

MENTAL HEALTH ALLIANCE

Pilot Program Report & Findings

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Down Syndrome Connection of the Bay Area
Empower - Inspire - Support



Introduction & Background

The Down Syndrome Connection of the Bay Area (DSCBA) has been providing services to children and adults with Down syndrome, their families, educators, and medical professionals since 1998. Our mission is to *empower, inspire, and support people with Down syndrome, their families, and the community that serves them, while fostering awareness and acceptance in all areas of life.*

Over the past 26 years, the DSCBA has grown to employ over two dozen staff and contractors and to serve thousands of people each year throughout the nine county San Francisco Bay Area and beyond. Our modest budget (currently just over \$1.3 million) has steadily grown over the years as we add programs and services. Our staff includes experts in developmental disabilities, education, social work, speech language pathology, alternative and augmentative communication (AAC), aging, dual diagnoses of Down syndrome and autism spectrum disorder, music therapy, and bilingual (English and Spanish) support.

DSCBA's current programs include the following:

Why We Did It: The provision of mental health services and support is critical for families with a member with Down syndrome to help them address or avoid issues such as depression, anxiety, regression, obsessive-compulsive disorders, repetitious behavior, physical aggression, and withdrawal, among many others. In addition, parents need support and counseling as they navigate the various stages

- Support throughout the lifecycle from new and young families to older/aging adults
- Medical Outreach Alliance
- Information, referral, and support
- The THRIVE Program (weekly developmental classes by age level, including several for adults; participants THRIVE when they are Together, Happy, Respected, Independent, Valued, and Empowered)
- The Down Syndrome Educational Alliance, which enables children with Down syndrome to learn, thrive, and reach their full potential in inclusive and special day school environments, and includes the intensive summer/fall Communication Readiness Program for children ages 4-7 preparing to enter school.
- The Down Syndrome and Autism Alliance
- Caregivers, grandparents, and siblings support groups
- Music therapy, and more.

of their child's life, from the first diagnosis all the way to their child's accelerated aging.

According to the National Association of Developmental Disabilities (NADD), 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder, and these disorders can have serious effects on a person's daily functioning "by interfering with educa-



tional and vocational activities, by jeopardizing residential placements, and by disrupting family and peer relationships.” (NADD, 2018). People with developmental disabilities are at increased vulnerability to mental health disorders due in part to negative conditions such as social rejection and stigmatization, and during and following the COVID-19 pandemic, people with intellectual and developmental disabilities (I/DD) experienced additional stressors due to further isolation and lack of routine. The problem is then compounded by limited coping skills due to “language difficulty, inadequate social supports, and a high frequency of central nervous system impairment.” (NADD, 2018).

Another barrier to mental healthcare for people with Down syndrome is the struggle to communicate due to speech intelligibility or being nonverbal, as well as cognitive delay, which makes communicating their feelings and needs difficult. DSCBA has strong Alternative and Augmentative Communication (AAC) training and assistance services, including an AAC Specialist and fully stocked lending library of communication tools, which we can offer to mental health providers struggling with communicating with individuals with Down syndrome.

A vast majority of the children and adults with Down syndrome we serve not only have various medical issues, but can also have a co-existing diagnosis consisting of autism, psychosis, ADD, ADHD, OCD, etc., which makes the need for mental health services even more critical; Many

times these co-occurring disorders can go undiagnosed or misdiagnosed. As youth with Down syndrome transition into adulthood, this can be a stressful time of loss, separation, and loneliness that can lead to depression, anxiety, and other mental health issues. People with Down syndrome also age at a much faster rate and are more likely to suffer from dementia starting as early as in their forties.

The DSCBA receives many phone calls each year from families in need of mental health services and looking for referrals. Families also need support when facing a new diagnosis of

Down syndrome, as well as with the stressors of being a caregiver for a child or adult with I/DD. Unfortunately, there are few specially trained mental health providers available for families or our members with Down syndrome to turn to.

What we hoped to achieve: To address the gap in mental health services for people with Down syndrome

and their families, the DSCBA launched the Mental Health Alliance (MHA) pilot program. The goal of the MHA was to train and support the mental health community in serving those with I/DD so that people with Down syndrome and other I/DD could better access services, communicate their mental health needs, and receive effective therapies. We provided training to mental health professionals in working with families with a child or adult with Down syndrome, as well as the communication supports and training clinicians need to effectively

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serve this population, along with an array of treatment modalities.

The DSCBA launched the Mental Health Alliance in 2021 with major seed funding from Ability Central and the California State Council on Developmental Disabilities. The program lasted into 2024 and ultimately was supported by grants from the following organizations, as well as individual donations:

- Ability Central
- Barr Family Foundation
- Global Down Syndrome Foundation
- RBC Wealth Management
- Rite Aid Healthy Futures
- Rosendin Foundation
- State Council on Developmental Disabilities
- WITH Foundation

Program Description

The Program Director was Marianne Iversen, with assistance from Program Coordinator Molly Neach, of DSCBA. Andrea Herskowitz was the liaison at Grateful Heart Holistic Therapy Center.

The MHA included the following components:

- Expert-provided training workshops for clinicians regarding the unique needs of individuals with Down syndrome and their families.
- AAC support, training, and a lending library of materials (such as tailored low-tech communication boards) for therapists working with individuals with complex communication needs.
- Referral to licensed therapy and subsidized payments for people with Down syndrome and/or their families.
- Workshops for families on self-care, wellness, and mental healthcare.
- Support Groups and Group Therapy, including for siblings.

Partnerships: The DSCBA's primary partner was the Oakland-based **Grateful Heart Holistic Therapy Center**, a nonprofit that provides affordable psychotherapy to individuals, couples, and families throughout the Greater Bay Area. In addition to psychotherapy, Grateful Heart provides internships to clinicians seeking licenses as Marriage Family Therapists, Licensed Clinical Social Workers, and Licensed Professional Clinical Counselors, as well as educational workshops for mental health practitioners.

Other partners included:

- **Michelle Mattox**, a therapist from North Carolina, who provided web-based workshops and webinars, as well as consultations with Grateful Heart therapists working with individuals with Down syndrome.
- Self-advocates with Down syndrome **Nicole Adler, Seth Hendricks, and Saida Mahoney**, in partnership with **Future Films** (of **Futures Explored**, a nonprofit developed for and by individuals with disabili-



ties), which created a training video targeted at institutes and therapy center.

- **Growing Together Therapy Center**, which provided a self-care workshop for parents.
- **LaVant Consulting**, which provided Disability Justice Training with DSCBA's staff.
- **Charlie's Clinic at UCSF Benioff Children's Hospital** in Oakland helped provide referrals for families in need of counseling.
- **Susan Fawcett, PhD**, Director of Therapy, Behavior & Family Support at Down Syndrome Resource Foundation, in Burnaby, BC, provided consultation with DSCBA staff, website and webinar content, and was a presenter at two webinars.
- **Marti Romero, Psy.D., LPC-S**, Clinical Director of Assets, Inc, in Anchorage Alaska, provided consultation, website and webinar content, and was a webinar presenter.
- **Abby Rowley, LCSW**, Social Worker at the Adult Down Syndrome Center, Aurora, Illinois, also provided consultation with DSCBA staff, website and webinar content.
- **Dennis McGuire, LCSW, PhD**, Co Author of the Mental Wellness of Adults with Down Syndrome and The Guide to Good Health for Teens and Adults with Down Syndrome, provided consultation and was a webinar presenter.

Clinician Training and Support: The DSCBA worked closely with Grateful Heart to develop a supported program to provide therapy to children, youth, and adults with Down syndrome and their families. We provided extensive and ongoing training with Grateful Heart clinicians through in-person and online workshops

and webinars, as well as one-on-one and group support as these clinicians worked with clients with Down syndrome. Grateful Heart helped create adapted outcomes measurement tools to help provide important data on the efficacy of the program.

The trainings focused on giving mental health providers an understanding of Down syndrome and common mental health issues for individuals with Down syndrome, other I/DD, and their families, as well as tools to aid in communication. Specific workshops and webinars included the following:

- Mental Health Services and the I/DD Population
- Expand Your Knowledge re: Mental Health Services and the I/DD Population
- Communication and Down Syndrome
- Perspectives from People with I/DD on the Need for Mental Health Services
- Mental Health Services: A Perspective from Self-advocate, Nicole Adler
- Feeling Down, Looking Up: Mental Health & Down Syndrome (a Down Syndrome Resource Foundation-created webinar that DSCBA shared)

The DSCBA created a set of standard and customizable low-tech communication boards for clinicians to use with individuals with Down syndrome or other I/DD who have difficulty being understood. For example, we helped create story boards about topics that interest and/or motivate the individual receiving therapy, with tips and suggestions on how to respond to negative thoughts or painful emotions. These tools were uploaded to DSCBA's MHA webpage



through Padlet. We customized and provided these communication boards to clinicians and families as needed, offering this service to all clinicians, with many of them using the visual aids we provided through the Padlet. We were encouraged to also see that through the AAC training and monthly consults with DSCBA staff, clinicians learned to create their own storyboards and visual supports.

Examples of communication boards and topics include:

- Anger
- Behavior
- Calming/Coping Strategies
- Caregiver Resources
- Depression
- Feelings/Body
- Sexuality & Relationships
- Social Story Examples
- Stress and Anxiety
- Therapy Schedule & Surveys

We continue to maintain and update the MHA page on our new website, which can be accessed at: dscba.org/Mental-Health-Alliance.php

Additionally, all of DSCBA's recorded webinars and video presentations are publicly-available on this site. DSCBA also continues to be available to clini-

cians to support them in providing therapy to individuals with Down syndrome.

Therapy: Licensed clinical therapy to individuals with Down syndrome (children, youth, and adults), as well as caregivers and siblings (in groups), was provided by Grateful Heart Holistic Therapy clinicians. Individual treatment was provided on average once per week for an average of 12 weeks, and was supported with communication tools, training and consultations by the DSCBA. The first few sessions were typically devoted to building a rapport, as well as naming and identifying emotions, followed by self-regulation skills-building, such as through calming strategies.

Zones of Regulation Communication Board

BLUE ZONE Sick Sad Tired Moving Slow	GREEN ZONE Happy Calm Okay Focused	YELLOW ZONE Excited Silly/Wiggly Frustrated Worried	RED ZONE Mad/Angry Terrified Yelling/Hitting Upset



Group therapy for siblings was also provided approximately once per week for 6 weeks during the program.

Training and Support for Parents and Caregivers: The DSCBA provided consultation as well as workshops and support groups specifically targeting parents and caregivers of individuals with an I/DD who have mental health needs, or who themselves are struggling with mental health. In particular, we conducted the following workshops/support groups:

- Promoting Strengths & Adaptive Resources in People with Down Syndrome (onsite, live workshop) presented by Dennis McGuire
- Mental Health - Life after the Pandemic webinar presented by Michele Mattox
- Preparing, Coping, and Conquering Stressful Medical Events: A Two Part Series:
 - Strategies for Children with I/DD (surrounding medical trauma) - The Center for Pediatric Trauma Stress
 - Strategies for Parents & Caregivers of Children with IDD surrounding Medical Trauma
- Caring for You is Caring for Others, an in-person wellness and self-care support group for parents/caregivers of individuals with I/DD

What We Did/Results

Activities: Over the three-year program, the DSCBA accomplished the following activities:

- Developed partnership with Grateful Heart Holistic Therapy Center and other collaborators.
- With Grateful Heart, adapted MyOutcomes (www.myoutcomes.com), an outcomes measurement evaluation tool for the program, to track and report on outcomes from the therapy provided, as well as a rating scale for participants to check in and check out at each session.
- Facilitated individual or group therapy for a total of 38 individuals with an I/DD and 29 family members of a person with an I/DD primarily through Grateful Heart, as well as Growing Together Therapy Center.
- Provided 14 therapists with one-on-one and group consultation, training, and support, discussing best practices and case studies, and providing support to clinicians who were seeing clients with Down syndrome or their families.
- Provided two clinician workshops and webinars to nearly 460 registrants, including stakeholders across California, such as Stanford, UC Davis, and various Regional Centers
- Provided five workshops and one support group to approximately 100 parents and caregivers of individuals with an I/DD
- Maintained the Mental Health Alliance webpages with resources and information, including the Padlet of AAC communication boards and the recorded training webinars (<https://www.dscba.org/Mental-Health-Alliance.php>).
- All Grateful Heart onboarding clinicians were required to watch our Mental Health



Alliance Training on AAC and the Mental Health Services and the I/DD Population webinars.

- Provided information about the program to 11 new entities, including 5 universities and 6 therapy centers
- Provided customized communication boards as needed, offering this service to all clinicians, with many of them using the visual aids we provided through the Padlet, and several learning to make their own visual supports.
- Consulted with and created an informational video targeted at training institutes and therapy centers with Self-Advocates Nicole Adler, Seth Hendricks, and Saida Mahoney, in partnership with Future Films.
- Engaged LaVant Consulting to provide Disability Justice Training with our staff.
- Developed a list using Padlet of clinicians and therapy centers stating that they have experience or are willing to work with individuals with an I/DD.

Outcomes: Through this program, the DSC-BA and our project partners increased access to mental health therapy for individuals with I/DD and their families, and increased the capacity of Bay Area therapists to successfully treat this population, particularly those with communication difficulties. The start of the program in 2021 was timely as the pandemic had been having lasting impacts on people with I/DD and their families, including more people with I/DD experiencing depression and grief

due to social isolation and loss of routine. This program helped participants process that loss.

Specifically we achieved the following results:

- We sent out surveys to 16 families who received weekly one-on-one therapy. Of this number, seven were completed (44%). Of these completed surveys, 100% stated that their experience with the clinician was positive, 86% said that they saw an improvement in coping skills, 86% said they saw an improvement in ability to communicate feelings, 86% said that the tools and visual supports provided helped them handle and cope with emotions, and 71% said that the sessions were successful.
- 100% of therapists who completed a survey stated that their clients with I/DD made progress in their treatment goals, adding that they noticed reductions in anxiety and depression, and increases in independence, mood, ability to identify coping strategies, being able to talk about emotions, and ability to make connections between what they want or need and how they express these wants/needs.
- 75% of therapists surveyed stated that their experience in this program has made them more comfortable with and more motivated to work with individuals with I/DD.
- 100% of clients receiving therapy after several sessions scored in the “green” or Service Target Zone as of their last session. The Service Target is the Outcome Rating Scale (ORS) score predicted at the end of

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successful treatment and reflects reliable change greater than chance, maturation, and measurement error. According to our evaluator, Jake Tomlitz, MSW, “the strong score here shows that—at this moment in time—therapists are successfully engaging with their clients in session and that clients are on track to benefit from therapy.”

- 100% of Caring for You is Caring for Others workshop participants stated that they learned techniques to improve mood and take care of themselves.

Client Feedback and Testimonials: We have received feedback from individuals with I/DD and/or their families who received therapy. N’s mom told us that N. had tried therapy off and on for a while but this was the first time that she had a clinician that wanted to work with someone with Down syndrome, which made a big difference for her. Additionally, three individuals with Down syndrome have continued their therapy post-program through private pay or through the Self Determination program.

From the participating families’ perspectives, they are thrilled that we recognize that they deserve the right to mental health services. We heard this from one family member about their prior attempts to find a therapist, “no one wanted to help us or recognized our needs!” This alone is an important boost for families and builds their morale as well.

The following comments from parents of participants in the program speak to the success of the program:

“O. was struggling in all areas of life-school and social. He started getting severe anxiety surrounding doing anything except staying in the

house. He became afraid of people and interaction. Unwanted behaviors became daily occurrences including hitting, screaming and eloping. This was NOT our son and we hated seeing him go through it and it was exhausting for all of us and his team at school. The school was unable to provide therapy or behavioral services. Finding this program changed our lives. O. is now back to himself-loving school, a social butterfly, trying new things. I see him practicing, daily, the coping skills he received from working with J. This program gave us our son and our lives back. We are eternally grateful. I do hope that another program like this is developed for others-it is such a valuable resource for the DS community. Thank you!”

“She was given techniques to utilize on her own to calm herself down when she was stressed out. She understood the techniques and uses them frequently and there have been less outbursts because of her new coping skills.”

“A.’s vocabulary it’s quite limited, however she can definitely express how much she likes to see K. She always gets ready and excited for her session by putting together all the new toys, coloring books, etc, she want to show K.”

“J. was wonderful to work with. She was very patient and adaptable. We tried to find therapy services before but none were a good fit. M. has become more self-aware since starting her sessions and we have had a significant reduction in negative behavior outbursts.”

“I think he felt that his therapist gave him the opportunity to share and process his feelings in a safe and supported space. The sessions with MB were something that J. looked forward to every week and he decided on his own when he was ready to stop having sessions with the



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therapist. It gave him insight into seeking help when he had challenges.

... I feel like working with the DS population comes with its own set of challenges. My son is not always able to express what is going on with his feelings. I appreciated the guidance and support from MB. I looked at this as a success and so does J.”

We also heard from clinicians about what they gained in the program, such as the following:

“I learned so much about myself as a clinician - mostly that I use my presence and creativity to process the here and now with clients, and it really is no different with clients with DS. I appreciate the opportunity to work with a different population... but are they really that different? Not so much from a therapeutic perspective. I especially appreciated that as a pilot program, I was free to explore what worked best for each client. The monthly supervision was incredibly helpful, especially to be able to hear from other clinicians working with this population.”



Self-advocate Seth Hendricks getting ready to be filmed by Future Films for an informational video for therapists.



Lessons Learned and Future Work

One of the biggest challenges we faced was a lack of enough clinicians to support the need for services among people with I/DD, in part due to leadership turnover at Grateful Heart. We also discovered that a typical short-term therapy model did not work for clients with I/DD. Many more sessions are needed to build a trusting relationship, enable successful communication, and then work on solutions to mental health issues.

Finally, the program model of having DSCBA subsidize the cost of therapy, even at a discounted rate, was not economically sustainable, particularly due to the lengthy time needed to support and resolve mental health issues for our target population. We worked to help patients find other resources for payment, such as Self Determination. DSCBA also researched and developed a list of alternative payment and insurance options for families.

Although one of the primary goals of this program was to help therapists communicate with their clients with I/DD, some therapists shared the continued difficulty in understanding what a client is saying. Other challenges therapists reported were some weeks in which clients did not make their appointments, helping clients feel heard when working through fantasies, and understanding how their clients are thinking.

Overall, however, the therapists felt that they and their clients made great strides in building rapport and trust, having fun (particularly in the group sessions), enacting self-agency, and learning new skills.

Going forward, the DSCBA will no longer subsidize the cost of therapy, but we will continue

to partner with Grateful Heart and other therapy centers, providing consultation and support to their clinicians on an as-needed basis, as well as providing informational sessions during Grateful Heart's onboarding process with clinicians. We will continue to refer clients with Down syndrome and their families for therapy using Grateful Heart and other partners. We will also maintain our website and Padlet of resources.

Based on our learnings from the pilot phases of the program, we have found that there needs to be a place where clinicians get together to share experiences and help each other, similar to what is done at National Center for Start Services, which is primarily crisis-oriented. In later phases of the MHA, DSCBA worked to implement a similar model as another way for therapists to collaborate, getting together (via Zoom) to discuss Down syndrome and ways they can adapt their work. We also worked to develop a peer network/roundtable that met twice a year.

Additionally, we are learning that Down syndrome training should be infused up front in initial education and training of clinicians, and a Mental Health for the I/DD Population curriculum needs to be developed for training institutions. The clinicians we spoke with who expressed interest in working with individuals with an I/DD were lacking in confidence due to their lack of education in working with this population during their training. Many had never even thought about mental health services and needs as it pertains to those with an I/DD.

**For more information,
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