

“Technology to free the MiND”



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Communications for people with physical disabilities

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*Dedicated to the love of my life, Mary Kathleen Klein,
who lost her life to Motor Neuron Disease (MND)*

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“Technology to free the MiND”

Introduction

There are many human diseases and accidents, which diminish or rob people of their abilities to effectively communicate and interact with other people in society.

Some diseases are progressive and may deteriorate a person’s physical ability over a short period of time. My own experience is that with my wife Kathy, who was diagnosed with having **Motor Neuron Disease (MND)** on 17th March 2011 and lost her life to it 27th May 2012; a fourteen (14) month journey.

Kathy was fit, healthy, exercised daily and ate healthy food. Within six months, Kathy could not walk, two months later she required a Percutaneous Endoscopic Gastrostomy (PEG) operation to be fed by tube through the stomach wall, a month later; she could not speak or use her hands.

Faced with physical deterioration on a weekly basis, daily activities including communication became a huge challenge for Kathy.

In my desperation to assist Kathy to communicate, I looked for known tools and aids for the disabled, when identified, were often highly expensive, dated and lacked integration into today’s ever pervasive electronic world.

I made use of some existing technologies as well as designing and developing a number of computer applications to assist Kathy to communicate.

The lack of modern and comprehensive communications technology to assist people with disabilities prompted this endeavor to develop an enhanced integrated solution, making use of contemporary, new and emerging technologies.

Our aim is to develop solutions that will allow people to *communicate quickly, effectively and with little effort*, using electronically spoken and written communications, in a modern electronic world.

Problem Statement

In modern cultures there is a high dependence on communications between people for social, work, medical or commercial reasons, to name a few. For those people who can speak, there are few barriers to communicate. For those who can use a computer or smartphone and type, there are few barriers to communicate. For those who have impairments to their speech and inability to type, their quality of life can be dramatically reduced with increased anxiety, frustration and alienation in their own society.

Current Options

There are many good technological tools currently in the market place to provide aid to people with disabilities, which are generally referred to as Augmentative Alternative Communications (AAC) and Assistive Technology Devices (ATD).

Many of these technology aids were developed five to ten years ago and are simplistic in their design and use, are stand-alone in their operation and have not kept pace with modern technology developments. Many of the tools come at a high cost, due to low sales volumes and the need for cost recovery by the manufacturers and sales outlets.

Praxis Solution

Taking the lessons learned from the past and the current offerings of assistive technology for people with disabilities, this project will explore and update those understandings and practices and raise the suggestion of using newer technologies to improve a person's interaction with an ever increasing electronic world.

There are a number of obvious benefits from the ability to communicate and I do not intend to provide tomes of prose on these topics. However the import of these benefits can only be understood when the ability to communicate is impaired or unattainable.

Benefit 1 – “State of Mind”

Without dwelling on the points below other than it is suffice to say that the ability to communicate is a basic need and function that engages and allows people to interact with other people in society; an inability to do so would see the opposite of these points

Lower Stress

Raise self-esteem

Lower Anxiety

Raise spirits

Lower Frustration

Raise self-confidence

Benefit 2 – “Engagement”

In some form or another we are ‘engaged’ to our communities. Whether it is relationships with neighbours, friends, work colleagues, sporting teams or social groups, we need to interact and communicate. If we are to survive as a person, the ability to communicate is critical for our ongoing existence in a community that seeks from its citizens to be sociable and generally ‘fit in’. The inability to communicate can often ostracise people, lead to boredom, loneliness and a life less fulfilled.

Integrate into Community

Improved Sociability

Benefit 3 – “Contribution”

The ability to communicate allows people to articulate their thoughts to others; to have their opinions and views heard and shared with others.

The ability to contribute, question and remark, on topics of living such as love, life, science, work and politics and to contribute and share in the society that we live in, is a fundamental requirement and necessity to enrich a person's life.

Implementation

The approach is simple; identify the type and severity of communication problems, experienced by people with physical disabilities and find solutions to address those problems. Firstly we must define a 'norm' as a baseline, Figure 1 & Figure 2 are our baselines for communications.

Figure 1 people talk and people listen

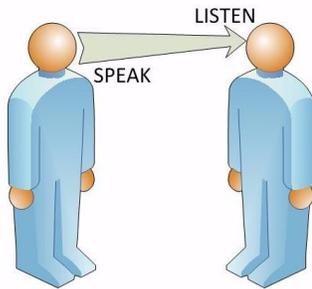
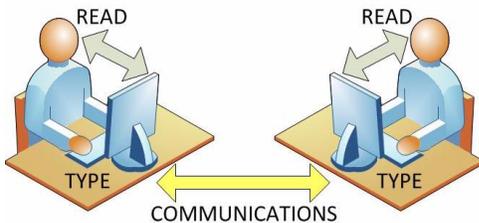


Figure 2 people type messages and people read messages

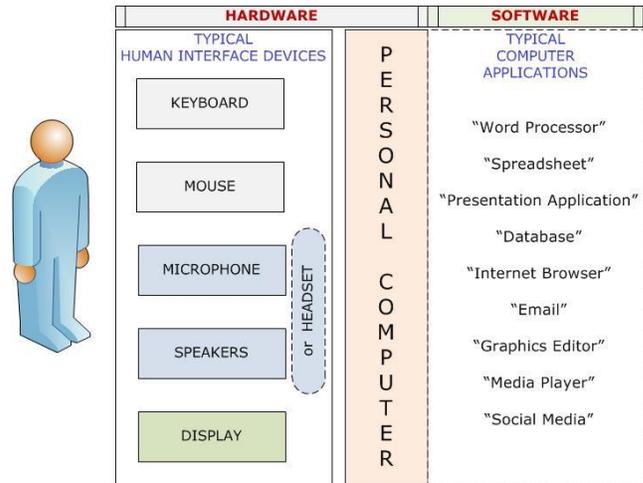


Where those communication functions are impaired or non-existent due to disease, accident or defect from birth. **The challenge** is to provide a person the means to communicate as near as practicable to the norms that we understand (Fig 1 & Fig 2),

Any proposed technology solution must provide the physically disabled user with the ability to *navigate, control* and *input data*, to technology devices as that afforded to an able bodied user.

The basic functionality of all modern personal computers (PC) requires the ability to **N**avigate around a computer screen; the ability to **S**elect an item on the screen or drop the cursor in a location and finally the ability to perform an **A**ction, which I refer to as **NSA**. To interface with a PC there are a number of external devices that we are all aware of, as seen in Figure 3.

Figure 3 Human Interface Devices (HID's)



Given a person's physical impairments traditional Human Interface Devices (HID's) may not be effective or appropriate and we will look at many other technology items that will facilitate the NSA control of a PC. As an example of the steps required to start a simple PC application on a Windows 7 system, such as Microsoft Word and without using desktop shortcuts; a user would need to navigate to the Windows **Start** button, click it, navigate to **All Programs**, click it, navigate to **Microsoft Office**, click it, navigate to **Microsoft Word** and click it. For an abled bodied person this is not a problem for a person with limited movement this is a frustrating and time consuming process.

Our starting matrix for addressing communication deficiencies and potential solutions, categorises speech and typing abilities into three groups, **Good, Impaired** and **Non-Existent**. Where **Good** can be determined as that of a person with no disability; **Impaired** indicates a sub-optimal ability and **Non-existent** identifies no functional ability. The following matrix includes initial technology suggestions to address deficiencies.

Table 1 Communication Function Matrix

Speech Good	Speech Impaired	Speech Non-Existent
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Typing Good	NORM	Type / VR / HT / BCI	Type / HT / BCI
Typing Impaired	VR / Type / HT / BCI	VR / Type / HT / BCI	Type / HT / BCI
Typing Non-Existent	VR / HT / BCI	VR / HT / BCI	HT / BCI

Type = Normal Keyboard Typing

VR = Voice Recognition technologies

HT = Head Tracking technologies

BCI = Brain Computer Interface Technologies

In some cases, solutions may need to be developed with electronic software and or hardware items. The use of modern technologies and computer applications will go a long way to augment or even replace those failed functions.

Example of the first quick fix

Voice recognition technology has been available for a number of years, and yet I have found that many medical advisors are not aware of it and the potential benefits that it could provide people with disabilities. The ‘*Quick Fix*’ for someone who cannot use their hands and has a good voice is to use a product such as *Dragon Naturally Speaking Professional* from Nuance, which will provide a person with an exceptional level of control over their PC, through the use of voice commands. This level of control could be extended to control other electronic devices around the home and work with specialised home automation tools or the advent of some developed computer applications to do so.

Users of Microsoft Windows should be aware that there are many Accessibility aids built into the system to make navigation and use of the system easier for them. Also within Microsoft applications such as Microsoft Office accessibility aids are included.

Approach

Before architecting the design and development of solutions, an understanding of the range and type of problems encountered by people with physical disabilities is required; to achieve this, requirements will be gathered from the experiences of patients and health professionals.

Another component of this research will be the identification of current technologies used to support patients as well as researching new and emerging technologies that make use of Brain-Computer-Interface (BCI).

In gathering requirements, a decision tree or matrix containing communication problem types and potential solutions will be created. An existing and useful decision tree is available at:

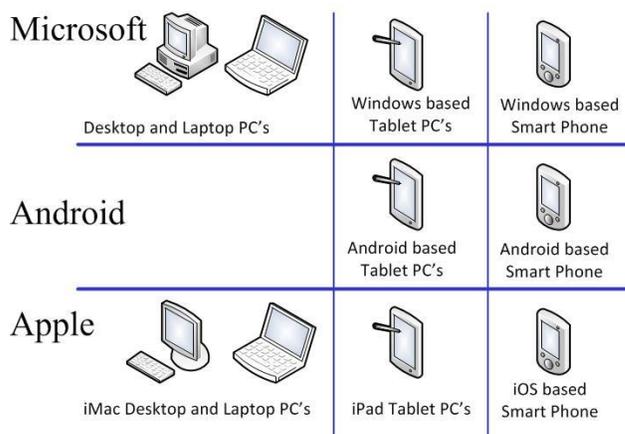
<http://download.microsoft.com/download/7/e/b/7ebfb5a1-69af-4e2a-aba7-7f11e2d66fed/atdecisiontree.pdf>

Microsoft provides a web site “*Microsoft Assistive Technology for Everyone*”, which has a rich source of technology information to assist people with disabilities.

<http://www.microsoft.com/enable/default.aspx>

Our initial priority for developing computer applications, will target Microsoft based devices, followed by Android based devices and finally, Apple based devices.

Figure 4 Development Platforms

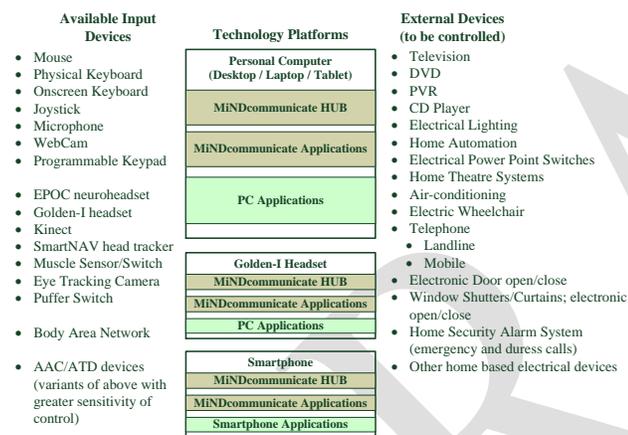


Initial PC solutions will provide smart text-to-speech (TTS) functions with user pre-defined

phrases, including medical and lifestyle instructions that can be relayed to carer's, medical professionals or other people. Where practicable, the use of predictive text to reduce the effort required to input words and phrases will be employed such as the SwiftKey product www.swiftkey.net

A primary consideration is the ability for the user to navigate and control technology devices prior to making use of any smart applications. The key aspects of this functionality are *navigation*, *selection* and *input*. BCI, head/face/eye tracking, voice recognition systems, smart switches and specialised controllers are able to address this functionality.

Figure 5 Considerations for input and external device control



There are many, new, emerging and innovative technologies coming to market almost on a weekly basis.



Where possible, the thrust and focus of our developments will make use of Brain-Computer-Interface (BCI) technologies such as the EPOC headset from www.emotiv.com to minimise the

need for physical movement and interaction. Emotiv have a number of 3rd party applications available to make use of their EPOC headset.

A number of research projects around the world are exploring the use of “*imagined speech*” whereby making use of BCI technologies, people who speak in their mind will have those words detected and transferred to text on a PC or even control the PC activities, similar to how Nuance Dragon Naturally Speaking is used on a PC using actual audible voice commands. This ability is many years away in being developed.

As mentioned in the introduction, a number of prototype applications were developed using a Rapid Application Development (RAD) approach. These applications included functionality, such as:

- Input Text Area
- Ability to speak text (Text-To-Speech TTS)
- Onscreen keyboard (OSK)
- Numerous predefined phrases and instructions in categories for carer's/medical professionals; phrases could be spoken with electronic TTS voice.
- Spellchecker
- Infrared transceiver control for controlling home electronics such as Television and DVD.
- Simple activation of applications such as, MS Word, MS Excel and MS Outlook
- Generate email and make use of an onscreen keyboard
- PC Sound volume control
- Simple activation of web browser to favourite web sites

Figure 6 EPOC Headset



Figure 7 P300 EEG intendiX Spelling Headset



Where people may have cognitive problems and unable to make use of BCI devices; smart headsets such as Golden-I www.mygoldeni.com, may prove to offer an alternative solution. Other technologies such as face-tracking systems, muscle or sensitive touch switches are also important components of potential solutions; the nature of a person's disability and their physical and mental capability, will determine what technologies are most suitable to meet their needs. There is no *'one size fits all'* solution.

Another possible benefit of using BCI devices is the passive recording of brainwave patterns which may assist MND researchers.

Figure 8 Golden-I Headset



To assist the user to enjoy a greater level of independence, the use of Body Area Network (BAN¹) technologies to monitor the persons vital signs and alert support personnel should parameters be exceeded; will be part of the solution.

¹ May also be referenced as MBAN – Medical Body Area Network

Our website www.mndcommunicate.com will eventually offer a number of *"free to use"* computer applications on an *"as is"* no liability licence. There may be associated cost for any equipment that the applications may make use of, and the user can acquire those items direct for the manufacturers or approved retailers.

The website will also provide links to known AAC, ATD and emerging technologies for people to research their own options.

At some point in the future the site may include a forum for people to share their ideas, suggestions, challenges and solutions.

Other sources of useful information can be obtained from existing support groups such as:

www.mndaust.asn.au

www.mnd.asn.au

www.mndresearch.asn.au

www.mndaq.asn.au

www.mndasa.com.au

www.mndnsw.asn.au

www.mndawa.asn.au

www.mndatas.asn.au

www.mndcare.net.au

www.neura.edu.au/health/motor-neurone-disease-mnd

www.mndassociation.org

www.alsmndalliance.org

www.alsa.org

Other considerations

Legislation

Overseas, many countries are implementing proactive programs via legislation to drive industries to provide support and access to electronics systems for people with disabilities. In the United states federal Legislation referred to as Section 508 see

<https://www.section508.gov/>

What is Section508.gov?

Section 508 requires that Federal agencies' electronic and information technology is

accessible to people with disabilities. IT Accessibility & Workforce Division, in the U.S. General Services Administration's Office of Government wide Policy, has been charged with the task of educating Federal employees and building the infrastructure necessary to support Section 508 implementation.

Patient Ability

One of the key concerns on suggesting technology solutions to people with disabilities, is their ability to engage with the technology. There are people who have a genuine apprehension or fear in using technological devices and suggestion a technology solution to improve their quality of life can only add to the sense of frustration and despair.

There are people who love technology and will easily adapt to using new technology solutions.

Care should be taken in assessing a patients emotional, mental and cognitive abilities to make use of some technology solutions (e.g. BCI) before suggestion their use.

With MND patients there is the potential to suffer from problems such as Fronto-Temporal Dementia (FTD) or emotional lability problem, which may impair the take-up of learning to use new technologies.

Summary

Our aim is to develop solutions that will allow people to *communicate quickly, effectively and with little effort*, using electronically spoken and written communications, in a modern electronic world; only then will the benefits be realised.

Our success developing smart tools will provide an improved quality of life through communications for people with disability problems such as:

- Motor Neuron Disease (MND) or
 - Amyotrophic Lateral Sclerosis (ALS)
- Muscular Dystrophy
- Multiple Sclerosis
- Parkinson's Disease

- Spinal Injuries
- Quadriplegia
- Paraplegia
- Dysphagia / Dysarthria
- Stroke Victims with impaired Hand and Voice abilities

The challenge is to develop interfaces to integrate appropriate technologies into one or more homogenous solutions to assist people to communicate effectively.

Given the talented technologist in today's world, I would like to think that many of them could take up the challenge and devote some time to develop tools to assist people to interact with those who know no barriers to communicate.

In some small way, my hope is this paper starts people thinking about the problems faced by many people in our communities and how new technologies are applied to improve their quality of life.

Where to from here – 2013 Plan

2013 is the year that I will begin developing prototype solutions and seek feedback from allied health and medical professionals who deal with MND patients and other diseases that cause physical disabilities. When appropriate we will seek volunteers to trial and test the prototype solutions and seek feedback and to then finalise the design and development and offer solutions for wider use.

Research into new and emerging technologies will continue with the view to include them into our solutions.

DEFINITIONS

Praxis is the process by which a theory, lesson, or skill is enacted, practiced, embodied, or realised. "Praxis" may also refer to the act of engaging, applying, exercising, realising, or practising ideas.

AAC	Augmentative Alternative Communications
ABSN	Autonomous Body Sensor Network
ALS	Amyotrophic Lateral Sclerosis
ASR	Automatic Speech Recognition
ATD	Assistive Technology Devices
BAN	Body Area Network
BCI	Brain Computer Interface
BSN	Body Sensor Network
EBAN	Extra Body Area Network
ECG	Electrocardiogram
EEG	Electroencephalography
HCI	Human Computer Interaction
HID	Human Interface Device
HVK	Hot Virtual Keyboard
ISM	Industrial, Scientific, Medical (radio band; 915-928 MHz)
MBAN	Medical Body Area Network
MBSN	Managed Body Sensor Network
MND	Motor Neuron Disease
MS	Microsoft
NSA	Navigate, Select, Action
OSK	On Screen Keyboard
PEG	Percutaneous Endoscopic Gastrostomy
RAD	Rapid Application Development
SR	Speech Recognition
USB	Universal Serial Bus
WPAN	Wireless Personal Area Network

REFERENCES

- Imagined Speech

<http://cnslab.ss.uci.edu/muri/research.html>

- Microsoft Assistive Technology for Everyone

<http://www.microsoft.com/enable/default.aspx>

- Microsoft Assistive Technology Downloads

<http://www.microsoft.com/enable/download/default.aspx#righttech>

N.B. "Assistive Technology Decision Tree" from UnumProvident, albeit an outdated document, it provides a good understanding of physical problems and communication solutions.

<http://download.microsoft.com/download/7/e/b/7ebfb5a1-69af-4e2a-aba7-7f11e2d66fed/atdecisiontree.pdf>

Our starting list of innovative and leading products:

- Golden-I headset (and partners)

www.mygoldeni.com

www.kopin.com

www.ikanos.com

www.ips.com

- EPOC neuroheadset

www.emotiv.com

- IntendIX EEG neuroheadset

www.intendix.com

- Nuance Dragon Naturally Speaking

www.nuance.com

- Infragistics Developer Controls

www.infragistics.com

- SwiftKey – Predictive Text

www.swiftkey.net

- ComponentOne – Doc2Help

<http://www.componentone.com/SuperProducts/DocToHelp/>

- ShellObjects

www.ssware.com

- Google Glasses

<http://www.nytimes.com/2012/04/05/technology/google-offers-look-at-internet-connected-glasses.html>

<http://www.youtube.com/watch?v=9c6W4CCU9M4&feature=youtu.be>

<http://phys.org/news/2012-02-google-rumored-built-heads-up-display-glasses.html>

- Oakley Glasses

http://www.computerworld.com.au/article/422248/look_google_oakley_developing_its_own_smart_glasses/?fp=4&fpid=1398720840

- ModelTalker

<http://www.modeltalker.com/>

- SmartNAV Head Tracking

www.naturalpoint.com

- USBUIRT

www.usbuirt.com

- IRCommander2

<http://www.wdpsoftware.com/>

- Olympus – Digital Voice Recorder DM5

<http://www.olympus.com.au/Products/Voice-Recorders/Business---Conference/DM-5a.aspx>

- eViacam

www.eviacam.org

- Claro FaceMouse

www.clarosoftware.com

- CameraMouse

www.cameramouse.org

- Hot Virtual Keyboard (HVK)

www.hot-virtual-keyboard.com

- MS HomeOS

<http://research.microsoft.com/en-us/projects/homeos/>

- AbleNet switches

www.ablenetinc.com/Assistive-Technology/Switches

Major Technology Operating System Providers

- Microsoft

www.microsoft.com

- Android

www.android.com

- Apple

www.apple.com

There are many AAC/ATD devices available for people with disabilities; here are a few that MND sufferers might consider using.

- Lightwriter
- Zingui
- TobII
- eTriloquist
- StaggeredSpeech
- LetMeType
- Dasher
- Say-It Sam
- Claro Facemouse
- eViacam
- CameraMouse

DRAFT