

# Neurodiversity in higher education: Insights from qualitative research by the BRAINHE project

by

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The following document contains the PowerPoint slides from the presentation and accompanying text discussing the slides and the content of the presentation in greater depth.

## Slide 1

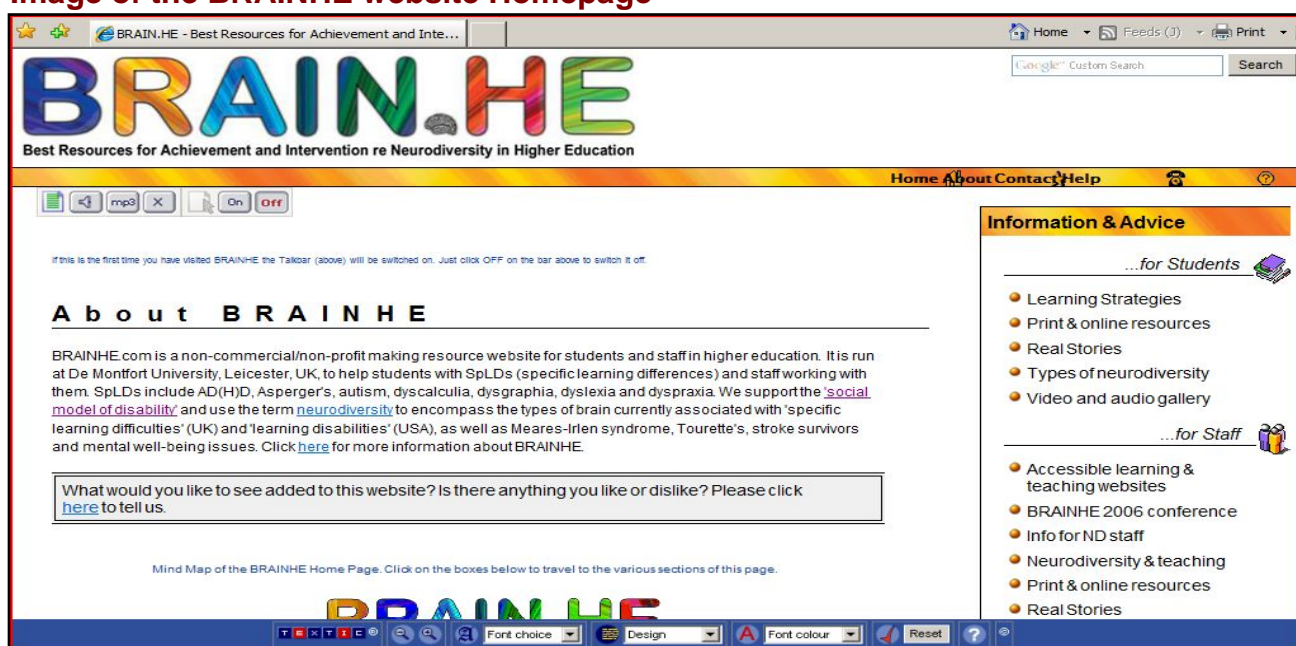
### Neurodiversity in higher education: Insights from qualitative research by the BRAINHE project

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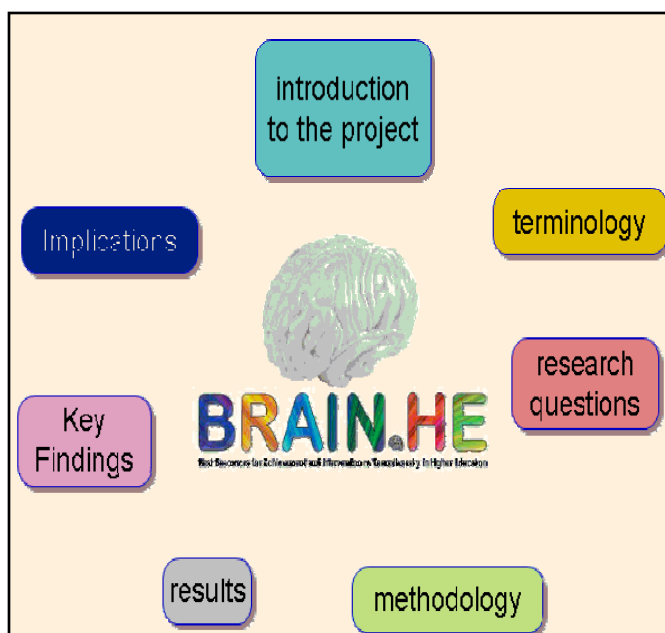
**BRAIN.HE** (Best Resources for Attainment and Intervention re Neurodiversity in Higher Education) is a National Teaching Fellowship Scheme project funded by the Higher Education Academy. It comprises primary qualitative research and analysis, with an active support and resource website for students with learning differences, and staff teaching them.

Link to website - [www.brainhe.com](http://www.brainhe.com)

## Image of the BRAINHE website Homepage



## Slide 2



This slide displays the contents of the presentation. It is also an example of a visual mind map which was constructed using software package Inspiration 8. Many neurodiverse students interviewed for the project frequently used mind maps and expressed a preference for information displayed in a diagrammatic and non-linear style.

- Introduction to the project
- Terminology
- Research Question
- Methodology
- Results
- Key findings
- Implications

## Slide 3

### Terminology

- **BRAINHE:** *Best Resources for Achievement and Intervention re Neurodiversity in Higher Education*
- Learning differences
- Medical model
- Social model
- Neurodiversity

Slide 3 accompanied a discussion of the terms used in the project. It is often helpful for students with learning differences to have some reference material explaining the key terms and concepts covered in presentations.

**BRAIN.HE** started life as a resource website for students and required a short, memorable and catchy title for the web address.

**‘Learning Difference’** is a more socially acceptable way of referring to a range of what are often known as ‘specific learning difficulties’ or ‘learning disabilities’. We prefer the term ‘learning difference’ as we feel it is more empowering and less judgemental.

There are two main models which have influenced modern thinking about disability: the medical model and the social model. Both of these models can be applied to learning differences (Cooper, 2006).

**The medical model** arose along side ground breaking advances in science and medicine in treating disability. This gave the medical professions the power and influence to dictate the lives of individuals with impairments. The medical model generally views disability as a part of the individual which directly disadvantages them. There is often no suggestion that society needs to change and become more accommodating.

**The social model** makes a distinction between disability and impairment. It argues that whilst people can have impairments, it is often the political and social barriers of society, and an inhospitable environment which disable these people (Oliver, 1988). We believe that this is partly the case within the educational system in the UK. Whilst the situation is slowly improving, we are still hearing of examples where the political, social and environmental barriers of the educational system are disabling students with learning differences.

**Neurodiversity** is an umbrella term for many types of learning difference. Neurodiversity is both a concept and a civil rights movement, developed by online groups of autistic individuals in the late 1990s (Harmon, 2004). In a broad sense the concept of neurodiversity argues that atypical neurological wiring is a normal human difference that should be tolerated and respected in the same way as any other human difference.

#### Slide 4



- Website ([www.brainhe.com](http://www.brainhe.com)):
  - Staff
  - Students
- Qualitative research project

The BRAIN.HE project began in 2005. It started life as an interactive resource website for neurodiverse students. This work involved communication with many such students, and it became apparent that 'being neurodiverse' was more than possessing deficits in certain areas; for many students it encompassed a whole life style. There were also many similarities in the experiences of such students, irrespective of their type of neurodiversity. This inspired us to conduct further research exploring the lives of neurodiverse students and we sought additional funding for the BRAIN.HE research project.

#### Slide 5

##### Research questions

- How do these students deal with their identity as being neurologically diverse, and how has their identity developed?
- What are the commonalities between the HE lives of students identified with various learning differences?
- What are the lessons for the sector?

To our knowledge no studies have explored a range of learning differences in this way. Slide 5 shows the research questions which were generated from previous communications with neurodiverse students and a thorough literature review of other works in the area.

## Slide 6

### Methodology

- 27 participants (from 11 universities)
- Many identified with more than one SpLD
- 8 types of learning difference
- 46 minutes
- Topics covered
- Method of analysis

Semi-structured interviews were conducted with 27 participants (14 male, 13 female) with single or multiple types of learning difference. Ages of participants ranged from 18 – 54 (mean 30 years, SD 12.2).

The learning differences shared amongst the participants were dyslexia, dyspraxia, dyscalculia, Asperger's Syndrome, ADHD, ADD, depression and acquired learning differences resulting from head injury and stroke. 8 of the participants had been identified with more than one type of learning difference.

The interviews focused on several broad areas: Being identified, what the label meant to them, school and college days, transition into HE, university course, university support, social life at university and future plans. Interviews were recorded using either video camera or digital audio recorder, and were conducted in a variety of small rooms, with only the interviewer and the interviewee present. Interview lengths ranged from 22:46 to 59:44 minutes (mean 46:03) Interviewees were offered incentives in the form of store vouchers.

Analysis of the data was independently performed by 2 researchers, one using the computer software package NVIVO 7 (Richards & Richards, 2007) and the other a traditional paper-based approach. It was observed that there was remarkable similarity between the two sets of coding. . The data was analysed using thematic analysis and a Grounded Theory epistemological position was generally adhered to (Strauss and Corbin, 1990).

## Slide 7

### Result Categories

- Experiences before assessment
- Identification process
- Labels and identity
- School experiences
- University experiences
- Learning strategies
- Beliefs and self-concept

The interviews covered a wide range of topics and most of the participants seemed relatively uninhibited and eager to talk; the data obtained was extremely rich. The analysis generated a total of 110 themes and sub-themes. The most relevant themes and concepts are shown below. The figures in brackets [ ] show the number of participants who expressed the concept. For some of the concepts we have included a quote which gives a flavour of what was said.

## **Results**

### **Experiences before assessment**

- Interviewees showed an awareness that they were different from other students before being identified [12]

*Sheila (dyslexia)*

*"I just thought it was something wrong with me"*

- Teachers used unpleasant epithets about participants before they were identified [9]

*Mandy (dyspraxia, ADD)*

*"I was just labelled stupid and careless,.. lazy"*

### **Identification process**

- The assessment procedure was a positive experience for some [4]
- For others, the assessment procedure was a negative experience [3]
- A third group found the assessment procedure both positive and negative [3]
- The explanation of learning difference was perceived as negative [2]
- The explanation was not clear [6]

*Amy (dyslexic) talking about psychologist report*

*"I got it after about two weeks and I attempted to read it, not a lot of it made any sense to me whatsoever, I couldn't read half the words that were in the report let alone try and figure out what they meant"*

### **Labels and Identity**

- Many expressed relief after identification, because they had a reason for their experience [11]

*Mandy (Dyspraxia, ADD)*

*"Well its explained all my life, explained why I was like, I was. It also gave me a purpose in life"*

- Some expressed unhappiness about the label [6]

*Antonia (dyslexia)*

*"I hated it, I didn't want to tell people that I was dyslexic, you know, I've only sort of in the last four months, started telling people that I am dyslexic and I hated it"*

- Many took a medical/deficit view of neurodiversity [12]

*Brian (ADHD, Dyslexia)*

*"I didn't really like it because you know it's like being diagnosed with something, well that's actually what he called it, diagnosing me with ADHD (....) it just sounds like a fault"*

- A large group spoke of strengths associated with neurodiversity [11]



*Ray (dyslexia)*

“As a dyslexic I tend to see the big picture, whereas a lot of my colleagues are very, very focused, (...) and they forget things. That’s always been a strength”

- Many reported a change in perception of neurodiversity since identification [11]
- A very large group spoke of social difficulties [16]

*Sheila (dyslexia, dyspraxia)*

“....in a club...what do you say? I go up to them and go ‘hi’ and they’re like ‘hi’, and then I get confused – then I just walk away (*laughs*)

### **School Experiences**

- Some were unhappy at primary school [5]
- Others found their primary school supportive [3]
- Some reported adequate support at secondary school [5]
- Encouraging and supportive teachers were mentioned [3]
- Poor and limited support at secondary school was also reported [4]
- In some cases, there was no support at secondary school after identification [3]
- Some were bullied at secondary school by peers [3]
- Some were angry because their schools did not identify neurodiversity [5]
- An inadequate response to neurodiversity by teachers came up several times [5]

### **University Experiences**

- A very large group was pleased with support from the university disability office (or equivalent) [15]
- Some reported inadequate support from the disability office [3]
- Many had good relationships with support tutors and mentors [12]
- For others, support tutors did not provide adequate support [2]

### **Lecturers and tutors**

- Lecturers could be helpful and supportive [5]
- They could also show awareness and understanding [3]

*John (dyslexia, dyspraxia)*

“I think some of them are very aware. I’ve encountered some excellent examples of good practice”

- Unsupportive, inaccessible course delivery was sometimes a problem [5]
- Negative attitudes towards neurodiversity were shown in some cases [4]

*Nuala (dyslexia)*

*“I’ve had some really nasty comments from lecturers before. I’ve been told before that I couldn’t get above a certain grade because I was dyslexic. When I, I went to see a lecturer about my essay he told me that there was no point aiming for any higher because you’re dyslexic”*

- Lack of awareness and understanding of neurodiversity was also shown [7]

*Sheila (dyslexia, dyspraxia)*

*“So I think, I think that a lot of them could do with, it just being explained to them. Its people have dyslexia etc, etc, but not really how it can affect them in their studies”*

## Learning Strategies

- Many participants reported a preference for visual learning techniques [12]
- They were often clear about their reading strategies (such as converting to large point size, taking regular breaks and using coloured overlays) [7]
- The majority of participants used assistive technology [16]
- Personal organisation was an issue for many [9]

A striking finding was the relationship between participants’ beliefs about their neurodiversity, language applied to them by teachers, and two important aspects of their self-concept. This is set out in Table 1:

**Table 1 – Participants’ view of neurodiversity in relation to unpleasant epithets, self-esteem and future plans**

Pseudonym	View of neurodiversity	Unpleasant Epithets	Low academic self esteem	Future Plans
Alvin	Medical/Deficit		Y	-
Andrea	Medical/Deficit		Y	Ambitious
Alan	Medical/Deficit		Y	Uncertain/negative
Amy	Difference/strengths	Y		Ambitious
Antonia	Medical/Deficit		Y	Uncertain/negative
Brian	Medical/Deficit		Y	Uncertain
Christine	Difference/strengths	Y	Y	Ambitious/negative
Cleo	Difference/strengths			Ambitious
Harriet	-			-
John	Difference/strengths	Y		Ambitious
Janet	Difference/strengths	Y		
Josh	Medical/Deficit		Y	-
Jack	Medical/Deficit		Y	Uncertain/negative
Kat	Difference/strengths			Ambitious
Kevin	-		Y	Uncertain/negative
Liz	Difference/strengths	Y		-
Mandy	Difference/strengths	Y		Ambitious
Mark	Difference/strengths			Uncertain
Marcus	Medical/Deficit		Y	Ambitious/negative
Nuala	Difference/strengths			Ambitious
Nate	Medical/Deficit			Uncertain
Nathan	Medical/Deficit			Uncertain
Ray	Difference/strengths			Ambitious
Sally	-	Y		-
Sebastian	Medical/Deficit			Uncertain
Sheila	Medical/Deficit			Uncertain
Stuart	Medical/Deficit			Ambitious

## Slide 8

### Key findings

- Similar experiences across the range of neurodiversity (in all findings)
- Before assessment: awareness of difference
- EP assessment: mixed blessing
- Medical language leads to poor self-esteem
- But teacher negativity >> more determination
- Disability staff: very good support
- Lecturers: lack of awareness
- Strategies: assistive tech. + visual methods

An unexpectedly high frequency of similarities across the spectrum of neurodiversity emerged from the data. None of the themes was specific to a particular type of neurodiversity. From a social constructionist perspective (Gergen, 1999), the research indicates that students, irrespective of their type of learning difference, interact with the education system in similar ways and generate comparable meanings in response to these interactions. Cognitive similarities reported by the participants support the views of Deponio (2004) and Kaplan et al (2001) that there is more overlap between the different types of neurodiversity than a separate categorisation system allows.

All students arrive in HE with emotional 'baggage' from their school days, but those identified with learning differences are likely to have more of this than most (Pollak 2005). This applies particularly to those who have not yet been identified. Many of the participants experienced difficulties in the education system prior to being assessed. They referred to three ways of being recognized: by parents, by teachers/lecturers or by self-awareness. Previous studies of dyslexic students (Pollak 2005; Riddick et al 1999) have noted such awareness on the part of parents, but recognition by lecturers seems to be an encouraging development, as does recognition of other types of neurodiversity by school teachers.

13 of the participants viewed their neurodiversity as an entirely negative matter. These participants frequently used negative or medical terminology when talking about their labels which indicated that they felt in some way broken or damaged. Of the 13 students who had this view, 8 indicated low academic self-esteem and expressed confusion and uncertainty about their future plans. Participants who viewed their neurodiversity as a difference which included strengths were more likely to have higher academic self-esteem, to have experienced unpleasant epithets from teachers and to have a clear ambitious view of their future.

Many students felt that the support came from several individual areas within the university, and the availability and quality of support varied considerably between the areas. The greatest degree of contrast was noticed between the disability office and lecturers and tutors. Support offered by the university disability offices, including learning support and mentors, was "very good" and "really helpful". Some students talked about the support extending into their personal lives, including emotional and personal support. Most of the students experienced some difficulties with their lecturers and tutors. Some reported conflict between lecturers and tutors and the staff in the disability office about the support they were entitled to. In some cases lecturers were ignoring the student's learning support agreement (or equivalent) and making it extremely difficult for the students to learn effectively. A few of the students thought that their lecturers were "ignorant" in understanding the nature of learning differences (LDs), and knowing how to support such students. Some felt that a small number of their lecturers were sceptical as to the



existence of some LDs, particularly dyslexia. These lecturers seemed to be of the opinion that students claiming to have LDs were just using them as an excuse so that they could get extra time in exams and extensions on course work deadlines. Whilst some of the students talked of helpful and understanding lecturers, the picture seemed inconsistent.

The use of assistive technology clearly benefited a large proportion of the interviewees, irrespective of their type of learning difference. Personal organisation was another area where many of the interviewees needed to adopt carefully selected strategies. This included the use of diaries, personal organisers and wall planners. Many of these participants felt that they needed to be more organised than their neurotypical peers in order to keep up with the demands of their education. The visual and multi-sensory teaching methods which are gradually becoming more popular amongst higher education institutions (Chipps 2007) will clearly benefit these students.

## Slide 9

### Implications

- DSA process encourages medical view
- University policy: showing awareness and acceptance >> student disclosure
- Mainstreaming inclusive practice (not remedial)
- Staff need to understand that neurodiversity has whole-life implications. Viewing it as a difference (not a deficit) = better self-esteem and career ambition
- In future, within-person labels should be abandoned

The process for obtaining the DSA and many of the processes involved in obtaining support are too focused on encouraging the medical/deficit model. Many of the students who thought of themselves as deficient were receiving support funded by the DSA, were happy that their 'condition' had been 'diagnosed', and were glad to be receiving learning support. Essentially the DSA compensates neurodiverse students for their disability. Students are presented with an analysis of their deficits and a medical/deficit label and are rewarded by a substantial financial grant.

The amount of additional funding obtained is often related to the so-called 'severity' of their deficits. However, many of the students felt that the support via the DSA was paramount to their success on their course. Acceptance of a 'patient' discourse is probably linked to low self-esteem; however a 'patient' discourse is often required for obtaining support within an HE institution.

There is indeed more to the lives of neurodiverse students than just their label. Recognition of this would help increase the understanding of learning differences in HE, and improve areas of support. Insights from positive psychology (Snyder & Lopez, 2007) could undoubtedly help this by encouraging neurodiverse students to explore, utilise and develop their strengths. New government targets aim to increase the population of young people at university to 50 percent. This increase will undoubtedly mean that even more neurodiverse students will be entering higher education. Whilst course delivery and assessment procedures are slowly becoming more accommodating, certain aspects of HE are still largely inaccessible. Staff awareness is inadequate, but there is a very good reservoir of knowledge in the learning support units, and better liaison is therefore needed. Projects such as the [AchieveAbility Network](#) are working on good resources for FE and the [InCurriculum Project](#) is doing the same for HE.

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