Age is a Beautiful Thing. How do adults with dyslexia navigate the non-dyslexic world? An investigation into the coping strategies used by dyslexic adults from a community education centre.

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Overview

For ten years I worked in a small charitable organisation in a large inner-city environment, supporting adults who struggled with their literacy skills. Over the years it became clear to me that the majority of our learners were in reality dyslexic; most were undiagnosed until they came to our centre, or had a late diagnosis as an adult. Many learners brought with them a startling amount of anxiety in relation to education, borne of years of perceiving themselves to be 'thick' or 'stupid'. One discussion topic which we all kept returning to was the daily stresses learners encountered in navigating the non-dyslexic world with this hidden disability. I also noticed that some individuals appeared to manage this navigation more effectively than others and that the levels of literacy skills a learner had told only some of the story. Why did some individuals appear to have transformed themselves into dyslexic adults who could function relatively successfully, while others floundered desperately? How had these transformations happened? What might help them to happen? Do individuals have particular coping approaches which guide their actions?

These questions led to a piece of research towards an M.A. in Special Educational Needs with six participants who I perceived to be at the more successful end of the coping spectrum in navigating the non-dyslexic world. These participants were holding down jobs successfully and portrayed an inner confidence which was absent in other learners. It was my intention with this research to explore the possible reasons behind or conditions necessary for success, rather than the reasons behind failure. If the research helped to unearth some answers, then these might offer support or advice to struggling learners. The participants were three females and three males, all white and spanning in age between thirty-two and seventy-three. Five of the six were engaged in the world of work and one had retired.

I was interested in discovering the unique, personalised perceptions and insights of these adults, therefore I took an ethnographic approach which recognised these participants as a 'cultural group'. Initially each person was given in advance seven laminated question cards showing the questions to be asked in a semi-structured interview. The questions asked were, broadly speaking, about their personal support networks, their approach to life in relation to their dyslexia and any examples of when they handled a difficult situation well.

I also gave each participant a disposable camera and asked them to make a visual record of images which represented their own experience of dyslexia. Dyslexic people are often described as 'picture thinkers' and visually literate, so my hope was that the use of another 'language' might prompt new insights into the experience of being dyslexic. Pink (2001) argues for a move away from the perception of the written word as the superior medium in ethnographic research. She suggests that although images should not replace words as the main mode of research, they should be viewed as 'equally meaningful' and incorporated when it appears enlightening to do so. I also hoped that the photographic task would help to create a more participatory approach to the production of the knowledge.

What links were found between the literature and the findings?

Despite the vast number of books and articles that have been written about dyslexia, there is an apparent lack of research and knowledge around what it feels like to be dyslexic, from the perspective of the person experiencing the dyslexia. My search through the literature explored theories around how our individual selves develop and the possible impact that the presence of dyslexia might have on the development of the self, an examination of theories around how we interpret life experiences, the exploration of a broader look at intelligence to include 'emotional intelligence', the relevance of peer support and specialist

versus mainstream provision and the possible significance of social networks and literacy viewed as a 'social practice'. The following sections will provide a flavour of theories within the literature, some of the findings which echoed these theories and also any themes emerging from the data which were not present within the literature.

'It all comes back to confidence and belief in yourself.'

Theoretical models around how we manage to navigate the world effectively include Bandura's (1997) theory of 'self-efficacy', which maintains that what we achieve in life is not simply down to our skills ability but to the agency with which we apply these skills. The agency with which skills are applied relates to our belief in our selves and our ability to succeed at any given task. A dyslexic person will also inevitably have experienced higher levels of failure than non-dyslexic individuals throughout their schooling. Their interpretation of these experiences appears to be significant within 'attribution theory', which maintains that those who attribute their success to internal factors such as ability and effort achieve greater academic success than those who attribute their success to external factors such as luck or task difficulty. Seligman's (1990) concept of 'explanatory style' echoes attribution theory in that your explanatory style is the way in which you generally explain to yourself why events happen. It is the habit of thinking which you learned in childhood and adolescence and has three dimensions; permanence, pervasiveness and personalisation. The third dimension, personalisation, describes whether we put the events that happen in our life down to internal or external factors. Negative explanatory styles can be combated with a cognitive behavioural approach termed 'learned optimism', which focuses on what you are thinking when you fail, to change the negative voices within. This approach is similar in intention to a therapeutic process called 'reframing', where individual concepts or viewpoints are placed in another 'frame' and thus given a different or better meaning. Gerber (1996) argues that reframing can mean the difference between success and failure for adults with learning disabilities and cites his own ethnographic studies of adults with learning disabilities, Gerber & Reiff (1991), as evidence that adults in the highly and moderately successful categories were those who had reframed their disabilities.

Research participants conveyed a strong sense of self-belief to persevere, despite describing

lives in which they had experienced high levels of stress and anxiety. Chris explained that she recently took on a supervisor's post because she knew she had the inner confidence to deal with any difficulties,

The will to better myself has always been stronger than keeping myself back because of my dyslexia. I've always been very ambitious.

Participants showed signs of positively embracing the opportunities inherent within their occasional failures. Alan's description of the spelling programme delivered in our centre conveyed a powerful understanding of the nature of learning, his own dyslexia and a positive explanatory style,

You won't get it right every time, and I think as a dyslexic you're not gonna get it first time and you've got to learn to accept your mistakes. I think the struggle is the biggest part of the thing cos if you don't struggle and get everything given to you, what do you learn in life?

'It's the struggle that gives you the wisdom.'

Over recent years the concepts of being literate in emotional terms, or possessing emotional intelligence, have become prevalent theories in any discussion around how we live our lives effectively. Sharp (2001) calls for an emotionally literate education system which considers the holistic development of both learners and educators. He does however recognise that to change our attitudes requires a major shift in a personal or family 'script' and a change in our inner dialogue. Interestingly, he sees adversity as an experience which can potentially turn problems into opportunities. Goleman's (1996) concept of 'Emotional Intelligence' also argues that our emotions play a major role in our thought-processes, decision-making and individual success and that school grades and IQ scores are poor predictors of who will succeed in life. The key characteristics of Emotional Intelligence include being able to motivate oneself, being persistent in the face of frustrations, being socially perceptive and having the ability to empathise.

All participants expressed a sense that it was the struggles or adversity in their lives which had brought them a good deal of wisdom and emotional literacy. Patrick explains,

Age is a beautiful thing. As long as you're not too young and you're not too old, age and

experience tells you that you'll get out. ... You learn so much by being knocked down, you learn the ability to get back up.

Bill recognises that he is a determined character because of his life experiences,

I think you have to fight a bit harder, you have to stick it out more.

'My support's gone wider now, so I can take on bigger tasks in my life.'

Ecclestone (2004) raises a voice of dissent against this growing trend amongst educators to label their learners as having low self-esteem and a preoccupation with emotional intelligence. She cites Furedi's (2003) concept of 'the diminished self' as a turn in popular culture, politics and the media towards,

Prurient interest in and empathy with public expressions of damage, fragility, vulnerability and feelings of being unable to cope with life's events.

Ecclestone (2004) argues that this preoccupation with 'the diminished self' has lead to a disempowering and patronizing culture which represents a shift away from the belief in people's potential for autonomy and their capacity to be resilient and stoical. She maintains that this leads in turn to the legitimization of professional intervention and that this may lead to a culture of low educational horizons and negative views of people. This implication that people need professional help and institutional recognition, rather than looking to the other forms of support around them such as family, friends and community brings us to the concept of 'social capital'. James & Nightingale (2004) argue that a key factor in the way we deal with events in our life can depend on the resources available to us. These resources can include the 'social capital' of,

Good support networks, friends and a place in the family, friendship groups and community networks.

Fingeret's (1983) study into the social structures of what she describes as 'illiterate' adults discovered complex social networks which operate on the basis of mutual exchange. Fingeret's (1983) participants have social networks which always include 'readers', but choices are made as to the most suitable helper dependent on the level of personal information revealed by the literacy task. She gives an example of the dynamics between a participant, Roger, and the few readers in his network. Roger states,

There's a lot of people who can't read and write, but they can do a lot of things that some people who can read can't do. ...My boss doesn't know anything about repairs. ... At home, my wife she has to help the kids with their schoolwork, but I'm the one fixes the leaks in the pipes. (P140.)

Her participants vary in their level of dependence within society. At one end of a continuum are 'cosmopolitans', who have driver's licences, know their children's teacher and interact with college-educated adults. At the other end, 'locals' are defined by their inability to engage with the social world and a narrow network of support. Therefore, 'illiterate' adults are not in themselves dependent by virtue of their lack of literacy, but due to their inability to engage with the community which surrounds them.

Participants in my research describe transformations experienced since coming to their learning centre. Irene explains,

My support's gone wider now, so I can take on bigger tasks in my life. I can take on the big topics in life. I'm passionate about politics.

While Alan's words seem to describe a recognition of the power of social capital and the reciprocity inherent in his experience of education,

Being able to speak to somebody, to empathise, to offer advice, to offer support, there's so many different ways that education works, rather than just having the ticket (exams).

Irene's images of greetings cards (see fig. 1) represent a recognition of how marginalised dyslexic people can feel because, without networks of support, they may be unable to express themselves in writing at key moments of the year such as friends and family birthdays or Christmas time.

In society it's not allowing you to mix in the way that we do, express our happiness or caring or whatever.

Fig. 1.
Individuals can be perceived as anti-social or 'a misery', but this may be down to a lack of family or friends to support them with a coping strategy.
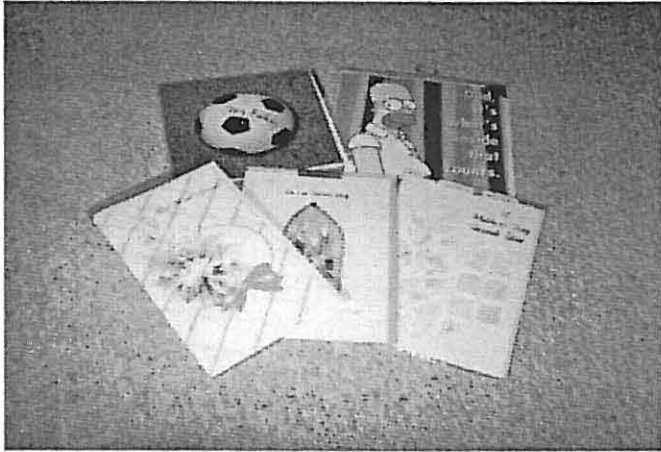
Then they won't mix with people, they won't be happy. They won't send Christmas cards, they're outside society.

Which brings us to Barton and Hamilton's (1998) model of literacy as 'social practice' and their view of literacy as essentially a social activity, located in the interactions between people, social institutions and power relationships

'It's a personality. It's who you are.'
If we consider Barton and Hamilton's (1998) model of literacy as 'social practice' and their view that literacy is essentially a social activity, located in the interactions between people, social institutions and power relationships, then these dyslexic participants' sense of personal identity may well have been shaped by this social practice. Participants described seeing their dyslexia as a personality, bound up with who they are. Alan identified his dyslexia as giving him a sense of his self,

My dyslexia has made me who I am, because I've had to learn for myself and I've had to teach myself. I've had to take it where I can get it. I've had to fight for everything I've wanted.

While Patrick recognised that although in the past he has felt unhappy about his dyslexia,

Now it's not the end of the world any more, that's just me.

'It's like a private club.'
The search for identity may have relevance to the ongoing debate around specialist versus mainstream provision within SEN research literature. Burden and Burdett's (2005) findings from a study of pupils' attitudes to learning and sense of personal identity within a high-achieving independent school for boys with dyslexia showed individuals with a strong sense of self-belief and feelings of depression having halved since entering the school. They argue that the results of this research 'fly in the face' of an overwhelming current push towards inclusion in schooling, suggesting that special education may have a great deal more to offer dyslexic children than is currently acknowledged. In adult terms, the DfEE report *Freedom to Learn* (2000) states that adult dyslexic learners believe that,

Only classes exclusively for dyslexic adults are worthwhile. (p23)

The report cites the many negative learning experiences which adults have had in non-specialist basic skills provision. Humphrey (2003) further suggests that the significant influence of peers might be utilised by creating peer tutoring and peer mentoring opportunities within the classroom.

Participants echoed the value of peer support and being together with people who are all dyslexic. Irene enjoys the sharing of stories,

There's no pain there now. It's a shared understanding because we have a coping thing now … it's like a private club.

Patrick explains that they will often share anecdotes about their confusion over language and see this as humorous because it is shared. The group will often say to each other,

We're all a band of idiots!

Alan describes the inherent therapeutic nature of sharing experiences with peers,

Talking to other students makes a vast difference in how you learn.

'Graceful on the surface, but paddling like hell underneath!'
Goatly (1997) describes metaphor as *an indispensable basis of language and thought.(p1)*and maintains that one of the major functions of metaphor is to express emotion. Lakoff and Johnson (1980) argue that metaphors exist in a person's conceptual system and that human thought processes are, in the main, metaphorical. Metaphors make sense of

innate human experience, it was interesting to note the number of metaphors which emerged within the photographic task. One example is Irene's image of a toy hamster in a revolving bubble; a metaphor for her prior life as a dyslexic person who wasn't coping with her dyslexia. (see fig.2)

Fig.2

That's what you feel like when you haven't got a coping strategy. You are going round and round in your own trapped world.

Metaphors involving movement, or lack of it, included Patrick's description of feeling like a swan,

Graceful on the surface, but paddling like hell underneath!'

as you try to keep up with everyone around you, whilst appearing to be in control. Bill also conveys a lack of forward movement in explaining that his dyslexia has been like an invisible brick wall he was unable to get past,

It's been like a brick wall all my life. An invisible brick wall I didn't know was there. When I eventually did find out, it was in my late forties. Although the brick wall was still there, it made it easier to climb. The trouble is other people don't know that the wall's there.

Fig. 3

Patrick presented a photo of Lee Evans's DVD covers and explained that his on-stage persona seems to represent the way you feel you appear as a dyslexic person, (see fig. 3)

Sometimes when talking to people you feel like Norman Wisdom or Lee Evans 'cos you do the freaky arm movements and you sweat and you talk fast. My brain only works when my mouth's talking rubbish, so I talk quicker, quicker, quicker cos I'm waiting for me brain to get a good idea so I try to fill the time ... As a dyslexic person in a stressful situation you think you are dripping in sweat, even though you're not. Your perception of how you look is greasy and horrid and you just want a shower, so Lee Evans is ideal.

'I can see people that are struggling to get in.'

One striking and unexpected theme not present within the literature but emerging from the data was that although these individuals may not be expert readers of text, they are expert readers of people! Many felt they had developed a strong sense of empathy and described this as a 'sixth sense'.This capacity to be empathetic also meant they were better at their jobs. Irene explains,

I can feel how people are distressed or happy more than somebody else. I know in my job I do, in frontline work, I can speak slowly to anybody travelling and I can feel whether they are lying or anxious, whether they're just anxious because they're just a traveller and have been stopped by somebody in authority or whether it's, oh I've done something wrong and they're not telling the truth. I just go slow and I feel extra things and I think that's because of my dyslexia.

Alan feels better at his job because of his dyslexia,

I have that empathy, because I understand what it feels like to be on the outside looking in. I can see people that are struggling to get in.

He describes being given more complex and challenging clients to manage in work, who are sometimes otherwise left out,

I've got to take that time to listen. I know how it feels to be fobbed off because you're not getting it the way they want you to get it.

Chris recognises the unique qualities in her dyslexic peers and offers an explanation for these qualities,

The people I've met with dyslexia have been far more experienced, giving people, because they've had to find the other qualities that they've got.

Eight key points

Although the participants were six individuals with their own unique personalities, there were strong similarities in the way they chose to deal with their dyslexia. The following eight points are a distillation of the advice and wisdom found within all of the data:

- Learn about your own dyslexia and the best way for you to learn information.
- Concentrate on and develop your strengths.
- Be with your adult dyslexic peers, either in a learning centre or support group.
- Ensure that your literacy class or group has a transparent focus on adult dyslexia.
- Share your stories with your peers.
- Recognise the knowledge gained from your years of struggle and use these skills to your advantage i.e. determination, empathy, social perception.
- Build personal networks of support within your community.
- Learn to take a different viewpoint and 'reframe' your experiences.

Limitations and Implications for practice

The limitations of this research lie in the fact that my small group of six participants cannot realistically represent all successful people with dyslexia, but they can give us a flavour of the coping strategies necessary to survive in a non-dyslexic world. The use of a visual methodology seemed a particularly effective way to elicit complex reflections from participants and the photos helped people to tell their stories, as well as acting as a bridge over to the more formal interview questions. The interviews also shifted something within those involved. Irene's feedback on the process of the research conveys something of this shift,

This has been like therapy for me.

When I pointed out the many positive strategies she has in place, she explained,

It's only doing this that's made me think about it. I feel really good. I felt really happy doing this.

Is it possible that being given 'a good listening to' has promoted personal transformation? Five of the participants went on to form a new adult dyslexia organisation which, two years on, is still going strong. I presented the findings to this new group and we are keen to source funding to create a comic book from the powerful stories and valuable advice we've gathered. I also feel that my prolonged engagement as their tutor has, on balance, led to deeper insights possibly not available to an outside researcher. Burden (2005) maintains that there has been comparatively little written around asking dyslexic people how they think and feel about their dyslexia. I would urge all tutors out there – ask your students to tell you how they think and feel and the results may be illuminating for everyone.

Poole (2003) argues for a shift of values in dyslexia education, where we move away from a narrow focus on lack of literacy skills and see an adult's whole life, including the skills they have gained along the way. While Fingeret (1983) urges us to create literacy programmes which learn to respond to adults in networks. I would extend this argument further and urge those delivering literacy programmes to encourage the development of *new* networks of support for learners, which build upon and recognise their existing social capital.

References

Bandura A. (1997) *Self-efficacy: The exercise of control.* New York: WH Freeman.

Barton D. & Hamilton M. (1998) *Local Literacies. Reading & Writing in one Community.* London: Routledge.

Burden R. & Burdett J. (2005) Factors associated with successful learning in pupils with dyslexia: a motivational analysis. *British Journal of Special Education* 32 (2) pp100 – 104.

Burden R. (2005) *DYSLEXIA & SELF-CONCEPT Seeking a Dyslexic Identity.* London: Whurr.

DfEE (Department for Education & Employment) (2000) *Freedom to Learn. The report of the working group looking into the basic skills needed for adults with learning difficulties and disabilities.* London: DfEE Publications.

Ecclestone K. (2004) Developing self-esteem and emotional well-being – inclusion or intrusion? In *Adults Learning.* Vol. 16.

Fingeret A. (1983) Social Network: A New Perspective on Independence and Illiterate Adults. *Adult Education Quarterly.* 33 (3) pp133 – 146.

Furedi F. (2003) *Therapy culture: creating vulnerability in an uncertain age.* London: Routledge.

Gerber P. & Reiff H.B. (1991) *Speaking for themselves: Ethnographic interviews with adults with learning disabilities.* Ann Arbor: The University of Michigan Press.

Gerber P.J., Reiff H.B. & Ginsberg R. (1996)

Reframing the Learning Disabilities Experience. *Journal of Learning Disabilities.* 29 (1).

Goatly A. (1997) *The Language of Metaphor.* London: Routledge.

Goleman D. (1996) *Emotional Intelligence. Why it can matter more than IQ.* London: Bloomsbury.

Humphrey N. (2003) Facilitating a positive sense of self in pupils with dyslexia: the role of teachers and peers. *Support for Learning* 18 (3) pp130 – 136.

James & Nightingale (2004) *Discovering Potential.* Leicester: NIACE

Lakoff G. & Johnson M. (1980) *Metaphors We Live By.* Chicago: University of Chicago Press.

Pink S. (2001) *Doing Visual Ethnography.* London: Sage Publications.

Seligman M. (1990) *Learned Optimism.* New York: Simon & Schuster.

Sharp P. (2001) *Nurturing Emotional Literacy.* David Fulton Publishers.