



Royal Hospital for  
Neuro-disability

A national medical charity

mnda

motor neurone disease  
association

AAC equipment funded by the MND Association that (probably)  
should be funded by local statutory services  
– What's the problem? Suggestions for next steps

Richard Cave SLT  
MND Association / Compass



## What's the situation?

Where a person with MND has a need for AAC but does not qualify for acceptance by an AAC Specialist hub...

...the MND Association often providing AAC equipment that probably should be provided by local SLT community services funded by CCGs

What are the risks and benefits of this?

## Next Steps

- We will support proposals for local services statutory funding where we can - get in touch
- Planning specific AAC/EC for MND training sessions with as an output of the HSCPs survey of training needs

Questions / Comments?

[Richard.Cave@mndassociation.org](mailto:Richard.Cave@mndassociation.org)

07898 721278

richard.cave@mndassociation.org  
07898 721278

# What was the situation in 2018?

- Lightwriters (approx. £6k a year budget for repair)
  - SL35s 25 loaned
  - SL40s 37 loaned
- Alloras
  - 9 loaned
- iPads/Tablets
  - 87 iPads gifted with various apps (£51k)
  - 26 Predictable apps gifted by itself (£4.2k)

# What is the outlook in 2019?

- iPads/Tablets
  - Forecast 150++ loans
- Lightwriters (approx. £6k a year budget maintaining)
  - Discussion to withdraw loaning SL35/SL40s

# Voice Banking

- Laptops 72 Loaned
- Headsets 105 loaned

For 2019 expected to be around 500 items given actual numbers in Jan and Feb

# Benefit and Risk to MND Association

## Benefit to the MND Association

- Working towards our objective of ‘ensuring pwMND get the care, support and information they need’

## Risk to the MND Association

- This is expensive for a charity with limited funds
- We are purchasing and managing a large amount of high-tech equipment without AAC Specialist Hub equivalent skills to maintain or manage
- Little quality check of appropriateness of request vs AAC Specialist hub triage and assessment

# Benefit and Risk to pwMND

## Benefit to pwMND

- Provide AAC to pwMND when local statutory services are unable
- pwMND require support in a timely manner

## Risk to pwMND

- Little quality check of appropriateness of request vs AAC Specialist hub triage and assessment
- pwMND may be receiving AAC based on the awareness of AAC options available by local therapist compared to the AAC options available and best suited to the pwMND (which may be the same thing)



# Benefit and Risk to local services

## Benefit to local SLT services

- Quick 'fix'
- Low or no cost
- Good way to postpone time-consuming review of the underlying issue until time and resource available (when?)

## Risk to local HSCP services

- HSCPs may be referring to us because it is easiest or only option and requesting equipment they are aware we can provide
- This is not helping local teams argue and justify their need with local statutory bodies who should be providing much of this equipment
- The MND Association cannot advise specifically on client on appropriateness or because we have not met the client and background to review
- This is not helping local teams build their knowledge base

## Next Steps

- We will support proposals for local services statutory funding where we can - get in touch
  - Case studies
  - AAC at different stages of MND
  - Insight and stats

# Next Steps

- In discussion for creation and delivery of specific MND AAC training sessions as an output of the HSCPs survey of training needs

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# Training style

- 149 responses to survey so far (09/11/18)

How do you prefer to learn? Please rank it

Answered: 130 Skipped: 19



# Training needs

What AAC knowlege and skills would you like to develop?

ANSWER CHOICES	RESPONSES
▼ Apps for communication (iPad, Windows, Android) - what's available and appropriate at different stages of MND	70.00% 91
▼ AAC - future technologies overview	64.62% 84
▼ AAC acceptance and use - working with significant others and key communication partners	60.77% 79
▼ AAC and Environmental Controls - the options for people with MND	58.46% 76
▼ AAC access methods - switch, head mouse, eyegaze etc	56.92% 74
▼ Low mood and communication with AAC - working as an MDT	56.15% 73
▼ Mental Capacity Assessments - providing support with AAC	52.31% 68
▼ Outcome measures for AAC (including TOMS) - tips and practical examples	46.15% 60
▼ MND and cognition, considerations for AAC	45.38% 59
▼ Strategies for AAC Assessment at different stages of MND	44.62% 58

# Training Proposal

- Hopefully partner with AAC / EC Specialist hubs and suppliers
- Focus on top 4 selected subject areas
  - Apps for communication at different stages of MND
  - AAC future technologies overview
  - AAC acceptance and use – working with significant others
  - Environmental controls – the options for MND
- Write training material in partnership
- Pilot where highest number of respondents are located

## Next Steps

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- Planning specific AAC/EC for MND training sessions with as an output of the HSCPs survey of training needs

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