NEGATIVE LIFE EVENTS, SOCIAL DETERMINANTS, AND SERVICE DELIVERY FOR CHILDREN WHO HAVE DISABILITIES AND MENTAL HEALTH CONCERNS by Leah Sulmonetti Peabody College of Vanderbilt University May 2024

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This study begins the process of examining negative life events, social determinants of health, and the parents' familiarity with mental health services concerning children with dual diagnoses. Using a state-wide survey in the state of Tennessee, this study examined 120 parents with children with dual diagnoses to understand what mental health services exist, the barriers that exist in accessing the services, and the parent's overall familiarity with mental health services. Results indicated that 72.7% of children with dual diagnoses faced at least 1 negative life event in the last 12 months. Parents expressed less confidence in accessing education, healthcare, and mental health services, which are crucial for children with dual diagnoses. Additionally, the study revealed that parents are less familiar with child-based services and family-based services. It was also found that parents who were not married, unemployed, spoke Spanish, had lower levels of education, or had poor mental health were less likely to be familiar with mental health services. In addition, low-to-medium correlations were found between social determinants of health and the parent's familiarity with mental health services. Given its results, it's important to further educate parents on what mental health services exist for their children. In addition, it is crucial to train mental health professionals to address social determinants of health to promote equitable mental health outcomes is crucial.

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NEGATIVE LIFE EVENTS, SOCIAL DETERMINANTS, AND SERVICE DELIVERY FOR CHILDREN WHO HAVE DISABILITIES AND MENTAL HEALTH CONCERNS

by

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CHAPTER I

INTRODUCTION

Although people with disabilities account for more than 12% of the population (Krahn et. al., 2014), the medical field has long focused on the physical health of typically developing people. Only recently has mental health become a topic of interest for typically developing people, and few studies have yet expanded this issue to people with disabilities. An estimated 17.4 million (32.9%) adults with disabilities experience frequent mental health concerns (CDC, 2023). When it comes to children with disabilities, many of them have co-occurring mental health disorders. According to Dekker and Koot (2003), approximately 30-50% of children with disabilities also have mental health concerns.

Within all groups, those with and without disabilities, mental health is thought to be influenced by a person's environment and the inequalities the individual faces in their life like discrimination or other social inequalities (Alegría et al., 2018). Environment and social inequalities in this instance refer to two issues, negative life events and social determinants of health. Each is discussed below.

Negative life events are displeasing, unavoidable, and traumatic experiences, which can negatively impact a person's overall mental health (Gungor & Sivo, 2021). These events include the death of a family member, financial problems, abuse,

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discrimination, and problems with housing. The negative life events can be very stressful and lead to the development of mental or behavioral health concerns including attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), anxiety disorders, depression, post-traumatic stress disorder (PTSD), and many more psychiatric disorders (Karcher, 2020).

To date, negative life experiences have been linked to mental and behavioral health concerns in typically developing children (Schilling et al., 2007). The negative life experiences during childhood can cause a child to be two times at risk later in life for mental health concerns (Bauer et al., 2022). These negative life experiences can be associated with more prevalent psychiatric disorders like anxiety and depression in children (Bauer et al., 2022). There's developing evidence showing the powerful connection linking overall risk in childhood and adverse mental and behavioral health concerns (Atkinson et al., 2015). For example, Atkinson et al. (2015) found in their study of a Canadian sample of 284 typically developing children aged 5 to 6 years old that negative life events were associated with future mental and behavioral health concerns including depression and other psychiatric disorders.

Several preliminary studies (including Hastings et al., 2004; Nevill & Benson, 2018; Wigham et al., 2014) claim that negative life events can precipitate mental and behavioral health concerns for adults with intellectual and developmental disabilities. According to a study by Wigham et al. (2014), it was determined that there is a connection between the negative experiences that individuals with disabilities face and the trauma that is a result of the experience. Past research from Hastings et al. (2004) found that 46.3% had experienced one or more negative life events in the past 12 months, and 17.4% experienced two or more. Hastings found that negative life events in the past year correlate with mental and behavioral health concerns. Additionally, in a study by Nevill and Benson (2018) of 80 adults with Down syndrome, individuals with higher rates of negative life events had higher amounts of depressed mood, generalized anxiety, irritability, and hyperactivity. Most research on negative life events in individuals with disabilities focuses on the cumulative total of life events across a lifetime (Hove, 2016). Not as much is known about negative life events in a span of 12 months and how that plays a role in the familiarity of mental health services.

Studies have shown that children with disabilities experience more health inequities including mental health concerns compared to the general population (Emerson, 2015). Children with disabilities have higher rates of psychiatric disorders or other mental health concerns (Staunton et al., 2020). Children with disabilities who experience more adverse childhood events seek or use mental health services more often than children who don't have adverse childhood events (Stewart et al., 2017). However, in children with disabilities, adverse childhood experiences or negative life events are often an overlooked component of mental and behavioral health disparities (Vervoort-Schel et al., 2021).

A second, related issue concerns Social Determinants of Health (SDOH). SDOH includes the environment that people are born and grow up in which influences a person's overall health outcome, including mental health (World Health Organization, 2023). Environmental factors or determinants of SDOH are access to mental health services, adequate healthcare services, an adequate education system, freedom from discrimination, affordable housing access, and feeling safe in their community. The disparities in mental health outcomes are not attributed to the personal choices or hereditary disposition of they are, but it is due to the factors of SDOH. According to the CDC (2020), there are five major domains of SDOH. These include education access and quality (e.g., child's education, if they graduate from high school, literacy skills), healthcare access and quality (access and quality of healthcare and mental health care services), social and community context (e.g., discrimination, belongingness, access to community resources), neighborhood and built environment (e.g., police presence, access to food, access to transportation, access to parks), and economic stability (e.g., socioeconomic status, cost of living, employment opportunities).

Similarly to negative life events, children who experience poverty, racism, or other SDOH factors may also encounter mental health challenges (Allen et al., 2014). For example, among children with mental health concerns who do not have disabilities, Allen et al. (2014) find that there is a complicated relationship between social determinants of health and mental health as economic, environmental, and societal factors influence one's mental health across their life. This scenario should be looked at closer to help understand the effects that SDOH has as a precursor for mental health disorders. In order to help a child have a fair playing field from birth is to make health a precedence and to be equal for all (Compton & Shim, 2015).

Considering mental health, socioeconomic status may impact both the risk of mental health disorders and parents and families may not be familiar with mental health services (Alegría et al., 2018). More explicitly, parents and families are not familiar with many of the mental health services that exist out there for their children (Shanley et al., 2007). In addition, children and adolescents often lack access to mental and behavioral health services facilitating social inequities (Copeland et al., 2015). Furthermore, there has been limited and minimal research on negative life events and social determinants of health for children with disabilities and their family's overall familiarity with mental health services. In order to access the services, a family member or caregiver must know what services exist out there for their child.

To date, few studies have investigated social determinants of health and negative life events and how they affect access or familiarity with mental health services, especially in the disability field. Although studies do show how social determinants of health and negative life events can affect one's mental health outcome, we do not yet understand the degree to which they affect a family's familiarity with mental health services. In this study, the following research questions were addressed: (1) To what extent do children with dual diagnosis have high negative life events; (2) To what extent do parents and caregivers have low social determinants of health scores; (3) To what extent are parents and caregivers less likely to be familiar about the four types of mental health services (i.e., special education, child-based, family-based, and community-based) and (4) To what extent do negative life events and social determinants of health correlate with parents and caregivers familiarity with mental health services?

CHAPTER II

METHODS

Participants - Parents and Caregivers

Parents were recruited from all across Tennessee. Respondents included 120 parents of children with disabilities. Of the sample, 75.8% of the parents were female and 23.3% were male. Out of all the parents/caregivers (terms used interchangeably), a majority of them were mothers (73.3%). In addition, 21.7% of the respondents were fathers and 4.2% were legal guardians. 46.2% of the respondents were between the ages of 30-39 and 35.1% were between the ages of 40-49. In terms of ethnicity, almost ³/₄ of the respondents were white and non-Hispanic, and 1/5 of the respondents were Black/African American. In terms of marriage, roughly 75% of the respondents were married or partnered while the ¹/₄ were single or divorced. For more information, refer to Table 1.

Table 1

Parent Demographics

	Frequency (%)
Gender	
Female	75.8%
Male	23.3%
Non-binary	0.8%
Who are they as the respondent	

Mother	73.3%
Father	21.7%
Legal Guardian	4.2%
Grandmother	2.5%
Foster parent	0.8%
Ethnicity	0.070
White/non-Hispanic	70.8%
Black/African American	18.3%
Hispanic	10.8%
Age categories (years)	10.070
20-29	7%
30-39	46.2%
40-49	35.1%
50-59	
	10.3%
60+ Munital states	1.8%
Marital status	
Single, never married	7.6%
Married	73.1%
Separated	3.4%
Divorced	10.9%
Widowed	0.8%
Partnered	4.2%
Education	
Some high school	6.8%
High school degree	11.9%
Some. College (including Associate's)	21.2%
4 year degree	30.5%
Graduate/professional degree	29.7%
Household Income	
\$0 to \$19,999	8.4%
\$20,000 to \$49,999	36.1%
\$50,000 to \$89,999	21%
\$90,000 to \$129,999	16.8%
\$130,000+	17.6%
Caregiver Disability	
Autism	6.7%
Pervasive Developmental Disorder	2.5%
Intellectual Disability	5%
Developmental Disability	8.3%
None	81.7%
Number of Total Children	01.770
	15%
2	40%
2 3	24.2%
5 4+	24.2%
	20.070
Number of Children with Disability	

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1	73.3%
2	20.8%
3+	5.8%

To participate in the study, all parents and caregivers must meet specific residency requirements: (1) parents and caregivers must live in Tennessee and/or (2) use services in Tennessee. In addition, the parents and caregivers must have a child with a disability who fits the two criteria: (1) children with a disability must be between the ages of 1.5 to 22 years old and (2) have a mental and/or behavioral health concern.

Participants - Children

Of the sample for children with disabilities, 59.2% of the children identified as male and 38.3% as female. In terms of disabilities (select all that apply), the most common were autism (60%), ADHD (32.5%), intellectual disability (21.7%), speech or language impairment (21.7%), developmental delay (19.2%), and learning disability (14.2%). Of the sample, 16.5% of the children were between 1.5-4 years old, 25% were between 5-9 years old, 33.3% were between 10-14 years old, 17.5% were between 15 and 19 years old, and 7% were between 20-22 years old. A majority of the children with disabilities attended public schools (60.8%), while the others attended private schools (16.7%), other schooling options (12.4%), or were not in school (10%). At the time of the survey, most children lived with either both of their parents (68.3%) or with one parent (25%). For more information, refer to Table 2.

Table 2

Children Demographics

	Frequency (%)
Gender	
Female	38.3%
Male	59.2%
Non-binary	2.5%
Age Categories	
1.5-4	16.5%
5-9	25%
10-14	33.3%
15-19	17.8%
20-22	7%
Ethnicity	
White/non-Hispanic	63.3%
Black/African American	20%
Hispanic	10.3%
Middle Eastern and North African	2.5%
Asian American	3.3%
Multiracial	4.2%
Living Arrangement	112 / 0
Lives with mom	21.7%
Lives with dad	2.5%
Lives with both parents	68.3%
Lives with both parents, but in two different homes	0.8%
Lives with grandparents or other relatives	3.3%
Foster care (Department of Children Services)	0.8%
Other living situation	2.5%
School Type	2.370
Public School	60.8%
Private School	16.7%
Home School	8.3%
Not in School	10%
Other	4.1%
Grade	7.170
Pre-k or Early childhood program	10.1%
Elementary school	34.5%
Middle school	26.1%
High school	15.1%
College or transition program	5.9%
Not in school	
	8.4%
Disability type(s)	60%
Autism Llogring Impointent	
Hearing Impairment	4.2%
Intellectual disability	21.7%
Orthopedic impairment	5%
Multiple disabilities	12.5%

Specific learning disability	12.5%
Speech or language impairment	21.7%
Traumatic brain injury	4.2%
Visual impairment	3.3%
Development delay	19.2%
Functional delay	7.5%
Intellectually gifted	7.5%
Down syndrome	6.7%
Cerebral palsy	3.3%
Learning disability	14.2%
Muscular dystrophy	1.7%
ADHD	32.5%
Other	20.7%

Procedures

We developed an anonymous mental health needs assessment to understand what mental health services exist, the barriers that exist in accessing the services, and the parent's overall familiarity with mental health services in Tennessee. To qualify, the parents must live in Tennessee and have a child with a disability between the ages of 1.5 to 22 with mental or behavioral health concerns. If the parent had more than one child with a disability, respondents were asked to answer for the youngest child. The survey itself took approximately 30 minutes to 1 hour to complete.

Before the distribution of the survey, it was shown to multiple mental health professionals to gather feedback and suggestions for the survey. Once the survey was complete, it was submitted to the Vanderbilt University Institutional Review Board (IRB). After receiving IRB approval, the survey was then transferred to REDCAP, a secure web application used across the world by researchers for survey data collection (Kianersi, 2021). Parents were recruited between June 2023 and October 2023. To acquire a varied and representative selection of participants, over 200 professionals in Tennessee were contacted via email. We also contacted many different local organizations that were dedicated to serving children or adults with disabilities, and we contacted local mental health organizations in Tennessee. Recruitment flyers were administered online through mass emails to many local organizations including The Arc, Vanderbilt Kennedy Center, Disability Rights Tennessee, Down Syndrome Association of Middle Tennessee, Center of Excellence for Children in State Custody, and Tennessee Department of Education. The flyers were also distributed at the Chattanooga Autism Conference, health fairs, and local Nashville events. Parents were also recruited on ResearchMatch which is an online recruitment registry that matches individuals to research studies they may qualify for in the United States (Harris et al., 2012).

Survey

The survey contained seven sections including (1) demographic information about the respondent (the parent/caregiver), (2) information about the child with disabilities and mental and behavioral health concerns, (3) the child's medical history as related to mental and behavioral health, (4) the child's abilities, (5) what mental health services parents have utilized or are familiar with (e.g., special education, child therapies, family-based, and community-based), (6) barriers to receiving mental health services as well as social determinants of health and negative life events, and (7) reflections about existing and/or needed mental health services. The response options included single answers, multiple answers, Likert-scale, and a few fill-in-the-blanks. Then, branching logic was implemented to ensure that participants encountered specific questions based on their responses to previous questions.

Dependent Variables

The dependent variables ranged across the following areas: negative life events in the last 12 months for the child, parent social determinants of health score, and parent familiarity with mental health services.

Negative life events in the last 12 months for the child

Respondents responded to yes/no questions about negative life events that happened within the last 12 months for the child. The negative life events include if anyone in the household was divorced/separated, death of a family member or close friend, financial or legal problems, health problems, child has been hospitalized, major change in residence or housing problems, anyone went to jail/prison, household member experience a mental health crisis/attempt suicide, misuse of alcohol or drugs, child lacked appropriate care, worried that child wouldn't have enough food to eat, verbal abuse, physical abuse, sexual abuse, and if child experienced discrimination. The negative life events scale was based on the Pediatric ACES and Related Life Events Screener (PEARLS) (Thakur et al., 2020). Cronbach's Alpha equaled .714. All items were computed into a single variable to simply analyze.

Parent social determinants of health score

Respondents rated how confident they felt in sixteens areas within their community: education, multilingual services, mental health services, healthcare services, medical insurance, safety in the community, police presence, gender discrimination, racial discrimination, inclusion in the community, community resources, healthy food, parks and green spaces, transportation, safe housing/affordable housing, and employment opportunities. Respondents answered on a 5-point Likert scale: (1) no confidence, (2) rarely confident, (3) somewhat confident, (4) confident, and (5) extremely confident. The social determinants of health areas were developed by the Colorado Community Health Network (2015).

Furthermore, the sixteen social determinants were split into five domains: (1) education (N/A for Cronbach's Alpha), (2) Healthcare, (3) Neighborhood and Built Environment, (4) Social and Community Context, and (5) Economic Stability. For the healthcare domain, the Cronbach's alpha was .790. In addition, social and community context was .825, neighborhood and built environment was .836, and economic stability was .808.

Parent familiarity with mental health services

Respondents rated how familiar they felt with the mental health services within their community in four service categories including special education services, childbased services, family-based services, and community-based services. Respondents answered on a 4-point Likert scale: (1) not familiar at all, (2) a little familiar, (3) familiar, and (4) very familiar.

Independent Variables

The independent variables ranged across the following areas: parent/caregiver respondent and child with a disability and mental/behavioral health concern.

Parent/caregiver respondent

Parents and caregivers reported their basic demographic information. We asked (1) who they are as the person responding, (2) age, (3) gender identity, (4) race/ethnicity, (5) current marital status, (6) primary languages spoken at home, (7) level of education, (8) employment status, (9) household income, (10) zip code, (11) overall physical health status, (12) overall mental health status, (13) disability diagnosis, and (14) number of children including number of children with a disability.

Child with a disability and mental/behavioral health concern

Parents reported the demographic information about the child as well as their mental/behavioral health concerns. The demographic information included (1) child's age, (2) sex and gender identity, (3) race/ethnicity, (4) current living situation, (5) type of school and grade, (6) disability diagnosis, (7) if they have an IEP or not, (8) IEP information (e.g., eligibility category and age they started receiving special education services), and (9) mode of communication.

The parents also reported the child's medical history as related to mental/behavioral health and their adaptive behaviors (aka child's abilities). The medical history consisted of two checklists including Preschool Pediatric Symptom Checklist (ages 1.5-5 years old) and Pediatric Symptom Checklist-17 (ages 6-22 years old) (Massachusetts General Hospital, 2023). The Preschool Pediatric Symptom Checklist and Pediatric Symptom Checklist-17 were brief surveys that were used to screen for developmental, behavioral, and emotional concerns in children. Medical history also consisted of questions about their child's mental health conditions and diagnoses, physical health status, mental/behavioral health status, medications, and hospitalizations. Lastly, the survey asked about the child's abilities consisting of their levels of independence in 15 areas that can be divided into the categories of self-care, sphincter control, transfer, locomotion, communication, and social cognition (Sprint et al., 2015). The 15 areas analyzed were getting into/out of a chair, walking, using the toilet, using the stairs, expression, social interaction, getting in/out of the tub/shower, eating, bathing, dressing lower body, dressing upper body, grooming, comprehension, memory, and problem solving. Each of the 15 areas were answered on a 7-point Likert scale: (1) total assistance, (2) maximal assistance, (3) moderate assistance, (4) minimal assistance, (5) supervision, (6) modified independence, and (7) total independence.

Analysis

After conducting analyses on the parent and child demographics, we analyzed the study's four research questions: (1) comparison of negative life event scores, (2) comparison of social determinants of health scores, (3) parent familiarity with the four types of mental health services (e.g., special education, therapies, family-based, and community-based services), and (4) correlates and predictors of parent familiarity with mental health services.

Comparison of Negative Life Event Scores

The first research question targets the means and standard deviations for each negative life event as well as the total number of negative life events in the past year. First, to describe the means of the 15 negative life events, we identified the means and standard deviations for each with "no-0" to "yes-1". We then calculated the grand mean for the 15 negative life events. A one-way repeated measures ANOVA determined which data was statistically greater or lesser than the total mean (Laerd Statistics, 2018). In addition, a one-way repeated measures ANOVA shows the different mean values for each item. In addition, a McNemar's tests were conducted to compare the proportions of "yes" answers between negative life events. Lastly, an analysis of variance (ANOVA) was conducted to

assess the impact of parent and family demographic factors on negative life events.

Comparison of Social Determinants of Health Scores

In the second research question, we identified the means and standard deviations of each social determinant of health with "1-no confidence" to "5-extremely confident". We then calculated the grand mean for the 16 social determinants of health. Next, a oneway repeated measures ANOVA was used to determine if there were determinants that were statistically higher or lower than the grand mean. We also identified the means and standard deviations of each of the social determinants of health domains. After identifying the means and standard deviations, we conducted another one-way repeated measures ANOVA to see if any domains were statistically higher or lower. Lastly, an analysis of variance (ANOVA) was conducted to assess the impact of parent and family demographic factors on social determinants of health.

Parent Familiarity with the Four Types of Mental Health Services

Then in the third research question, we analyzed the means and standard deviations of the parents' familiarity with each mental health service. We conducted a one-way repeated measures ANOVA to determine if there was a difference in mean scores for each service type (i.e., special education, child-based, family-based, and

community-based). In addition, we conducted an analysis of variance (ANOVA) which was conducted to assess the impact of parent and family demographics on the familiarity of the mental health services.

Correlates and Predictors of Parent Familiarity with Mental Health Services

In the last research question, we looked to see if there were any correlations for familiarity with mental health services with negative life events and social determinants of health. We conducted correlations between negative life events, social determinants of health (total score and 5 domains), and parent familiarity with mental health services to see if there were any relationships between the variables and how close they are connected.

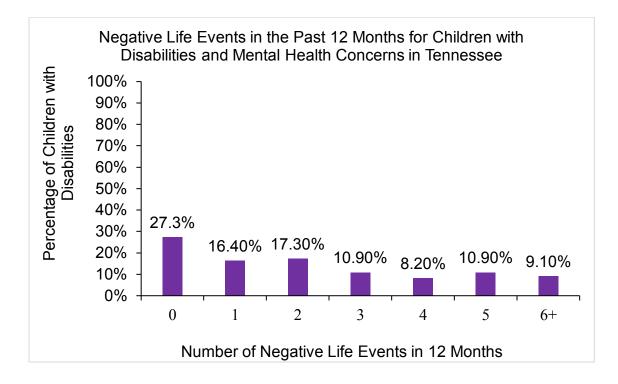
CHAPTER III

RESULTS

To what extent do children with dual diagnosis have high negative events?
 In the study, the grand mean for negative life events for a child with dual diagnosis in the last 12 months is 2.48 (SD 2.59). Overall in examining the negative life events, around 73% of the children with dual diagnosis had experienced one or more negative life events in the past 12 months. Refer to Figure 1.

Figure 1

Negative Life Events Graph



Looking at the binomial distribution for negative life events in the past year, the following events had higher means than the overall mean including: financial or legal problems, household health problems, child experiencing discrimination, and child being hospitalized. The following events had lower means including: child living with someone who went to jail/prison, child lacking appropriate care by any parent, child having been verbally abused, child having been physically abused, and child having been sexually abused or assaulted. Refer to Table 3.

Table 3

Negative Life Events	Mean (SD)	High or Low?
Divorce or separation?	0.10 (.299)	
Death of a family member or close friend?	0.16 (.369)	
Financial or legal problems?	0.36 (.482)	High
Anyone in the household had health problems?	0.43 (.498)	High
Child been hospitalized?	0.21 (.406)	High
Change in residency or problem with housing?	0.19 (.398)	
Child has lived with anyone who went to jail/prison?	0.02 (.133)	Low
Household member experience a mental health crisis or attempt suicide?	0.15 (.359)	

Live with anyone who misused alcohol or drugs?	0.09 (.285)		
Child lacked appropriate care by parent/caregiver?	0.06 (.244)	Low	
Worried that child would not have enough to eat?	0.14 (.351)		
Child been verbally abused by parent/caregiver?	0.05 (.226)	Low	
Physically abused by parent/caregiver?	0.04 (.207)	Low	
Sexually abused or assaulted?	0.04 (.186)	Low	
Child experienced discrimination?	0.29 (.457)	High	

McNamar's test was conducted to compare the proportions of successes between negative life events. It was found that there was a significant difference between the negative life events with high means and negative life events with low means. This data suggests that there is notable change between negative events that were higher and negative events that were lower.

The results revealed a statistically significant effect of marital status (married vs unmarried), employment status (employed vs unemployed), parent mental health (poor vs good), and the child's living situation (living with both parents vs other living situations) affected the social determinants of health score. Therefore children who lived with both parents or had parents who were married, employed, and in good mental health were more likely to have fewer negative life events in the past 12 months. Refer to Table 6.

2) To what extent do parents and caregivers have low social determinants of health

scores?

Overall, the social determinants of health parents were least confident in compared to the grand mean are mental health services, multilingual services, education system, healthcare services, and feeling included in the community. The determinants parents were most confident in compared to the grand mean are community resources, healthy food, and parks and green spaces. For additional information, refer to Table 4.

Table 4

Social Determinant	Mean (SD)	High or Low?
Access to parks and green	3.7	High
spaces		
Access to healthy food	3.62	High
Access to community	3.46	High
resources		
Access to transportation	3.28	
Feeling safe in my	3.24	
community		
Police presence makes me	3.24	
feel safe		
Access to medical	3.22	
insurance		
Freedom from gender	3.18	
discrimination		
Safe housing/affordable	3.1	
housing access		
Access to employment	3.07	
opportunities		
Freedom from racial	3.03	
discrimination		
Feel included in my	2.82	Low
community		
Adequate healthcare	2.81	Low
services		
Adequate education system	2.76	Low

Social Determinants of Health Frequencies and Grand Mean Comparison

Access to multilingual	2.65	Low
services		
Access to mental health	2.59	Low
services		

The one-way repeated measures ANOVA determined whether items showed different mean values, with social determinants of health domains indicating which items were statistically higher or lower than the grand mean. These analyses showed that the health domain and education domain had lower means, and the neighborhood and built environment domain had a statistically higher mean. Within the health domain, the mean was significantly lower for adequate healthcare services (mean = 2.59) and the mean was higher for access to medical insurance (mean = 3.22). However, within the neighborhood and built environment domain, parents were most confident in access to parks and green spaces (mean = 3.70) and access to healthy food (mean = 3.62). Refer to Table 5

Table 5

$\alpha \cdot ir$)eterminants		CTT 1.1	D ·	T	•
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		\mathcal{O}	11000000	Donnan	1 1 0 9 0	

Social Determinant	Mean (SD)	High or Low?
Domains		
Neighborhood and Built	3.41 (0.92)	High
Environment		
Economic Stability	3.08 (1.16)	
Social and Community	3.01 (0.90)	
Context		
Healthcare	2.87 (0.93)	Low
Education	2.76 (1.26)	Low

An analysis of variance (ANOVA) was conducted to assess the impact of demographic factors on social determinants of health. The results revealed a statistically significant effect of marital status (married vs unmarried), employment status (employed vs unemployed), parent mental health (poor vs good), and the child's living situation (living with both parents vs other living situations) all affected the social determinants of health score. Therefore parents who were married, employed, and had good mental health were more likely to have a high social determinants of health school versus parents who were unmarried, unemployed, and had poor mental health. Refer to Table 6.

Table 6

Negative Life Events and Social Determinants of Health: Potential Predictors for Factors

	Factor I					Factor II			
			alth			Neighborhood and Built Environment			
	п	Mean (SD)	F or <i>t</i>	Sig	п	Mean (SD)	F or <i>t</i>	Sig	
Family Demographics									
Marital Status			17.007	<.001			11.521	<.001	
Unmarried/Divorced	26	6.77 (2.58)			26	14.50			
						(5.49)			
Married/Partnered	86	9.17 (2.61)			85	17.87			
						(4.06)			
Employment			3.911	.050			.651	.422	
Employed	85	8.91 (2.71)			84	17.27			
						(4.37)			
Unemployed	27	7.70 (2.88)			27	16.44			
						(5.44)			
Parent Mental Health			2.757	.068			3.168	.046	
Poor/Fair	31	7.61 (2.30)			30	15.27			
						(4.94)			
Good	54	8.87 (2.78)			54	17.48			
						(4.08)			
Very good/Excellent	27	9.07 (2.93)			27	17.96			
		~ /				(4.74)			
Living Situation of Child			6.380	.002			8.496	<.001	
Live with mom or dad	29	7 10 (2 12)			29	14.24			
Live with mom of dad	29	7.10 (3.12)			29	(5.50)			
Live with both perents	76	0.14(2.45)			75	(3.30) 17.97			
Live with both parents	/0	9.14 (2.45)			15				
Other living situation	8	0.12(2.70)			8	(3.74) 18.87			
Other living situation	ð	9.13 (2.70)			ð				
						(4.88)			

Table 6 Continued

	Factor III Social						or IV c Stability	
	п	Mean (SD)	F or <i>t</i>	Sig	п	Mean (SD)	F or <i>t</i>	Sig
Family Demographics								
Marital Status			15.527	<.001			6.692	.011
Unmarried/Divorced	26	12.19 (4.49)			26	5.15 (2.38)		
Married/Partnered	84	15.96 (4.19)			84	6.48 (2.25)		
Employment		()	5.654	.019			4.925	.029
Employed	83	15.64 (4.20)			83	6.42 (2.31)		
Unemployed	26	13.30 (5.15)			27	5.30 (2.22)		
Parent Mental Health		(0.10)	4.131	.019			2.069	.131
Poor/Fair	31	13.10 (4.30)			30	5.33 (2.18)		
Good	52	15.71 (4.33)			53	6.19 (2.35)		
Very good/Excellent	27	15.81 (4.25)			27	6.78 (2.38)		
Living Situation of Child		(1120)	8.891	<.001			5.579	.005
Live with mom or dad	29	12.24 (5.01)			29	5.00 (2.15)		
Live with both parents	75	16.13 (3.74)			74	6.51 (2.20)		
Other living situation	7	(5.74) 15.43 (5.62)			8	7.13 (2.85)		

Table 6 Continued

		Factor V Education				Negative I	Life Events	5
	n	Mean (SD)	F or t	Sig	п	Mean (SD)	F or <i>t</i>	Sig
Family Demographics		X / /		<u> </u>				0
Marital Status			23.043	<.001			3.585	.061
Unmarried/Divorced	26	1.81 (.94)			26	3.11 (1.97)		
Married/Partnered	87	3.05 (1.21)			86	2.14 (2.37)		
Employment			14.986	<.001			1.880	.173
Employed	85	3.00 (1.20)			83	2.22 (2.25)		
Unemployed	28	2.00 (1.16)			26	2.92 (2.43)		
Parent Mental Health			4.069	.020			4.917	.009
Poor/Fair	31	2.26 (1.06)			31	3.39 (1.94)		
Good	54	2.83 (1.26)			51	1.80 (1.91)		
Very good/Excellent	28	3.14 (1.33)			27	2.22 (2.99)		
Living Situation of Child			11.598	<.001			2.472	.089
Live with mom or dad	29	1.90 (1.11)			29	3.14 (2.18)		
Live with both parents	77	3.10 (1.18)			73	2.14 (2.33)		
Other living situation	8	2.63 (1.06)			8	1.63 (2.00)		

3) To what extent are parents and caregivers less likely to be familiar about the four types of mental health services (e.g., special education, therapies, family-based, and

community-based)?

The analysis utilizing a one-way repeated measures ANOVA looked at the parent's familiarity with the four types of mental health services. The analysis revealed there was little difference in the means for the types of each service and the grand mean. Refer to Table 7.

Table 7

Familiarity Mean of Each Type of Mental Health Service

Type of Service	Mean (SD)
Special Education	2.51 (.817)
Services	2.41 (.735)
Community-based	
Services	
Family-based Services	2.33 (.903)
Child-based Services	2.32 . (787)

Compared to the grand mean within special education services, the service that parents knew more about was individual counseling support. The services they knew less about were daily check-ins with identified adults, daily check-ins with identified peer buddies, and trauma-informed counseling or support.

Compared to the grand mean within child-based services, the services that parents were more familiar with were individual therapy/counseling, group therapy/counseling, family therapy/counseling, cognitive behavioral therapy, applied behavioral analysis therapy, music therapy, and play-based therapy. The services parents were less familiar with were humanistic therapy, acceptance and commitment therapy, dialectical behavior therapy, comprehensive child and family treatment, continuous treatment team, and childparent psychotherapy.

Within family-based services, compared to the grand mean, parents were more familiar with family therapy or counseling. There were no other significantly higher or lower means for other family-based services. Within community-based services, compared to the grand mean, parents were likely to be more familiar with state agencies, schools, places of worship, and primary care providers. The services they were less likely to be familiar with were housing assistance, transportation assistance, postsecondary education assistance, financial assistance, and legal assistance.

An analysis of variance (ANOVA) was conducted to assess the impact of demographic factors on familiarity with mental health services. The results revealed a statistically significant effect of parent race (white/non-Hispanic vs other race/ethnicity), primary language spoken (English vs Spanish), marital status (married vs unmarried), level of education (higher level vs lower level of education), and parent mental health (good vs poor mental health) all had an effect on parents' familiarity with mental health services. This indicated that parents who were white, spoke English, were married, had a higher level of education, and had good mental health were more likely to be familiar with mental health services versus parents who were of another race/ethnicity, spoke Spanish, unmarried, had lower levels of education, and poor mental health. Refer to Table 8.

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Table 8

Familiarity of Mental Health Services: Potential Predictors for Factors

		Fac	tor I			Fact	tor II	
	Special Education Familiarity			Child-Based Services Familiarity				
	n	Mean (SD)	F or <i>t</i>	Sig	п	Mean (SD)	F or <i>t</i>	Sig
Family Demographics								
Parent Race			7.733	<.001			5.375	.006
White, non-Hispanic	81	2.54 (1.13)			74	2.37 (.72)		
African American	21	2.32 (.61)			17	2.54 (.81)		
Hispanic or Latino	11	1.74 (.86)			11	1.64 (.90)		
Language			11.967	<.001			6.662	.011
English	103	2.59 (.78)			91	2.39 (.75)		
Spanish	9	1.65 (.80)			10	1.73 (.94)		
Marital Status			.005	.943			3.347	.070
Unmarried/Divorced	25	2.53 (.88)			24	2.07 (.71)		
Married/Partnered	87	2.51 (.81)			77	2.40 (.80)		
Education			3.859	.052			6.572	.012
High school or some	44	2.33 (.90)			41	2.08 (.84)		
college								
4-year and above	67	2.64 (.73)			59	2.23 (.79)		
Parent Mental Health			2.088	.129			1.395	.253
Poor/Fair	31	2.26 (.97)			29	2.16 (.92)		
Good	55	2.60 (.80)			53	2.34 (.73)		
Very good/Excellent	26	2.63 (.59)			19	2.54 (.73)		

Table 8 Continued

		Fact	or III			Fact	or IV	
	Family-Based Services Familiarity			Community-based Services Familiarity				
	n	Mean (SD)	F or <i>t</i>	Sig	п	Mean (SD)	F or <i>t</i>	Sig
Family Demographics								
Parent Race			2.850	.062			4.420	.014
White, non-Hispanic	82	2.37 (.72)			81	2.49 (.73)		
African American	22	2.45 (.83)			20	2.40 (.68)		
Hispanic or Latino	10	1.70 (.89)			8	1.70 (.63)		
Language			3.600	.060			2.499	.117
English	105	2.37 (.89)			101	2.44 (.73)		
Spanish	8	1.75 (1.00)			7	1.99 (.73)		
Marital Status			4.257	.041			.476	.492
Unmarried/Divorced	27	2.02 (.84)			24	2.32 (.73)		
Married/Partnered	86	2.42 (.91)			84	2.44 (.74)		
Education			3.459	.066			.075	.785
High school or some college	43	2.21 (.91)			42	2.39 (.85)		
4-year and above	69	2.44 (.87)			65	2.43 (.64)		
Parent Mental Health			6.378	.002		× /	2.810	.065
Poor/Fair	32	1.88 (.84)			30	2.16 (.67)		
Good	54	2.45 (.98)			55	2.55 (.80)		
Very good/Excellent	27	2.62 (.60)			23	2.39 (.60)		

4) To what extent do negative life events and social determinants of health correlate with parents' and caregivers' familiarity with mental health services?

The bivariate Pearson Correlation analysis revealed no significant correlations between negative life events and the four mental health services investigated meaning there was no significant relationship between the two. However, correlations were observed among social determinants of health (i.e., economic stability, healthcare, neighborhood and built environment, social and community context, and education) and familiarity with mental health services. The results of Pearson correlation analysis revealed that there were 13 potential predictors. Among the predictors identified, the healthcare, neighborhood and built environment, social and community context, and education domains had medium positive correlations with child-based, family-based, and community-based familiarity meaning the higher the social determinants score was, the more familiar the parent was in mental health services for their child. In addition, the neighborhood and built environment domain displayed a slight positive correlation with special education familiarity mean. For detailed correlations, refer to Table 9.

Table 9

Correlations o	of Social Determinants of	of Health and	Familiarity of Services

	SDOH Score	Economic Stability Domain	Healthcare Domain	Neighborhood and Built Environment Domain	Social and Community Context Domain	Education Domain
SPED Familiarity Mean	.141	.007	.113	.241*	.119	.142
Child-based Familiarity Mean	.171	.065	.255*	.273**	.227*	.270**
Family-based Familiarity Mean	.286**	.120	.326**	.328**	.322**	.350**
Community- based Familiarity Mean	.185	.125	.362**	.236*	.207*	.201*

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

CHAPTER IV

DISCUSSION AND CONCLUSION

The study begins the process of understanding how negative life events and social determinants of health play a role in service delivery for children who have disabilities and co-occurring mental health/behavioral health concerns. We examined the relations of negative life events and social determinants, as well as how each related to familiarity of mental health services. The study provides four major findings, each with implications for both research and practice.

Our first finding indicated that around 73% of the children with disabilities in the study experienced at least one negative life event in the past year. The most common events were financial and legal problems, household health issues, discrimination, and hospitalization, with child abuse, jail or imprisonment of a family member, and lack of appropriate care were lower. Overall, however, a prevalence rate of almost ³/₄ experienced any life events, with over 1/3 of the children experiencing 3 or more, is noteworthy. Even compared to other studies, such rates are exceptionally high. Hastings et al (2004), for example, reported that among his adults with intellectual disability, one or more life events were experienced by 46.3% of subjects. This sample, then, reported exceptionally high rates of adverse events.

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The second main finding related to social determinants of health, which showed importance differences across items. Parents were more confident about their access to parks, healthy foods, and community resources. Parents were less confident in accessing adequate healthcare, education, and mental health services. Given the needs of their children – specifically, their children with disabilities who have mental healthcare needs – it is alarming that parents expressed decreased confidence in health, education, and mental health services, the very services that were most needed by these respondents' children. Specific demographic aspects of parents and families are also related to social determinants of health. For example, those parents who were married (vs. unmarried), employed (vs. unemployed), good mental health (vs. poor health), and living with both parents (vs. other living situations) were more likely to have a higher social determinants of health score.

A third finding related to parents' familiarity with services in specific areas of mental health services. Specifically, respondents were more familiar with mental health services within the schools such as individual counseling support, social skills/friendship group, and behavior intervention plan/behavior support plan, but less familiar with mental health services that were child-based (e.g., cognitive behavioral therapy, humanistic therapy, and comprehensive child and family treatment) and family-based (e.g., family therapy or counseling), and community-based (e.g., legal assistance, state agencies, and primary care provider).

Specific demographic aspects of parents and families are also related to familiarity. For example, those parents who were White (vs. Black and other), spoke English (vs. other languages), married (vs. unmarried), had higher levels of education (vs. lower), and good mental health (vs. poor) were more likely to be familiar with mental health services. While perhaps not surprising, these findings show that needed mental health services or even knowledge of such services are not penetrating dually diagnosed groups overall, even less so with those subgroups within the dually diagnosed population that may be most in need.

Lastly, low-to-medium correlations existed between the parents' social determinants of health, including the five domains (i.e., economic stability, healthcare, neighborhood and built environment, social and community context, and education), and parents' familiarity with mental health services. Thus, those respondents who scored lower on social determinants had less familiarity with mental health services. Again, it appears that those parents-children most in need of mental health services are least knowledgeable about the presence of such services.

Implications for Research and Practice

Our findings have implications for parents as well as mental health professionals. Given our study's insights into the difficulties encountered by parents of children with dual diagnoses, targeted interventions and supports are imperative. The implications for research and practice include developing targeted educational programs focusing on specific mental health service types that parents are less familiar with (e.g., child-based services) and training mental health professionals to address social determinants for health to promote more equitable mental health outcomes for children with disabilities. All together, these findings have implications that may begin to address the disparities that children with disabilities and mental health concerns face. One implication concerns the parent's familiarity with mental health services that exist for children with disabilities. According to data from the study, it was found that many parents were not very familiar with a lot of the services specifically family-based and child-based mental health services. To increase mental health service familiarity, it is important for more education and outreach to families and caregivers from diverse backgrounds. Tailored educational programs targeting less familiar mental health services for parents are essential to have children with dual diagnoses get the care they deserve. It is also important to provide accessible materials in various languages and formats to enhance accessibility and understanding for parents especially parents who come from diverse backgrounds and/or lower socioeconomic status.

Additionally, increasing accessibility could also be accessible through online resources for continual learning and accessibility. In addition, educational programs should partner with community organizations for outreach and education initiatives. For example, NADD (previously known as the National Association of the Dually Diagnosed) which has been around for over four decades has helped train mental health professionals to treat individuals with mental health concerns via many conferences, books (published by NADD Press), organization-sponsored journal (*Journal of Mental Health Research in Intellectual Disabilities*), and continuing education properties (NADD, 2022). Properly training mental health professionals to treat individuals with dual diagnosis will increase the parent's familiarity with mental health services that are available for their child.

Another implication is that mental health professionals need to pay more attention to children with dual diagnosis, specifically social determinants of health. According to results from the study, there's a critical need to integrate training on addressing social determinants of health for mental health professionals. This could be done through "service learning" (The National Academies of Sciences, Engineering, and Medicine, 2016) which is a framework that entails continuing professional development through training and service that comprises of hands-on work intentionally put together to accommodate the needs of the community, along with time for consideration and assimilation of professional development into clinical and various health courses (The National Academies of Sciences, Engineering, and Medicine, 2016). The framework focuses on four areas including scholarship, partnership, programs, and growth.

The overall goal of the framework is to better prepare medical professionals including mental health professionals on how to effectively work with diverse populations as well as addressing social determinants of health. In addition, it would be appropriate to provide mental health professionals with assessment tools and resources to identify social determinants that impact mental health outcomes. It would also be appropriate to offer guidelines for tailored interventions that target social determinants of health during mental health assessments and treatment planning. This would significantly influence equitable mental health outcomes for children with dual diagnoses.

Limitations

The study did have some limitations that need a mention. First, the data represents only a small sample of parents and caregivers in Tennessee with children with disabilities and mental health concerns. With that being said, respondents were primarily white, and the study did lack diversity in different races and ethnicities. Secondly, we did not collect data on adverse childhood experiences, but instead, collected data on negative life events in the past 12 months which may have affected the overall relationship between adverse childhood experiences and familiarity with services.

Conclusion

This study begins the process of examining negative life events, social determinants of health, and the parents' and caregivers' familiarity with mental health services concerning children with dual diagnoses. Despite the limitations, the study lays a critical foundation for understanding and addressing the multifaceted challenges faced by parents and caregivers as well as their children with dual diagnoses. This insight is crucial for making more interventions and supports for addressing the complex challenges faced by parents and their children with dual diagnoses.

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