

**NENDA ANNUAL REPORT**  
**May 2005**

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Since the first meeting in December, 2003 NENDA has come a long way.

Having established a membership and formed an Executive Committee, we adopted a Constitution in April, 2004.

The NENDA web-site appeared in the summer of that year.

In March, 2005 the NENDA bank account was opened.

May, 2005 sees the first NENDA Annual General Meeting and the first elected NENDA Committee.

We began by holding monthly meetings in Newcastle.

These were soon replaced by weekly social gatherings in Newcastle and, occasionally, in Sunderland.

We have recently revived the monthly meetings, booking guest speakers to give these slightly more formal meetings a focus.

The social gatherings give individuals (diagnosed with a neurodiverse condition or not) the opportunity to meet other people with a similar condition, with similar problems, challenges, talents and interests. These gatherings have enabled people to be able to compare life-experiences, make friends and to organise spontaneous social activities.

The guest speakers we have had so far have included:-

- Paul Shattock, OBE, Director of the Autism Research Unit, Sunderland University speaking about the metabolic aspects of neurodiversity,
- Lynne Moxon, psychologist, speaking about ASDs and sexuality,
- Jackie Sochocka, Lead Officer on Learning Disability with The Northumberland and Tyne & Wear Strategic Health Authority who invited us to comment upon the draft strategy for people with autism,

- Nicola Moxon, Regional Officer for the North East with the National Autistic Society speaking about the work of the NAS in the North East of England.

In addition we have held occasional parties (summer '04, Hallowe'en and Christmas).

The NENDA web-site ([www.neurodiversity-northeast.org.uk](http://www.neurodiversity-northeast.org.uk)) has recently been re-formatted and we are in the process of adding further content and links to other useful sites.

One of NENDA's aims is to raise awareness of neurodiverse conditions and to this end we are interested in making presentations on neurodiversity to relevant organisations.

We have already made such a presentation to the Newcastle, North Tyneside and Northumberland Mental Health NHS Trust Patient and Public Involvement Forum.

This forum is facilitated by North of Tyne Patients' Voice (NoTPV), an organisation which supports eight Patient and Public Involvement (PPI) fora north of Tyne.

NoTPV has offered to organise a special meeting of several PPI fora, including those of the three Primary Care Trusts north of Tyne, with the specific purpose of enabling NENDA to make another such presentation.

We are also to make a presentation to the Newcastle Disability Forum later in the year.

We have, during the course of the last year or so, engaged with other organisations in an attempt to further the interests of neurodiverse adults.

Several NENDA Committee members are involved in working with the Disability Rights Commission (DRC) to establish a Neurodiversity Action Group. This is a significant step forward as the DRC already supports a Learning Disability Action Group and a Mental Health Action Group and, however influential or otherwise the ND Action Group proves to be, we have, at the very least, achieved recognition from a government funded national organisation that neurodiverse people are a distinct sub-group of disabled people with their own distinct needs.

We have become involved in the implementation of the Valuing People white paper on learning disability and have engaged with the Valuing People Implementation Team locally, regionally and nationally.

We have become involved with the Northumberland and Tyne & Wear Strategic Health Authority (SHA) and are involved in the re-drafting of the SHA strategy document for people with autism. We have been promised further involvement with the SHA. Whilst we welcome the SHA's attempts to address the problems associated with autism, we would like the SHA to focus on the other neurodiverse conditions.

We are in the process of affiliating to the national organisation DANDA (Developmental Adult Neuro-Diversity Association). Two NENDA Committee members are also part of the DANDA Committee.

Perhaps the most important service that we are currently able to provide is in assisting individuals towards an appropriate diagnosis. Receiving an appropriate diagnosis can prove to be an extraordinarily difficult process.

Consequently, our efforts in this area are proving to be beneficial in two ways; being not only helpful to individuals but also helping to draw the attention of the relevant NHS Trusts towards the problems of diagnosis.

We are making the case that the diagnostic pathways for adults with neurodiverse conditions are, at best, obscure and, at worst, non-existent.

### The Future

NENDA is planning to hold a National Conference on neurodiversity in Newcastle early in 2006.

We plan to publish a NENDA Newsletter.

We are interested in partnership working with other voluntary sector organisations and with statutory service providers.

We intend to publicise NENDA as widely as possible and significantly increase our membership base over the next twelve months.