

Characterising The Profile Of Children With Worster-Drought Syndrome:

The role of augmentative communication to support unclear speech

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What's argumentative communication? I get enough of that already...

Augmentative..it means supporting, or boosting. It refers to the sort of communication methods that can be used by people for whom clear speech is difficult. These channels might be manual signing, printed symbols, or the use of voice output communication aids ("speech synthesisers"), and supplement other ways of communicating without speech such as gesture, facial expression, nodding and shaking your head etc.

Are those extra things just for children who don't speak at all?

No, they seem to have proved useful for some children who DO have speech, but cannot always make themselves understood. They can use augmentative communication as a back-up.

We can understand what my child says: surely he doesn't need a device then?

Children are always understood best in their family. You know what they are likely to be talking about, you are used to listening to their speech patterns...it's often in school that difficulties first become clear, as staff change, or classrooms are noisy, or as teachers need to hear specific vocabulary

But won't all that stop the children from trying to speak?

Not in our experience, and no, not according to the small amount of research that has been done in this area. Having access to another channel of communication seems to increase the children's confidence as communicators: some families have even reported improvements in speech for children who use AC (augmentative communication). And there is some evidence that hearing words spoken, even through a device, supports developing reading skills for some children.

5. So should you stop working to try and improve speech altogether? I've been fighting hard for MORE speech and language therapy time for my child, not less...

This is where the value of a careful discussion comes in. Children with Worster- Drought Syndrome tend to make some improvements in their speech, whether they see a speech therapist or not. This rate of progress will obviously vary, depending on the severity of the child's motor problems, learning difficulties and motivation to communicate. The children seem to make their best progress up to the age of 8-9 years: after that, it is very hard to make big steps of progress with speech clarity. The decision to "add-in" another channel of communication will need to be discussed with your child's speech and language therapist: s/he can make a referral for a further opinion to a specialist centre (see below). It is also possible, where such a centre has access to a paediatric neurologist to have a discussion about speech development: such a team will give an opinion on the expected outlook for the development of clear speech (particularly for older children).

If AC is thought to be useful, the role of a speech and language therapist will be crucial to support and explain the use of such methods to your child's school staff.

How do you select the right device?

The appropriate communication device, and the support needed to make it useful, will be selected after discussion with your child, yourselves, local health and Education staff and a specialist AC centre.

Aren't they expensive? Will I have to fund-raise?

Devices can seem expensive. But if the discussion "team" (see Q5) can show from their assessment that your child needs this device to access the

National Curriculum, and to help them in their social development, it is rare that such devices are not funded. There is no "set" route for such funding: the Education Authorities, Health Trusts and Social Services have all had a role in supporting children using AC. Specific funding issues should be discussed with your child's speech and language therapist.

My child had an assessment and they said he wasn't suitable for one of these machines. It was disappointing.

The technology available can sometimes seem as if it can solve more difficulties than it actually can. Their use is very complex, and even children who learn new things quickly and are already good communicators with signing or printed symbols sometimes take a long while to remember where all the vocabulary is stored, or how to build a sentence. A specialist centre will help your local team and yourselves decide the next step for your child's communication development. For some children, particularly those who have severe learning difficulties, or features of their behaviour akin to autism, a complex device may not be appropriate. Families who have had inappropriate devices recommended tell us that having an unusable device in the house is very disappointing too.

How do I get to a specialist centre of this sort of assessment?

Discuss this with your child's speech and language therapist, and school. Both Education and Health have such centres, and your local support will know which routes they have used and found useful.

I can't even program the video. How on earth am I going to learn how to put words into a voice output device?

Don't worry! Firstly, you will have support: whatever you can't manage to do, someone has been there before and it doesn't all have to be done by a parent. Sometimes families have "techie" brothers, sisters, aunts who enjoy this sort of challenge. And if not, there are always training courses available from the distributors of the machines.

Useful Addresses

Specialist AC Centres

There are a number of specialist Centres offering assessment for children using AC. Discuss a referral with your speech and language therapist, Head Teacher or Community Paediatrician.

Distributors of devices

Cambridge Adaptive

Communication

8 Farmbrough Close,
Aylesbury Vale Industrial Estate,
Stockiake,
Aylesbury,
Bucks HP20 1DQ,
UK Tel: 01296 719736
Fax: 01296 3719735

Email: info@cameleon-web.com

Website: www.cameleon-web.com

Prentke-Romich International

Minerva House,
Minerva Business Park,
Lynchwood,
Peterborough
Cambridgeshire PE2 6FT,
UK Tel: 01733 370470
Fax: 01733 391939

Email: info@prentromint.com
Website: www.prentromint.com

Sensory Software International Ltd

Liberator

Whitegates,
Swinstead,
Lincolnshire NG33 4PA,
UK Tel: 0800 4582288 (Eire 1800
535035)
Fax: 0147-655-0357

Email: staff@liberator.co.uk
Website: www.liberator.co.uk

RSL Steeper Ltd

Assistive Technology Dept,
Riverside Orthopaedic Centre,
Medway City Estate,
Rochester,
Kent ME2 4DP,
UK Tel: 01634 226101

Email: greg.dodd@rehab.co.uk
Website: www.rsisteepers.co.uk

Sunrise Medical Alliance Plc

Sunrise Business Park,

26 Abbey Rd,
Malvern WR14 3HD,
UK Tel 5 Fax: +44 (0)1684 575868

Email:info@sensorysoftware.com
Website:www.sensorysoftware.com

High Street, Wollaston,
West Midlands D78 4PS,
UK Tel: 01384 446688
Fax: 01384 446699

Email:david.morgan@sunmed.co.uk
Website:www.sunrisemedical.co.uk

Useful websites

There are many sites describing the use of AC: these will lead you on to most of them...

www.wdssg.org.uk
www.communicationmatters.org.uk
www.ace-centre.org.uk
www.becta.org.uk