68th Legislative Session

House Appropriations-Human Resources Division

Chairman Nelson and other members of the Committee. I am Rebecca Quinn and serve as an associate director at the Center for Rural Health at the University of North Dakota School of Medicine and Health Sciences. The Center for Rural Health is contracted by the Department of Health and Human Services to operate the North Dakota Brain Injury Network. My testimony today is on behalf of all the individuals and families impacted by brain injury in North Dakota.

Brain injury impacts every facet of an individual's life and individuals with brain injury are represented across all service system. Depending on the age of the injury, deficits the person may have, and resources available an individual may qualify for various service systems creating a vast array of available options. Throughout the development of North Dakota's brain injury services, there has been identified the need for a centralized brain injury hub to provide information, support, and training. The North Dakota Brain Injury Network meets these needs by providing a centralized, statewide source of information regarding brain injury and delivers resource facilitation services to individuals with brain injury. The importance of NDBIN is to help individuals with brain jury, their families and the professionals working with them to navigate the complex system of care and resources that might be available.

To continue to serve individuals with brain injury in the state I would encourage the committee to conserve all the brain injury funding in the SB2012.

Thank you for your time and I welcome any questions.

My name is Calvin Samek. I live each day with the effects of a TBI. There are moments in our lives where a definitive line can be drawn between what used to be and what is to be. I believed my last injury was one of those. For months after, I felt totally hopeless and defeated by my injury. I was alive but not living. Slowly I saw my world around me disappear. Things kept falling by the wayside. The list is much to long to share in this single page letter.

After several attempts at treatment for diagnosis that didn't work, I was referred to a neuropsychologist. That doctor diagnosed me with a TBI and when I started treatment schedule for that my life had started to find a direction once again. Along the way I was introduced to Rebecca Quinn (NDBIN) and accompanied her to the capitol many years ago. Who would have thought that her mission would become so very important to me? My own story kind of parallels the story of NDBIN.

In the past few years, I went from being homeless to earning my Social Work Degree. And now this year for the first time since my injury I have returned to work full time. I am climbing mountains everyday with the help of folks like the ones at the NDBIN. I know I would not be anywhere close to where I am without them.

Over the past 9 years my life has been enriched by the NDBIN directly and indirectly in so many ways. The website has been an invaluable resource for support, education, information, and general comfort in knowing that there are those out there that are continuing our cause. All the people I have met along the way have been a necessary part of who I am today. I find that my life is enriched by those that have offered support.

Thanks for your consideration,

Calvin

Recent Feedback

"You continue to do amazing work."

"Providing a muchneeded service to people."

Thank you so much for doing what you do. You are incredibly appreciated.

Brain Injury Defined

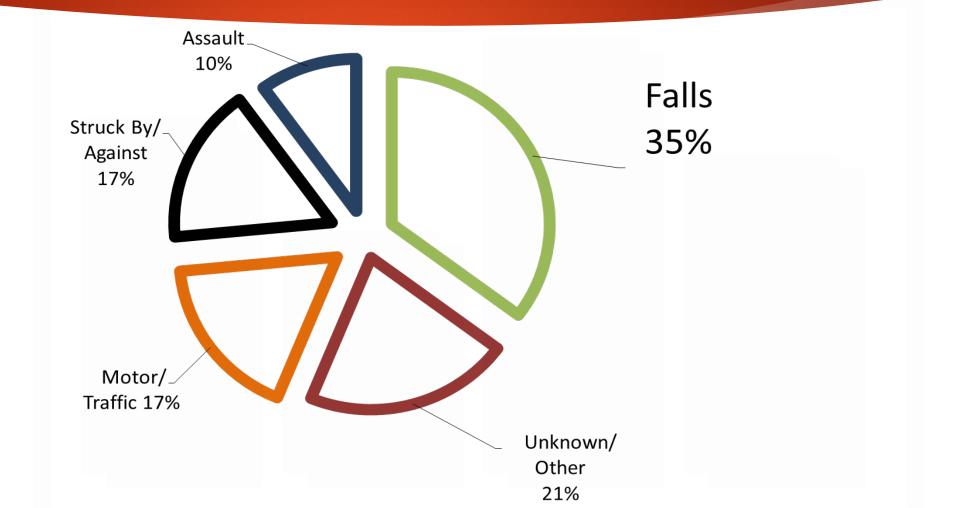
Acquired Brain Injury (ABI)

Traumatic Brain Injury (TBI) Non-Traumatic Brain Injury

External Events: assault, fall, blast injury, motor vehicle crash

Internal Events: stroke, tumor, anoxia, aneurysm, infection

Leading Causes of TBI



Severity Continuum

Mild	 75-90% cases LOC less 30min Up to 15% have long term impairments
Moderate	• 10-30% cases LOC between 30min-24hrs Up to 30-50% have long term impairments
Severe	 5-10% cases LOC greater 24hrs Up to 80% have long term impairments

Possible Impairments after a Brain Injury

Physical

- Motor coordination
- Hearing and visual Loss
- Spasticity and tremors
- Fatigue and/or weakness
- Loss of taste and smell
- Balance
- Mobility
- Speech
- Seizures
- Headaches or migraines
- Pain
- Changes in sleep patterns

Cognitive

- Memory loss
- Difficulty with decisionmaking, planning, sequencing
- Impaired judgment
- Slowed ability to process
- Problem-solving difficulties
- Organizational problems
- Impaired perception of self, others
- Inability to complete task without reminders
- Trouble concentrating

Emotional/ Behavioral

- Depression
- Mood swings
- Problems with emotional control; impulsive behavior
- Inappropriate behavior
- Inability to inhibit remarks
- Lack of response to social cues
- Problems with initiation
- Reduced self-esteem
- Difficulty relating to others
- Difficulty maintaining or forming relationships
- Increased anxiety and frustration

100% 90% 80% 70% 60% 50% 40% 30% 20% 10% 0% Gen Pop Homeless Beh Health Justice IPV BI No BI

BI Prevalence within Special Populations

North Dakota Brain Injury Network Biennial Report

July 2021-December 2022

Submitted to: North Dakota Department of Health and Human Services Behavioral Health Division

NORTH DAKOTA BRAIN INJURY NETWORK

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Overview

For the period of July 1, 2021 through Dec 31, 2022 NDBIN provided:

- 727 clients served; 401 new referrals; 391 closed cases; ave cost per client \$487.07
- 71,760 NDBIN website views; 182 postings to online calendar
- 55 support groups; 7 Living Life Fully groups
- 35 Webinar Wednesdays; 23 trainings with 394 attendees
- 487 individuals completed online training courses, 3 Certified Brain Injury Specialist Trainings for 50 professionals
- 68 attendees at annual Mind Matters Conference and 205 attendees at 2 annual Concussion Symposiums

Support Services

Resource Facilitation

- Resource facilitation for brain injury is an evidenced based service that assists individuals along the path of recovery and increasing independence. This vital service has been adopted by over 40 states and is seen as a core for state brain injury service development by the Federal TBI grant program.
- This biennium NDBIN has provided resource facilitation to a total of 727 clients served; 401 new referrals; 391 closed cases; average cost per client \$487.07.

Support Groups

- Facilitated 55 support groups, both in person and virtually.
- NBDIN facilitates a monthly support groups in Devils Lake, Grand Forks, and virtually.
- NDBIN also provides support and promotion to the other five independently run support groups in the state.

Survivor Connections

- Launched in spring of 2021
- Phone based program for new individuals with brain injury to connect them with trained volunteers to provide support for those new to the injury.
- The program has completed 35 Survivor Connections calls.

Awareness and Outreach

Website

- Maintained a comprehensive website with over 71,760 unique page views
- Searchable online resource guide, maintained events calendar
- Developed new content regarding caregivers, special education, and related services

Adapted the REAP for ND

- This is an evidenced based return to learn guide developed by CO and adapted to over 20 states.
- What is REAP?
 - R = Remove/Reduce physical and cognitive demands

- E = Educate the student athlete families, educators, coaches, and medical teams of the potential symptoms
- A = Adjust/Accommodate for the student athlete academically
- P = Pace the student athlete back to learning, activity, and play

North Dakota Brain Injury Guide

• Partnered with the North Dakota Stroke Association to publish a new North Dakota Brain Injury Guide for new survivors.

Unmasking Brain Injury

- The purpose of this project is to not only create awareness for brain injury, but to also give the survivors a voice. The project allows individuals with brain injury to create an art mask to tell their story as a means to educate others of what it is like to live with a brain injury. It also gives brain injury survivors an outlet to show others that those living with this disability are like anyone else. By combining therapy, art, and advocacy, this project presents an entirely unique perspective on life with brain injury for survivors, care givers, and professionals.
- Currently NDBIN has over 130 masks in our collection
- <u>http://unmaskingbraininjury.org/north-dakota/</u>

Screening

Screening Protocols

- Facilitated a Brain Injury and Criminal Justice Workgroup to assist in selecting a screener.
- Selected and adapted a brain injury screening and supports protocol for implementation within reentry and community-based programs serving individuals with mental health and substance use disorders.

Screening Portal

- Designed and developed a virtual screening toolkit with a HIPAA protected data entry portal for use by community partners to aid in data collection and management.
- Provided seven trainings for community-based providers on the use of the screening toolkit and data entry portal.

Screening Numbers

Screening data for the period of July 1, 2021 – December 31, 2022:

- Number of Short OSU/ABI screenings = 132
 - \circ Number of individuals who screened negative for TBI = 10
 - \circ Number of individuals who screened positive for TBI = 122
 - Number of symptom inventories completed = 121 (one individual screened positive for TBI but did not have a symptom inventory completed for them)

Education and Training

Mind Matters Conference

- March 2022-68 attendees
- Past conference attendee quotes:

- I like having the information to share with clients that struggle with TBI
- Love the Mind Matter conferences
- We are fortunate to have such an important conference in ND.
- Oh my-all speakers were amazing! Connecting with everyone and sharing what workswhat does not.
- Well organized-good job and thank you!
- I thought the conference was great. I enjoyed all the speakers-nice variety and topics and good information.

Online Brain Injury Training

- June of 2019 NDBIN launched 5 online training courses
- This biennium 3,589 individuals enrolled and 487 have completed

Certified Brain Injury Specialist (CBIS) Training

- Nationally recognized credential for professionals working in brain injury services. This certification is administered by the Brain Injury Association of America and involves formal coursework and a written examination.
- NDBIN has provided 7 CBIS trainings in ND since July of 2019.
- Total of 79 officially certified CBIS in ND as of December 2022.
- NDBIN hosts a quarterly call for all CBIS to share information and collaborate.

Webinar Wednesdays

- These FREE webinars cover a range of brain injury topics and are designed to meet the needs whether you are a brain injury/stroke survivor, caregiver, or provider. Variety of continuing education credits are offered, and they are archived online.
- Total of 35 Webinar Wednesday's.

Virtual Concussion Symposium

• Have hosted 2 Annual Concussion Symposiums with over 200 attendees altogether

Brain Injury Basics Training

- February of 2021 was the first training
- New training developed to be less intensive than the Certified Brain Injury Specialist, but more engaging than the online courses.
- This training is based on an interactive approach and will provide direct care staff, peer support specialists and caregivers of individuals with brain injury a general knowledge of brain injury and what that means for the individuals they serve, practical techniques for handling difficult behaviors of individuals with brain injury, as well as building rapport for the individuals within their care.
- Provided on a requested basis.

ND Train courses

- Developed in December of 2022
- Three courses designed to complement the online courses but geared specifically towards direct service providers in North Dakota working with clients with brain injury

Living Life Fully After Brain Injury Courses

- This seven-class series provides survivors with tools and techniques to help them understand, cope with, and proactively manage life after brain injury.
- Facilitated by a peer support specialist with lived experience with brain injury and a Certified Brain Injury Specialist
- Since April of 2022 have held 7 courses in person and online. 32 attendees total.

2021-2022 NDBIN Satisfaction Survey

Reporting period: July 1, 2021 – December 31, 2022

- Responses in Qualtrics = 39
- Selected Comments:
 - "The information available online has been very helpful and useful."
 - "NDBI Network provides great information and support."
 - "Very informative website and resources available. User friendly"
 - *"Fabulous program. intellectually and educationally. Thank you to Carly for her unending upbeat personality and for all the staff. Thank you!"*
 - "The information and education that is offered through North Dakota and with the fantastic help from Carly Endres, Rebecca Quinn, and others is very impressive and appreciated!"
- Satisfaction Ratings
 - Overall, I was satisfied with my experience with the North Dakota Brain Injury Network (n=38)
 - Completely Agree = 18 (47.4%)
 - Agree = 15 (39.5%)
 - Neutral = 4 (10.5%)
 - Disagree = 1 (2.6%)
 - Completely Disagree = 0 (0.0%)
 - The staff who provided support were polite and respectful toward me (n=38)
 - Completely Agree = 21 (55.3%)
 - Agree = 14 (36.8%)
 - Neutral = 3 (7.9%)
 - Disagree = 0 (0.0%)
 - Completely Disagree = 0 (0.0%)
 - I was comfortable being open and honest with the staff about my needs and concerns (n=38)
 - Completely Agree = 20 (52.6%)
 - Agree = 12 (31.6%)
 - Neutral = 5 (13.2%)
 - Disagree = 1 (2.6%)
 - Completely Disagree = 0 (0.0%)
 - The North Dakota Brain Injury Network provided me with options regarding resources/referrals (n=38)
 - Completely Agree = 15 (39.5%)
 - Agree = 14 (36.8%)
 - Neutral = 8 (21.1%)
 - Disagree = 1 (2.6%)
 - Completely Disagree = 0 (0.0%)

- The North Dakota Brain Injury Network met my needs (n=38)
 - Completely Agree = 18 (47.4%)
 - Agree = 11 (28.9%)
 - Neutral = 8 (21.1%)
 - Disagree = 1 (2.6%)
 - Completely Disagree = 0 (0.0%)
- The North Dakota Brain Injury Network provided me with help in a timely manner (n=38)
 - Completely Agree = 18 (47.4%)
 - Agree = 12 (31.6%)
 - Neutral = 7 (18.4%)
 - Disagree = 1 (2.6%)
 - Completely Disagree = 0 (0.0%)
- I will seek support from the North Dakota Brain Injury Network in the future (n=38)
 - Completely Agree = 17 (44.7%)
 - Agree = 16 (42.1%)
 - Neutral = 5 (13.2%)
 - Disagree = 0 (0.0%)
 - Completely Disagree = 0 (0.0%)
- I would recommend the North Dakota Brain Injury Network to other people (n=38)
 - Completely Agree = 21 (55.3%)
 - Agree = 12 (31.6%)
 - Neutral = 4 (10.5%)
 - Disagree = 1 (2.6%)
 - Completely Disagree = 0 (0.0%)
- Summary
 - Overall, 87% of individuals who responded were satisfied with their experience with the North Dakota Brain Injury Network (i.e., responded agree or completely agree)
 - 87% of individuals who responded would recommend the North Dakota Brain Injury Network to other people (i.e., responded agree or completely agree)
 - 92% of individuals agreed or completely agreed that the staff who provided support were polite and respectful toward them.

Webinar Wednesday Evaluation Data Analysis

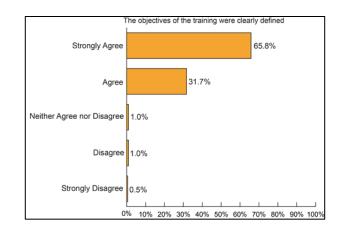
Time Period: July 1, 2021 – December 31, 2022

Total number of webinars = 26

Webinar	Number of Evaluations Completed
50-30-20 Budget	4
ABA Consultants	9
Adult Foster Homes	14
Bumped His Head and Went to Bed	23
LSS MN	3
North Dakota Programs with Heather Brandt	6
PCAND	2
Show Your Doctor Your Symptoms and Manage Your Care	3
Support System for Caregivers	7
Tinnitus with Dr. Fire	2
Post-Concussion Inc (Bella Paige)	6
Chelsey Asiala/PAM (Post-Acute Medical)	7
Community-Based Services	4
Community Options	5
COVID and the Brain (Dr. Ala Lysyk)	18
Emotional Dysregulation Podcast	19
ETIPS Research Study	7
Fair Plains Housing	4
Kara Welke	6
Lit up my Mind	6
Neuroplasticity, Setting Goals, and Creating Hope After Brain Injury and Stroke with Craig Philips	12
Podcast-Learning Accommodations	9
Saving Shannon	13
Synapse	4
Vocational Rehabilitation	8
Will I ever be able to drive again?	6
TOTAL	207

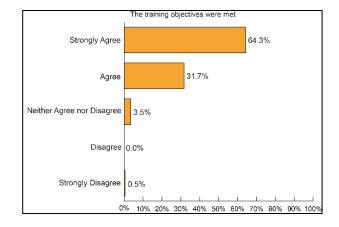
Q1. The objectives of the training were clearly defined

Strongly Agree = 133 (65.8%) Agree = 64 (31.7%) Neither Agree nor Disagree = 2 (1.0%) Disagree = 2 (1.0%) Strongly Disagree = 1 (0.5%) **TOTAL = 202** *Missing = 5



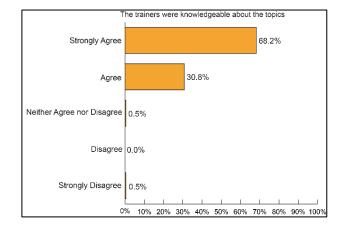
Q2. The training objectives were met

Strongly Agree = 130 (64.3%) Agree = 64 (31.7%) Neither Agree nor Disagree = 7 (3.5%) Disagree = 0 (0%) Strongly Disagree = 1 (0.5%) **TOTAL = 202** *Missing = 5



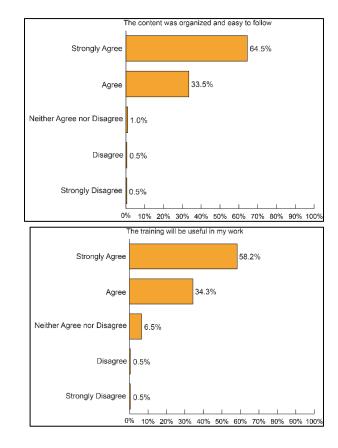
Q3. The trainers were knowledgeable about the topics

Strongly Agree = 137 (68.2%) Agree = 62 (30.8%) Neither Agree nor Disagree = 1 (0.5%) Disagree = 0 (0%) Strongly Disagree = 1 (0.5%) **TOTAL = 201** *Missing = 6



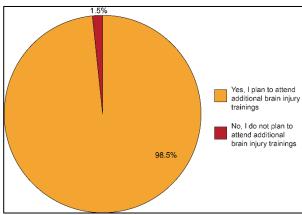
Q4. The content was organized and easy to follow

Strongly Agree = 129 (64.5%) Agree = 67 (33.5%) Neither Agree nor Disagree = 2 (1.0%) Disagree = 1 (0.5%) Strongly Disagree = 1 (0.5%) **TOTAL = 200** *Missing = 7



Q5. The training will be useful in my work

Strongly Agree = 117 (58.2%) Agree = 69 (34.3%) Neither Agree nor Disagree = 13 (6.5%) Disagree = 1 (0.5%) Strongly Disagree = 1 (0.5%) **TOTAL = 201** *Missing = 6



Q6. Do you plan to attend any of the additional brain injury trainings?

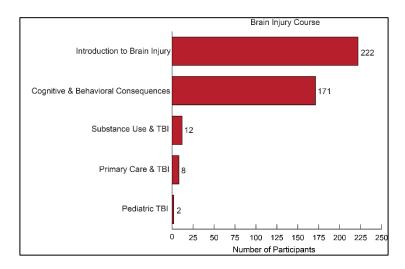
Yes = 200 (98.5%) No = 3 (1.5%) **TOTAL = 203** *Missing = 4

TBI Course Evaluation Data Analysis

Time Period: July 1, 2021 – December 31, 2022 Total responses = 415

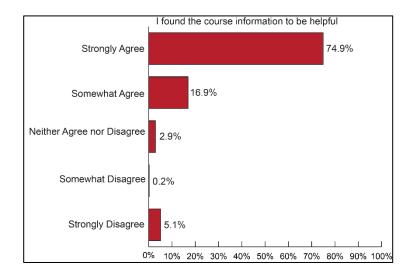
Q1. Which Brain Injury Course are you filling out this evaluation for?

- Introduction to Brain Injury = 222
- Cognitive and Behavioral Consequences of Brain Injury = 171
- Substance Use and TBI = 12
- Primary Care and TBI = 8
- Pediatric TBI = 2



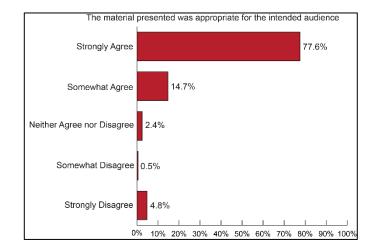
Q2. I found the course information to be helpful. Strongly agree = 311 (74.9%) Somewhat agree = 70 (16.9%)

Neither agree nor disagree = 12 (2.9%) Somewhat disagree = 1 (0.2%) Strongly disagree = 21 (5.1%) **TOTAL = 415**

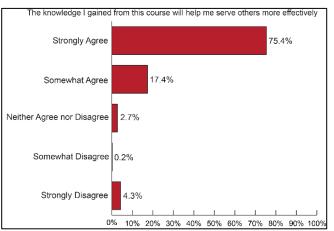


Q3. The material presented was appropriate for the intended audience.

Strongly agree = 322 (77.6%) Somewhat agree = 61 (14.7%) Neither agree nor disagree = 10 (2.4%) Somewhat disagree = 2 (0.5%) Strongly disagree = 20 (4.8%) **TOTAL = 415**

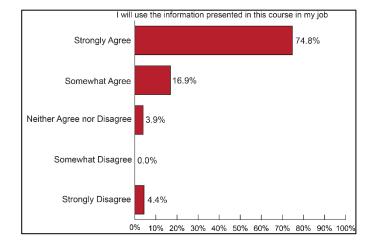


Q4. The knowledge I gained from this course will help me serve others more effectively. Strongly agree = 312 (75.4%) Somewhat agree = 72 (17.4%) Neither agree nor disagree = 11 (2.7%) Somewhat disagree = 1 (0.2%) Strongly disagree = 18 (4.3%) TOTAL = 414 *Missing = 1



Q5. I will use the information presented in this course in my job. Strongly agree = 309 (74.8%) Somewhat agree = 70 (16.9%) Neither agree nor disagree = 16 (3.9%) Somewhat disagree = 0 (0%) Strongly disagree = 18 (4.4%) TOTAL = 413

*Missing = 2



Resource Facilitation Data

Quarter	Number of Clients	Total Expenditures	Cost per Client
July 2021- Sep 2021	313	\$59,339.87	\$189.58
Oct 2021 - Dec 2021	318	\$59,339.87	\$186.60
Jan 2022 - Mar 2022	73	\$59,339.87	\$812.87
Apr 2022- June 2022	74	\$59,339.87	\$801.89
July 2022- Sep 2022	103	\$59,339.87	\$576.12
Oct 2022 - Dec 2022	167	\$59,339.87	\$355.33



	New Referra Is	% of Total	Number of Clients	% of Total	Closed Cases	% of Total	Cost per Region	Cost per Client
Region I	1	3%	20	6%	0	0%	\$3,791.68	\$189.58
Region II	2	5%	37	12%	3	18%	\$7,014.62	\$189.58
Region III	3	8%	28	9%	0	0%	\$5,308.36	\$189.58
Region IV	7	19%	46	15%	0	0%	\$8,720.88	\$189.58
Region V	15	41%	83	27%	12	71%	\$15,735.49	\$189.58
Region VI	4	11%	25	8%	0	0%	\$4,739.61	\$189.58
Region VII	5	14%	50	16%	2	12%	\$9,479.21	\$189.58
Region VIII	0	0%	24	8%	0	0%	\$4,550.02	\$189.58
Total	37	100%	313	100%	17	100%	\$59,339.87	\$189.58

July 2021 - Sep 2021

Oct 2021 - Dec 2021

	New Referra Is	% of Total	Number of Clients	% of Total	Closed Cases	% of Total	Cost per Region	Cost per Client
Region I	1	10%	20	6%	0	0%	\$3,732.07	\$186.60
Region II	3	30%	38	12%	0	0%	\$7,090.93	\$186.60
Region III		0%	28	9%	0	0%	\$5,224.89	\$186.60
Region IV	2	20%	47	15%	0	0%	\$8,770.36	\$186.60
Region V	1	10%	83	26%	0	0%	\$15,488.08	\$186.60
Region VI		0%	26	8%	0	0%	\$4,851.69	\$186.60
Region VII	3	30%	52	16%	0	0%	\$9,703.37	\$186.60
Region VIII		0%	24	8%	0	0%	\$4,478.48	\$186.60
Total	10	100%	318	100%	0	0%	\$59,339.87	\$186.60

Jan 2022 - Mar 2022

	New Referra Is	% of Total	Number of Clients	% of Total	Closed Cases	% of Total	Cost per Region	Cost per Client
Region I	2	3%	6	8%	18	6%	\$4,877.25	\$812.87
Region II	7	11%	7	10%	37	13%	\$5,690.12	\$812.87
Region III	4	6%	7	10%	24	8%	\$5,690.12	\$812.87
Region IV	15	23%	15	21%	42	14%	\$12,193.12	\$812.87
Region V	12	19%	19	26%	75	26%	\$15,444.62	\$812.87
Region VI	8	13%	3	4%	26	9%	\$2,438.62	\$812.87
Region VII	7	11%	11	15%	49	17%	\$8,941.62	\$812.87
Region VIII	9	14%	5	7%	22	8%	\$4,064.37	\$812.87
Total	64	100%	73	100%	293	100%	\$59,339.87	\$812.87

	April 2022-Jun 2022										
	New Referra Is	% of Total	Number of Clients	% of Total	Closed Cases	% of Total	Cost per Region	Cost per Client			
Region I	1	2%	3	4%	5	16%	\$2,373.59	\$791.20			
Region II	3	7%	7	9%	4	13%	\$5,538.39	\$791.20			
Region III	0	0%	6	8%	5	16%	\$4,747.19	\$791.20			
Region IV	8	19%	14	19%	4	13%	\$11,076.78	\$791.20			
Region V	7	16%	21	28%	5	16%	\$16,615.16	\$791.20			
Region VI	9	21%	4	5%	1	3%	\$3,164.79	\$791.20			
Region VII	14	33%	13	17%	7	22%	\$10,285.58	\$791.20			
Region VIII	1	2%	7	9%	1	3%	\$5,538.39	\$791.20			
Total	43	100%	75	100%	32	100%	\$59 <i>,</i> 339.87	\$791.20			

July 2022 - Sep 2022

	New Referra Is	% of Total	Number of Clients	% of Total	Closed Cases	% of Total	Cost per Region	Cost per Client
Region I	4	3%	3	3%	2	5%	\$1,728.35	\$576.12
Region II	7	6%	8	8%	4	10%	\$4,608.92	\$576.12
Region III	23	19%	13	13%	3	8%	\$7,489.50	\$576.12
Region IV	22	18%	17	17%	8	21%	\$9,793.96	\$576.12
Region V	30	24%	30	29%	8	21%	\$17,283.46	\$576.12
Region VI	4	3%	2	2%	5	13%	\$1,152.23	\$576.12
Region VII	23	19%	22	21%	4	10%	\$12,674.54	\$576.12
Region VIII	10	8%	8	8%	5	13%	\$4,608.92	\$576.12
Total	123	100%	103	100%	39	100%	\$59,339.87	\$576.12

Oct 2022 - Dec 2022

	New Referra Is	% of Total	Number of Clients	% of Total	Closed Cases	% of Total	Cost per Region	Cost per Client
Region I	4	3%	4	2%	0	0%	\$1,412.85	\$353.21
Region II	0	0%	8	5%	1	10%	\$2,825.71	\$353.21
Region III	23	19%	30	18%	0	0%	\$10,596.41	\$353.21
Region IV	11	9%	25	15%	1	10%	\$8,830.34	\$353.21
Region V	49	40%	60	36%	1	10%	\$21,192.81	\$353.21
Region VI	9	7%	5	3%	1	10%	\$1,766.07	\$353.21
Region VII	27	22%	30	18%	6	60%	\$10,596.41	\$353.21
Region VIII	1	1%	6	4%	0	0%	\$2,119.28	\$353.21
Total	124	100%	168	100%	10	100%	\$59 <i>,</i> 339.87	\$353.21