

Leaving School – Crisis or Opportunity Which is it for AAC Users?

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Introduction

When young people leave school, typically they are glad to be ‘let out’, looking forward to what they believe will be more freedom, and hoping to move into further or higher education, or into the work place. They see a range of opportunities ahead; a few crises will arise but parents, friends or family acquaintances can usually help solve the problems – or between them they will know someone who can!

Is this the case for young people with severe communication difficulties? I am sure that many of them, like their peers, are keen to leave school. But even if none of the standard sins have been committed – like buying them a new communication aid just before they leave school and not having time to teach them how to use it effectively – who or where do they turn to when they need help because their equipment has broken down, their circumstances have changed, their equipment no longer meets their needs, or they wonder if something new is now available which would make them faster or more efficient communicators? Parents or friends are rarely expert sources of information or help on these issues, and I wonder if school-leavers do know anyone else who can advise them.

Over the seventeen or so years that I’ve worked in this field, although I have worked across the age range – birth to turf as I call it – I have probably spent more time working with adults than with children. Despite knowing how hard the staff work in schools to educate children and to prepare them for the big wide world, I still often wonder what had happened during the school days of the adults that I meet. I also wonder what had happened to the support networks that should have been monitoring them to prevent them from getting into the dire circumstances in which I typically come to meet them.

This is where the title of this conference is so apt – *Widening the Perspective*. Through a chance conversation with someone from a centre with which I had contact very rarely, I found that I was not alone in my musings.

The CENMAC Experience

CENMAC (Centre for Micro-Assisted Communication) is a service which supports the communication needs of children with physical disabilities who are receiving their education in both special and mainstream schools throughout London. All inner London boroughs subscribe to this service and their subscriptions pay for the staffing, buildings, assessments, reviews, equipment loan and maintenance. The service is, therefore, free at the point of delivery, i.e. at the schools, and is therefore used for every child who may benefit from it.

CENMAC staff were increasingly finding that young people whom they had helped while at school were trying to come back to CENMAC after they left school for help and support when equipment broke down or their circumstances changed. Strictly speaking, these young people were now outside their brief. CENMAC wondered how many other young people were out there with equipment that was no longer working or meeting their needs, and whether there was an organisation already in existence to which such young people could be referred. They therefore sent a questionnaire and a letter containing the following section to all clients of CENMAC since its inception in 1958, who had now left school, were now between 19 & 25 years of age, and whose home addresses were available:

“We have been given some funds to find out:–

- i. whether you still have equipment*
- ii. if you do have equipment, whether it is still working*
- iii. if you have received any help or new equipment from any organisation*
- iv. if you need help now to be able to write and/or speak to whoever you wish*

At the moment we do not have enough money to help everyone who might need advice or new equipment. If we can find out how many people need help, however, we may be able to get the funds to start a service for them.”

Of the 135 questionnaires dispatched, 30 were returned, giving a response rate of 22%. Of the responders, twenty-four (80%) were still using equipment and fifteen (50%) asked for help to identify or obtain new equipment.

Some of those reporting that they were using equipment but did not currently need help, described the

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considerable difficulties they had experienced in obtaining help with AAC equipment. Others reported that they were currently using equipment on loan from college, the implication being that they will be seeking help to obtain their own equipment as they near the end of their college courses.

Given the nature of the questionnaire and the accompanying letter, it must be recognised that there was a greater incentive to reply for those who currently need help or who anticipate needing help in the near future, and therefore it would be unrealistic to generalise that 50% of those children who had help while at school would still need help in the future. However the 15 of those to whom questionnaires were sent who did request help (11% of the total surveyed) present a very worrying picture – one that certainly points to the need for wider perspectives on the part of all agencies.

Sadly, many of these young people had fallen through all the safety nets established by Education, Health and Social Services. They were largely living at home with at least one of their parents, usually with no additional help, with equipment that was no longer working or crawling along by the skin of its technological teeth. Not surprisingly in the circumstances, ten respondents indicated that they stayed home most days.

Through the stories of D, E and M, three of the young people who responded to the questionnaire, I would like to illustrate, and raise for discussion, many of the issues which I have come to think are crucial in deciding whether leaving school results in crisis or opportunity.

Crisis

While he was at school, D used a unicorn headpointer stick to operate an electronic typewriter and a Memowriter, and to point to a Bliss chart. His spelling was good, he is remembered as having a sunny personality, and he has a loving family. D is, however, one of six children, the youngest of which is only 5 years old and another of whom also has disabilities. On leaving school D was placed in a residential home. Within this setting D was not allowed to drive his powered chair – without consultation with the family it was returned to the wheelchair clinic as being no longer required – no-one had time to communicate with him via his Bliss communication board, and due to lack of physical activity he lost the ability to control the unicorn stick to point to his computer keys, Memowriter and Bliss board. After a year his parents brought him back to the family home while they sought another more suitable residential placement for him and initiated requests that he be re-seated.

Issue 1 – Where should responsibility lie?

Whose responsibility was D's placement on leaving school? Can those who know him and the system so well close the file on him the day he leaves school? How did D end up in such an unsuitable placement? Who chose it and on what basis? Should schools widen their perspective beyond the school gate? Should they check up that all is well for past pupils at 6 months after leaving school – but even if they do this, who should they hand them on to, since social workers in general know little if anything of the possibilities available in the field of technology?

Shortly after D arrived home, the CENMAC questionnaire plopped through the letter box. D's mother did not initially complete the questionnaire, she just immediately phoned asking if we could help D to communicate once more.

When I was introduced to D, no part of him moved, his face and eyes just remained blank. While I chatted to his mother D showed no sign of understanding. I decided, however, to show D a light pointer and how he could use it to point to letters – his mother had mentioned that he hated symbol systems and always wanted to use letters. D watched but his face still remained blank. Having shown him the system and asked if he would like to try it, I received no signals at all. I nonetheless mounted a letterboard on his wheel chair and the lightpen on him. The effect was amazing: he immediately, but very slowly, began moving his head to start spelling out messages. "How much does it cost because Dad is old" was one of the first! His mother, in tears, rushed to get a pencil and paper to write down the letters. After about 30 minutes I had to excuse myself and go – D had not stopped talking. His mother said she hadn't seen him so animated since he had come back home.

Where to go from here? Given that he could use an optical pointer, liked and was good at spelling, he clearly needed a system that could be operated by an infrared pointer and had word prediction to speed up his communication. Another task for Widening Perspectives! I had previously talked to Mardis about such an input for the ORAC communication aid, so I phoned them. We reached the agreement that if I could track down a Photonic Wand (an input device designed for the BBC computer in the early 1980's) they could provide software to make it work the ORAC. The grapevine was activated. Most centres had thrown away their Photonic Wands since they were no longer used, but the CALL Centre had not, and were willing to loan the device. Mardis came up with the software and cable and within three weeks I was back to demonstrate the new device to D. This time he greeted me with a slow, but ultimately very wide, smile.

I had set up both 32- and 64-location Speak and Spell overlays. The 32-location version offered each letter of the alphabet, three prediction keys, Delete, Clear and a Return key which moved D to a second page on which 32 messages could be stored. In fact D had the ability to accurately point to the 64 locations and in fact found this easier to use than the 32-location version. I gave D a couple of messages, but we agreed that D would organise his brothers to record messages for him – he preferred the digitised voice to the synthetic one. When I returned a week later D had a small number of messages recorded by several different people and the tone and person seemed appropriate to each message e.g. “Don’t do that” by his father, “Wait till Mum comes back” by his sister – largely for use with his youngest brother – and a very whining “Muuuum” by a brother for use when he wanted to get around his mother!

D, at his request, has now moved onto a 128-location overlay which does not speak out letter by letter, i.e. he constructs his message and then speaks them out. He now also has about 100 messages in synthetic speech divided between the alphabet and message pages with the letters acting as memory joggers, such as “Arsenal” under A, “Come here please” under C and “Only if I have to” under O.

When D is at home his infrared pointer is attached to a towelling sports head band which he is quite happy to wear. Unfortunately when his hair is freshly washed the head band does not always stay put and requires his mother to adjust it when she passes by or he calls her. Unfortunately this is more of a problem when he goes on respite care. No-one there adjusts the headband until D is very clearly upset about something. D has also had the pointer put onto his headband so that it faces in the opposite direction to the ORAC! When attempting to discuss the situation with staff I was told that there are 72 care staff there and I could not expect them all to know D’s needs! I have also found, when I visited him after 4 weeks at the centre, that he was only using single words rather than the fullish sentences he used immediately and naturally while at home. This resulted in the need to follow up with many yes/no questions. When I asked him why he was only using single words, the speech therapist interjected that nobody had time to wait for whole sentences here, care staff would be gone before D got a whole sentence out! There is now a high probability that D will be offered a permanent place at this home. He likes it there. He has a nice room, activities are organised each day, and it is not far from a small but adequate shopping centre. Several people are in powered chairs but no-one else actually uses a VOCA – although two other residents own them!

Issue 2 – How much do staff need to know?

The staff of this residential centre appear to need to widen their perspective and the training package ‘Attitudes and Strategies Towards AAC: A Training Package for AAC Users and Carers’¹ would be an excellent place to start.

Issue 3 – How much liaison should there be?

D’s new seating mould has now arrived, 9 months after he was measured for it. There has been no mention of getting D independently mobile. D cannot operate the standard powered wheelchair controls. Do we accept this, pressurise the wheelchair clinic, approach other experts in the field, or what? Who within the standard services should be responsible for ensuring that D becomes independently mobile again? (The wheelchair clinic is not, I would suggest, an adequate answer.)

Issue 4 – How much help should be available?

D has never had an environmental control system. With his pattern of cognitive abilities and physical disabilities he clearly needs one. Without such a system he is entirely dependent on others to change the TV channel, operate his compact disc system or turn lights on/off etc. Why has this form of help never been initiated?

Issue 5 – How can independence be supported?

With D’s level of physical disability he is unlikely in the foreseeable future to get a job (although in an ideal world I would not need to think this). He has, however, a very lively mind and might enjoy access to E-mail, Internet and the World Wide Web. Through such means he could interact with others in an entirely independent way. But unless he is given this access soon, he may get out of the habit of writing full sentences and therefore be unsuccessful in establishing and maintaining links through the Web.

Opportunity

In contrast to D’s rather crisis ridden story let us look at someone for whom leaving school has opened a continuous range of opportunities. E lives independently in her own flat just a stone’s throw from a major shopping street. She has an environmental control system and her own van specially adapted to take her powered chair. She has carers of her own age who are with her 24 hours a day. E has a severe physical disability which until now has necessitated her use of head operated switches to control a computer. While

better than nothing, this method of using a computer for word-processing etc. is painfully slow. Fortunately, E's speech is only minimally affected, so with the Dragon Dictate system implemented on a powerful computer she is now able to control the computer by speaking to it. In this way she is able to access all the activities that anyone else can on a computer via a conventional QWERTY keyboard. E is taking courses in a college of further education where she also works training other children and young people with disabilities to use computers. She also acts as a consultant to local employment services. E's new computer system may enable her to increase her work load and become eligible for a grant to purchase equipment from the employment services under the Access to Work scheme.

Issue 6 – Why is there such a difference between the stories of D and E?

Given that both D and E are cognitively able, have sparky personalities, but have severe physical disabilities, why has one experienced crises and the other opportunities? Could it all hinge on the fact that E has easily understandable speech and can therefore maintain her own demand profile whereas D cannot? If this is the reason, then the case is very strong for the development of a knowledgeable service of people who can advocate across a range of issues for people with more severe spoken communication difficulties.

Crisis or Opportunity?

M is severely physically disabled and has no speech. This young man is, however, literate, intellectually very able, and has also shown enormous promise as a composer. He operates a music keyboard with his big toe and can control a computer via a foot switch. He left school with a sophisticated VOCA which was state-of-the-art at that time. Unfortunately, M is also someone whose physical condition has deteriorated, due, according to his mother, to the non-availability of physio- and hydro-therapy now that he has left school. As a result of this deterioration, M can no longer sit in his powered wheelchair on which his CAMPAC communication aid is mounted. He has been supplied with a non-powered chair, but no-one has addressed how he can communicate when in this chair. Since he is a very sociable young man who goes out frequently, this is a major issue. This young man has also shown enormous promise as a composer, and has had a composition played on a television programme. He could not be interviewed, however, due to lack of a communication system. He has no back-up low-tech system: at home the powered chair is kept in the living room at the side of the armchair in which he can be comfortably seated, to allow him to communicate.

The opportunities that have opened up for this young man through the development of his musical abilities were thus being partially thwarted through lack of communication. He was seeing his GP regularly, plus a number of eminent specialists, yet not one of these took a wider perspective on this young man and ensured that he continued to be able to communicate. It is also worth noting that his system had evolved and grown: each alphabet letter had two or three pages of words associated with it, so that each time he sought a word he scanned through an enormous number of words to find the one he was seeking. No-one had reviewed the suitability of the system with him since he left school. Fortunately, M has now upgraded to a Cameleon system using word prediction, which is easily mounted on his wheelchair or removed for use in his home. M changed from one system to the other without any difficulty and now communicates significantly faster. He has made two after-dinner speeches and is currently on a music tour of the eastern seaboard of the USA.

Issue 7 – Breadth of the “Assessment of Need” as specified in the Community Care Act

Is no news good news? M's family knew he had a good communication system but didn't see how it could be used on the new wheelchair. The Social Services who are supplying his carers obviously did a limited assessment of need – it may not have been limited by design: it is more likely to be limited by knowledge, or rather, by the lack of it. Should we be widening the perspectives of Social Services both by telling them what is possible and by offering them a service which scans all their clients for requirements in these areas?

Issue 8 – How can we go forward?

I became involved with D on a purely chance basis. I know many people involved in this and related fields and am aware of much of what is possible. Strictly my remit is to establish or re-establish and maintain communication. This somewhat restricted remit is typical of most of the services working in the disability field.

Issue 8A – Where should responsibility lie for support of the whole person – the overseeing brief?

How can we ensure that D (and others) can experience the full range of opportunities many of which we have identified above? Would a citizen advocate be able to help D to identify and secure the equipment and services he needs? Do such people exist, is this the best solution and if so how do we

create them?² If not, who should be taking on this role? How can we ensure that D's perspectives are widened and that he and others experience opportunities rather than crises? How can we ensure that another potential crisis already noted on the horizon for D does not occur?

Issue 8B – How can we ensure smooth transitions?

Leaving school has already resulted in one set of crises for D. Would application of the “passport system”³, which identifies what someone can do, how they do it and who can be talked to if problems arise, have prevented or minimised the crises experienced by D in his first residential placement?

In Conclusion

We must remember that augmentative communication is a very new field, a young science/art form. We have come a long way since 1983 when ISAAC⁴ was first formed. Initially the focus was on the technology, but slowly the perspective has widened as people realised that the technology on its own solved nothing – as fast as it opens one door another hundred doors are presented each hiding their own range of challenges and issues, such as:

- How do we ensure that young children using AAC develop literacy skills?
- Does the use of symbol systems – particularly multi-meaning icons – affect thinking and problem solving skills?
- Can we ensure that people actually receive the equipment which can enable them to communicate most effectively and then obtain the training to ensure that they can use it efficiently?
- How can we increase the awareness of families and carers of how to facilitate the learning and use of AAC systems?
- Are there ways of encouraging AAC users to initiate conversations?
- Are there ways of ensuring that young children never stop initiating conversations?
- How do we raise awareness in everyone of the range of ways in which people communicate other than by speech?
- Can we develop a theoretical model of receptive and expressive language, and cognitive processes, in AAC?
- Do signing systems which support language development and communication within a school environment enable users to survive and grow in the environments beyond school?
- How do we ensure that AAC users have the opportunity to have as wide a perspective as possible on life and maximum autonomy, through independent mobility, environmental controls, education, work, computer access and leisure – games, Internet, E-mail?
- Where, when and how should employment services be integrated into the network? Will the recent amalgamation of the government departments of Education and Employment help with this?

CENMAC did not discover an organisation to whom they could refer past users of their services, so they instigated a new charity MACE (Micro-Assistance in Continuing Education). I am now working for this charity, and my original brief has been broadened to include a whole person approach. We are working towards forming an integrative network which will include employment services, fundraising organisations, and colleges which can provide training in AAC techniques, as well as other assessment and support services.

Technology has opened many doors for many people. By widening our perspectives let us ensure that it continues to hold new doors open and never slams them in anyone's face. Let us ensure that we keep our perspectives as broad as possible at all times, and remember that where people are concerned, the whole can be so much more than just the sum of the parts. And finally let us face up to the issues that this young field of AAC keeps throwing at us thereby ensuring that young people have many more opportunities than crises.

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