

# Communication Readiness Program



## 2013 Report



Down Syndrome Connection of the Bay Area  
*Encouraging the unlimited potential in children and young adults with Down syndrome*

# Acknowledgements

Programs such as the Communication Readiness Program (CRP) are made possible by the Down Syndrome Connection of the Bay Area’s generous funders, families, and individual supporters, and we are extremely grateful to you.

We would like to especially thank the following funders who earmarked grant funds specifically for the Down Syndrome Education Alliance and the CRP, including the California Communications Access Foundation, the Lowell Berry Foundation, the Quest Foundation, the San Ramon Valley Kiwanis Club Foundation, and the Global Down Syndrome Foundation.

We are also truly grateful for our members and the community who attended and gave generously through our “Fund a Need” drive at our spring Gala.

Special thanks to the parents, teachers and volunteers who have given their time and talents to this program.

*Report design and layout by Tempura Board.*



# Table of Contents

Executive Summary.....	Page 3
Organization Background.....	Page 4
Need for the Program.....	Page 4
Program Overview.....	Page 5
Results & Outcomes.....	Page 6
Staff and Volunteer Profiles.....	Page 9
Methodology.....	Page 10
Activities and Therapies Conducted.....	Page 11
Student Profiles.....	Page 15
Challenges and Recommendations for Future.....	Page 23



**Down Syndrome  
Connection  
of the Bay Area**

101-J Town & Country Drive  
Danville, CA 94526  
925.362.8660  
[www.dsconnection.org](http://www.dsconnection.org)

# Executive Summary



In the summer of 2013 the DSCBA piloted the CRP with a cohort of eight children ages four through six with Down syndrome, including one child dually diagnosed with Down syndrome and Autism.

The goal of CRP is to provide preschool- and kindergarten-aged children with a multi-modal means of communication and facilitate a total communication environment. This is accomplished through a summer intensive 8-week preschool and by following each child into school with the supports that were found successful over the summer. Program components include: 1) use of a variety of communication systems, including Augmentative Alternative Communication (AAC) (no, low, light, and high tech), speech, signing, etc., individualized for each child; 2) oral placement therapy, a specific therapy designed to improve speech intelligibility; 3) literacy; 4) socialization; and 5) parent and teacher education, providing the necessary tools and training to facilitate communication in the classroom to support maximum integration and learning among children with Down syndrome.

The DSCBA conducted the pilot 8-week summer intensive from June 17 through August 9, 2013, which included Monday through Thursday class at DSCBA's Danville headquarters from 9 a.m. to 12 p.m. Fridays were reserved for administration, team meetings, and meetings with parents

(as needed) to provide further education and training in communication systems, speech clarity therapy, literacy skills, and oral motor therapy. We maintained a ratio of one trained adult staff or volunteer to one student.

Our objectives were to improve communication and expression of basic needs; school readiness; and verbal sound development, consistency, and accuracy among at least 7 out of 8 children, as well as to provide personalized communication profiles and parent and teacher training for all students.

**CRP met or exceeded nearly all of its stated objectives.** Every single student in CRP improved their communication abilities as a result of the program. The level of improvement and the areas improved varied with each child, but some common themes emerged:

- With regard to speech and oral motor therapy, 100% of students increased syllable length, oral movement for the production of clear speech, and overall speech clarity.
- 100% of the students improved their sight recognition of letters, words, colors, and objects, with several learning to read and follow along with books that they previously always pushed away in frustration.
- 100% of students improved in socialization, some quite dramatically, which includes paying attention and listening to others, as well as sharing and communicating.
- 75% of students' education teams (6 out of 8 children) were delivered a transition binder, provided with training and one-on one-consultation, and utilized books, materials and AAC devices from our lending library. These teams continue to utilize our program for support and assistance with their student.

Most participants built enormous confidence through their newfound ability to express themselves and many found their "voice" by the end of the program.

*"The CRP was highly successful for every child. We saw daily breakthroughs. It was Monday morning of the third week when the parents started reporting all of the differences they were seeing at home...that was my first 'ah-ha' moment."*

– Heather Peterson, MS, SLP-CCC

# Organization Background



The Down Syndrome Connection of the Bay Area (DSCBA), headquartered in Danville, CA, was started in 1998 by a group of parents seeking to fill a void in services and support available to children and adults with Down syndrome and their families. DSCBA is now recognized as the premier resource for children and adults with Down syndrome in the greater San Francisco Bay Area. DSCBA works closely with school districts and health agencies to ensure that they have the most current information about resources for families with a new diagnosis of Down syndrome.

Our mission is to promote the unique contributions of children and adults with Down syndrome by providing direct services to them and their families, and to educate the general public by fostering inclusive and integrated involvement with the Down syndrome community and society at large.

Current programs include prenatal consultation, multiple support groups (including parents, grandparents, fathers, siblings, and K-12 education), information and referral, education and workshops, one on one advocacy, developmental Step classes for all ages, a resource and lending library, music therapy, outdoor field trips for teens and adults, community events for families, an Alternative/Augmentative Communication (AAC) program, and our Down Syndrome Education Alliance (DSEA) program. We also have a private Speech Therapist and Reading/Writing Tutor on site at our Danville headquarters for the convenience of our participants. The DSCBA is an affiliate of the National Down Syndrome Congress and the National Down Syndrome Society.

## Need for the Program



Because of significant communication challenges due to issues such as hypotonia, apraxia of speech, and language delay, many children with Down syndrome (DS) are non-verbal or have limited verbal skills. When entering the school system children with DS are assumed incapable of interacting with peers and learning so they are often segregated into special day placement (labeled as moderate to severely handicapped) because of their lack of ability to express themselves. Research shows that many children with DS have a higher receptive than expressive language and with the appropriate supports they are very capable of learning and participating. Research conducted over 30 years has shown that children with DS learn best when included with their typically developing peers.<sup>1</sup> This is in part due to their unique visual learning style and their social and emotional strengths.

The Communication Readiness Program (CRP) is in many ways a culmination of what we have learned over DSCBA's 16-year history: (1) we must reach children, when possible, before they enter the school system; (2) the use of multimodal communication supports early on opens the doors to life-long learning, participation, friendships, literacy strength and independence for children with Down syndrome; and (3) due to budgetary constraints, and lack of training and administrative support in many school districts, DSCBA, as an agency dedicated to the successful integration of people with DS in every aspect of community, must be ready to support and train a child's education team on his or her unique learning profile so that the classroom and child is set up for success.

<sup>1</sup>Bray M, Woolnough L. *The language skills of children with Down's Syndrome aged 12 to 16 years. Child Language Teaching and Therapy.* 1988;4:311-324. [Ref list]

*Gestures and words in early development of children with Down syndrome. Caselli MC, Vicari S, Longobardi E, Lami L, Pizzoli C, Stella G. J Speech Lang Hear Res.* 1998 Oct; 41(5):1125-35.

# Program Overview



In the summer of 2013 the DSCBA piloted the CRP with a cohort of eight children ages four through six with Down syndrome, including one child dually diagnosed with Down syndrome and Autism.

The goal of CRP is to provide preschool- and kindergarten-aged children with a multi-modal means of communication and facilitate a total communication environment. This encompasses using a variety of communication systems, including Augmentative Alternative Communication (AAC) (no, low, light, and high tech), speech, signing, etc., individualized for each child. A large component of this program is oral placement therapy, a specific therapy designed to improve speech intelligibility.

This extremely specialized, collaborative

program incorporates parent and teacher education, providing the necessary tools and training to facilitate communication in the classroom to support maximum socialization and learning among children with Down syndrome.

CRP is part of our Down Syndrome Educational Alliance (DSEA) program, an innovative program partnering with Bay Area school districts to develop, train, and fully support all school district personnel to ensure that students have the support, tools, and resources to enable them to reach their highest potentials. This program has given us great insight into the lack of school district training, and the overall classroom communication and academic supports that are lacking for children with DS to participate and become successful in academic skills, such as numeracy and literacy, for example.

The DSCBA conducted the pilot program from June 17 through August 9, 2013, which included Monday through Thursday class at DSCBA's Danville headquarters from 9 a.m. to 12 p.m. Fridays were reserved for administration, team meetings, and meetings with parents (as needed) to provide further education and training in communication systems, speech clarity therapy, literacy skills, and oral motor therapy. We maintained a ratio of one trained adult staff or volunteer to one student at all times.

In addition to the eight-week class, DSCBA is offering in classroom consultation and conducting teacher training and follow up now that all children in the cohort have been placed in school. Meetings have been held with the educational teams of all but two of the summer participants due to changes in their placement. The purpose of these meetings was to present a comprehensive transition binder of information on the summer program and provide insight into the types of support needed in school for each child to be successful. We covered communication, literacy, speech, and AAC along with strategies, goals, and results of evaluations. We are continuing to work with four of the eight participants once per week for additional communication and literacy training.

# Results & Outcomes



Our measurable objectives for the CRP are the following: (1) Improvement in communication and expression of basic needs through any means of communication by a minimum of 85% of participants; (2) Improvement in school readiness: such as following instructions, social interaction and engagement by a minimum of 85% of participants; (3) Improvement in verbal sound development, consistency, and accuracy of verbal production in 85% of participants; (4) Provision of a personalized communication profile and (as applicable) AAC system for 100% of participants; (5) Provision of parent and teacher training in communication and AAC systems for 100% of participants who enter kindergarten or first grade.

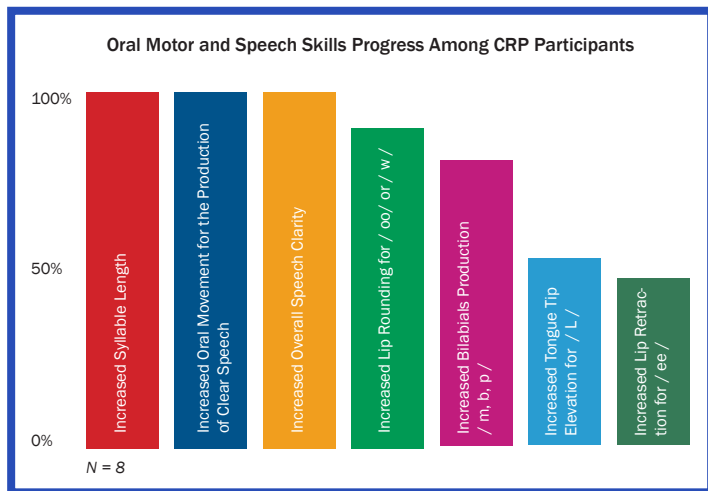
“The CRP was highly successful for every child. We saw daily breakthroughs. It was Monday morning of the third week when

the parents started reporting all of the differences they were seeing at home...that was my first ‘ah-ha’ moment. Ainsley’s mother talked about how she was commenting about so many things over the weekend, that they caught themselves almost ‘shushing’ her. This is a child that has always spoken in one to two-syllable approximations. Now she was approximating three to four regularly, and with increased ease! Her personality really began to show!”

–Heather Peterson, MS, SLP-CCC

CRP met or exceeded all of its stated objectives. Every single student in CRP improved their communication abilities as a result of the program. The level of improvement and the areas improved varied with each child, but some common themes emerged. With regard to speech and oral motor therapy, the students increased the control of their jaw, lips and tongue for the precision necessary for speech sound production (see Table I, below). Students also learned sight recognition of letters, words, colors, and objects, many learning to read and follow along

Table I

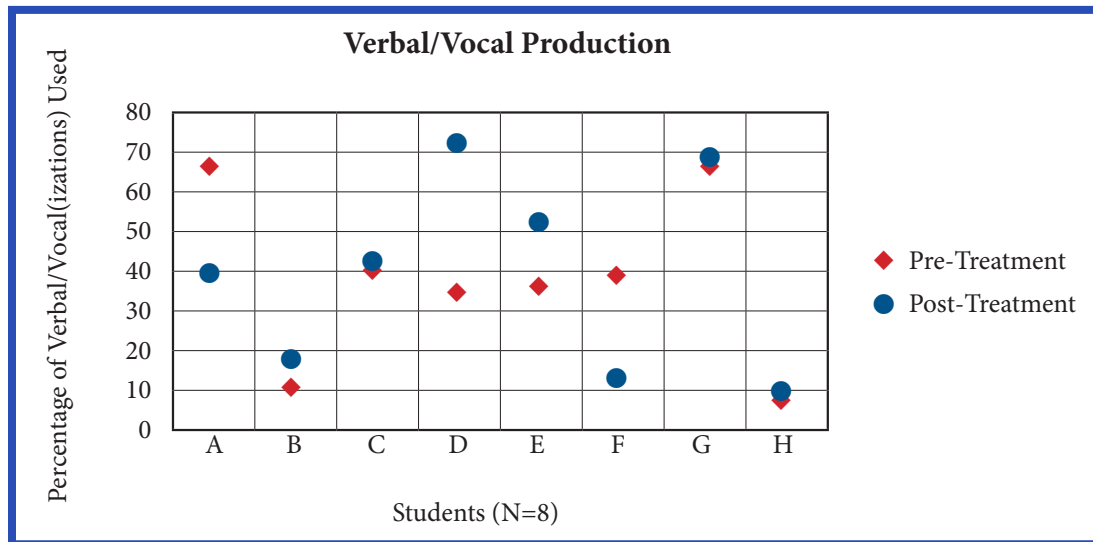


with books that they previously always pushed away in frustration. Socialization dramatically improved for all participants, which includes paying attention and listening to others, as well as sharing and communicating. Most participants built enormous confidence through their newfound ability to express themselves and many found their “voice” by the end of the program.

With regard to communication and expression, Tables II and III provides a visual representation of the frequency of various communication means (i.e. verbalization/vocalization, augmentative alternative communication) utilized by the participants in the Communication Readiness Program (CRP) as measured pre and post the intervention. The data was collected using the Communication Sampling and Analysis (CSA), “an assessment tool designed

for infants, toddlers, and children with multiple physical, sensory, speech, and/or cognitive/linguistic challenges. CSA provides speech/language pathologists an objective (clinical) measure for observing and analyzing communicative behavior in the natural setting. The purpose of the

Table II



CSA is to capture and qualify the nature and extent of communication behavior of the communicatively challenged with partners during interactive settings and contexts” (Buzolich, Russell, Lunger-Bergh, & McCloskey, 2011).

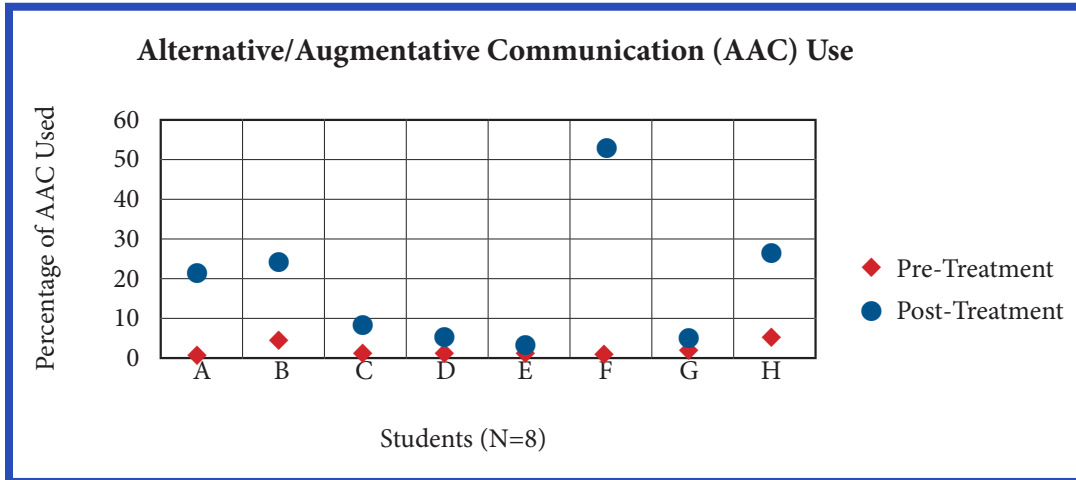
Sampling was completed in educational and social environments by trained speech and language pathologists.

Table II: Verbal/Vocal Production shows the frequency at which verbalization and/or vocalizations were utilized by the participant. The authors of The CSA define “discrete vocalization as vocalizations that are distinct and differentiated including audible breathing, grunt/groan, cry, whimper, laugh, pleasure sounds, scream, tongue click. Verbalizations are defined as verbal word approximations, spoken words, and phrases such as: /i/ for “eat”, /ma/ for “mom”, /ai/ /wa/ for “I want” (Buzolich, Russell, Lunger-Bergh, & McCloskey, 2011). The percentage of verbal/vocal production increased in 6/8 participants following the CRP program. Frequency of verbal/vocal production decreased in 2 of the 8 participants (though as is shown below, AAC use increased for these same participants). In one instance, the decrease in verbal/vocal production was with respect to inappropriate yelling (vocalization) by this participant, which also may support the program’s ability to improve behavior and reduce frustration.

Table III: AAC use shows the frequency at which AAC devices and strategies were utilized by the participant. The authors of The CSA define AAC as “Use of symbols (pictures/words), aid (physical object/device), strategies (indicate from a field of choices) and techniques (gestures, directly selects, scans). Activates a message on a speech generating device, points to a symbol on a manual board, points to a picture mounted on a wall, gazes at a symbol given a choice of two symbols, picks up a miniature toilet and gives it to a person to request bathroom.” (Buzolich, Russell, Lunger-Bergh, & McCloskey, 2011). The percentage of verbal/vocal production increased in 8/8 participants following the CRP program. AAC was not available to and or/ utilized by 6/8 participants in the environments where baseline CSA Sampling was conducted.

From these visual representations, we can conclude post CRP intervention that vocalization/ verbalizations were utilized with more frequency for a majority of the participants and AAC was utilized by all participants. The data shows the participants (A, F) who experienced a decrease in verbalization and/or vocalizations post CRP, exhibited the most significant increase in frequency of AAC use. Participants B and H were significant for limited changes in verbalization and/or

Table III



vocalizations but significant increase in frequency of AAC use. Participants B and C an increase in both means with a larger increase in AAC use. Inversely, Participants D and E exhibited a more significant increase in vocalization/verbalizations in

comparison to AAC use. From these conclusions, we may begin to further research the following hypotheses.

We believe the initial pilot program was successful due in large part to the following key factors:

- Experience and commitment of the staff and volunteers involved;
- Provision of assessments to understand each child’s baseline, and his or her specific needs;
- One-to-one adult to student ratio, which allowed for highly personalized and individualized attention;
- Daily interaction with students, which allowed for repetition of key concepts;
- Use and training in a variety of no-, low-, and high-tech communication systems and AAC devices tailored to each child;
- Regular (daily) speech and oral placement therapy;
- Parent and teacher involvement to reinforce concepts, behaviors, and therapies learned in class;
- Use of short (no more than 5 to 15-minute) activities to maintain the attention of the young students;
- Use of personalized themes (such as personalized story books with pictures of the students themselves) to maintain interest; and
- Maintaining flexibility to address unforeseen issues.
- Daily meetings to discuss necessary changes.

1) *Vocalization/verbalizations production decreased or plateaued when AAC became a more successful means of communication.*

2) *AAC support provided a linguistic scaffold resulting in increased vocalization/verbalizations.*



# Staff and Volunteer Profile



Jennifer Cooper and Mason



Kati Skulski and Sandro

The CRP is being implemented by the following team:

- Jennifer Cooper, Assistant Teacher, holds an M.A. in Education, is K-12 multi-subject credentialed, and has a child with Down syndrome. She currently consults with DSCBA part time as an Education Liaison and Support Director.
- Karen Baca, Education & Technology Specialist, Lead Teacher is a certified Assistive Technology (AT) specialist with eight years of supervisory experience in AT use and training. She currently consults with DSCBA on AT use.
- Laura Briggs, Assistant Teacher, is a Special Education teacher who has worked with children with special needs for nearly 20 years. She has taught developmental Step classes for DSCBA for 15 years, specializes in early childhood education, and has a son with Down syndrome.
- Kathy Miles, Co-Lead Teacher, is a preschool teacher at Noah's Ark Preschool and specializes in promoting literacy through communication. She holds a Child Development Master Teacher Permit and B.A. in Human Development. Kathy teaches a reading program using research-based methods at the DSCBA part-time.
- Heather Peterson, MS, SLP-CCC, is a Speech and Language Pathologist specializing in Oral/Sensory Motor and Feeding Therapy. She offers services three days per week onsite at the DSCBA for the benefit of DSCBA members.
- Kati Skulski, MS, SLP-CCC, is a Speech Language Pathologist specializing in AAC. Kati is also the lead SLP for the Expression Connection project at DSCBA, working with many families on implementing communication systems.
- Loren Spina is a Special Education teacher and a mother of a child with DS.
- Shawna Marcus, MS, SLP-CCC, is a Speech Language Pathologist and works for the San Ramon Unified School District.

# Methodology



Pre, mid, and post assessments of the participants are a core program component of CRP. Extensive video and data collection was taken. We used formal and informal assessments that have been used by our consulting speech/language pathologists, and reading and special education teachers, to measure communication means and functions, articulation accuracy, classroom participation (sitting for longer periods, being engaged, interaction with peers and with a group, staying focused), vocabulary, and expression of language through the use of AAC devices. One of our goals is to help these children learn how to go to school and to set them up for successful inclusion. This means being able to line up with the class, follow directions, and appropriately interact with their peers and with adults. Through our experience we have found that when children with DS enter the school system without being able to do these tasks, they are immediately set up for failure.

Another major goal is to identify what each child needs to communicate, and to send each child to kindergarten or first grade with a communication and learning system that is user friendly for all parties involved (teacher, child, family, etc.). This included both a verbal speech clarity program as well as an AT program. The AAC component

could be anything from a no or light tech device to a high tech system, depending on the child. Now that each child is in school, CRP staff are conducting in-class observation, assistance, and teacher training and consultation to continue to improve communication and integration of the recommended communication system, when welcomed by the school district. DSCBA will continue to assess the program and make adaptations in the second year based on lessons learned. We will report the outcomes of the program to share as a model for educators throughout the Bay Area and beyond.

The program began with thorough assessments of each participant by our speech and language pathologists and educators to provide a baseline and initial set of individualized needs and goals for each participant. Assessment tools included the Communication Sampling and Analysis (CSA) tool, an assessment tool designed for infants, toddlers, and children with multiple physical, sensory, speech and cognitive-linguistic challenges,<sup>2</sup> as well as the Talk Tools Oral Placement Assessment and an informal motor based speech evaluation. Data collected included quantitative measures of communicative means (e.g. gestures, verbalizations, etc.) and communicative functions (e.g. request, protest, etc.), speech sound inventories, and oral motor abilities (e.g. movements of the articulators).

<sup>2</sup> Developed by Buzolich, Russell, Burns-McCloskey, Lunger-Berg Services (<http://csa.acts-at.com>), the purpose of CSA is to capture and qualify the nature and extent of communication behavior of the communicative challenged with partners during interactive settings and contexts.

# Activities and Therapies Conducted



Major components of the CRP program over 12 months include the following:

1. Pre- and post-assessments;
2. Implementation of the 8-week summer intensive communication “preschool;”
3. Compilation of a personalized binder for each child to be shared with his or her parents and education team, which includes a summary of the assessments, class activities, progress toward communication and other goals, recommendations for going forward, and specific tools such as curriculum adaptations, communication devices, etc.;
4. Ongoing communication with parents and school district personnel to assist in IEP goal development and classroom needs;
5. Training of school personnel and provision of resources on the needs of children with DS
6. Video documentation and data documentation;
7. Post-program consultation with Fall 2013 teachers; and
8. Shared outcomes of the pilot program will be presented to Bay Area preschools/grade schools, the Global Down Syndrome Foundation, National Down Syndrome Congress other national Down syndrome associations, as well as Talk Tools Therapy and ASHA.

Classroom activities included art, music, reading and literacy, movement, and oral placement therapy. Goals incorporated into those activities include: increased communication, following instructions, oral motor development, articulation and sound development, gross and fine motor development and potty training. The emphasis of this program was to create multi-modal communication systems that allow the students to participate with peers and express basic needs in the classroom. Communication systems (low, light, and high tech, such as GoTalk Ones, Talking Photo Albums, iPads, Step by Step communicators, etc.) infused all of the activities throughout the day. Parents were provided daily logs with progress to date, and recommended homework activities to support each child’s individualized summer goals.



## Major Classroom Components:



**Literacy:** The classroom design was created to provide a print-rich environment for all students. Classroom items were labeled using clear large font and photos of items. The classroom schedule was posted using digital times, large font labels and icons to match the activities. There was a large group word wall organized by alphabet for posting sight word vocabulary. Each reading station included a chart with all current sight words posted. There were several book racks with books based on student interests. There was large easel paper for recording student sentences. There were teacher-made books and class books that included all the students. There was a large calendar for daily circle activities with large labels that were removable to allow students to handle and see them. There were a variety of writing materials that included triangular markers, triangular crayons, and the iPad used with the App Crayon for writing.

Reading materials were created to meet the needs of the students. Books were adapted and created following guidelines recommended for emergent readers. Text was created using sans serif fonts like Comic Sans, Arial, Chalkboard, and ABC Print. Font was at least size 24 or larger, and double space between words was provided. (Samples are provided as examples.) Sight word books were created using the Story Book Maker app by Merge Mobile. Words and sentence frames were chosen based on several lists of high frequency words as well as core vocabulary lists from several AAC studies. The books were also presented on the

iPad, but the students showed more interest in the paper version. Custom books were created which included the students in the book, and these quickly became high interest books with the students. Initially students were presented with text to books recorded on a Step-by-Step to allow them to read text aloud and begin to track left to right with their finger.

Phonemic awareness lessons were conducted using materials from the Accessible Literacy Learning (ALL) Reading Program by Janice Light and teacher-made materials based on Words Their Way by Donald R. Bear, Shane Templeton, Marcia Invernizzi, and Francine Johnston. Hear-The-Sounds Alphabet Buttons were also used in activities to allow students to hear corresponding letter sounds. Consultation with Heather Peterson, SLP, was done to determine the developmentally appropriate phonemes to be taught and strategies to increase student production of the phonemes. Facial prompting was used to facilitate correct production of the phonemes. Consideration was given to students with hearing impairments in the choice of phonemes to be taught, and only phonemes that could be adequately heard by all students were chosen.

The daily lesson block was designed based on A Reading and Language Intervention for Children with Down Syndrome by Kelly Burgoyne, Fiona Duff, Paula Clarke, Glynnis Smith, Sue Buckley, Margaret Snowling, and Charles Hulme. Activities included name recognition, letters, phonemic awareness, sight word reading and instructional book reading. Activities were 3 to 5 minutes each per day. Here is an example of what the schedule for the daily block looked like:

Name recognition/letter recognition	2-3 minutes
Sight word reading	2-3 minutes
Sounds and phonology	5 minutes
Instructional book reading	5 minutes

**Speech and Oral Placement Therapy:** An Oral Placement Therapy (OPT) program (Talk Tools) and traditional speech therapy techniques were used during the eight-week CRP program to increase the articulation abilities of the child. An OPT program was run three days per week in CRP and was highly suggested two days per week at home. Parents/caregivers were individually trained to work with their children at home. All children targeted the following:

- Jaw stability and strength to support sound development and clarity of connected speech.
- Increased oral sensation to support tactile – kinesthetic feedback of the articulators for proper sound learning and placement.
- Tongue retraction to support proper articulation of speech sounds.
- Access to airflow to pair with verbalizations to create new sounds as well as to support abdominal grading for supporting connected speech.
- High levels of sound, syllable, word, sentence repetition for motor planning development.
- Slow – moving hierarchical techniques used to decrease tactile defensiveness when using tools (or feeding) in oral cavity.

**Alternative/Augmentative Communication:** AAC was put into place each day for students with the use of a Little Step By Step Communicator (LSBSC). Out-of-context news from home and school

was recorded by parents and teachers each day to enable the students to share happenings that occurred in various environments. It was observed that every child required support for communicating information out of context and when given AAC supports (Step-by-Step Communicators) were successful with more complex communicative functions (i.e. relaying information about previous events). Each student was provided with a personal Step-by-Step Communicator and their family and (some) educational teams were provided with training for utilizing the device. Four of the eight students who attended CRP were clear candidates for AAC due to presenting with one or more of the following: significant expressive-receptive gap, less than 50% intelligibility, severe apraxia of speech, communicative frustration, and/or communicative intent. These four children were provided with systems customized to meet their communicative needs and abilities. Curricular materials and activities within the class were modified to facilitate the use of AAC for these children. Training with these various systems were provided to the parents of each child. Training and individual services were additionally offered to the school system. Currently, all four of our AAC candidates have loaned AAC equipment from our lending library and are utilizing these systems in their home and school environments.



## Post-Summer Program Follow Up and Additional Training:



As mentioned earlier, DSCBA worked to schedule meetings with the education teams of all of the students participating in the summer program. Our goal was to hand off what we had learned and what the children had worked on. Each student's parents were given a large personalized binder that include their progress using AAC, oral motor ability, and academics and literacy, along with recommendations for further work. Most of the meetings were onsite at the child's new school. One student's entire team came to the Connection for a multi-hour meeting.

After these initial meetings, Karen Baca, DSCBA's Education and Technology Specialist, had regular contact with most of the students, including in classroom assistance and monitoring, one-on-one training with teachers in using technology such as the iPad and communication apps, regular contact and assistance to the children's Speech and Language Pathologists, and additional assistance and training

for parents. Karen also works with four children every Saturday on continued communication and literacy as an adjunct to what they are receiving in school.

This follow up has been critical to the continued success of this pilot program and of the students themselves. For four of them, their schools have or are in the process of purchasing high tech AAC equipment for them, which was recommended by our specialists. These tools sometimes cost several thousand dollars. For others, they received iPads and other tools they needed. In many cases DSCBA facilitated communication between school and the technology companies. We are thrilled that the schools have followed through and they continue to collaborate.

Working with the children after the initial summer program also allowed us to see their further growth and development. For example, Karen has been working with Lulu her on literacy for the past several months and has seen tremendous growth. Lulu is now reading. She is tracking words and is able to approximate most of the letter sounds. This is something that was not happening at all initially. Use of AAC has been the focus for the other three children. Work included helping their teachers and/or parents to program and personalize their devices. In some cases, we taught the parents how to program and they in turn taught the teachers. Use of AAC has been huge for Ainsley in particular. When we first started working with her, she could verbalize only a few words and was very difficult to understand. Now she can carry on whole conversations.

In some cases we provided quite a bit of follow up in person and on the phone with the educational teams and teachers initially, and once the teachers gained confidence and experience working with the child and the AAC devices, they were "off and running" with success.

# Student Profiles

## Ainsley



**Age:** 7

**Communication Tools Used:** iPad with TouchChat application; Little Step-by-Step Communicator

**Favorite Activity:** Reading

“Ainsley rarely used her voice when she started the program. Even when asked she would speak in quiet tones. By the end of the program she was using a voice that was loud and clear, and it was wonderful to hear her read aloud as she tracked words with her finger.” –Karen Baca

A pre-assessment was conducted with Ainsley before the start of the summer program. In the pre-assessment Ainsley was able to identify her name and identify some capital letters. She was unable to name the letters in her name, identify any letter sounds/phonemes, or any sight words. She demonstrated two concepts of print.

Ainsley was eager to learn and made significant gains in her use of language. Ainsley enjoyed book reading activities and reading aloud was an area of growth for her this summer. She participated well in most literacy activities, and grasped the concepts for phonemes quickly. She was very motivated by personal custom books, and loves to see her picture in books and read her name. She does best with repetition and multiple opportunities for practice and when instruction is supported with sign language.

**Recommendation:** Ainsley’s primary mode of communication is verbal speech, however because she is difficult to understand and talking out of context can be challenging, it is recommended that a speech generating device (iPad) be taught in the event that Ainsley needs to augment her speech.

## Alesandro (“Sandro”)



**Age:** 6

**Communication Tools Used:** Step-by-Step Communicator, Springboard Lite

**Favorite Activity:** Reading using AAC device

“Sandro began the program with little expressive language. By the end of the program he was able to utilize an AAC device to create two to three-word phrases and was able to read books aloud in this manner.”

–Karen Baca

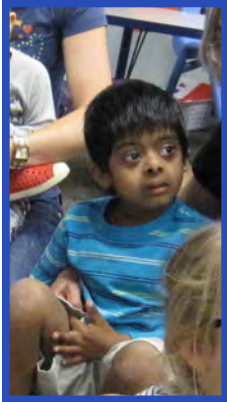
In Sandro’s pre-assessment, Sandro could not identify his name, letters, letter-sound phonemes, sight words, or basic concepts of print. He was reluctant to look at books and pushed them away.

Sandro enjoyed book reading activities and reading aloud was an area of growth for him. Overall there was a significant increase in his ability to pay attention and his willingness to participate in activities. Once he was given access to an AAC device for reading, Sandro quickly began to find the words needed to read books aloud. He was very motivated by custom books that included his picture and name in the story. He also increased his ability to repeat the letters of his name verbally and also used sign language. Use of speech prompts for production of phonemes was very successful for Sandro.

**Recommendation:** Sandro is a loving and kind child. He needs a lot of one-on-one attention to help him focus and meet his needs. Work on vocabulary and using the Springboard talker to enhance his vocabulary. Have a structured environment and firm guidelines for him. Sandro uses multiple means of language to communicate (verbal, sign, and AAC) and it is recommended that all means continue to be targeted in Sandro’s school, home, and community environments.



## Aniruth



**Age:** 6

**Communication Tools Used:** iPad with TouchChat app; Little Step-by-Step Communicator

**Favorite Activity in CRP:** Music

“Aniruth would not even look at a book but rather pushed them away at the start of the program. When presented with a custom person book, Aniruth was focused and followed the supplemental sign language. When presented with the page with his picture, he stared at the book for a while, pulled it close and gave his picture a kiss. He also began to sign the words in the books as he read.” –Karen Baca

“Aniruth’s mother reported that he was saying ‘p,’ ‘b,’ ‘m’ sounds at home. This is a child who has only ever been able to say ‘oo.’ The oral placement therapy was really helping him feel the movements of the speech sounds so that he could practice and create them daily.”

–Heather Peterson

In the pre-assessment Aniruth did not respond to any of the tasks or items he was presented with, and he could not identify his name, letters, or even basic concepts of print.

Aniruth was initially resistant to participating in literacy activities. He was observed to throw his name card when presented with it, clear the table when presented with materials, and showed lack of interest in looking at books and pushed them away. He did not show any comprehension of materials or tasks, and did not attempt to communicate in any way.

Although Aniruth’s participation with different literacy activities fluctuated day to day, there was overall a significant increase in his ability to pay attention and his willingness to participate in activities, especially when combined with sign language. He was interested in using the iPad for writing using tracing apps to trace the letters of his name using his finger.

Aniruth’s greatest area of growth was concepts of print. Aniruth was presented with sign language as much as possible in addition to materials. Reading materials were created with “colors” as a theme as this is an area of high interest to Aniruth. He began to show more interest in books presented and would spend several seconds examining each page and eventually he would sign the color displayed on the page.

Throughout the summer, Aniruth was observed to bring materials close to his face when looking at them. He may be having difficulties with his vision and may be eligible for a low vision clinic at UC Berkeley.

**Recommendations:** Aniruth should continue to be presented with high interest reading materials. Custom personal books should be made to continue to motivate him to read. Aniruth’s primary modes of communication were gestures and AAC. It is recommended that AAC and sign language along with speech continue to be targeted in Aniruth’s school, home, and community environments.

## Leah



**Age:** 7

**Communication Tools Used:** Little Step-by-Step Communicator

**Favorite Activity:** Socializing

“Leah did not have any phonemic awareness at the start of the program. By the end of the program she was able to identify targeted phonemes and discriminate and sort them.” –Karen Baca

“It was so exciting to see Leah’s growth this summer! She is an eager communicator and made significant gains in her use of language.” – Kati Skulski and Shawna Marcus

In the pre-assessment Leah was unable to identify her name, name the letters in her name, identify letters, identify any letter sounds/phonemes, or any sight words. She demonstrated one concept of print.

Leah participated well in literacy activities and enjoys demonstrating what she has learned. Leah enjoyed book reading activities and reading aloud was an area of growth for her this summer. She participated well in most literacy activities, and grasped the concepts for phonemes quickly. She was very motivated by personal custom books, and loves to see her picture in books and read her name. She does best with repetition and multiple opportunities for practice.

In the assessment conducted the final week of the summer program, Leah was able to identify her name from of field of three names, recite the letters in her name, and identify, sort and classify some phonemes. She is developing a proper pencil grasp and can use the app crayon to write her name on the iPad. She demonstrated six concepts of print.

**Recommendations:** Leah would benefit from an individualized literacy program based on A Reading and Language Intervention for Children with Down Syndrome by Kelly Burgoyne, Fiona Duff, Paula Clarke, Glynnis Smith, Sue Buckley, Margaret Snowling, and Charles Hulme. It could be supplemented by activities based on Words Their Way by Donald R. Bear, Shane Templeton, Marcia Invernizzi, and Francine Johnston. At CRP Leah’s primary modes of communication were verbal speech and gestures. It is recommended that speech continue to be targeted in Leah’s home, school, and community environments. She benefits from linguistic models and partners who ask her open ended questions.

## Lucas



**Age:** 6

**Communication Tools Used:** Little Step-by-Step Communicator

**Favorite Activity:** Reading

“Lucas could not read any sight words and did not demonstrate many concepts of print. By the end of the program he was reading sight word books independently and recognizing sight words.” –Karen Baca

“Lucas and Lulu were amazing during the program. They began using 2-5 syllable utterances, both had increased jaw stability and lip puckering for the ‘oo, oh’ sounds as well as both began using tongue tip elevation for the ‘L’ sound. At the end of the program they could both say their names! That was really an exciting moment for me.” –Heather Peterson

In the pre-assessment Lucas could identify his name and identify some letters. He could not spell his name, identify phonemes, read sight words, and only demonstrated one concept of print.

Lucas participated well in literacy activities and enjoys demonstrating what he has learned. He is eager to try new things and an enthusiastic participant in most activities. At times he would get restless while waiting for his turn, but a reminder that he would get to ring the bell at the end of the session would get him back on task. Use of speech prompts for production of phonemes was very successful for Lucas.

In the final assessment, Lucas was able to identify his name from a field of three similar names, recite the letters in his name, identify the letters in his name, identify, sort and classify certain phonemes, and he could read the sight words I, see, like and want. He is developing a proper pencil grasp and can use the app crayon to write his name on the iPad. He demonstrated six concepts of print.

**Recommendations:** Lucas’ primary mode of communication is verbal speech, and it is recommended that speech and language continue to be targeted in Lucas’ school, home, and community environments. Lucas would benefit from an individualized literacy program based on A Reading and Language Intervention for Children with Down Syndrome, supplemented by activities based on Words Their Way.

## Lulu



**Age:** 6

**Communication Tools Used:** Little Step-by-Step Communicator

**Favorite Activity:** Socializing and Reading

“Lulu could not spell or recognize her name at the start of the program. By week six she was reciting all the letters in her name, and recognizing it amongst a field of three similar names.”

–Karen Baca

Lulu was an eager and strong communicator in the summer program. With regard to the reading pre-assessment, Lulu could not identify her name, letters, or even basic concepts of print. By the final assessment, Lulu was able to identify her name from a field of three similar names, recite the letters in her name, identify the letters in her name, identify phonemes, sort and classify pictures according to phonemes, and could read the sight words I, see, and like. She is developing a proper pencil grasp and can use the app crayon to write her name on the iPad. She demonstrated six concepts of print.

Lulu was an eager and strong communicator, and increased her mean length utterances significantly by the end of the program. She participated well in literacy activities and was often called on to model for other students. Her social skills and empathy for fellow students were strengths that allowed Lulu to be a leader and demonstrate proficiency for other students. Lulu enjoyed reading books and was presented with sign language in combination with print. She is eager to learn and an enthusiastic participant in all activities.

**Recommendations:** Lulu would benefit from an individualized literacy program based on A Reading and Language Intervention for Children with Down Syndrome by Kelly Burgoyne, Fiona Duff, Paula Clarke, Glynnis Smith, Sue Buckley, Margaret Snowling, and Charles Hulme. It could be supplemented by activities based on Words Their Way by Donald R. Bear, Shane Templeton, Marcia Invernizzi, and Francine Johnston. Use of prompts for speech production for phonemes is highly recommended. Approaches to phonemic awareness and reading instruction need to take in consideration Lulu’s reported hearing loss.

## Mason



**Age:** 5

**Communication Tools Used:** Little Step-by-Step Communicator

**Favorite Activity:** Reading

“Mason did not demonstrate any concepts of print when he began the program. During week five, he sat with me and he read the book ‘Pete the Cat’ to me! He approximated the text and read with expression; it was amazing to see that progress in such a short time. With sight word readers, he was able to read independently and track words with his finger.” –Karen Baca

Mason was assessed informally by observation within the first week of the summer program (a pre-assessment did not occur due to an illness). Mason was able to identify the letter M, but could not identify his name. He could not identify the letters in his name, sight words, or any letter-sound phonemes.

Mason enjoyed book reading activities and reading aloud was an area of growth for him this summer. Overall there was a significant increase in his ability to pay attention and his willingness to participate in activities despite seeming to be very tired some days. He participated well in most literacy activities, and grasped the concepts for phonemes quickly. He was very motivated by personal custom books, and loves to see his picture in books and read his name.

**Recommendations:** Mason’s primary mode of communication is verbal speech. It is recommended that speech continue to be targeted in Mason’s school, home, and community environments. Mason should continue to be presented with high interest reading materials. Custom personal books should be made to continue to motivate him to read. Mason needs to develop a proper grasp for writing and pyramid crayons are recommended for coloring activities. Use of prompts for speech production for phonemes is highly recommended. For writing, assistive technology is recommended and text to speech software like Intellitools Classroom Suite could be used to create custom literacy activities for Mason.

## Nico



**Age:** 5

**Communication Tools Used:** Little Step-by-Step Communicator; GoTalk 4

**Favorite Activity:** Fine motor/music

“Nico would not come to the table for reading work and had difficulty sitting for tasks. By the end of the program he would come to the table and work on the letters of his name. He also was able to complete a custom name puzzle independently.”

–Karen Baca

“Throughout the program the kids continued to surprise us. Nico, a child who has a dual diagnosis of Down syndrome and Autism has never spoken more than a squeal of ‘E’ or ‘ay!’ was heard to say ‘down’ and ‘oh’ during Old MacDonald. He also learned to blow air consistently which is a precursor to creating speech.” –Heather Peterson

In the pre-assessment Nico could not sustain attention to materials and could not sit long enough to attend to any tasks presented. When presented with books he pushed them away, and sometimes threw other materials. By the end of the program Nico had improved in his ability to come to the table and attend to the first task, which was practicing the letters of his name. Custom name puzzles were created for Nico to use while reviewing the letters of his name. He was able to do the puzzles with minimal assistance and the pieces were put on the floor to allow him movement while doing the activity. He improved in being able to make a choice of two books, and would

sit and participate during reading for short periods of time. The books were interactive and allowed Nico to Velcro items in the books. The books were also based on songs as music is highly motivating for him.

Nico is still developing a proper pencil grasp so he used his finger to trace his name on the iPad. iPad activities are highly motivating for Nico, but it can be difficult to transition him to a less preferred activity after the iPad. Nico did best when activities were kept short, and he was reinforced with lots of praise and clapping.

**Recommendation:** Nico is a very happy child. He loves to smile and loves finger plays and music. Nico needs a lot of movement and hands on activities. He loves working with puzzles.

**Goals:** Working on sounds to make words and participating in more activities that will meet his needs.

# Challenges and Recommendations for Future Years:



We found that the program could be improved in future years with a few changes, including:

- Assignment of a dedicated program manager to oversee all aspects of the program;
- Identify students at the outset needing more one-on-one and personalized attention and assign staff accordingly;
- More movement and dramatic learning options (many of the children learn well with movement involved, while still for long periods is difficult. We know that children must gain practice with sitting still and paying attention, as they will be required to do this in regular education classrooms. We can work towards longer periods of sitting still if they are punctuated by movement, dance, and other active teaching methods);
- Addition of a behaviorist to the staff;
- More space (the classroom we had available at DSCBA was smaller than optimal for the eight students and minimum of eight adults in the classroom at any one time); and
- Additional AAC training as needed before and/or outside of the class time.
- A clearer understanding of our role in working with the school districts and follow up with families.



Down Syndrome Connection of the Bay Area  
*Encouraging the unlimited potential in children and young adults with Down syndrome*

