Motor Neurone Disease – Assess, Support, Communicate Project (MND-ASC)

Developing a model of care for assistive technology intervention for communication difficulties and the provision of appropriate and functional assistive technology

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Communication

Face to face

Telephone

Written

Online
“we have heard ........ about these, but don’t really have the expertise to know how to go about making these functional or see if they are good for my situation. We are in need of some hands on expert help in this field badly but don’t know where to go to access this expertise”

Person with MND
“The high tech AAC area is where I struggle. I am not a tech-savvy person and find it daunting, especially as technology is developing and changing at such a rapid pace”

“unfortunately isolation, limited resources and time do not usually result in a positive outcome”

Health professionals
MND-ASC Project – 2 parts

1. Review of current pathways for assessment, prescription, provision and support of assistive technology; identify areas for improvement and develop and pilot key implementation strategies.

2. Review of communication, computer access and environmental control devices available through the MND NSW equipment loan pool and investigation, acquisition and evaluation of new technology.
Background review

Literature review

• AAC is important for people with MND and assistive technology is a valuable tool for communication
• Screening and discussing communication before it becomes an issue can be helpful
• Acceptance of AAC can be an issue for some people
• Identifying an AAC system should be client centred and implementing a system can be challenging
• A flexible system should be considered
• Timely support, regular review and monitoring is important
• Support is often required to customise the system and learn new technology
• Comfort level of carers and other support network plays a large role in the acceptance and use of technology
Background review

Consultation with key stakeholders

On reflection optimal outcomes are achieved when:

• Teams work together
• Clients are able to make informed decisions about their communication needs
• Intervention is driven by client goals
• There is little waiting time for assessment and equipment for trial or use
• Support is provided with set up
• Ongoing technical support is available
• Clients are regularly monitored and have access to timely review
Key recommendations

1. That specialist assistive technology services provide a high quality service that is responsive, accessible and flexible.

2. Increase knowledge and capacity of health professionals to support clients at a local level.

3. That clients and families have access to knowledge so they are able to make informed decisions about communication issues and, if inclined, they can broker and facilitate services to best address their needs.

4. Continue to ensure that people have access to the right equipment at the right time.

5. Encourage collaboration between specialist services, MND clinics, frontline clinicians and equipment providers.
Possible strategies

Flexible range of strategies to address the unique needs of individuals and challenges of different regions.

• Develop, centralise and update information about technology tools and strategies

• Provide a continuing education program for local therapists that translates the knowledge base, is practical and includes reflection of local barriers to good practice

• Establish greater collaboration between specialist assessment services, MND clinic professionals, local health professionals and equipment providers

• Knowledge brokering
Possible strategies continued

• Specialist assessment services review procedures and practices

• Summarise the evidence and make information accessible for people with MND

• Offer “Introduction to technology” sessions for people with MND who are not confident or familiar with technology.

• Investigation of funding pool to improve equity

• Review referral processes for requesting equipment
MND NSW Equipment Loan Pool

Review of communication, computer access and environmental controls in MND NSW ELP completed February 2012

- in house audit
- reviewed demand on devices 2010-11 and 2011-12
- survey MND NSW member iPad use

Investigate new devices for possible inclusion

- explore replacement options for Lightwriter SL35 and expand current equipment available
- limited published Literature around appropriate devices
- consultation with healthcare professionals and assistive technology organisations
  - correspondence with ComTEC Yooralla, Ability Technology, and Northcott CATS
  - meetings with TASC and EnableNSW

70 new devices were recommended for inclusion in the MND NSW loan pool from consultation
New Acquisitions to ELP

Decisions criteria for inclusion

• ease of use/ adaptability to changing user needs
• safety and security of the device during use
• cost
• infection control for reissue in the MND NSW ELP
• availability within Australia
• servicing or access to spare parts/components for devices

Purchases made Post audit March 2012 include

• Computer mouse – Joystick, touch pad
• Computer software and Apps – Grid 2, Assistive Chat, Predictable, Proloquo2go, Speak It and Verbally
• Environmental Controls - HouseMate
• Lightwriter SL35 replacement options
  – Tablet; iPad for member loan and healthcare professional short term trial
  – Speak Out; scanning model
• Mounting systems – new to ELP
• Switches - more specialised; Magic Wand, Papoo, Scatir
ELP documentation

Electronic Equipment Loan Referral Form

MND NSW now has two Equipment Loan Pool Lists

- Standard Equipment
- Communication, Computer Access and Environmental Control Equipment
  - Available on www.mndnsw.asn.au

iPad Criteria of Loan

- for member Loan and
- healthcare professional short term trial

New device instructions – simple and comprehensive

Evaluation forms - hard copy and survey monkey
Preliminary uptake data and evaluation

225 devices and support components have been purchased

Loans data range: 1 July 2012 – 31 August 2012

48 items loaned
  • iPad
    – 6 loaned to members
    – 4 healthcare professional trial iPads loaned

Evaluation of devices from member and healthcare professional perspective
  • Option for member of hard copy or survey monkey link
  • Healthcare professional via Survey monkey
  • posted 4 weeks AFTER loan
What are we hoping to achieve?

Person with MND

- Assess
- Communicate
- Support
Acknowledgements

and

NSW Government Family & Community Services, Ageing, Disability and Home Care
References


References


References


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