

ASD KIDS COMMUNICATE PROJECT

“CHANGING THE OUTCOMES”

On 17th April 2011 the Lions Club of Lugarno tabled a potential project to the MD201 Convention at Launceston. This project was titled “Preschool Autism Spectrum Disorders Education & Therapy” and was unanimously accepted by the Convention. The project called on all clubs to make contact with their respective local members and highlight the plight of families who have preschool children suffering from an Autism Spectrum Disorder (or ASD). At subsequent MD201 Conventions in Perth (2012) and Tamworth (2014) Lugarno Lions sought extensions to the project by way of a second and third phase which asked clubs throughout Australia to seek out and assist any ASD groups in their local areas. This, again, was overwhelmingly received by the Convention with the project extended to 30th June 2017.

Encouraged by the support of Lions across Australia, Lugarno Lions sought opportunities to assist local groups with funding and/or equipment. One such group was the Autism Community Network (ACN) which was setup by the father of a child with an ASD and provided information and support to local families. The Lions soon discovered that this group was struggling to survive despite being recognised within the wider ASD network as playing a vital role in promoting ASD awareness. This was evidenced by the organisation being constantly canvassed to setup splinter groups in many areas of Sydney.

During a brainstorming session it was suggested that one ‘missing link’ was a method of communicating with children who had an ASD. There has been much research into this field of communication and it was found that a method of using ASD-specific software installed on an iPad seemed to be well favoured in many countries throughout the world.

As a result Lugarno Lions launched the idea for the ASD Kids Communicate Project.

ASD Kids Communicate Project

The project seeks to provide a ‘device’ (technically known as an Assistive and Augmentative Communication device) to non-verbal children with an ASD primarily in the Sydney region. The ‘device’ comprises both the iPad and a software package named Proloquo2Go (P2G). This technology can provide a bridge from a life where thoughts, feelings and needs are held in silence, to a life where interaction, expression and learning are possible.

Experts say that Autism Spectrum Disorders affect 1 in 110 children in Australia. The inability to communicate effectively, which is one of the major impairments seen in this group, often presents a barrier to learning and literacy. It also creates significant obstacles to social and emotional development and independence.

Used together the iPad and P2G are very important resources for individuals with Autism and their families. Since the release and increase in the use of tablet technology, many individuals living with Autism and in particular those who are non-verbal have discovered

new opportunities and ways to communicate. The iPad is an invaluable piece of equipment for individuals and families as it assists through using auditory, visual and tactile mediums. The iPad uses images, sounds and words, and allows access too many innovative Autism specialised applications which have been shown to assist an individual with Autism to develop their communication skills, social communication, language ability and literacy skills.

Outcomes to Date

This project has successfully provided the 'device' to 120 non-verbal children with ASD in the Sydney region. The equipment allocation was coordinated by members of the Lions Club of Lugarno and the Autism Community Network (ACN) management team.

How did we do it?

Over a period of two years 16 Lions Clubs and one Lioness Club from District 201N5 contributed \$37500 towards "Kids Communicate Project" (phase 1,2 and 3) plus \$41,400.00 from three Foundations (viz. the ALF, the LCIF and the St. George Foundation), total raised \$79,000.00

PHASE3 SPECIAL THANKS TO LCIF SEED GRANT GA14133/201-N5 US\$10,000

AUTISM KIDS COMMUNICATE PROJECT- A LOUD VOICE

This initial phase (phase 1) enabled forty seven families of non-verbal children with Autism Spectrum Disorders receive an iPad with P2G together with a training program. Of the recipients, twenty four families participated in the research component and data was recorded over six months. Final responses were collected from 16 recipient families across two age groups; 0-7 years and 7 years and above.

Research Questions

The research component aimed to investigate the following questions.

1. What is the efficacy of P2G in facilitating communication skills in non-verbal children with autism spectrum disorders?
2. Does P2G impact a child's motivation to communicate?
3. What is the efficacy of the parent training program in developing technical skills in parents/ carers and their children with ASD?

Data Collection Techniques

As a qualitative case study design, data collection techniques included parent surveys using a 5 point Likert scale to assess both the verbal and communication abilities of the child adapted from the Hanen stages of communication (2011, The Hanen Centre). This was distributed to participants at 3 intervals; initial, mid-data point and end point. Similarly the

child's level of motivation to initiate communication was also tracked using a 5 point Likert scale. Semi structured parent interviews were used together with anecdotal parent observations and videos of which were coded for emerging themes.

Procedure

1. Parents/Carers completed a questionnaire at three interval points using a 5 point likert scale to measure child's communication abilities, verbal abilities, motivation levels and technical skills.
2. Parents/ Carers were invited to attend an initial iPad and P2G training workshop and two subsequent workshops to further develop skills in P2G.
3. A Facebook page was established to provide ongoing support and information for parents/ carers.
4. Information was distributed by the ACN via an online forum on the ACN website.
5. Semi structured interviews were conducted at each of the training workshops.
6. Parents were requested to keep a journal throughout the program.
7. Optional video with parental permission was taken of the child's progress.

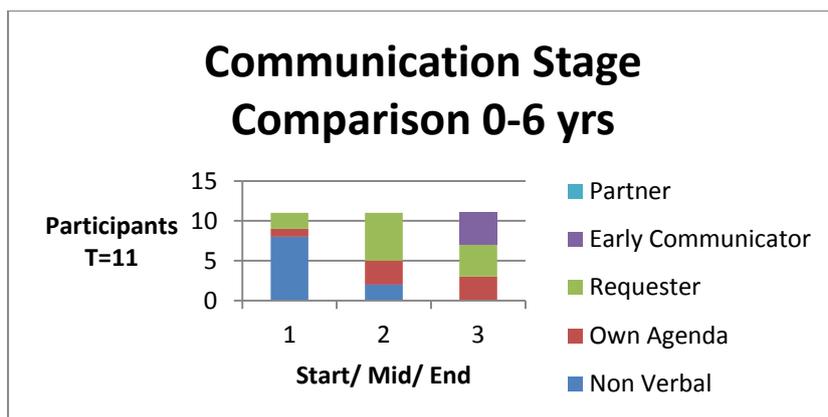
Results

Results indicated 15 participants demonstrated a positive incremental change in expressive communication skills, verbal capabilities and technical skills. Parents reported increased motivation, participation and initiation of communication in their child when using P2G. Reported positive changes in overall family dynamics included reduced child frustration and increased parent satisfaction in identifying and responding to their child's needs. In regards to the training program, parents anecdotally reported satisfaction (and gratitude) at the level of support provided with the subsequent workshop sessions offered and greater confidence when integrating P2G in conjunction with a Speech Therapist. Barriers to parent confidence in using new technology included 'lack of time in the week' and 'distance to travel to the workshops offered'.

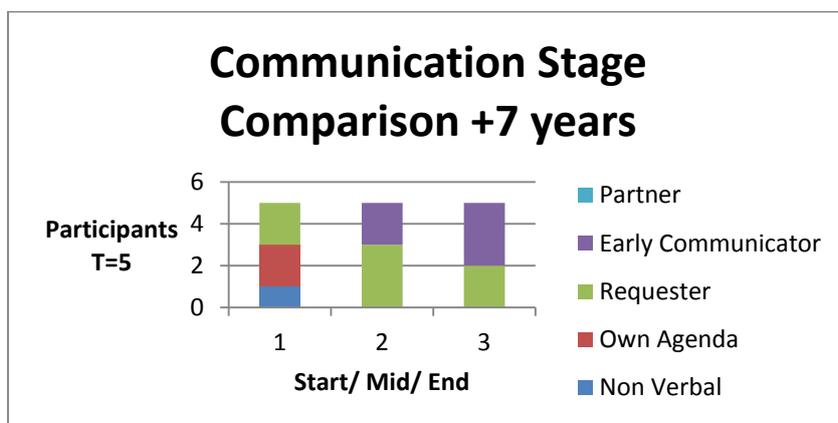
Discussion

There were three aims of the study. In regards to the first aim surrounding the efficacy of P2G in facilitating communication skills in non-verbal children with ASD results concluded that 94% of participants demonstrated a positive incremental change of between 1-3 likert points . Participants recorded their child's communication stage using 5 descriptors: nonverbal, own agenda, requester, early communicator and partner stage. The results are shown below.

Graph 1.



Graph 2.



At the initial stage, 56% of all participants were at the Non Verbal stage of communication, 18% at the Own Agenda stage and 25% at the Requester stage. This compares to the end of the study which show 0% at the Non Communicator Stage, 18% at Own Agenda, 37% at the Requester whilst 43 % had progressed to the Early Communicator stage of communication. This shows a steady positive progression of children developing communication skills using the iPad and P2G.

The older children (7+ age group) demonstrated a faster rate of change incrementing two stages, whilst the 0-7 age group improved at a steady rate. It is hypothesized that cognitive ability of the older children together with skills in technology may have contributed to the faster rate of change however further research is required.

Anecdotal comments from parents reinforce these findings.

'Currently my son does not speak and he only communicates with gestures. He struggles when he wants to let us know what he needs. At first it (iPad) was hard to use for my son but then we put actual pictures on it and he started looking at it. He now uses P2G for his needs than earlier, It is easier for us too' - Sadeev 3 years

'She has started to associate requesting by using the pictures on the iPad and selecting the appropriate button.' -Ayushi 4 years

'As well as requests he will answer questions using P2G e.g. how old are you- he will answer '7'.' -Robbie 7 years

Results also indicate a positive incremental change in verbal expression with 69% of participants demonstrating a 1-2 point change. At the beginning, 75% children expressed themselves through sounds and gestures compared to 43% at the projects end. . Less than 1% children were able to express single words and phrases initially compared to 43% at the end, with 18% shifting beyond this to commence sentence construction (Graph 3 & 4).

Parent anecdotal reports highlight participant progress.

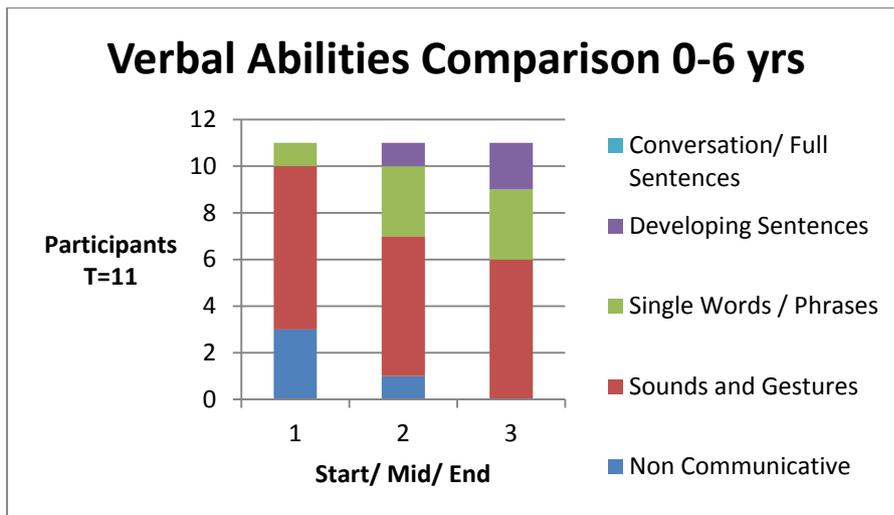
"His articulation was poor but now he tries to copy the voice on the machine and his words are clearer," -Masato 6 years

"His words are clearer. Harry is starting to copy words on the iPad and understands simple phrases" - Harry 6 years

"When he wants something he tries to type the words to be meaningful and show that he is serious." -Nicholas 15 years

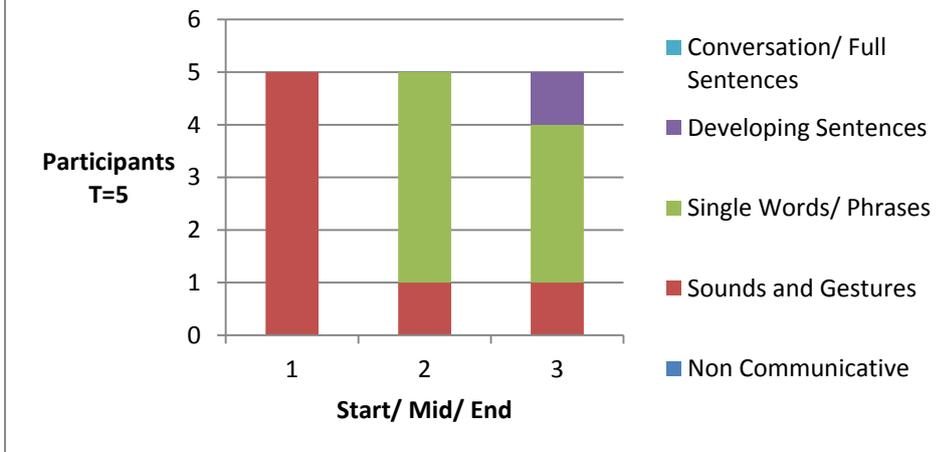
'Previously, she would communicate using 'I want' with a lot of prompting and showing the object before. Now she spontaneously makes requests using P2G especially for food." - Saatchi 7 years

Graph 3.



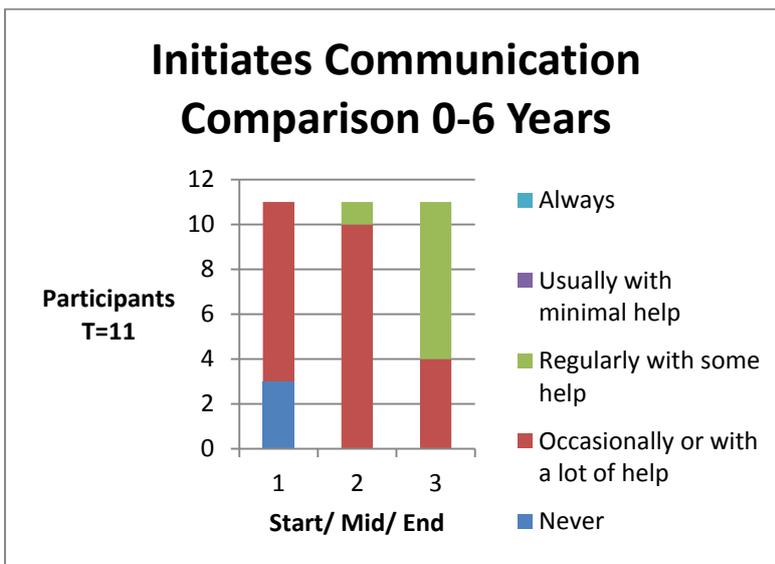
Graph 4

Verbal Abilities Comparison +7 Years



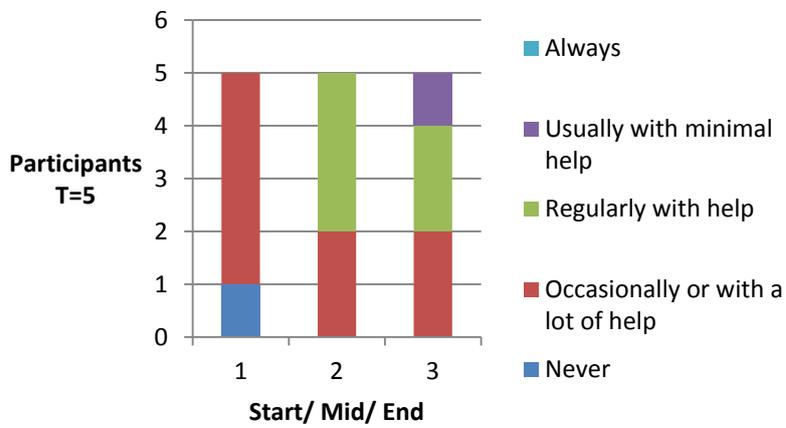
The second aim of the study surrounded the impact of P2G on a child's motivation to communicate. In regards to imitating communication, results indicate 43% of participants demonstrated a 1 point positive incremental change, and 25% showed a two point positive incremental change. Prior to this offer 25% of participants never initiated communication and 75% only did so occasionally or with a lot of help (Graph 5-8). At the end of this study, 56% participants were initiating communication regularly with some assistance. In regards to individual willingness to participate in communication attempts using P2G, 56% showed a positive incremental change ranging from 1-2 scale points (Graph 5 & 6). The iPad and P2G offers a visual and portable form of AAC together with speech generated voice output that has captured the visual learning style characteristic of children with ASD.

Graph 5.



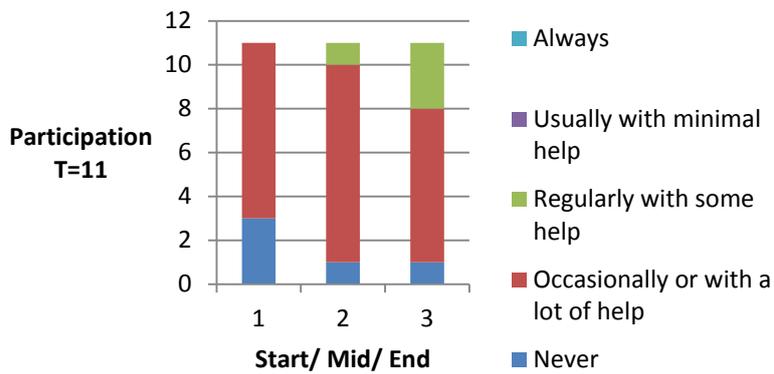
Graph 6.

Initiates Communication Comparison +7 Years

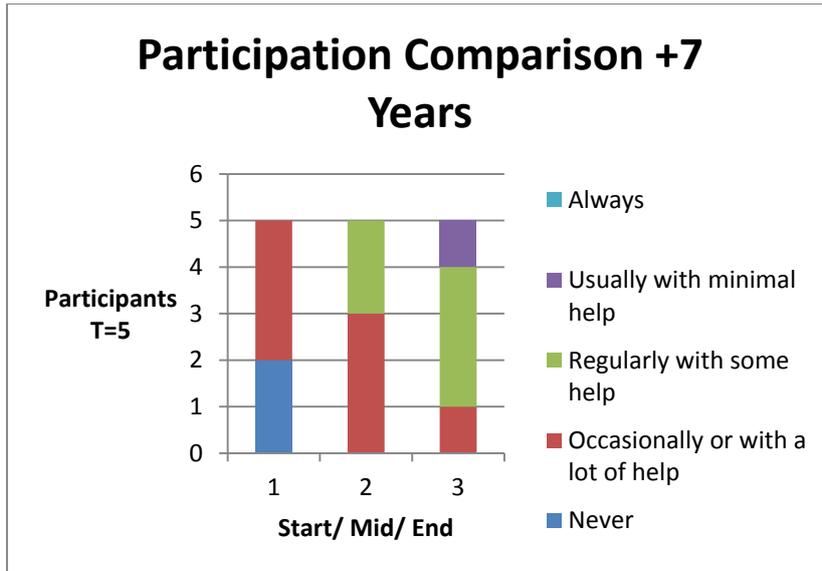


Graph 7.

Participation Comparison 0-6 Years

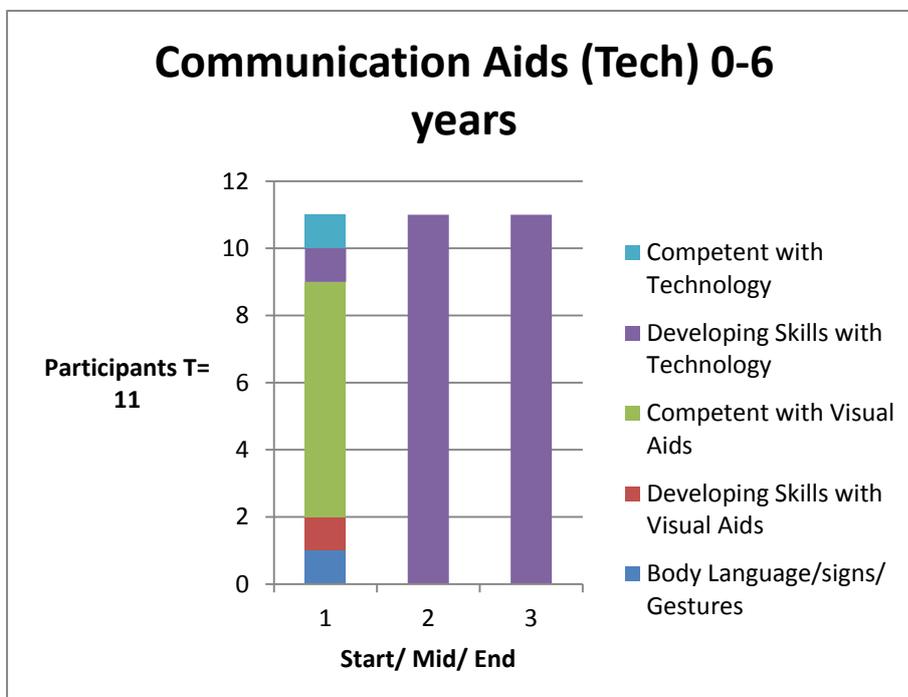


Graph 8.

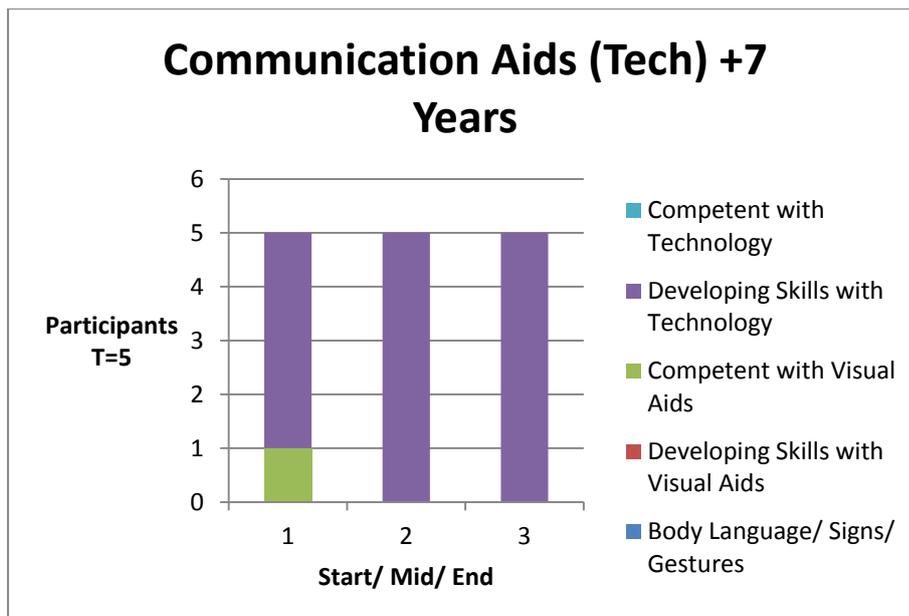


The third aim was to assess the efficacy of the parent training program in developing technical skills in nonverbal children with ASD. Results show that 69% participants demonstrated an improvement in technical skills, a positive likert scale increment of between 1-3 points. At the initial stage 50% of children were competent in visual communication aids however only 31% had developed skills in using technology. Data collected shows a significant positive change with all participants now currently using technology. The 0-7 age group showed the highest incremental changes whilst the participants in the 7+ age group showed less change as they already had developed initial skills in technology use (Graph 9-10)

Graph 9.



Graph 10.



Emerging themes based on parent interviews include other reported benefits and minor challenges which include:

1. Facilitates an understanding of routines and environment

'Abigail has increased her understanding of environment and routines.' - Abigail 4 years

'The iPad is easy and convenient. We can take pictures and use them immediately to explain to Gregory what is going to happen.' - Gregory 3 years

2. Reinforces concepts at school

"Aaron follows P2G and learns new words and reviews concepts he learns in school e.g. colours and numbers using the visual signs in P2G and we prepare simple social stories." - Aaron 6 years

"It provides flexibility and diversity of teaching resources I can create." - Eric 5 years

3. Allows the expression of choice

"Fynn can tell me what he would like. He is also learning 'no' e.g. when he requests a biscuit and I suggest banana." - Fynn 5 years

"She independently takes the Ipad and uses the App with confidence to ask for things. But when I press 'no' she presses the 'yes' key." - Saachi 7 years

4. Reduces concern behaviours

"..some Apps make him calm when he uses them." - Sadeev 4 years-

"It has helped him tremendously to focus on detail and to calm and distract him." - Nicholas 15 years

5. Utilises the child's strength in visual learning

"Provides an alternative way to communicate. Similar to PECS however more effective and easy to use as it is very visual and uses multimedia." - Ayushi 4 years

"Eric is more willing to comply with what we are teaching him because he is very visual." - Eric 5 years

6. Portable

"Rather than dragging me around he will press the buttons on P2G. It has also substituted PECS ." -Robbie 7 years

"It is easy to transport, carry in bag, text to speech is better than just visuals and no voice." -Aidan 5 years

7. Voice output

"The benefit is he can easily request his needs and (hear) the voice so he learns what it says." - Harry 5 years

8. Difficulties encountered

"Yes, Fynn is happy to use it but not at first. A few teething problems but we have set up multiple folders to not show desirable items like biscuits (but he is learning how to switch folders - cheeky bugger!) " - Finn 5 years

Conclusion

The initial results are promising though further longitudinal research containing empirical data is recommended. Emerging themes support recent reports highlighting ease of portability and program individualisation, and increased effectiveness when families partner with a therapist or teacher. Barriers include initial difficulties with, child motivation, initial P2G navigation and access, and time required by parents for effective implementation. This project adds to the growing research surrounding the impacts of iPad technology and P2G in facilitating communication for nonverbal children with ASD.

Quotes from parents

"Thank you so much. We feel very fortunate and humbled by this very generous donation. The impact that having this device for our Benny will make such a difference to his (and our) day to day life. We really can't say a big enough thank you for this." Julie & Damien

"This is fantastic news; we have been researching the Proloquo2Go program for our non-verbal daughter and are very excited to be offered this opportunity to support her. My

husband and I really appreciate this and are looking forward to attending and learning as much as possible on this application.” Toula and Ismael

“Thank you so very much for this wonderful news. I would like to confirm that I will attend the presentation and training. Thank you once again.” Sunny

“Thank you Lions, many families that received the equipment have had positive results, certainly worthwhile and life changing results for many” Claudia

Many thanks to the wonderful people at the Autism Community Network, Warren Thompson, Steve Drakoulis, Claudia Walters and Jane Tzakos.

If any Clubs wish to know more about the Kids Communicate project or how they could assist their local ASD Community Networks, please contact Elvio Munzone at elviomunzone@bigpond.com or Claudia Walters at claudia@autismcommunity.org.au

PDG Elvio Munzone
Project coordinator
Lions Club of Lugarno