

My way to Language and Literacy

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

Objectives

- * To share how my dysarthria and hearing impairment and using high tech AAC has impacted on learning to read and write.
- * To possibly make people think about the way language and literacy is taught to children who use AAC

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The objectives of the paper are to share how my cerebral palsy has impacted on learning to read and write. This is my personal experience. It may not be relevant to others. That is for you to decide.

Content

- * My background
- * The influences on my presentation
- * Ages and stages
 - * Learning to read and spell
 - * Learning letter shapes
 - * Learning to write
 - * Thinking in pictures
 - * Finding my inner voice
- * Assessments and testing
- * Secondary school vocabulary
- * My way to improving my reading
- * Summary




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I am going to share my challenges of reading, sounding out, spelling, writing, developing vocabulary, and finding my inner voice. And the impact on story telling and developing social narratives. Also how this affects me today. To begin I want to tell you briefly about my disability.



Athetoid/Dystonic Cerebral Palsy – 4 months

Dysarthria – 30 months

High frequency hearing loss – 6 months
Continual glue ear until 12
General hearing loss from 10 years

Vision/focus – 10 years then 16 years

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I was a full term baby. Due to birth complications I have cerebral palsy. This affects my gross and fine motor skills. I have a dysarthria, this means a muscle weakness around my mouth and tongue. I can speak but I have been assessed as only about 90% unintelligible to a stranger. Actually I think my intelligibility has changed but that is a whole different presentation! There was concern about my hearing from birth due to drugs. At 6 months I was diagnosed with a high frequency hearing loss. This means I do not hear f, s, v, and th sounds. At 10 I also developed a generalised loss, despite tests we don't know why.

Education

- * Village playgroup
- * Village infant school
- * Village junior school
- * Local girl's secondary school (to age 13)
- * Special PD school (age 13 to 19)



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I was in mainstream school until I was 13. Things started to fall apart soon after I went to secondary school. It was only after I moved to a special school things got back on track.

A lot of things happened to make me feel it was the right time to tell this story.

I've been influenced by things I have seen and heard at previous Communication Matters conferences, and at ISAAC. And I also have been asked a lot of questions by parents of younger children who use AAC. Earlier this year I did some work at Dundee University. I had several conversations with the AAC computing team about how my literacy and language developed. This made me start to think. I then bumped into a teaching assistant from infant school. She shared her recollection of my learning. Because of this I spoke to my special needs assistant from junior school and started asking my Mum a lot of questions. This is what I found.

Influences on this session

- * Communication Matters and ISAAC
- * Parents of children who use AAC
- * Dundee University Department Computing
- * Meeting primary school staff again



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Home up to 4.3 years

- * Computer games
- * Sharing books
 - * Playschool homework
 - * Own books
- * Learning letters and colours
 - * Letterland
- * Learning to count



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At home Mum read aloud to me lots. When I was 15 months old, the teacher for the hearing impaired gave her advice about lip reading, speaking clearly, quiet locations and light and shadow. From then on I was always positioned to see her face and the book. At 18 months we got a computer at home and loved P B Bear, an educational game. I would play on this, with help, using a tracker ball or point to the answers on the screen and mum moved the mouse. Along with my reading, knowing colours and learning to count this gave my parents normal expectations of what I could achieve.

Playgroup – age 2.4 to 4.3 years

- * Normal expectations
- * Normally played on own with 1-1
- * Year before school (age 3) reading lessons
- * Top reader in group



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I went along to playgroup with a 1 to 1. Maybe like other 2 year olds I liked to play alone, or with adults who did what I wanted. In the year before school all children were introduced to reading. I loved this and it surprised no-one at the playgroup that I was a top reader.

Key stage 1

Had to start to read again

Jolly Phonics



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So it came as a shock when I got to school and the teacher did not think I could read. Or maybe she just didn't understand what I was saying. I was put back onto picture stories which was boring! This was my first introduction to Jolly Phonics. For me it was not so jolly.

Why phonics?

“Phonics instruction is frequently the first step in teaching a child to learn how to read”.

“Phonics helps children learn to read because recognizing those letter-sound connections is the first step in decoding, or sounding out, words”

Source: [How to teach phonics to your child | eHow.com http://www.ehow.com/how_2283582_teach-phonics-child.html#ixzz245TRWver](http://www.ehow.com/how_2283582_teach-phonics-child.html#ixzz245TRWver)

Phonics are supposed to help children learn to read as it establishes the relationship between letters, groups of letters and sounds to help with sounding out. I now know for many children with special needs phonics are not the best method of learning. But I guess you all know this.

“Teaching Assistants say” Sounding Out 1

Jolly Phonics (KS1)

“you always joined in and did it correctly. ... it was **difficult** for you to **sound out and blend** but it definitely helped you to know letters.”

Sounding Out

(KS1) “Therapists used to come in and give me things to do with you ... but I thought that for you it was **tiring**”

(KS2) “At first I found it difficult some of your end consonants sounded the same. Over time, however, I learnt that this was not true – **the emphasis was different** for each consonant”

My teaching assistants think phonics helped me to learn my letters but said sounding out was just tiring, and although it was hard to distinguish what I said it was possible to someone who knew me well.

My view (Sounding Out 2)

- * Even today impossible to sound out verbally or in my head
- * Saying it aloud easier but I only hear what I can physically say
- * Needed different strategies to learn to read and spell effectively
- * Support at home essential

Phonics might have helped me learn letters but I find it impossible to sound out verbally or in my head. I only hear what I can physically say so I had to learn other methods to learn to read and spell. Mum did lots of research and found different ways to help me.

Teaching Assistants say (Reading 1)

KS1

"I could understand you were reading it correctly. I would ask you questions I purposely said something wrong to see if you corrected me and you always did!"

KS2

"When you were reading and came across a word you did not know, I used to break the word down so that you saw only three letters at a time. When I was reading something to you, I made sure you were following and looking at the words."

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My view (Reading 2)

- * I learn every word as a whole word by shape
- * Slow to read
- * Unable to page turn
- * Listening to unabridged tapes with book gave pace
- * Helped overcome decoding vocabulary
- * Know the word but not the spelling
- * Dyslexia programme helped – back to basics practice at age 8

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My view (Reading 3)

- * Text reader – BRILLIANT
 - * Follow on screen
 - * Hear the words
- * Doesn't help in English assessments BUT I need multiple inputs to best assimilate

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At 4 my teaching assistant soon realised I could read. Although she had to persuade the teacher. I have never been one to allow a mistake so would jump in if they tried to trick me. I found I needed to learn each word as a whole word using the letter shape. In junior school as words got longer, we started to break down each word into groups of 3 letters, so I could see the shape. Nothing has changed. Even at 18.

I still learn every word as a whole word by shape and recall whole words. My reading is slow but not helped because I find page turning difficult. I read Harry Potter using unabridged tapes and following the book at the same time. This helped me decode words I already knew from general speech but couldn't spell or sound out and kept a good pace whilst I fumbled with the pages as I could catch up when ready.

I do not have dyslexia but I got a dyslexia reading programme at home when I was 8. This involved hearing, reading and seeing words and starting back at the basics of reading. This was really, really boring but useful as I had missed lots by having glue ear. This also taught me a text reader really helped for comprehension.

I could follow the text on screen and at the same time hear the words. It might not help in exams but demonstrated I need to learn in a multisensory way. I now learn all vocabulary using multiple strategies.

Teaching Assistants say (New Vocabulary 1)



KS1 "... I read the word and explained its meaning, you usually understood and remembered it. If you didn't understand I explained the meaning in a different way. You always remembered the word though!"

KS2 "I created a page on your Dynavox..... You were able to ... find the word you wanted. By doing this you showed you recognised the words and knew when to use them."

In key stage 1 the teaching assistant used different contexts to help me learn new words. The special needs assistant in key stage 2 found I used my dynavox as a dictionary. I knew what I wanted to type and would go and search for the word, where I knew it was stored, so I got it right. I still do this today.

Mum and I say (New Vocabulary 2)

- * Which means that
- * Watch my face
- * Put it into context
- * Spell it out, learn its shape
- * Put it in lightwriter
- * Other words that mean the same
- * Talk to me in adult way (from being a baby)

At home I was successful if I watched Mum say a word, she then gave me the word in different contexts, wrote it down, put it into the lightwriter and explained other words that meant the same thing.

Teacher for Hearing Impaired (Vocabulary 3)

- * Guidance to school
 - * 1-1 session
 - * New vocab in context
 - * Hear it
 - * Spell it
 - * Say it
- * KS4 onwards once a week

These strategies were coupled at the age of 10 with more advice from the teacher for the hearing impaired. This coincided with my first hearing aids. For all new vocabulary I needed a weekly one to one session to see and hear new words in context. To see the spelling, to lip read it and say it.

Unfortunately mainstream secondary, along with quite a few other things, didn't think this was necessary. But once I got to special school they understood the issues and gave me what was needed.

Reading and Comprehension Tests Teaching Assistants say...

- * KS1 "There was **never enough time** for you to read through and answer questions **you were capable of more.**"
- * KS2 "Even with double time to complete the tests. **I do not think the results showed your true ability, you never completed all the test**lowered your score."

Assessments have been annoying since I was little. My teaching assistant in key stage one says I didn't get enough time. The results were probably right but I was capable of much more. Whilst in key stage 2 my assistant said I never had enough time. I got 100 per cent extra but still left questions unanswered which automatically lowered my scores.

Teaching Assistants say (Spelling 1)

Spelling

KS1 "you knew when something wasn't spelt correctly so **in my mind you knew** how to spell but there wasn't the appropriate software at the time that could help you"

KS2 "The dynavox... Another way you used it was for spelling- you **looked up the words** to use in your work."

I've already mentioned strategies for reading and sounding out. The same goes for spellings. My teaching assistants knew I knew the words and I had strategies for spelling but I still found it all very hard.

I say (spelling 2)

- * Sounding out next to useless
- * Learned whole words (spelling and reading)
- * Always knew start of words
- * Often mix up middles especially consonants
- * Don't get word endings unless read back to me and I see (lip read) and hear
- * Best strategies
 - * Learning a key word then copying
 - * Seeing it written down by typing and amending
 - * Looking it up on communication aid

Sounding out was like having a chocolate hot water bottle. Useless! I can always start a word and know when it isn't right. It I can only experiment with the letters I know are in the word until the shape is right by the beginning, middle and end.

My view (Hand Writing 1)

- * Fine motor control challenging
- * At 11 still not getting some letters right
 - * size and backwards
- * Strategies – upper and lower case
 - * Hand writing with lined paper – practice
 - * Walking the letters
 - * Hand over hand
 - * Making play-doh letter
 - * Writing in sand and water



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My literacy wasn't helped by my hand writing. Looking like a giant spider had crawled over the page I did everything to make the letters as easy as possible to form. Getting over this wasn't easy as I couldn't make the hand movements necessary to pattern the shapes. In the end, after doing a lot of research, mum had me do things like walking the letter shapes, doing hand over hand patterns, making giant play dough letters and writing in sand and water.

My view (Writing 2)

- * Typing helps – letters even sized
- * Lower case best with use of CAPs for sentence starters
- * Word predication excellent (but need to be able to read and spell to be effective)
- * Love 'natural selection'

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As I don't write well I find it best to type in lower case, the letters are even sized and I just use capitals at the beginning of a sentence or for a name. This helps me recognise shapes, new sentences and names quickly. Word prediction is a life saver and I love the natural selection on the Lightwriter.

Visual strategies for learning MIXED MESSAGES

- * Line drawings from the SLT
- * Pictures from the Language and Literacy Specialist
- * Pictures the teacher used for the whole class for key words
- * Symbols on my dynavox (later Mind Express)

MADNESS

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Throughout school visual strategies helped me learn. Everyone used different symbols, so I became used to recognising the words associated with different pictures. It might have been better if everyone had agreed on one symbol source because it sounds mad to have learned so many different variations for the same word. In fact it is not as mad as it sounds.

Madness....or is it

I THINK IN PICTURES

- * Symbols
- * Imagination
- * Photographic images
- * Text shapes
- * Physical

Words become pictures that flash past

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A couple of years ago I found I was different to most people in how I think. Every thought is turned into pictures, I don't use any words, just glorious technicolour images, these simply form themselves in my head. This might explain why some of the strategies used for people with dyslexia, and other learning difficulties, work better for me rather than phonics.

Maybe because I don't hear words when I think I found it hard to develop my inner voice. I am told children move to reading silently about age 8. Not me! I practiced lots but somehow it just wouldn't come. This normal skill has only developed in the last 18 months after I got an i-Phone and began reading the news every morning. Suddenly I could just do it! Not being able to read quickly or silently had a huge impact for exams and tests throughout school.

Developing my inner voice - a normal reading development

- * Practice, practice, practice
- * Tried at 7/8 and again from age 10/11 as holding me back
- * Much easier to say out loud or whisper to myself (slow)
- * Only came at 17 when I started reading news and doing searches on iPhone



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Exams and assessments (2)

- * Age 12 reading and comprehension still age 10
- * Age 15 picture word vocabulary age 11
- * Age 16 (new hearing aids) picture word vocabulary age 15
- * Age 17 GCSE
English Language Grade D and English Literature Grade D

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The explosion of vocabulary in secondary school and no specific vocabulary help meant my reading plateaued. At this stage my hearing was also deteriorating and although I had hearing aids I was only getting 95% of what was actually said.

The amazing thing for me was the change of hearing aids at 15 to a higher quality digital set. Now I hear 99% of what is said. Less than 6 months after getting these my picture word vocabulary had jumped by 4 years. I learn and use new vocabulary every day, whilst I still need to improve my English grade to get into

university I am pleased with my 2 current D grades in English Language and English Literature.

Developing Language and Literacy in school

- * Found 'what happens next' questions hard until in teens
- * Prefer facts, often think in bullet points
- * Never had time to do more than the minimum
- * Never completed any work including GCSE exams
- * My focus on getting the basics down not the frills

Story Telling – My Questions

- * Was my imagination inadequate
- * Did I have the time and energy
- * Was there an expectation I could be creative
- * Needed scaffolding for creative story telling

Use of a social partner

- * I choose to use a social partner in some scenarios to relate a story
- * Easy, fast and effective
- * Not reliable ongoing – need to access my own social narratives, stories and directives quickly



A great deal of credit has to go to my English Teacher Ros Brown. She has helped me move from preferring facts and never completing any work, including my first attempts at GCSEs, to being more descriptive and adventurous in how I write.

I wondered if my imagination was not good enough. In school everything takes much longer, teachers cannot wait for answers, so the focus for me was on just delivering the basics. My story telling needed scaffolding, but 'what happens next' is reliant on the programming in a communication aid so this can be pretty difficult. I was exhausted by holding a pen, trying to type, or sit up so I could do the work. Children with CP use twice as much energy as their peers to sit still, and up to 5 times more when we are active. I now know being creative means being I have to relax.

Creatively I am at my best in the bath or in bed when my body is 100 per cent supported. Sometimes I cannot sleep when my mind goes into over drive. Now I know I just need the right time and space.

My struggle for time and energy does have an impact if I want to recall social stories when I am with others. If I am with someone who knows me well, and knows my social narratives, then I use them to help me. I might use a few key words verbally or on my lightwriter then indicate for them to take up the story. Whilst this is a fast and effective method it is not reliable moving forward. I want to access my own narratives in an efficient way.

Where that leaves me today

- * Good functional communicator
- * Limited access **quickly** to social narratives
- * Speed for spontaneous anecdotal recollections
- * Discussions with Toby Churchill on developing the Lightwriter
- * Looking at alternative strategies, but don't want 2 different electronic communication methods

Functionally I think I am a good communicator but I do need a more spontaneous way of retrieving my stories. I have started discussions with Toby Churchill. As an alternative I could use another piece of tech, but actually I want just one communication device. Practically, it is not viable to have lots of different bits of technology to carry around. It looks like I have work to do to make this happen!

If only.....

- * All the professionals could have had a common focus
- * Teachers could teach individuals in a way that suits them rather than one size fits all (multisensory/visual and audio learning)
- * I could complete an exam and have unlimited time
- * I didn't have to order my thoughts to 'speak' and then direct a scribe or someone to do practical work
- * I had had the best available hearing aids before 15

The outcome of my journey is that I do have good literacy and language. I did not follow a conventional learning route but things have worked out. It might have been different if assessments had been easier, or I didn't need a scribe, or the best hearing aids were available sooner. But I cannot change the past. The important thing is that I was given a lot of support.

Thanks

BECAUSE

Without incredible teachers and **teaching assistants**

Without Dr Janet Larcher and Ruth McMorran from Surrey

Without Ms Brown inspirational English Teacher at Valence

Without the dogged determination of my Mum

I would not be here doing this

That leaves me to say thank you. Without the support of The Vale Primary School, Valence Special School and the Surrey ICT team I would not be writing this.

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