



Communication First Report 2019

Introduction

To set the scene for the reader of this report it would be helpful to imagine what it is like to live in a world without communication. The following excerpts are from two individuals who have written books describing their 'nonverbal worlds' before, by chance, opportunity arose for them to learn to communicate through the written word.

(Bryan B, *Eye Can See*, 2018) "Can you imagine not being able to speak or communicate? The silence, the loneliness, the pain. Inside you disappear to magical places, but most of the time remain imprisoned within the the isolation. Waiting, longing, hoping. Until someone realises your potential and discovers your key, so your unlocking can begin. Now you are free, flying like a wild bird in the open sky. A voice for the voiceless."

"Listening, looking and waiting to be heard, I spent the first part of my childhood unable to tell my story. In silence I lived behind labels. Labels attached to my dysfunctional body. Severe cerebral palsy, Profound Multiple Learning Difficulties (PMLD), nonverbal, these labels defined me. Expectations founded on my outward appearance. But more than the rest, the silence shrouding my personality, silence suffocated my identity - my very being sealed shut; with my loves passions, dislikes and sharp mind deadened in the soundless void."

(Pistorius, M, 2011) "Not having a voice to say I'd had enough food or the bath water was too hot or to tell someone I love them was the thing that

made me feel most inhuman. Words and speech separate us from the animal kingdom, after all. They give us free will and agency as we use them to express our desires and refuse or accept what others want us to do. Without a voice, I couldn't control even the simplest things and that's why frustration so regularly started her violent lament inside me."

Almost everyone is capable of communicating to some degree given the appropriate tools and environment. This project aimed to explore communication possibilities using available software, so the voice of the beneficiaries could be heard and their communication enriched.

Summary of Activity

During the first year we worked with eighteen beneficiaries with various communication difficulties, followed by a further seventeen beneficiaries in year two, totalling thirty five over the longevity of the project. The beneficiaries had varied communication difficulties including individuals who were nonverbal, elected to be nonverbal, had limited communication, degenerative conditions causing increased communication difficulties over time, Autistic Spectrum Disorder (ASD), PMLD, in addition to some individual difficulties, which exacerbated the individual's ability to communicate effectively.

Volunteer Trainers

The planned collaborative work between trainers with a learning disability and beneficiaries raised concerns from the onset, as though some initial work was carried out during the research stage for the project, issues arose when more in depth training commenced. Though it was evident they were learning how to use the software well and had adequate IT skills, it soon became apparent that the partaking trainers were unable to separate their opinions and experiences when using the communication software during role play training sessions. To ensure validity and eliminate bias whilst handing ownership to the beneficiaries it was imperative volunteer trainers remained neutral, so the information gathered was solely that of the beneficiary and void of any outside influence. It is fundamental to all the work Monmouth People First undertakes that it is wholly person

centred. As the most important person centred thinking skill is to be able to keep separate what is important 'to someone', from what is important 'for someone' it was vital to ensure we were clearly hearing what was important to our beneficiaries without any outside influence. To be completely person centred our volunteers were required to separate 'important to' from important for' in addition to remaining impartial. It was evident this was not happening and became clear it would take a considerable amount of work and time to progress. In addition for many of the beneficiaries decisions are often made for them, rather than with them so the importance of giving them time and space to communicate their thoughts was paramount. Often there is a long wait before beneficiaries respond, and again we found the volunteer trainers found it difficult to wait for a response, often rushing the process by repeating questions and/or suggesting responses.

We continued working with interested trainers to try and overcome these difficulties during the first six months of the project, but it became apparent to ensure best practice a considerable amount of time would need to be allocated to potentially overcome the issues discussed, which was outside the scope of this project. In addition, and of equal concern - commitment was also an issue, which had to be taken into consideration as often training sessions were cancelled at short notice by the volunteer trainers. As the project progressed only one trainer from the initial four remained, who wanted to both commit and was able to remain impartial and work in a person centred manner. This trainer will continue to support one of the beneficiaries, and a good working relationship has been established. With regard to the other three trainers; one was taken ill and the other two found it difficult to give their time on a regular basis due to family commitments. Though both commitment and working impartially were issues the former was given as the reason we couldn't continue as we wanted to ensure that if the trainers decided to utilise their skills in the future they would have gained confidence from their involvement with the project.

During year one we were approached by a member of a local network in Monmouthshire who wanted to be involved in volunteering opportunities

within the project. We completed initial training with one of their volunteers but again commitment was a concern. Time was allocated for training but we were disappointed that due to other commitments the volunteer did not stay long. The time given to training, which was initially predicted to be an integral part of the project has been disappointing as it has not benefitted the project, or led to some of the outcomes hoped for. However it has served to highlight the issues faced in finding suitable volunteers to work in this area. This is not to detract from the fantastic work volunteers do within our communities, but will be a lesson learned as to the difficulties of investing in volunteers and meeting the outcomes of this project. As mentioned to have continued with volunteer training would have detracted from the predominant aim of the project to enhance communication for adults with communication difficulties. It was decided that further work to train volunteers would cease at this point, apart from the one trainer mentioned above.

We were pleased with the support given by social services in the settings where we worked with beneficiaries during day service time. This provided a quiet environment conducive to working on a one to one basis, in addition to having available wifi, which is often not the case in the supported living houses where many of the beneficiaries live.

During year one we were asked to deliver training to support staff and put relevant software on some of the tablets owned by Monmouthshire day service centres. We planned for trainers with a Learning Disability to deliver training to staff rather than to beneficiaries due to the issues previously highlighted. It was hoped this would set a precedent for best practice when working with individuals with communication difficulties, so communication is maximised, information shared and partaking individuals have their voices heard. However, though a minimal amount of information regarding the software to date was shared, it appears there is a long way to go before support staff readily want to utilise available software tools and move away from the limited communication methods that appear to be generic in most settings. Within the support networks of many of our beneficiaries support was good at delivering what is important for someone – for example medication and personal care, and this information was usually passed from carer to carer. Unfortunately, often due to time

constraints what is often missing in communication between support, is what matters to the beneficiaries and we'd hoped by enhancing and highlighting communication resources this would improve. Often it appears staff rely on believing, as they have known the individual for a long time they know what that persons likes/dislikes are, and that remains static - there appears to be a consensus that the individual will not change their mind over time or develop new interests. For example whilst doing a Talking Mat with a beneficiary who had a long time support worker with them they were shocked when the beneficiary stated they didn't like a particular activity, saying 'but you've always it'. Similarly to the issues mentioned with volunteer trainers, when someone offers their thoughts and opinions it is disempowering for the individual when facilitating ways for them to have their voice, if it is then immediately questioned, and doubt is cast on what they are communicating. As Martin Pistorius so eloquently describes (Pistorius, M, 2011) " I'm usually trying to listen to the radio when someone comes to disturb me with a smile. I know they mean well, of course, but I'm the eldest here and the activities are aimed at much younger children. No one seems to consider that even people who are thought to be intellectually impaired can change as they grow older."

The group we mentioned in the year one report who wanted to get together to play games and communicate using some of the listed software (please refer to the Software section) was a concern. It was decided to attempt firmly establishing the group was not a productive way forward as we didn't feel confident it would continue after the end of the project. If it wasn't going to be sustainable it was unfair for the beneficiaries to become accustomed to holding a weekly group.

It had been thought prior to commencing the project access to suitable tablets might be difficult and it was predicted fundraising for suitable equipment would be necessary. However it appears most Day Services have suitable resources but they are often not being used. Often, for example, an iPad has been purchased and set up by a member of staff who has subsequently left and the Apple ID etc has been lost, thus updating suitable apps becomes an issue that it seems is all too often not addressed.

Software

Within the project we started with a small number of apps based on initial research, which expanded throughout the project to meet individual needs, improve motor skills, and make sessions fun, whilst ensuring the beneficiaries experienced feelings of success at all times.

Apps

<https://www.talkingmats.com> Web results Talking Mats | Improving communication, improving lives

[Social Story Creator Educators](#)

[Bob Books Reading Magic #1.](#)

[Phonics and Reading With McGuffey | Lite](#)

[Reading Raven](#)

[Spelling Games For Kids](#)

[Phonics Genius](#)

[Phonics Match](#)

[Articulation Station](#)

[Read with Phonics Games](#)

[Matching family game: Cars](#)

[Cake Pop Maker](#)

[My Pizza Shop - Pizza Maker](#)

[Memory • Classic](#)

[Happy Colour by Numbers](#)

[Sensory Light Box](#)

[Sensory Sound Box](#)

[AntiStress Adult Coloring Book](#)

[The Piano.](#)

[Drum Kit](#)

[Djembe!](#)

[Joy Doodle: Movie Color & Draw](#)

[Pond Koi](#)

[4 in a Row Classic Connect](#)

[Snakes & Ladders King](#)

<https://apps.apple.com/ec/app/musical-paint-pro/id643923851?l=en>

[Super Puzzle Kids Jigsaw Game](#)

<https://appadvice.com › app › heat-...Web resultsHeat Pad - Relaxing Heat Sensitive Surface! by Padadaz - AppAdvice>

Sessions were always punctuated with some of the listed apps to avoid too much intense concentration, improve motor skills, and build confidence, in addition to following individual interests, by providing user friendly resources. For example one beneficiary had always wanted to play a musical instrument but their mobility difficulties made it impossible to do so in any meaningful way. However digital alternatives made it possible for them to have a go on a keyboard and drums, which helped their feelings of well being and they were in total control of their musical experience. Another beneficiary who elected to be nonverbal enjoyed and gained confidence by recording their voice when repeating given words. In time this led them to verbalise on occasions and make simple choices/requests using their own voice to communicate.

Much of the work with beneficiaries included using Talking Mats to find out a bit more about the individual and their likes and dislikes, things that were important to them, aspirations etc. Many sub-mats were produced to help look in more depth at, for example the particular sports beneficiaries liked, or finding information about the individual before putting it into a social story app. Beneficiaries found these activities empowering and it was good to see them taking ownership of their stories. By using Grid Player and Talking Mats in conjunction beneficiaries were fully engaged in directing the course of their stories. For example one beneficiary wanted information in their story to include all the sports activities they liked and were able to be involved with, in contrast to others where their support was taking part on their behalf. They went on to describe how it didn't matter if it took a long time to, for example wash up their coffee cup, they wanted to be actively taking part rather than always being the observer. We were able to use a 'feelings' board on Grid Player to facilitate a way for them to say how they felt when people did things for them without asking if they'd like to be involved, which in this case evoked feelings of anxiety and sadness. These social stories were used to produce a folder that could travel with the beneficiary to share with whoever they wanted to, in addition to improving understanding for those working with the beneficiary of what was important to them. It was disappointing that within a short period of time some of the social story folders were lost. We hope for those whose folders still travel with them that their benefits can be utilised and information shared with significant others. It would be empowering for the individual to be able to share their stories if they chose to in their reviews, which would also benefit anyone else attending by giving them a 'flavour' of the individual if they didn't already know them.

It wasn't possible to use some of the software with all of the beneficiaries, for example to use Talking Mats effectively participants require to understand symbols, and for this reason Talking Mats isn't in most instances an effective tool for people with profound cognitive difficulties. Talking Mats uses a circles model as a useful way of thinking about the cognitive demands placed on someone during interactions, and when working with beneficiaries it was not always an appropriate

communication tool. However different methods were often tried and adapted and ways of ensuring the beneficiary always experienced feelings of success were imbedded into sessions.

For those beneficiaries where cognitive ability meant Talking Mats and Grid Player were not an option, many of the apps listed above were helpful for the individual's well being. For example visible changes in facial expressions were noted when using the sensory apps. Inclusive Technology (www.inclusive.co.uk) mentions "While only a limited amount of software is written specially for the PMLD group much early learning and switch operated material can be used. It is also worth looking at other computer software that can provide the bright and attractive images and sounds that will attract and hold attention." In addition sensory apps can often improve feelings of well being.

As some beneficiaries started to experience enriched forms of communication it became evident they wanted their voices to be heard and be involved and consulted on matters that impact on their everyday lives. At present due to lack of one to one support and transport issues, involving these individuals with available opportunities is difficult, and some have expressed their desire to have these barriers to inclusion addressed. However we managed to organise a few outings, which the beneficiaries involved had expressed a wish to do. On these occasions a Talking Mat(sub mat) was devised to find out what questions the beneficiary wanted to ask. Once the information was ascertained it was voice recorded for them on their social story app, which they could activate independently and thus feel both engaged and involved in asking their questions, and in turn encouraged the person answering to address the individual rather than their support, which sadly often happens. For example, a beneficiary was interested in visiting the local fire station to ask some questions. Another beneficiary was interested in attending an event where an opportunity to ask a member of the royal family a particular question arose, again we used Talking Mats to ensure we had the right question recorded and they were able to ask if they were 'feeling happy today'. This process could easily be adapted and used for individuals to prepare for reviews, be involved in consultations or any other situation where the individual wants to have their say.

It is important to remember for many individuals being given real choices is a new experience and one that is hard to take ownership of if a life time to date has included choices always being made on their behalf by others. As Martin Pistorius states (Pistorious, M, 2011) “ I’ve never told anyone what I want before. Would I be able to make choices if I was given them? Would I be able to tell someone that I want to leave my tea to cool instead of drinking it in hurried gulps when they left a straw in my mouth because I know it will be the only opportunity I’ll have to drink it for several hours? I know most people make thousands of decisions every day about what to eat and where, where to go and who to see but I’m not sure I’ll be able to make even one. It’s like asking a child who is growing up in the desert to throw themselves into the sea”.

Partners to share findings with

We will be sharing this report with relevant organisations and individuals to help raise awareness of our findings and hopefully to improve both inclusion and communication. Throughout the project we have met with some organisations and will ask them in turn to share the report with others.

We have met with All Wales People First to feedback information from beneficiaries. This included the thoughts of a small number of beneficiaries who had expressed an interest in being involved in opportunities to have their voices heard. A Talking Mat (sub-mat) was produced to look at how these beneficiaries felt about having their voices heard at relevant conferences meetings etc and what the barriers for this to happen were. The findings showed they would all like to be involved in a meaningful way but in order for this to happen many barriers have to be overcome. These include access and travel issues, one to one support, times of meetings, information given out prior to meetings, and facilities for those with communication difficulties to put their points across, in addition to having

time to prepare. From Monmouth People First's experience the voices of adults with a learning disability come from those individuals who are the most independent of one to one support, are able to vocalise their thoughts and are mobile. I once heard the People First movement described as being for 'the walkers and talkers'. On this premise there is a need for individuals with more severe communication and mobility issues to be provided with an inclusive platform to have their say and an acknowledgement that the voices being heard are not representative of all adults with a learning disability.

We have recently shared information about our findings with Digital Communities Wales and it is hoped they will be offering training to the staff of relevant organisations where we have been working with beneficiaries. We have shared information about the software we have used and suggested ways of enriching communication. We believe for real progress to be made effective training for staff is imperative if a change in practice to use technology whenever possible to enrich communication is to happen.

We have talked to the University of Wales about a working party to include beneficiaries doing access audits on one of their campuses, and are hopeful this will progress and create opportunities for better integration and inclusion. We have given a presentation to Learning Disability student nurses on Talking Mats and Grid Player, which is hoped they will use in their everyday practice.

We are holding a Workshop at the Learning Disability Wales conference in November 2019 to demonstrate Talking Mats and Grid Player and share our findings.

We have discussed our findings with Adult Learning Wales who have agreed to provide two digital literacy classes, initially in two venues in Monmouthshire focused on providing learning for this cohort, which will enhance learning and communication.

What was achieved? Successes and lessons learned.

Monmouth People First strived to be a Self Advocacy Group where the voices of all its members were being heard effectively, and we recognised the difficulties in ensuring this happened in a meaningful way. These included barriers with communication for individuals with a range of communication difficulties. Also transport issues for individuals who require one to one support and can not access public transport, in addition to the accessibility of venues. The issues faced by individuals with mobility and communication difficulties often have no parity to those adults with a learning disability who can independently access all that is available to them. However self advocacy provision appears to be available to those that are able to readily access it and the plethora of issues faced by those with complex needs are not being voiced at present. As they are all viewed as one cohort when consultations etc are taking place a wealth of information is not being gathered, simply because of the barriers outlined.

It became evident when working with beneficiaries that those with literacy skills were advantaged in the range of communication options available to them. Further research found that many of the beneficiaries enjoyed literacy at school and held varying degrees of literacy skills, though had never been offered any further education to develop these skills to a point where they became functional within their everyday lives. Support staff often assumed there to be no level of literacy with the individuals they were working with and the individuals had no way of communicating their desire to further their skills. This cohort are being left behind due to lack of literacy opportunities, and the expectancy that everyone can access digital information further exacerbates their exclusion on a daily basis.

Quotes from beneficiaries

“If I could read more it would make my life bigger in everyday life.”

“When I go shopping at the moment someone helps me with money I would like to do this myself.”

“ I learnt about money and reading at school. When I left nobody asked me if I wanted to carry on learning. If I had been asked I would have said I want to carry on learning.”

“ I have done some education since I left school but I have never been asked exactly what I want to do.”

I would like to do more literacy and more money skills. I would like to work on an iPad to help when I am in day service.”

“Sometimes I get bored when I haven't anything to do and I would like to play games. I like learning to read and about money and to do colouring on an iPad”

“ I liked reading at school but stopped when I left and have never been asked if I wanted to carry on learning. It would have been useful. I would like to learn on an iPad and continue what I'm doing now.”

Jonathan Bryan stated (Bryan, J, 2018) “During the nine years of being effectively locked in by my severe cerebral palsy, words and phrases had been banked while my mother read to me. Unable to develop the physical skills of my peers, maybe my mind had more room for academic learning. Whilst Jonathan Bryan's mother observed (Bryan, J, 2018) “With limited resources and constrained by the assessment tool, they never saw Jonathan's best. Lack of resources and school funding play their part in Jonathan's story but I believe the biggest barrier is a lack of expectation. Until the system hopes and expects that all children may be able to academically achieve, they won't be able to”. Talking of his school experience Jonathan Bryan reflects “Special school was only a short drive away, but so distant from the rest of my world that it might as well have been a foreign country. It even had a foreign language. Imagine the voice used to talk to a baby: high pitched excitable, slightly louder than usual. Mix that with how you talk to a foreigner with little understanding of the language: slow, loud and clear with short sentences and no complicated words. You are now close to talking 'Special'. In the classroom our wasted school hours days weeks and years hang heavy, suffocating expectation

with mindless activity. While I sat through 'reading'(which meant being subjected to Farmer duck, the same preschool storybook we had last week, art (having my hand painted and stamped onto a piece of paper) and 'golden time' (lying in a semi darkened room watching lights on the ceiling while listening to yet more nursery rhymes."

Indeed time and time again we witness people talking to adults with a communication difficulty as if they are small children.

When researching for this project the lack of relevant research was concerning surrounding adults with a Learning Disability and communication difficulties, though the thoughts and experiences from both Jonathan Bryan and Martin Pistorius, who became 'unlocked' through the written word have been invaluable in further understanding the issues faced by some beneficiaries. Throughout the project, as our learning progressed and understanding increased as to the barriers to communication and research/info has been sought, again there is little to draw from surrounding the cohort we work with. However it has been invaluable to have the opportunity to explore these barriers and look for solutions. One point of great importance is to appreciate how much the little things make a difference to feeling included and valued. For example one beneficiary described, using a variety of resources, how important it was for them to be able to do as much as possible by themselves, just being able to help, for example, load the washing machine gave them feelings of well being - we all like to take part and contribute and by doing so we increases our serotonin levels leading to improved feelings of well being.

At the beginning of the project we met with the local Speech and Language therapy team, who told us in South East Wales cuts to their funding had impacted on their ability to address communication with adults for over ten years. Anita McKiernan fro the Royal College of Speech and Language Therapists (McKiernan, A) states "Communication with others is at the heart of our social functioning, enabling us to express ourselves, build and maintain relationships and get our needs met - all of which are important for our well-being and resilience,"

The Evaluation of speech and Language Service Pilots in Wales 2008 mentions "The long term impact and social cost of speech, language and communication difficulties is not proportionally represented by its priority within health. The assembly should consider raising the priority of speech, language and communication difficulties within Health through the setting of appropriate SaFF targets"

The SEN Code of Practice for Wales (2012) states: "Collaboration practice is essential for successful intervention with children and young people with speech and language difficulties".

It was both surprising and concerning that little to no information was readily available for the partaking younger beneficiaries who had relatively recently moved from Children's to Adult services.

As mentioned there has been a common theme amongst the majority of beneficiaries as to their lack of literacy education or choice in Further Education. It appears many picked up a 'skeleton' of literacy skills at school and were never given any opportunity to further build on these skills or for them to become an effective communication tool. (Reading assessments for students with ASD: a survey of summative reading assessments used in special educational schools in the UK, cited Arnold, S) "Literacy can be taught at any age and stage. If progress hasn't occurred for a child or young person at the same time or rate as it has for their peers, that doesn't mean it's not happening".

(Department for Education 2014 cited Arnold, S) "The development of literacy skills is one of the upmost aims of education, not only as a life skill but also because it provides access to all other curriculum areas." However it seems attitudes need to change; Speaking on behalf of the communications charity, chief executive Virginia Beardshaw Comments "If a child cannot speak, they will be unable to read and write" (I CAN, 2014). Arnold (Arnold, S. & Reed, P. (2016) states " This view may unfortunately be a reflection of current general attitudes in education, which could well ensure that non-verbal pupils will continue to be excluded from an 'inclusive education system'. Arnold further purports "A literature search for reading tests tailored towards those with special educational needs, with a particular focus on minimally verbal children, revealed no reading test specific to this population appeared to be in common use. In fact, in

terms of research relating to the reading abilities of nonverbal or minimally verbal school aged children with ASD, there appears to be very little conducted, which has been noted by previous studies and reviews (Muchetti 2013; Tager Fusberg & Kasarri 2013)

We had two referrals to the project for individuals who had lost their ability to communicate verbally due to illness, but who were literate. The options to communicate were greatly increased and enhanced for these individuals as they could use alphabet boards, type, read etc so were not excluded to the degree non literate nonverbal individuals are, the difference in life options being profound.

It has been surprising given today's technology that younger beneficiaries have experienced similar poor literacy experiences to that of their older peers. All beneficiaries consulted appear to be aware how detrimental not being able to communicate through literacy is and all have demonstrated a motivation to learn and maximise both their communication and potential by improving their literacy skills. This has included specific motivations, for example being able to use the internet to look up music, sport, local news, and individual interests; be able to spell out commands, thoughts, opinions to optimise options and move away from the all too often offer of two alternatives offered by support, who have thought up what they think the person might like, which doesn't facilitate deviation and there remains the likelihood that the individual may really like to communicate something completely different.

Arnold (Arnold, S. & Reed, P. (2016) concludes "Whilst teachers may resort to their own methods of assessment, one could argue that these are professionals being made to make the best of a bad situation. The danger then, is that students who are nonverbal, but have an ability to read, may be underrepresented in whole-school data; with therefore no provision being made for these skills to be further developed, or suitable adjustments being made to the curriculum. Since literacy provides access to the rest of the curriculum, the negative impact of this could be pervasive in terms of a child's whole education.

Arnold, S. & Reed, P. (2016) states "Schools have an obligation to assess the literacy skills of their students, and the provision of reading instruction to students includes the ability to measure progress in this

area. However, the design of reading tests includes the ability not only to read words, but also the ability to verbalise them. How this issue is generally overcome is currently unknown.”

One purpose of education assessment is to establish a baseline of the learners’ ability in order to develop plans for lifelong learning and achievement. If there is an inability on the part of schools to accurately assess the reading abilities of nonverbal students, then it would be fair to assume that this could have a negative impact on the provision of learning opportunities for this cohort. Education and to some degree areas of social care aim to meet individual needs, but the processes that are in place to measure the individuals’ progress is far too often generic, without any facility to measure individual strengths. For those who have little to no voice it is hard to reach their potential when there remains no facility to measure progress - no box to tick!

Recomendations

1. Talking Mats to be used in reviews for individuals with communication difficulties. Training for staff working with adults with communication difficulties to receive Talking Mats training. Talking Mats state (talkingmats.com) “ Engaging with people who have difficulty communicating can take time and may result in misunderstandings which can cost a lot in terms of time and cost and emotion for all involved. Research and anecdotal evidence have both shown that using Talking Mats is efficient and cost effective in that staff or carers can get better quantity and quality of communication with the people they work in a shorter time with than with usual methods of communication. The average time for someone trained in Talking Mats to have a Talking Mats conversation is 15 minutes, although some people may choose to talk for longer. In addition, staff often rely on relatives to gather information about a person’s needs and preferences. The process of gathering that information can be protracted

owing to availability of family members and, because it is second-hand, is liable to misinterpretations. This in turn can lead to frustrations which can damage relationships, result in poor care and cost time.”

2. A recognition that not all adults with a learning disability share the same issues and their needs to be meaningful representation for those with more complex communication and mobility issues. For many years Monmouth People First have attended consultations/events aimed at establishing what is important to this cohort and how they want to spend their days etc. We have witnessed the thoughts, ideas and aspirations coming from a few individuals who are able to attend but the information gathered is not representative of individuals with more complex needs, whose set of goals may bare little relation to the individuals who are speaking on their behalf.

3. There needs to be more partnership working and better communication between the organisations involved in the beneficiaries’ lives and a real desire to share a common aim.

4. Support staff to be given training on a range of communication resources.

5. If desired by individuals with communication difficulties to put together their social story (which can remain fluid and travel with them) to be shared with whoever they choose, to improve information sharing, individual identity, confidence and feelings of well being.

6. Suitable Education available for those whose preferred communication is literacy, to include up to date technology and utilise the wealth of free software available which can enrich lives.

7. For adults with a learning disability who want to volunteer and/or progress into paid work to be offered comprehensive and meaningful training.

8. Information on communication preferences to travel with the individual when they move from Children's to adult services.

Final Thoughts.....

It is only relatively recently that technology has improved to become so user-friendly. Most of the apps used on this project were free. It is perhaps fitting to mention the advancements in technology have not been matched by advancements in adopting their uses with relation to communication, to enrich the lives of individuals with communication difficulties.

The digital world has developed so rapidly to benefit the majority within our communities. For example if we want to find out information quickly, we have in a short space of time become dependent on 'Googling it' and we have also swiftly become reliant on communicating through email, text, Skype, social media etc - we expect most things to be available to us in an instance. Contrast that to the individuals who struggle with communication and literacy, the two having a negative impact on each other and leading to a world that does not benefit from the digital times we live in, and thus furthers the exclusion divide. It seems incredible that many beneficiaries are still communicating with often little more than an either/or choice. The findings from this report evidence how digital communication tools can enhance and enrich adults with communication difficulties, by handing them the opportunity to express themselves, give opinions, and make requests, etc, things we take for granted. In addition the detrimental consequences highlighted surrounding the starvation of knowledge that our education system bestows on those with communication difficulties leaves, at present, this cohort sadly way behind - they deserve and want so much more.

Jonathan Bryan (Bryan, J 2018) "Like a bird let out of its cage, the picture that words can generate was free to fly in my reader's mind and assume a new life of its own.

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