CAYA

Communication Assistance for Youth and Adults

2017—2020
RETROSPECTIVE REPORT

Promoting independence Through Communication

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Communication Assistance for Youth and Adults is pleased to report on activities and initiatives for the period from 2017 to 2020. This report follows on the last retrospective report from 2012 to 2016.

Communication Assistance for Youth and Adults (CAYA) is a Provincial Service Program that supports adults aged 19 years and older who require an augmentative or alternative communication (AAC) system due to a severe communication disability, i.e. speech that is not functional for daily communication. The goal of CAYA is to ensure that eligible individuals have access to the communication tools and professional support to enable them to create and maintain an adult life to the best of their abilities.

Out of recognition and respect for the relationship Indigenous peoples have had with these lands for thousands of years, we acknowledge that our programs and services take place on the traditional territories of local First Nations, Metis, and Inuit peoples.

Our provincial office is located on unceded Coast Salish Territories; the traditional and ancestral territories of the xʷməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

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HISTORY AND ORIGINS

CAYA was created in July 2005 to address the needs of young adults with severe communication disabilities leaving the K-12 education system. Before CAYA, young adults who used augmentative and alternative communication (AAC) had an uncertain future as they left behind communication support services and technology. In 2010, the provincial government mandated CAYA to provide communication technology and supports to adults of all ages, ensuring these individuals can maintain vital links to the world through independent communication. From 2005 to 2012 CAYA received annual operating grants from the Ministry of Social Development. In 2012 CAYA was formally included in the BC budget with secure annual funding now extending to 2022. CAYA now provides service to all eligible adults; young, middle-aged, and elderly, over the age of 19 years.

BACKGROUND

Since 2005, over 4300 BC residents with severe communication disabilities have come to CAYA for assistance. As of October 2020, 1829 clients in all parts of BC were actively receiving services from CAYA, including communication assessment, and provision, support, and repair of communication systems on a long-term loan basis. Statistics from recent years prior to the pandemic, 2018 and 2019, indicate that the annual client presentation rate (i.e. the number of new Clients presenting themselves for service) continues to be a stable fraction of the total BC population at an average of 468 new Clients per year. This presentation number accurately follows predictions based on detailed demographic research and modeling of populations in Canada, USA, Australia, and Europe.

MISSION

CAYA ensures that adults with severe communication disabilities can maintain a vital link to the world through independent communication. CAYA offers communication tools and support to enable individuals to create and maintain an adult life to the best of their abilities.

OPERATIONAL FUNDING

For the three year period 2019-2022, CAYA has received operational funding of $9.3 million (average of $3.1 million per year).

SERVICE PRIORITIES

CAYA operates on 3 intake cycles per year. To ensure that the needs of individuals are addressed with fairness and responsiveness, Requests for Service are triaged and activated based on a range of individual factors including:

» urgency (e.g. terminal diagnosis, imminent loss of housing or employment due to loss of communication)
» geographical factors (CAYA provides service across BC, to keep costs down we cluster visits to remote regions)
» transition factors (enabling individuals to smoothly leave school, or move from institutional to individual living situations)
» length of time on waitlist
» other factors as identified

WHO ARE CAYA CLIENTS

CAYA Clients have either never had or have recently lost the capacity for functional speech. The origins of these disabilities stem from difficulties at birth (e.g. cerebral palsy) or genetic conditions (e.g. Down's syndrome) or acquired conditions (e.g. traumatic brain injury, ALS). Most CAYA Clients have long-standing communication disabilities and CAYA is there to ensure that they have the communication supports to build or maintain an adult life of the greatest possible independence.

CAYA equipped us with valuable training and strategies so Harrison could have meaningful communication.

Todd has a diagnosis of ALS and uses his tablet to communicate with his eyes.

Erin struggles with Autism and a Seizure Disorder. She uses a PODD symbol book to communicate.

SERVICES

CAYA provides a time dependent service. Assessment and intervention are intended to occur during a service cycle of four months. Following these four months of active service, the Client and her/his Team are expected to assume responsibility for continued implementation and use of the communication system. CAYA service is comprised of the following modules:

Assessment

» CAYA provides assessment services through our skilled Speech-Language Pathologists (SLPs).
» Teams comprised of SLPs and SLP Assistants determine the best augmentative or alternative communication system for eligible clients and develop a thoughtful implementation plan incorporating the resources and strengths of the client's supporters and families.
» Teams and families who support CAYA Clients must agree to:
  – participate in the assessment process and,
  – continue the implementation of the communication system on a regular daily basis as part of a Personal Support Plan.

Equipment

CAYA maintains a loan bank of communication technologies.

Following the recommendations of the SLPs, CAYA lends communication systems for an indefinite period of time to CAYA clients. Communication is an essential human function, therefore broken equipment is supported and repaired as quickly as possible. Client's supporters and families are expected to safeguard equipment. CAYA will repair equipment damaged in daily wear and use, but individuals may be required to assume repair costs in cases of negligence. If equipment is no longer required by the client, it is returned to the loan bank, cleaned, repaired, and made ready for use by the next eligible Client.

All CAYA Clients receive appropriate non-technical communication systems made of paper, ink, and plastic, as an essential communication support. All technology fails at some point – batteries die, components fail, devices break. A viable non-technical system ensures that clients have access to basic communication needs at all times.

Daily / Regular Use

Once the appropriate communication system has been determined and the Client and Team Members trained in its use, the Client is placed on "monitor" status, and daily implementation and use becomes the responsibility of the Client and her/his support team.

Monitor and Follow-up

CAYA follows through with clients after the conclusion of the initial assessment and provision process with regular calls and contacts. Technical support is available to all CAYA Clients to keep their technology functional.

Training and Resources

CAYA provides families and other care providers with periodic training opportunities and information about support groups, webinars, videos and other resources to ensure the successful implementation of AAC initiatives. Many CAYA Clients live in group homes and attend day programs. Managers of these facilities are expected to allow relevant staff to participate in CAYA training activities related to the daily support of the Client's communication system.

ELIGIBILITY

Since 2010, individuals eligible to receive CAYA services include:

» Adults aged 19 years and older who require an AAC system due to a severe communication disability, i.e. speech that is not functional for daily communication
» Adults aged 19 years and older who are already using an AAC system, but require further training and resources to improve or maintain communicative function
» Students in the last year of their K-12 program who require transition support for their AAC system as they move to adulthood

Gordon of Prince George

I had a stroke in March 2015. It took me 4 months to learn to walk again, and I have limited use of my right hand. I can get by with the physical handicaps. With aphasia, it's a different story. I'm a musician and singer. It breaks my heart that I can't sing or play my guitar with all my capabilities. Not being able to communicate doesn't help either. I didn't go out much or see too many people other than family. It's too frustrating not being able to communicate, so I just stayed home. In late 2016, Barbara from CAYA introduced me to the Predictable Program on an iPad. I had a choice of 3 programs, but I felt Predictable was right for me.

You can't imagine how elated I was being able to communicate. With Predictable, I can save phrases and bring them up later as I need them. It saves me time at Tim Hortons or any restaurant or business for that matter. I still can't sing or play my guitar worth a damn, but I can communicate with the outside world, and that says something.
Gordon

LOCATIONS AND SERVICE PARTNERS

CAYA service is delivered through service partners and in conjunction with other health and community service providers. CAYA has mapped service delivery across the province consistent with the Health Regions of BC. The provincial centre is located in Vancouver.

SERVICE PARTNERS

Vancouver School Board

The host organization for CAYA providing administrative and logistical support services

Health Authorities

CAYA funds contracts for clinical staff in the Coastal, Island, Interior, Fraser and Northern health authorities

CAYApartners

CAYApartners are select community SLPs with a specific experience and skill set, serving adults who are non-speaking. CAYApartners are trained in the CAYA assessment and lending procedures, have restricted database access, and can request a limited range of AAC technology for specific clients.

ALS Society of BC

The ALS Society of BC supports CAYA with an annual grant of $25,000 for the provision of communication systems to CAYA clients with ALS.

SERVICE DELIVERY

SERVICE DELIVERY

Adults requesting services complete and submit a Request for Service (RFS) to CAYA (detailed information on this process available on the CAYA website). The RFS is reviewed for eligibility and at a subsequent time, the Client is assigned to a CAYA Speech-Language Pathologist (SLP). The SLP then conducts an assessment and equipment trial resulting in a Communication Assessment Action Plan (CAAP). The CAAP forms the basis for an equipment loan and implementation plan. SLP Assistants provide training and support to ensure independent use of technology by clients and support from their families and teams.

01 Request for Service	02 Triage & Assignment of Case	03 Interview & Assessment with SLP	04 Equipment & Communication System Trial	05 Communication Assessment & Action Plan (CAAP)
06 Loan Request & Technology Delivery	07 Training & Implementation	08 Follow -Up & Support	09 Technical Support & Maintenance	10 Client Need Met

Chelsea from Prince George

My daughter Chelsea is 23 years old and has cerebral palsy that has left her with limited limb control and no means of verbal communication. However, she is very social and loves to be with people and laugh a lot. She has struggled to communicate with others in the past and has often been very upset when she cannot tell us what she wants.

Over the years, we have tried various means of communication devices and programs. Unfortunately, we have always encountered difficulties finding programs that support her physical and intellectual challenges and devices that support my limited technical skills. The advent of the iPad has helped. However, after a program we were using was no longer supported, I struggled to find a new one, so Chelsea's OT referred us to CAYA.
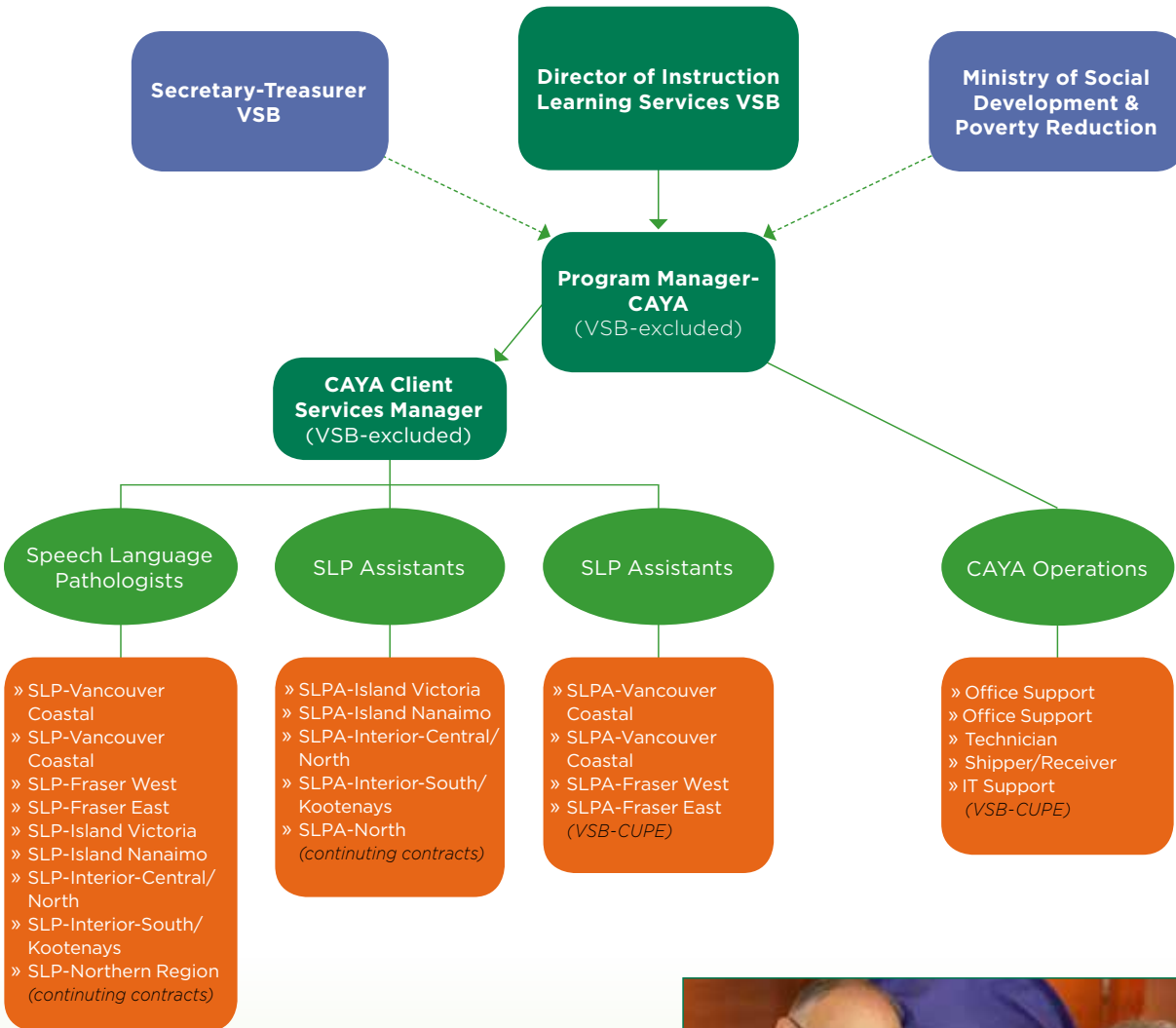
After a short wait to get accepted, we met Ashley and Kristi. They did an assessment and recommended a program for Chelsea. As a result, she now has an iPad loaded with the program TouchChat. Without their support, it would have been challenging to decide which program to best support Chelsea's abilities. As programs are often costly and time-intensive to trial, we are grateful to have access to the knowledge and resources CAYA provides.

SERVICE DELIVERY

ORGANIZATIONAL CHART

As a provincial service program, CAYA is funded by the BC Ministry of Social Development and Poverty Reduction and administered by the Vancouver School Board. CAYA employs staff in several locations across the province. Staff who are not employed by the host organization, the Vancouver School Board, work under continuing contracts between CAYA/VSB and local health authorities. The main office and warehouse are located in south Vancouver.

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Secretary-Treasurer          Director of Instruction        Ministry of Social
       VSB                    Learning Services VSB          Development &
                                                             Poverty Reduction

                              Program Manager-
                                   CAYA
                              (VSB-excluded)

          CAYA Client
       Services Manager
        (VSB-excluded)

  Speech Language      SLP Assistants      SLP Assistants      CAYA Operations
   Pathologists
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Speech Language Pathologists
- » SLP-Vancouver Coastal
- » SLP-Vancouver Coastal
- » SLP-Fraser West
- » SLP-Fraser East
- » SLP-Island Victoria
- » SLP-Island Nanaimo
- » SLP-Interior-Central/ North
- » SLP-Interior-South/ Kootenays
- » SLP-Northern Region
  (continuing contracts)

SLP Assistants
- » SLPA-Island Victoria
- » SLPA-Island Nanaimo
- » SLPA-Interior-Central/ North
- » SLPA-Interior-South/ Kootenays
- » SLPA-North
  (continuing contracts)

SLP Assistants
- » SLPA-Vancouver Coastal
- » SLPA-Vancouver Coastal
- » SLPA-Fraser West
- » SLPA-Fraser East
  (VSB-CUPE)

CAYA Operations
- » Office Support
- » Office Support
- » Technician
- » Shipper/Receiver
- » IT Support
  (VSB-CUPE)

Our Dena is now 41. Until her 36th birthday, she could only express herself through augmentative communication picture symbols. All questions asked of Dena were yes/no questions. Family, friends and caregivers had picture symbols to ask her questions. It's cumbersome and time-consuming, and then came the Tobii! The Tobii has given Dena a fuller, better understood, and finally a more respected life. Dena now became heard. Her feelings and emotions, thoughts and wishes, fears and pleasures were all able to be expressed. Dena talked. There was no more questioning or guessing what Dena wanted to do, needed to have, etc., at any particular time or moment. She told us herself with her voice.

Dena of Richmond

CAYA Program Staff, November 2020.

HIRING AND TRAINING OF STAFF

People who require AAC are a small subset of the larger population with speech and language disabilities. The graduate school training of Speech-Language Pathologists focuses primarily on the assessment and treatment of speech and language problems with an expectation that speech will be the primary production mode. This is particularly true for adult clients who are generally assumed to have fully formed speech and language. Therefore, university formation in this specialty area is quite limited (UBC currently offers only a one-semester course in AAC covering all age ranges and disabilities). Demographic research and CAYA's operational experience confirm the small incidence of people with complex conditions who need AAC – estimated to be 0.12% of the general population. Most SLPs in general adult practice encounter only a few, if any, of these clients per year. This limited exposure is not sufficient to maintain the knowledge and skills required for this specialty area. When general adult practice SLPs do encounter clients who need AAC, they are often challenged as to where to start, what to do, and how to select and program appropriate high and low technology solutions. CAYA has implemented a structured training program to ensure professional staff have the specialized knowledge and skill to effectively deliver service.

Due to the complexity and diversity of CAYA Clients, a new CAYA SLP generally will not be fully productive in terms of number of cases handled and completed per service cycle until after the first cycle (4 months) after start date. Throughout the year, CAYA SLPs are required to engage in continuous training and professional development to ensure their skills remain current with rapidly changing technology and scientific knowledge. Practice is continually monitored by CAYA managers through frequent caseload reviews.

New CAYA SLPs are provided orientation and training on the following areas:

Assessment Tools, Procedures and Protocols
Application and adaptation of specialized, standardized, and non-standardized assessment tools, procedures and protocols to assess individuals without functional speech across a wide disability spectrum of congenital and acquired disabilities (everything from Autism Spectrum Disorder to ALS).
Theory and Methodology
Theory and methodology on the selection of appropriate technology (including feature matching, environmental requirements, and communication partner factors) for use in assessment and application with clients
Assessment Practices
Integration of assessment practices with input from other team professionals, including but not limited to: Behavioural Consultants, Audiologists, and Occupational Therapists.
Programming AAC Technology
Programming and operation of basic, medium, and high complexity AAC technology. Use and application of programming tools, and production technology for designing and producing low-technology solutions.
Counseling
Counseling around loss and acceptance of a severe communication disability
Engagement of Family and Community
Engagement of family and community supporters in the selection, implementation, and long-term support of the AAC technology solution, including training challenges for clients and supporters
Virtual Service Delivery
Virtual Service Delivery arranged using a hybrid service delivery model, providing AAC service along the continuum using in-person and virtual strategies as appropriate to the situation
CAYAdata
All aspects of CAYAdata for documentation, e.g.: clinical practice and documentation, requesting and managing loans, equipment service and repairs, caseload management, and follow up requirements, etc.
CAYA Virtual Resources
All aspects of CAYA virtual resources including Office 365, Meraki, Zoom for Healthcare and Sync.
Safe and Accountable Practice
All aspects of safe and accountable practice including: WorkSafe practices for client home visits; security of persons, information, and assets; CAYA policies and procedures; etc.
Other Practice Requirements
Other practice requirements related to client group activities, etc.

SERVICE DELIVERY

DATA MANAGEMENT - CAYAdata

CAYA operations encompass a wide variety of activities and responsibilities. All of the information pertaining to CAYA services, assets, and records are managed through a central database, CAYAdata.

CAYAdata was created as a clone of SET-BC's database, SETdata. CAYA greatly benefits from the gift of this clone which contains extensive custom programming. Without CAYAdata, CAYA's complex operations spanning across the province would be impossible.

CAYAdata has been updated recently and continues to provide staff across the province with access to information required to do their jobs.

CAAP

CAYA's formal assessment protocol is the Communication Assessment and Action Plan (CAAP). This on-line tool built into CAYAdata, provides a standardized reporting format to ensure efficient and clinically consistent documentation from SLPs working across the province. The CAAP is based on the current scientific foundations of the field of AAC and evidence based practice. As a digital tool, the CAAP ensures the structured collection of data and the possibility of comparative analysis of client progress over years.

CAYApartners

In 2010, the provincial government mandated CAYA to provide communication assistance to adults of all ages. This represented a nearly five-fold increase in the number of people eligible for CAYA service. Natur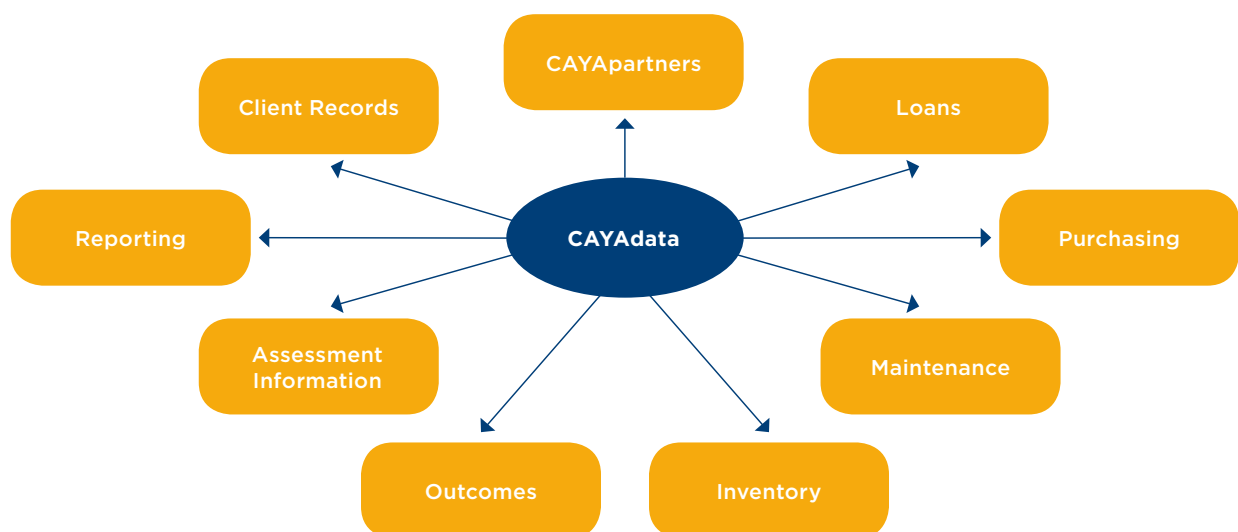ally, a significant jump in eligibility resulted in a spike in wait-times for service. SLPs working in the community with nonspeaking adults began approaching CAYA to borrow communication devices to address clients on their active caseloads.

CAYA needed a solution to provide secure data access to non-CAYA SLPs. The goals were to ensure maximum service options to people in need, maximum utilization of CAYA resources, and continued adherence to professional standards of practice.

The solution was to create the CAYApartners Program. Community SLPs must attend the CAYApartners course (offered twice a year) and periodic update training sessions in order to participate in the program. The CAYApartners Program allows community SLPs who have been trained in CAYA procedures to access their particular client's information, complete the CAYA CAAP, enter progress notes, and request equipment.
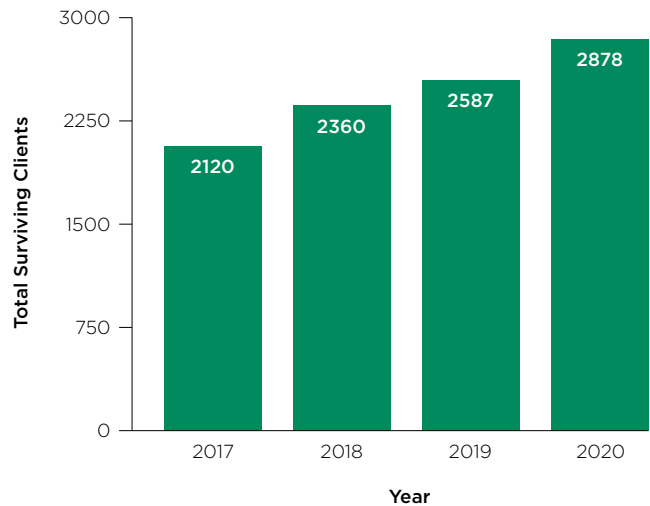
Hybrid Service Delivery

People in need of CAYA services live everywhere in the province and can be in challenging locations. Management had been exploring the option of virtual services for years, but until the pandemic occurred, there was not the logistical will in the service sector to support such a model. On March 17, 2020, Ministerial Order 85 was enacted in BC, which allowed CAYA to obtain the resources and develop a model of hybrid service delivery that is consent-based, evidence-based, efficient, and cost effective. Clients can choose from a continuum of service offerings based on their unique situations and preferences. This new model allowed CAYA staff to provide essential human communication services to our clients during the pandemic and will continue to be an option for them in the future.
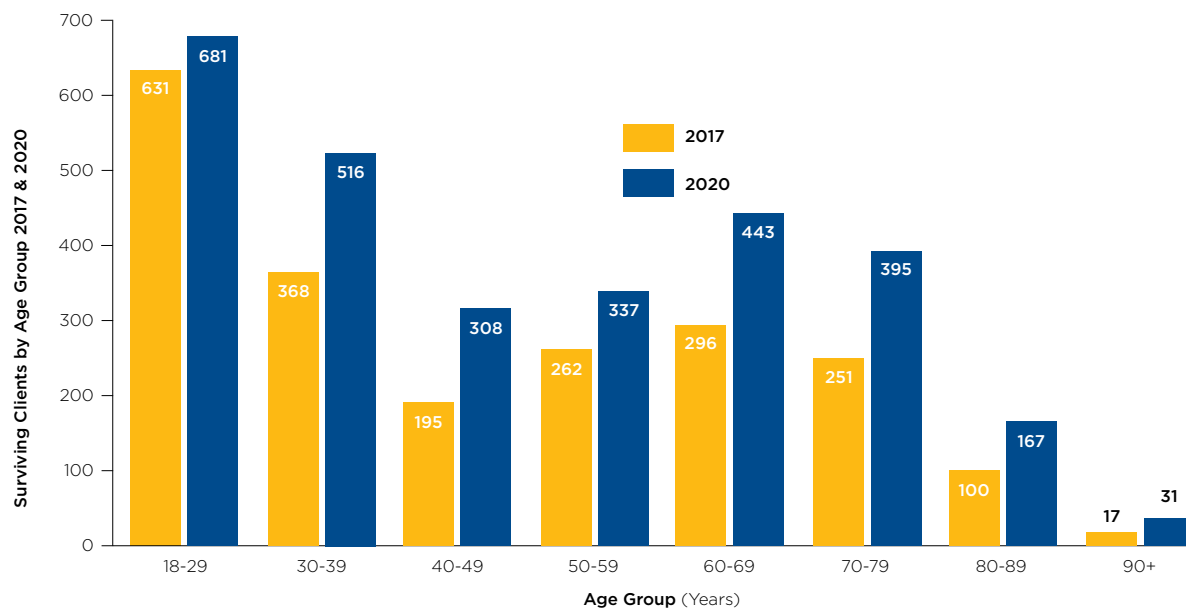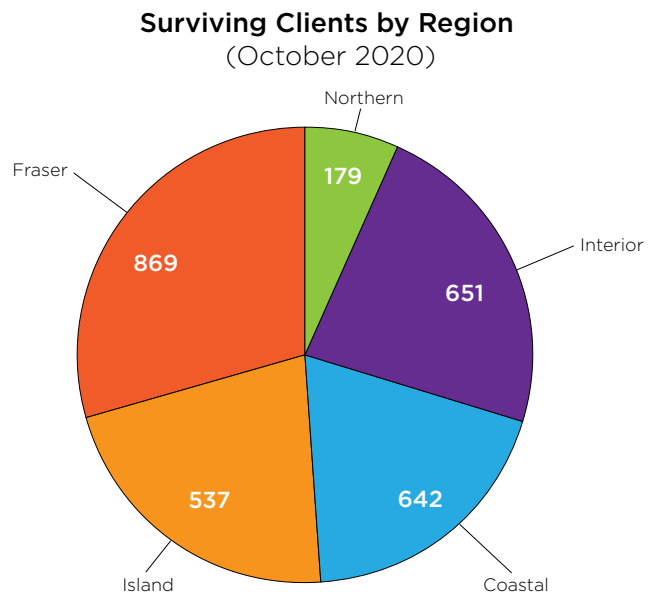
CLIENT STATISTICS

SURVIVING CLIENTS BY REGIONS
(Annual Snap Shots as of October 15th each year)

Health Regions (excluding deceased)	2017	2018	2019	2020
Northern	148	156	165	179
Interior	483	538	611	651
Coastal	413	482	553	642
Island	445	476	492	537
Fraser	631	708	766	869
TOTAL	**2120**	**2360**	**2587**	**2878**

The distribution of CAYA client numbers by region is consistent with the general population distribution of BC

SURVIVING CLIENTS BY AGE GROUP
(Annual Snap Shots as of October 15th each year)

Decennial Age Groups (excluding deceased)	2017	2018	2019	2020
18 – 29 years	631	645	664	681
30 – 39 years	368	424	474	516
40 – 49 years	195	233	269	308
50 – 59 years	262	286	315	337
60 – 69 years	296	347	382	443
70 – 79 years	251	284	334	395
80 – 89 years	100	122	132	167
90+ years	17	19	17	31
TOTAL	**2120**	**2360**	**2587**	**2878**

Total Surviving Clients by Year (bar chart): 2017: 2120, 2018: 2360, 2019: 2587, 2020: 2878

Surviving Clients by Region
(October 2020)

Pie chart: Northern 179, Interior 651, Coastal 642, Island 537, Fraser 869

Surviving Clients by Age Group 2017 & 2020 (bar chart):
- 18-29: 2017 = 631, 2020 = 681
- 30-39: 2017 = 368, 2020 = 516
- 40-49: 2017 = 195, 2020 = 308
- 50-59: 2017 = 262, 2020 = 337
- 60-69: 2017 = 296, 2020 = 443
- 70-79: 2017 = 251, 2020 = 395
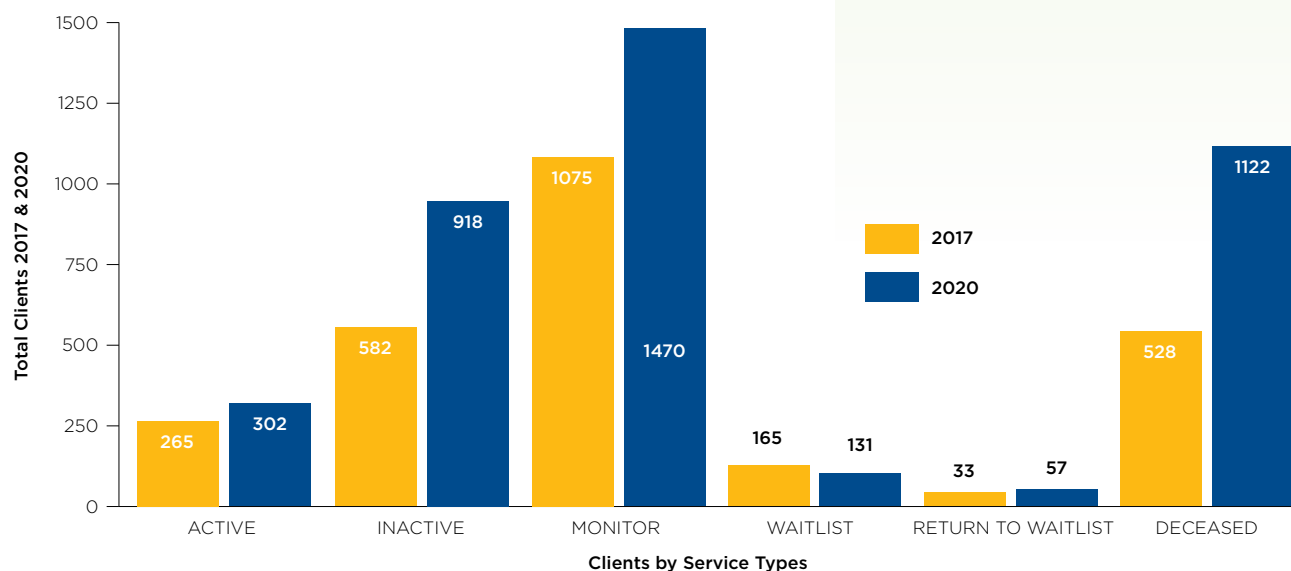- 80-89: 2017 = 100, 2020 = 167
- 90+: 2017 = 17, 2020 = 31

CLIENT STATISTICS

CLIENTS BY SERVICE TYPES
(Annual Snap Shot as of October 15th each year)

Client Categories	2017	2018	2019	2020
ACTIVE-clients who were actively receiving intensive professional services, e.g. assessment, implementation of technology, and training	265	222	244	302
INACTIVE-clients who due to illness or inability to respond to service initiatives, were deemed currently unserviceable. These clients may reactivate their cases with a future request or contact.	582	695	776	918
MONITOR-clients who have successfully received technology and service, and have completed training. These clients are only contacted for annual follow up information	1075	1201	1342	1470
WAITLIST-clients who have submitted requests and were awaiting service initiation	165	190	170	131
RETURN TO WAITLIST-clients who received service in the past and require an update due to physical changes or technological obsolescence	33	52	55	57
DECEASED	528	720	934	1122
TOTAL CLIENTS	2648	3080	3521	4000

The client numbers for CAYA are a product of two factors, incidence and presentation. The incidence of a severe communication disability in the human population is approximately 0.12% (Bloomberg and Johnson, 1990) a small number of people with a high need for support. This number is modulated by the presentation factor, i.e. the number of individuals who step forward to request assistance in a time period, e.g. per year. (In any health, education, or social initiative, there is always a subset of eligible people who request or accept assistance, and others, for a variety of reasons, who do not – this is the presentation factor.) Presentation rates are driven by many factors including awareness of, and accessibility to, supports.

When eligibility for CAYA services was expanded in 2010 to all adults, the presentation rate was estimated to be 8% of BC residents with severe communication disabilities per year, or a total of 360 new clients presenting per year. The number of surviving CAYA clients increases each year and additionally, CAYA clients die each year due to the severity or nature of their disabilities, thereby reducing the total of surviving clients, and modulating the impact of new clients presenting for service. When the mortality factor is included in the year-to-year comparisons, the number of new clients presenting for service each year is an of average 454, or 9%. This is very close to the original presentation estimate from 2010.
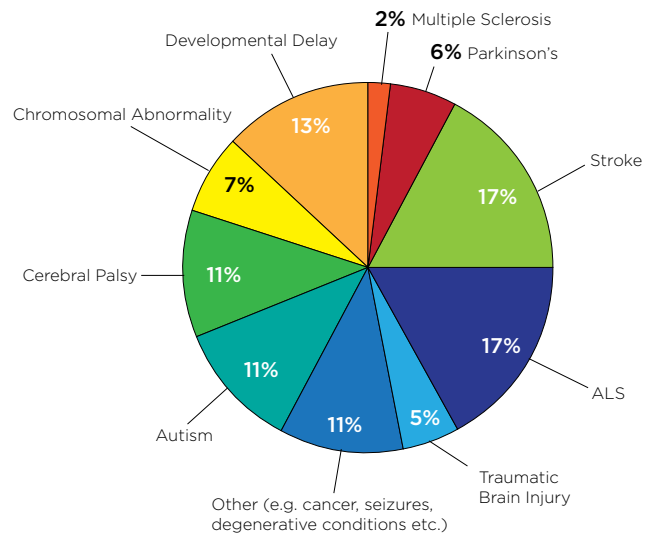
The incidence of a severe communication disability of 0.12% of the general population is stable. The growth in the CAYA client numbers from 2017 to 2020 reflects the response of individuals continuing to become aware of available assistance. The presentation rate for CAYA services remains stable.

Clients by Service Types

CLIENT STATISTICS

DIAGNOSTIC DEMOGRAPHICS TO DATE
(July 2005 - December 2020)

Diagnosis	Percentage of Served Clients
ALS	17%
Autism	11%
Cerebral Palsy	11%
Chromosomal Abnormality	7%
Developmental Delay	13%
Multiple Sclerosis	2%
Parkinson's	6%
Stroke	17%
Traumatic Brain Injury	5%
Other (e.g. cancer, seizures, degenerative conditions, etc.)	11%

Diagnostic Demographics to Date
(July 2005 - December 2020)

Pie chart segments:
- 2% Multiple Sclerosis
- 6% Parkinson's
- Developmental Delay 13%
- Chromosomal Abnormality 7%
- Stroke 17%
- ALS 17%
- Cerebral Palsy 11%
- Autism 11%
- Traumatic Brain Injury 5%
- Other (e.g. cancer, seizures, degenerative conditions etc.) 11%

Approximately 42% of CAYA clients have congenital disabilities, and 58% have later acquired disabilities.

Bo-Peep of Chilliwack

My name is Bo-Peep, and I was given one of your tablets to help me communicate. First of all, I want to thank you for such a wonderful gift! Without it, life would look a lot different for me. It is beneficial. It has made my life so much easier. Sometimes I have a hard time finding the words for what I'm trying to say, and the communication apps help me form the thoughts in my head so that my caregivers can understand me better. Before I had the tablet, I would have to say things I wanted to say over and over until someone could understand me.

When I was sick, my voice suffered. It made me mad that people couldn't understand what I was trying to say. With my CAYA tablet and all the apps, I can communicate clearly, be understood quickly, and even make jokes! I especially like that when I want to have a private conversation, I can type my thoughts, have my mom read them quietly and respond. It allows me to communicate in any way I could ever want. Speaking freely can be taken for granted so easily, so I am forever grateful for such a priceless (to me!) gift. Thank you from the bottom of my heart.
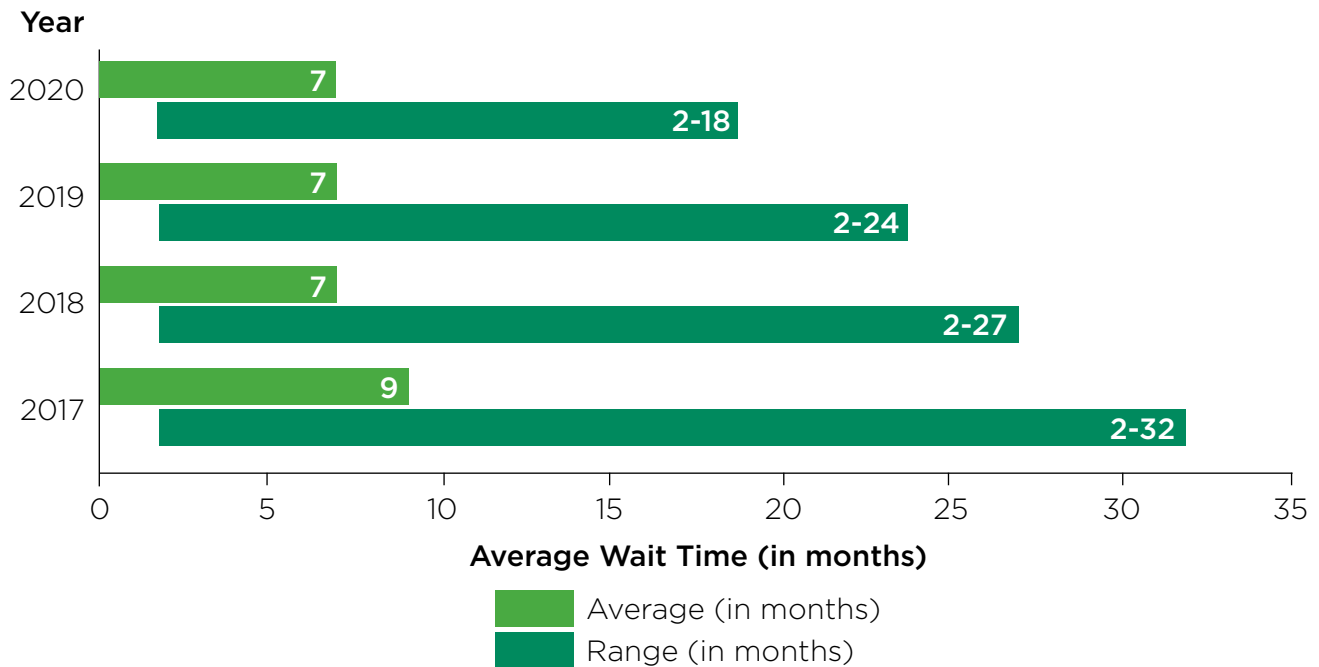
Yours Truly,
Bo-Peep

CLIENT STATISTICS

WAIT TIMES FOR SERVICE
(Annual Snap Shots as October 15th each year)

Service requests are triaged using the CAYA Service Priority Model based on factors of urgency, geography, transitions, time on the waitlist, and other factors. Please see Service Priorities (page 3 or CAYA Website) for more detail.

The longest wait time for applicants has reduced by 43% from 2017 – 2020. Additional funding is resulting in decreased wait times for people who cannot communicate their daily needs, increasing their quality of life tremendously.

Year

Year	Average (in months)	Range (in months)
2020	7	2-18
2019	7	2-24
2018	7	2-27
2017	9	2-32

Average Wait Time (in months)

■ Average (in months)
■ Range (in months)

After 15 years of an in-person service model, the pandemic launched CAYA into an almost 100 percent virtual model. At the peak of COVID, our teams developed charts and shared experiences to offer service to assess clients both formally and informally. Virtual Think Tank is a committee that was struck to look at the ethics and practice of Virtual Service to choose and implement AAC services. CAYA is now working as a Hybrid Model with services offered both virtually and in-person.

Bill and Debbie, husband and wife who are both CAYA clients, have truly experienced this shift in service. Bill began service pre-COVID, was initially assessed under our in-person model and attended our monthly Chat Room in person in Summerland. Debbie became our client during COVID and was evaluated virtually. We now continue to support Bill and Debbie with a hybrid model, both in person and virtually. Bill and Debbie both communicate with iPads with the Touch Chat Word Power app and live in the Okanagan.

Tara Commandeur, M.Sc.(A), RSLP (C)

Tim and Tara from CAYA provide virtual service to B. Watson and D. Watson.

EQUIPMENT LOAN BANK

AAC TECHNOLOGY AND SYSTEMS

» CAYA provides a range of tablets, apps, dedicated speech generating devices systems and non-technical communication systems to assist an individual to communicate. Equipment is provided to CAYA clients on an indefinite long term loan basis.

» Low Tech systems include a variety of simple digital messaging and signalling devices valued under $1,000.

» Medium Tech systems include tablets and more complex digital speech output systems using symbol and picture access displays, valued between $1,000 and $5000.

» High Tech systems include devices with synthetic speech output and a variety of access methods for people with physical disabilities including switch scanning, Morse code, and remote head and eye pointing systems, valued over $5,000.

» Non-Tech communication systems are made of paper, ink and plastic and have no electronic component; they are often complex in their organization using pictures, symbols and printed instructions, and may be used by clients as back up systems in the event of technology failure. Non-Tech systems typically cost between $500 and $1000 to produce (materials and labour).

EQUIPMENT DELIVERED TO CLIENTS

» Communication systems provided by CAYA are almost always a combination of technology components that comprise a complete solution. To capture the composite characteristics and utilization of these systems across clients, client equipment loans were surveyed over two sample years of 2018 and 2019.

» The solutions fall into these main categories:
 – A commercially available tablet with apps for language and accessibility options
 – A dedicated communication device or system with software or procedures for customized language and accessibility options
 – Both options may also accommodate technology to allow access such as styluses, keyguards, protective cases, switches, head movement trackers, eye tracking, etc.

» Of the sample group:
 – 77%, received tablet solutions
 – 23%, received dedicated communication device/system solutions

Nothing is scarier than facing a disease that traps you in your body. I'm 46 years old about to have my third anniversary with ALS. My body is weak when not so long ago I could do more pull ups than kids half my age or grab my wife for a spontaneous dance when that special song comes on. We all have special things that we are being

Todd of Vernon

robbed of. Now my voice is very nasal-y, weak and slow. People have a hard time understanding me. Some do but some not at all. My hands struggle too. I can't hold my cell very well so I've gotten really good at texting with my nose but that is tiring on the neck and eyes. I needed help.

I recently got a tablet from CAYA. I was referred to CAYA by the ALS Clinic at GF Strong. I am so overwhelmed that I can write with ease! I was pumped after the first day. I could write lists of things I needed to do, I could write texts, all with ease. And the best thing I now had a voice! I could talk using the tablet to be heard and understood... Clearly. I just write whatever is on my mind. Whether I need something or just want to engage with the person in the room. I can! With punctuation even lol. Its easy and I have lots of support too. After a few days I was able to really control the tablet as a pc. Do all the things I used to be able to do sitting at my laptop. I'm really excited about this. Whether you just want to be able to speak, text, email or do all the things you used to do on a computer. You need to try this. I wrote this within days of receiving my tablet from CAYA. Thank you Michelle (CAYA SLP)

MOUNTING OF TECHNOLOGY

Secure mounting of the system is essential to ensure the client can successfully access the technology, and that the technology will be protected from drops and damage. Communication systems can be mounted on wheelchairs, table stands, floor stands, bedside tables, and many other places in a client's environment.

AVERAGE COST PER CLIENT OF SGD SOLUTIONS AND MOUNTING

In 2019, the average total cost for an SGD and mounting was $5,600 per client served in BC. From 2018-1019 the average cost of a mounting system was $854.29 per client. Mounting system cost ranged from $108.70 to $2,314.49.

MAINTENANCE AND REPAIR, AND RECYCLING OF TECHNOLOGY

» In daily intensive use, communication technology has an anticipated operating life of 3-4 years.

» Technology that is no longer required by a specific client is returned to CAYA, where it's cleaned, repaired, and refurbished for use by future clients. When equipment is no longer useable, it is responsibly recycled by the Vancouver School Board.

» The CAYA equipment loan bank is continually acquiring, repairing, and recycling equipment. Clients are contacted and loans are tracked to ensure that technology in use has not become obsolete and unusable. Clients are offered replacement equipment when current systems are reaching the end of their operational life, but some become very attached to their communication systems and are not willing to relinquish them until the last opportunity. CAYA staff make every effort to work with clients to assist them to have as seamless a transition as possible.

EyeGaze device on a rolling mount allows for communication access in a variety of locations around the home.

Meet the CAYA Aphasia Group! We have been meeting in person in Kelowna since 2018. COVID threw us a curveball, and we have been meeting on Zoom for Healthcare ever since.

The CAYA aphasia group is where we can practice, talk and be understood. We have good days and bad days, but we have people who understand what it's like! For example, it is hard to talk to friends and neighbours because they don't know what to say or act with someone who struggles with words or uses a device to speak. In the aphasia group, we are at home with people that understand.

We do miss being in person, especially the cookies at break! The technology is sometimes difficult to navigate, but Zoom meetings have brought us some unexpected bonuses. We now meet every two weeks, whereas the in-person group could only be together once a month. As a result, we don't have concerns about travel in bad weather. The best change is that we get to welcome people from other communities.

We have gotten to know people from Kelowna, Penticton, Peachland, Vernon, Kaslo, Nelson and Cranbrook!

We look forward to the group each time, and especially during COVID, the CAYA aphasia group has been life-saving. We can count on these people.

CAYA Aphasia Group

EQUIPMENT LOAN BANK

Striving for the best communication independence, CAYA provides a full range of communication solutions from basic single message devices to sophisticated eye-gaze systems. Here are some examples

LightWriter SL40 (high tech SGD)

BigMack (low tech SGD)

NovaChat (high tech SGD)

Zoom Digital Recorder (accessory)

MegaBee (medium tech device)

SurfacePro with PC Eye Mini (high tech)

Harrison from Richmond

The transition from a low-tech to a mid-tech communication system (TouchChat) went smoothly, with many opportunities to learn and adapt. Harrison's school team connected us with CAYA, and Monica and Samantha graciously helped us navigate through each step of the process. It was inspiring for Harrison's first time exploring new communication systems. He talked about his surroundings at a park during our first time trying mid-tech systems and enjoyed the experience. We eventually chose TouchChat as Harrison's communication system. Monica and Samantha equipped our family and Harrison's support staff with valuable training and strategies so Harrison could have meaningful communication opportunities with TouchChat at home and in the community.

BUILDING COMMUNITY AWARENESS

International Day of Persons with Disabilities Fair, Roundhouse, Vancouver

The incidence of a severe communication disability in the human population is approximately 0.12% (Bloomberg and Johnson, 1990) a small number of people with a high need for support. One of the greatest challenges of a severe communication disability is the isolation from family and community. Due to the inability to interact and communicate, many of these individuals are literally silent and socially invisible. Compounding this challenge is the fact that a severe communication disability usually occurs with sensory, mobility, or cognitive disabilities. Families and caregivers are often overwhelmed and have difficulty finding appropriate supports and resources. CAYA strives to ensure that these individuals, families and caregivers can find and access vital communication supports offered by CAYA. CAYA staff regularly participate in a variety of conferences, disability fairs, and activities, to inform people with complex communication challenges, families, caregivers, and professionals about CAYA's valuable supports. CAYA's community awareness participants include…

- » Accessibility Consultation Committee (Ministry of Social Development & Poverty Reduction)
- » ALS Society of BC
- » ATS – Assistive Technology Service (at GF Strong Rehabilitation Centre)
- » Communication Disabilities Access Canada
- » Community Living BC
- » Disability Alliance BC
- » Disability Transition Fairs hosted by school districts and communities across BC
- » GF Strong Rehabilitation Centre
- » Inclusion BC
- » International Society for Augmentative and Alternative Communication
- » March of Dimes Canada
- » Neil Squire Society
- » Rehabilitation Equipment Expo (sponsored by GF Strong Rehabilitation Centre)
- » Rick Hansen Foundation
- » Sam Sullivan Disability Foundation
- » Special Education Technology-BC
- » Speech & Hearing BC
- » Speech-Language Audiology Canada
- » Stroke Recovery Association of BC
- » Technology for Living

Just over ten years ago, I was diagnosed with PSP, and while that is not totally confirmed, my speech and mobility began to deteriorate. Now for approximately six years, my speech has deteriorated so that today it is 98% gone. I used to struggle to communicate by multiple repeats & hand gestures. My ability to write had also deteriorated. Sharing in conversations & making my needs known became almost impossible. Then I received this iPad and excellent instruction from CAYA. What a sense of relief to communicate again. A very positive impact with family & friends. I can now voice my opinion. Because of my mobility issues, it is difficult to pursue new opportunities. I can continue participating in our Parkinson Support Group, Gideon's and church. Words cannot express how grateful my family & I are to CAYA.
Gary

Gary from Prince George

Paul of Delta

My name is Paul, and I was diagnosed with ALS in October 2016. My progression seemed slow initially, but over time, I began to struggle with accessibility issues while using technology due to muscle loss in my limbs, which has restricted movement.

With ALS, speech also becomes difficult, and CAYA set me up with voice banking. This was great as if I can no longer speak, I can still use technology to project my thoughts in my voice. In addition, I have always been a very socially talkative person, so having this will help me communicate with my family and friends.

I have nothing but praises for all the incredible team at CAYA. They are always so patient and considerate when working with me, teaching me how to operate new systems, and assisting me as I adapt to the daily changes and struggles this disease brings. I also find that they can always respond back to me very soon and get me the help I need with no hesitation.

Tim and Tara (Cool Communicators group)

SERVICE INITIATIVES

As David Beukelman explains in the master textbook, Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs (5th edition, 2020), *"AAC technology is not magic. A piano alone does not make a pianist, nor does a basketball make an athlete. Likewise, AAC technology alone doesn't make one a competent, proficient communicator."* CAYA's service initiatives and support programs make available the scaffolding required to encourage a person who uses AAC strategies to communicate, to the best of their abilities.

CAYA SOCIAL COMMUNICATION GROUPS

Creating a sense of community is very important for people who communicate differently. One way that this is accomplished, is through participation in CAYA sponsored monthly social support groups, which take place in the Mid-Island, South-Island, Lower Mainland and Okanagan Valley. In these groups, people practice interpersonal communication skills by meeting new people, talking about their shared experiences, discussing news, and participating in activities. The longest established group, in Nanaimo, began in 2002, and CAYA was happy to begin supporting it in 2005.

ONLINE AAC/APHASIA GROUPS

With the increased availability of virtual meeting software and spaces, CAYA staff have begun to host online support groups for clients with aphasia who wish to practice with their AAC systems. These groups have been very well received and many clients are asking them to continue indefinitely.

"Having a communication device doesn't make you an effective communicator any more than having a piano makes you a musician."
—**David Beukelman**, 1991

SERVICE INITIATIVES

CAYA SLP providing virtual services

CHAT COURSES

A major challenge for CAYA clients and their families with new communication technology is solidifying skills to effectively use the tools. Group settings are excellent opportunities to teach, model, and build effective communication device use, as well as providing structured practice with new interaction strategies. Results from CAYA Chat courses are people who use communication systems with greater competence, and increased confidence to speak up effectively. Group settings also enable services and training to be delivered to more people in an efficient and cost effective manner. Caregivers accompanying clients to these courses also benefit from structured practice in supporting the technical aspects of the device and witnessing their clients engaged in successful communication. Chat courses have been offered in the Mid-Island, South-Island, the Lower Mainland, and the Okanagan Valley.

CAYA CLIENT PARTICIPATION IN THE WIDER COMMUNITY

» At CAYA we understand that communication opens the doors to a full life, and a full life ensures that communication abilities remain vital. CAYA has provided support for clients to participate in a wide variety of events where they can interact with peers using AAC technology to gain independence. The power of successful peer role models can never be underestimated, particularly for individuals with severe disabilities.

» Some of these events have included:
  – The Biennial ICEwest Conference (ICE = Independence, Community, Empowerment)
    » CAYA is a major supporter of the ICEwest conference, a biennial event that brings together people from across BC who communicate using AAC. Conferences have been held in October 2013, 2015, 2017 and 2019 at the Nikkei Centre in Burnaby and are modeled after a similar conference in Toronto. In

Erin of Enderby

Hi, my name is Erin, and I live in Enderby. I struggle with Autism and Seizure Disorder. I have difficulty regulating my emotions when there are changes to my routine, staff changes, or an activity that I prefer is unavailable. With the onset of COVID 19, many of the activities I enjoyed, like gymnastics and swimming, were unavailable. This was very stressful for me and hard to understand.

Katherine and Michelle from CAYA helped my team and me by introducing me to my PODD system. My PODD gives me a voice! It helps me to communicate to my staff when I feel scared or sad. I can tell people what I want and need. I can tell everyone what I like and don't like. I have my language, and my PODD helps translate the messages I say so that everyone can understand.

With the help of Katherine and Michelle from CAYA and my team at Kindale, I am learning new words and vocabulary. Using my PODD was hard at first, but with the dedication and perseverance from my team, I slowly gained more confidence and have become more familiar with it. My PODD has increased my independent skills and opened my world. I am excited to keep learning and setting new goals for myself. With my PODD, challenging situations become easier to manage because staff can understand what I need and want quickly and help me to feel safe. My voice is important, and I am so grateful to have the opportunity to use it.

Written by Erin's caregivers

SERVICE INITIATIVES

Joy of Nanaimo

Joy has participated in CAYA's Cool Communicator group in Nanaimo since it started in 2005. Cool Communicator participants have been a huge inspiration. CAYA staff have provided Joy and her supporters with a lot of guidance and technology and tech support, moving her forward from a simple yes/no communication by "beeps" to the opportunity to use an "Accent" speech device to share news and play games with friends.

As her access to her device improved, a question arose. Could Joy use two switches instead of only one? Possibly that would enable her to scan more choices and to select her words more accurately? CAYA staff Rheanne and Jan arranged for Joy to have a virtual appointment with GFStrong in Vancouver. Adele (OT), assessed Joy, and CAYA lent Joy switches to try with her hand and adjusted Joy's Accent to use two switches.

Here is "news" Joy shared with her friends at Cool Communications in March 2020: " I had an appointment with a communication specialist called Adele. Jan and Rheanne had set up my speech device to have the option of using two switches. Adele was helping us figure out the best switch. Maybe I will use a different one. For now, I am practising lots, using the bobble switch. It is fun and exciting to learn a new way. And frustrating too. What are you doing that is new, interesting, or frustrating?"

Joy tried several switches and is now using the proximity switch. Her progress continues!

Thanks, Kathy (Joy's mom).

ICE West October 28, 2017

October 2017, simultaneous and collaborative ICE conferences were held across three locations in BC, Alberta, and Ontario. The hallmark of the conference is a Town Hall Meeting, where only individuals who use AAC can moderate and speak. The most recent conference in 2019, featured the theme "Travel: From Commuting to Globetrotting."

– ISAAC, the International Society for AAC, hosts a biennial conference with 1200 - 1500 delegates from around the globe, including up to 200 people who use AAC.

– Participation in International AAC Awareness Month events held every October. CAYA has sponsored a number of these events across BC in order to raise public awareness of AAC and to enable CAYA clients to meet the public with pride, dignity, and independence.

RESOURCE DEVELOPMENT AND REVISIONS

CAYA has developed resources that are available for free on our website. These are very popular downloads and are updated when necessary, to remain current with technology and strategies.

Topics include…

VOICE/MESSAGE/STORY BANKING

When a person first receives a diagnosis of a degenerative condition such as ALS, she or he generally has not yet experienced a major impact to speech. This early time is a unique window for them to "bank" their voice using digital recording technology available on short-term loan from CAYA. Later, when their voice is no longer available to them, clients can continue to communicate with a synthesized or recorded voice that is customized to sound like their own. Individuals with a diagnosis of ALS are a significant portion of CAYA clients (17%). Staff at CAYA have worked closely with John Costello at Boston Children's Hospital to develop a protocol and resource that guides people through the recording process (available at www.cayabc.net/resources/). Current communication devices and software are able to integrate these personalized recordings into voice output that helps the individual retain his/her identity through the disease progression.

APHASIA

» Aphasia is an impairment of language, affecting the production or comprehension of speech, and the ability to read or write, occurring most commonly as a result of a stroke. Individuals with aphasia are a significant proportion of CAYA clients (17%). CAYA staff have developed two important resources to support communication for people with aphasia
  – The "AAC Resource for Individuals with Aphasia" is a comprehensive resource to guide SLPs working with people with aphasia. Created by SLPs at CAYA, it describes potential client skills and challenges, and provides ideas for assessment, therapy and technology provision (available at www.cayabc.org/resources/)
  – "Communication Journey: Aphasia" is a page set co-created by SLPs at CAYA and GF Strong Rehabilitation Centre to address the unique communication needs of people with aphasia. This specific page set is available at no additional charge when purchasing the TouchChat app on iOS tablets and the Nova Chat app on Nova Chat (Android) tablets at www.touchchatapp.com/page-sets)

Jan of Gulf Islands

My name is Jan. In 2012 I was diagnosed with a progressive degenerative neurological disease. I was referred to CAYA in 2013 when my speech became slurred and difficult for people to understand when caregivers couldn't understand what I was trying to say. My handwriting was laborious and very slow. The CAYA team, a Speech-Language Pathologist and an SLP Assistant came to my home on a small Northern Gulf Island.

The team assessed my needs and made a plan with me. They showed me how to use text-to-speech programs on a CAYA iPad. Through email, they helped use the text-to-speech programs more proficiently. As my illness progressed, CAYA has continued to adapt my speech aides with special switches and mounts to safely use the iPad to communicate when I am in my wheelchair. They have worked collaboratively with other health professionals to support my communication.

When my spouse died, I no longer had a voice to make phone calls. CAYA introduced me to the IP relay service, which allows me to make phone calls with the help of an operator.

I moved to a residential facility in 2019. I met a new CAYA team who picked up where the Island team had left. My needs in a facility were quite different than living in my home. CAYA formulated a plan, supporting and educating the health professionals on how to communicate with frontline staff. As a result, many innovations were quickly implemented, and the CAYA team also created a training video for the facility to use as an educational tool with staff.

As my condition changes, CAYA is there to assess my new needs and find new ways to continue communicating.

The ongoing support of CAYA has enabled me to meet new friends, continue to be engaged with advocacy groups, and strengthen relationships with people I love. Most importantly, I have a way to communicate my wishes and decisions, large and small.

COMMUNICATING IN THE ICU

» The onset of a severe communication disability often comes without warning, as a result of injury or disease. Potentially, any one of us can suddenly find ourselves in a grave situation, and unable to speak, e.g. intubated in an intensive care unit. Communication between patient and provider is of utmost importance in all aspects of health services. In a multitude of scientific studies and surveys, communication failure is consistently identified as one of the top 3 sentinel events in patient care. (A sentinel event is defined as any unanticipated event in a healthcare setting resulting in death or serious physical or psychological injury to a patient, not related to the natural course of the patient's illness.)

» CAYA has collaborated with the Assistive Technology Service at the GF Strong Rehabilitation Centre and hospitals in BC as they create Communication Access Carts in their ICUs and train their staff in AAC communication strategies.

» CAYA clients by nature of their complex disabilities may find themselves in this situation multiple times over their lifespan. CAYA teams do not provide service in urgent/acute care settings, but following on the mandate to support adults in BC without functional speech, CAYA is contributing its unique expertise to this initiative by supporting hospitals to create these Communication Access Carts containing effective patient-provider communication supports. These supports include ready-at-hand low-tech communication systems, storage options for hearing aids and glasses, patient-caregiver interaction protocols, and customized AAC solutions.

TRAINING THE PROFESSIONALS OF THE FUTURE

» CAYA collaborates with the UBC School of Audiology and Speech Sciences in the training of new speech-language pathologists through…

    – Development and delivery of the graduate course in AAC science and practice

    – Clinical practicum placements for SLP students

Carly from Nanaimo

"Hi. My name is Carly, and I'm 33 years old. I have been using a program called TouchChat since 2013. It is on my iPad. I take it with me everywhere I go. I use it to help me communicate with people. I can talk, but sometimes people don't understand me, so I can use my iPad to help. When I get tired or have many things to tell someone, I use TouchChat. I would like to thank CAYA for doing this for me."

LOOKING TO THE FUTURE

Challenges And Opportunities

» The past decade has brought dramatic changes in technology and the way we communicate with one another. In the most remote communities of our province, people who once lived in relative isolation are now connected to the entire world through smart phones, tablets, the internet, and a multitude of social media options for communicating including sharing news, photos, messages, and opinions. The challenge for CAYA is to continue to support eligible BC residents to communicate and participate in daily life in this modern context. It is important to bear in mind that while technology has changed dramatically, human beings and the conditions that create a severe communication disability have remained essentially unchanged for millennia. As individuals we continue to need to communicate directly with one another every single day of our lives. The more our independence is compromised by disabilities of all kinds: physical, mental, cognitive, or sensory, the more vital is our access to functional communication with others.

» Since the expansion of CAYA's service mandate in 2010 to include all eligible adults 19 years and older, CAYA services and technology are now vital components of support to thousands of individuals with disabilities across BC. In the delivery of services CAYA staff interact and collaborate with all aspects of BC's human services systems including health, education, and social services.

» The future challenges and opportunities for CAYA are focused on technology and human services and include…

  – Continuing to innovate service delivery systems to increase the capacity of BC's health, education, and social service systems to assist CAYA in supporting independent communication for individuals with severe communication disabilities. Initiatives in this area include:

» The acceptance of virtual service delivery as a result of the pandemic, and CAYA's response to this by creating a hybrid service delivery model, thus ensuring that CAYA clients will receive the most timely, appropriate and evidence-based service possible, no matter where they live in BC

» Increased virtual capacity for training of relevant professionals in BC's health/education/social service systems.

» Expansion of the CAYApartners Program to support community SLPs to provide an enhanced service for their active clients and to participate in cooperative goal-based client-targeted work amongst all service providers for this clientele

  – Creating organizational flexibility, resiliency and succession at CAYA to ensure that knowledge, skills, and expertise continue to be developed and preserved, ensuring that eligible individuals receive the supports they need to create and maintain an adult life of the greatest independence. This challenge includes working with all stakeholders to ensure continuity of resources and services to provide clients with the most reliable and smoothest delivery of vital communication supports.

Hi, my name is John. I go to Cool Communicators with my talker. I love CAYA very, very much. I use my talker to talk to people every day during my day program at my home. I also use my talker when I go out into the community. It helps me communicate with people very easily.

John from Victoria

"If all my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest." (Daniel Webster, 1782 – 1852)

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BRITISH COLUMBIA
CANADA

CAYA is a province-wide service program funded through the Ministry of Social Development and Poverty Reduction.

We support independent communication through the use of technology.