There are no right or wrong answers and nothing you say will impact your relationship with the SCDDO or other providers. Your comments will help the SCDDO and other providers understand services for those who have co-occurring disorders and what can be done to make them more helpful. No one will collect your name or other identifying information during the group so your answers will remain anonymous. This group is only open to persons who are 18 years or older.

Your participation in this group is purely voluntary and, if you decide to participate, you can stop or leave at any time. But we hope you’ll attend and provide the SCDDO with your feedback about services for co-occurring disorders.
APPENDIX K

Professional Quality of Life Scale (ProQOL)

Compassion Satisfaction and Compassion Fatigue (ProQOL) Version 5 (2009)

When you [help] people you have direct contact with their lives. As you may have found, your compassion for those you [help] can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a [helper]. Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the last 30 days.

1. I am happy.
2. I am preoccupied with more than one person I [help].
3. I get satisfaction from being able to [help] people.
4. I feel connected to others.
5. I jump or am startled by unexpected sounds.
6. I feel invigorated after working with those I [help].
7. I find it difficult to separate my personal life from my life as a [helper].
8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I [help].
9. I think that I might have been affected by the traumatic stress of those I [help].
10. I feel trapped by my job as a [helper].
11. Because of my [helping], I have felt "on edge" about various things.
12. I like my work as a [helper].
13. I feel depressed because of the traumatic experiences of the people I [help].
14. I feel as though I am experiencing the trauma of someone I have [helped].
15. I have beliefs that sustain me.
16. I am pleased with how I am able to keep up with [helping] techniques and protocols.
17. I am the person I always wanted to be.
18. My work makes me feel satisfied.
19. I feel worn out because of my work as a [helper].
20. I have happy thoughts and feelings about those I [help] and how I could help them.
22. I believe I can make a difference through my work.
23. I avoid certain activities or situations because they remind me of frightening experiences of the people I [help].

24. I am proud of what I can do to [help].
25. As a result of my [helping], I have intrusive, frightening thoughts.
26. I feel "bogged down" by the system.
27. I have thoughts that I am a "success" as a [helper].
28. I can't recall important parts of my work with trauma victims.
29. I am a very caring person.
30. I am happy that I chose to do this work.

/www.isu.edu/~bhstamm or www.proqol.org. This test may be freely copied as long as (a) author is credited, (b) no changes are made, and (c) it is not sold.