

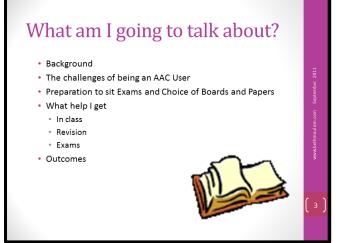
This is a paper presented at the Communication Matters conference in September 2011 and an adapted version for an international audience at ISAAC 2012. Please contact me if you have questions and feel free to quote me but make sure you cite me in your work.

Conversations with my thirteen year old self Conversations with my thirteen year old self

You're angry
I know this
The world couldn't care less
You're lonely
I feel this
And you wish you were the best
No teachers
Or guidance
And you always walk alone
You're crying
At night when
Nobody else is home

Come over here and let me hold your hand and hug you darling
I promise you that it won't always feel this bad
There are so many things I want to say to you
You're the girl I used to be
You little heartbroken thirteen year old me

I began by playing a particularly important piece of music to me by Pink, called Conversations with my 13 year old self. This was how I felt at mainstream secondary school. It was a miserable experience at the time, especially when I was told not to expect to do well with GCSEs. Now when I look back I can laugh because I know I can achieve in life. I wish I knew then what I know now.



I would like to take you through, briefly, my educational experiences, my challenges using AAC in school, the exams I've sat, and I'm still sitting. The support I've had to do this and how I've done so far. For me this is a personal celebration, if I had listened to some people along the way I wouldn't be sat here now.

I will be happy to try and answer your questions at the end.



First, my background. I understand I had a difficult start in life although I was a few days late. Right from the start my parents were warned that I might have a disability and following lots and lots of tests and hospital visits I was diagnosed with Athetoid Cerebral Palsy and a High Frequency Loss Hearing Impairment. By 2 and a half, it was clear I had

speech challenges. At 10 my hearing got worse but we never found out why, despite lots of tests. Two years ago things changed and I got a new diagnosis of Dystonic CP – I get uncontrolled jerks cause by pain, stress, being over tired or physically exhausted. These don't happen all the time so I manage them with pain relief and by talking to people I trust.



My Education started like all other children. I went to playgroup with a one to one, then to the Village Primary School. I did my SAT's like everyone else. The difference was the use of AAC and IT which changed as my literacy skills developed. Also, the many professionals who came into school to give specialist advice. My Annual Reviews were in the school hall as the 18 people present couldn't get into the office or the staff room.



When I was doing Key Stage 1 SAT's and again for Key Stage 2 I went for Neuropsychological Assessments which showed I was developing normally and needed to be doing the same as everyone else. What was different was needing to make the work accessible, having a reader for my own work so I could lip read tenses to know it was right, extra time etc. At 10 it was suggested I needed a special school

placement who could provide access to a mainstream curriculum. BUT I am stubborn.

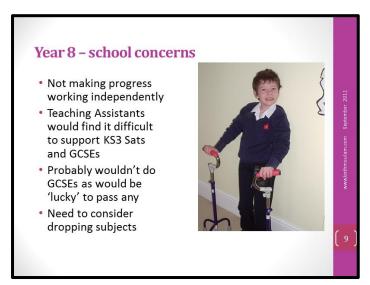
Mainstream secondary



- MY Choice
- Year 7 and part Year 8
- Only pupil in school with chair and AAC
- Team of teaching assistants to support learning and preparation of work
- Withdrawal of support 'to make me independent' by TA's
- Emphasis on typing and quantity of work – keeping up
- Questions if homework was my own work

I didn't want to board and wanted to stay with my friends. So it was my choice to go to the local girls school. It started well but didn't work out over time. They kept thinking that if I could do something with help I was cured. This meant they kept taking away all my help. It wasn't fair and

they were only interested in my typing speeds. Also they didn't like my homework as they didn't think I did it. I did, but Mum knew how to support me and we worked effectively together in the same I do now at Valence.



The mainstream school said I wasn't making progress in working alone. I guess, looking back now, I think they didn't understand or want to care. I will always need to direct people to help me. My Educational Psychologist challenged the staff. He asked if I could successfully use a ramp to get up a step in my chair would they take it away when I was doing well. They began to worry they couldn't support me to do my Key Stage 3 SAT's or GCSE's, in fact they didn't

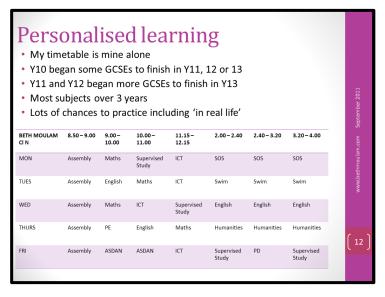
want to support me at all. They wanted me to drop all practical subjects like DT, some Science, Art and PE. I refused although I didn't do French. By Christmas in Year 8 it was clear to me and my family that they were unable to support me.



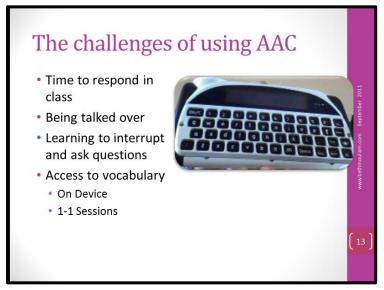
I was off sick a lot and after a big fight, supported by my educational psychologist, my social worker and my AAC consultant, education finally agreed things were not working out. We think they didn't want to admit failure because they were a very successful school. I eventually left the mainstream school in February. After 7 weeks, out of school, I got into Valence, thankfully.



How refreshing! I loved Valence from the word go. Suddenly I could access the subjects mainstream couldn't offer me like DT and food technology. Everyone seemed to understand what I needed and I was happier than ever before at any school. Although I have had some ups and downs due to my health whilst I have been there.

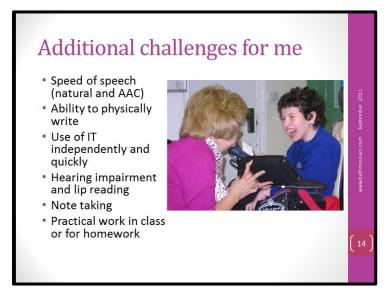


Valance offers a personalised curriculum for every individual student. It is great. So GCSE's are over two, three, or four years. For example science started in 2008 and is done over three years with two modules each year. I have just completed this in the summer. This year I have 4 sessions of supervised study so I can concentrate on ensuring I finish everything by next summer.



AAC can be a challenge, not just for me as the user but also for the other students and staff. Others have to learn to wait. Yes, it can be frustrating to be talked over. But even people who speak get talked over sometimes by others. I had to learn to be assertive and patient. We worked on strategies for me to interrupt and ask questions, but I still find it hard in bigger groups. Access to the huge vocabulary needed for GCSEs is essential. My teacher

for the hearing impaired gave school guidance on how to make this work. I get a 1 to 1 session every week to hear new vocabulary in context. This really helps.



I love to talk but it isn't very clear. My speech is very slow and tiring, but using AAC is also slow. I can write, but again it's difficult to read, slow and tiring. Using IT helps but is still physically tiring. My hearing impairment means that I lip read so it's impossible to make notes and listen. All this means I need one to one help, especially for scribing and practical work where I need to direct someone to do what I cannot.

Revision

- Weeks and weeks of Revision
- No notes just practice papers
- DVD's, CD's and Audio
- Practical Activities
- Education would not fund
- Social Services would not fund
- All Revision with Mum or my PA's using Direct Payments for Social Activities
- Took a lot longer than I planned

Revision has been a big challenge. I cannot make notes or underline key words. It takes hours to make a mind map so I have listened to DVD's, CD's and podcasts. I've done practice papers and practical activities at home to visualise activities in science like boiling the kettle or using food colouring to learn about chromatography. Revision has taken much longer than I planned. I worked every day each holiday and most

weekends. Sadly neither, education or social services have felt funding for revising was important. So revision has been mostly at home with mum or using my direct payment money with a P.A. rather than going out. BORING!

Consideration to sit exams/choice of exam boards and papers

- Looking at classroom support
- Working out how long it takes to do a piece of work
- High course work content
- Exams in modules over several sittings
- Foundation level papers with less writing







Valence School have years of experience of picking the right boards and papers for students. They know it's important for us to have the same support in exams as we do in class. My GCSE's have a high coursework content to reduce the importance of the exam. Mostly we do foundation level papers as there is less writing. Taking modules means we can resit if necessary, unless the syllabus changes. I have been with the same class now for four years, we are put together by the level of work we do. As my timetable is individual there can be just three of us doing a subject or the whole group. This means lots of one to one teaching as we can all be at different stages. Also there is always the chance to recap as the topic is done again by younger students, this has really helped me.

Valence classes

- Mixed age groups by ability eg GCSEs
- Small classes 3 to 10 students
- Lots of 1-1 eg Maths
- Courses over 3 years to allow all ages to access materials
- Staggered start on subjects to give longer learning time

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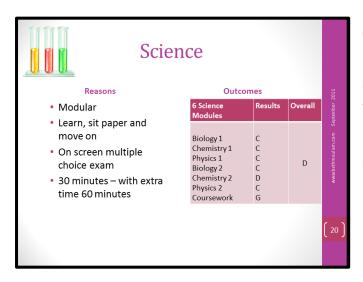
For exams I get at least one hundred percent extra time, the exam officer applies to the exam board for this and is given permission. We have asked for more for me to re sit English language and maybe RE as I didn't finish the papers. I get breaks when I ask. The breaks are still under exam conditions so that includes meal times if necessary. My one to one types what I say which is a mix of my voice, my AAC and me taking over the keyboard if necessary. I get a

reader, except in English, both for speed and because I need to lipread. The large print paper's means I can focus just on the words and not on diagrams or tables. It also means I get a room on my own, but then so does every valence student sitting an exam.

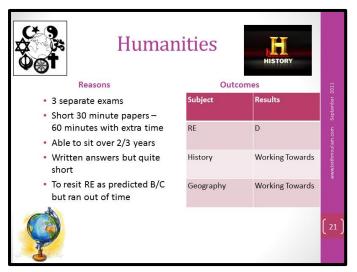
Preparation to sit exams • Practice with entitled help • Planning for paper • How and when to use Fatigue Breaks • Always the same 1-1 in exams and often in class

I spend time doing practice papers at home and school. These are the actual past papers downloaded from the exam board website. The supervised rest breaks are essential. In English literature the 2 and a half hour exam takes about 7 hours. That's 5 hours plus breaks to go to the loo, have a drink and eat, have a stretch etc. After a marathon like this I usually fall asleep straight after the exam in the boarding house. On exam days I have to

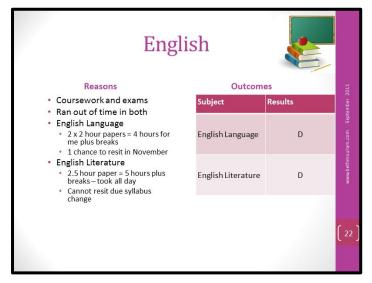
conserve my energy and get fed all my meals and help to do everything I normally do independently. So how did I do?



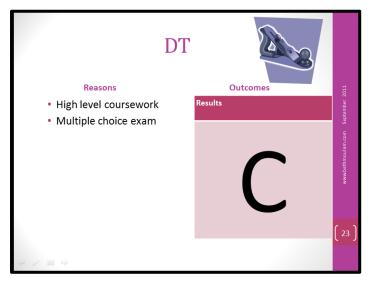
As I said the science exam was modular. I have done some resits when I didn't get a C grade but overall was very pleased until I got the final result, without the practical I would have had a C so I'm disappointed with the D grade.



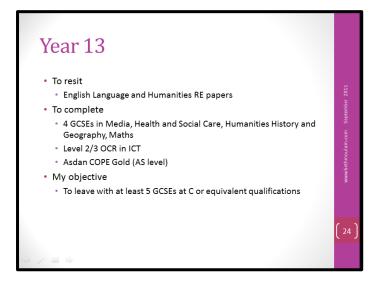
Humanities is work in progress. I hope to resit the RE as I did very little revision because I ran out of time at home revising and I was predicted to do better. But I still have geography and history to do next summer and so could pull up my grade that way.



English Language and Literature was pleasing but not what I wanted. I am going to re sit English Language in November as I need a C. I am unable to re sit the Language paper as the syllabus has changed. Learning the literature was challenging but I enjoyed it. I went to see the play an inspector calls twice. I had DVDs and audio guides which I listened to in the car, I had the printed play and study guides but best of all I had an inspiring teacher – Miss Brown.



DT was a challenge to say the least! I made a wooden box with 28 Dovetail Joints and lots of glue. It was designed to go on the back of my wheelchair and swing to the side so I could get things out on my own. With a bit of adaptation it is now used at home for Magazines. The teacher asked me to consider A level but I was pleased when it was over as I found the directing very tiring.



So, the plan for this year. I hope to Re sit, Complete and leave Valence with 5 C Grades or equivalent. That's if everything goes to plan. I didn't mention I am doing an OCR in IT. Its 100% course work and I'm hoping to get a level 3 qualification by the time I leave, but will definitely get the level 2 which is at least a C grade. I am also doing the ASDAN certificate of personal effectiveness Gold award. It is a level 3 course equivalent to an A S level and

focuses on things like citizenship, global awareness and career planning. So fingers crossed to ticking all the boxes I need for my college course.

Career Plans · I need 5 C grades or equivalent including Science and English Language

- To do a Health and Social Care Level 3 Diploma
- · Go on to University to train as an OT in AAC and assistive technology

I still dream of being a OT and the 5 C's are my stepping stones to a level 3 course in Health and Social Care, before University. I know that some people are a bit sceptical about me being able to do it with my communication but I am determined to give it a go.

My recommendations

- Believe in yourself and aim high
- School must believe in you
- · Learning is life long, it doesn't matter if it takes longer
- Revise a way that suits you (me - by doing past papers)
- Do subjects you enjoy
- · Look at whats needed for future courses
- · Don't try and do too much
- School and home <u>MUST</u> work together



I guess if I was giving my 13 year old self some recommendations and moral support I would be say. "you can achieve your dreams". But you need to be in the right school and have people who understand AAC support you. Learning is lifelong so time doesn't matter if it takes longer. Find strategies to revise that suit you, choose subjects which will get you there over time. Finally find a school that wants to work with

you and home. Then celebrate your achievements. They will come if you work and keep at it.

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