

THE NATIONAL AUTISTIC SOCIETY
393 City Road, London, EC1V 1NG

MINUTES OF THE ANNUAL GENERAL MEETING

Held on Saturday 24 November 2007
at The Cardiff Marriott, Mill Lane, Cardiff

There were present: 51 Members and 12 staff

Apologies: received from 15 Members

Poll: It was declared that voting in respect of all Resolutions would include proxy votes

1. MINUTES

1.1 The Minutes of the Annual General Meeting held on Saturday 18th November 2006 were approved nem con and signed.

2. CHAIRMAN'S REPORT

2.1 Members received a report from Colin Barrow, Chairman of the Society; a copy is attached.

3. TREASURER'S REPORT AND ACCOUNTS

3.1 Alison Halsey, Honorary Treasurer of the Society reported on the audited accounts for the year ended 31 March 2007, and the report of the auditors thereon. The salient points arising from this report were:

- a surplus on the year of £1.4M on a total income of £74.4M, principally arising from additional surpluses in fee-based services, a 45% increase in overall income in the last five years – the growth had been spread relatively evenly over the education and social support services, with a small extra growth in voluntary income;
- a core income growth of 8% (reduced on a total income basis to 6% after taking into account the sale of a surplus property);
- £3.4 million was expended on capital items, including the completion of the senior campus at Daldorch School, Ayrshire and the construction of new 52-week accommodation at The Robert Ogden School. The other major spend was on providing better housing solutions for individuals at the Juniper House service in East Anglia, which property had since been handed back to the housing association owner;

- 85% of income came from fees for social support and education services, with a slightly increased percentage of 11.6% from donations and grants, and the remainder from interest (1.3%) and other sources;
- Expenditure had increased by 58% over the same five year period to £73.0M; 83.7% of expenditure being accounted for by way of providing services, 12.1% on other charitable activities (a total of 95.8% on charitable activities), 3.8% on fundraising and (as in the previous year) only 0.4% on governance;
- Despite higher capital expenditure, the charity's general funds had continued to grow in the year under report; however having built up a prudent level of unrestricted reserves, the charity was now increasing its level of investment in growth, and despite the persistent annual challenge to ensure education and social support services were properly funded by local authorities, was able to spend more confidently than in the past – consequently the target level for risk reserves had been reduced from £8M to £4M to release more money for development – cash levels and free reserves would therefore reduce over time;
- Looking forward, total projected income in the current year was £80.0M (a further 8% increase, year on year) and total expenditure £79.5M, an increase of 9%, leaving a small surplus of £0.5M.

4. ADOPTION OF STATUTORY REPORTS & ACCOUNTS

- 4.1 The Members approved nem con that the Accounts and Balance Sheets of the Society and the Reports of the Trustees and the Auditors thereon in respect of the year ended 31 March 2007 be formally adopted.

5. APPOINTMENT OF AUDITORS

- 5.1 The Treasurer reported that the Board recommended that the current auditors, Horwath Clark Whitehill LLP, be re-appointed.
- 5.2 The Members approved (99.58% in favour - 3 proxy votes against) the re-appointment of Horwath Clark Whitehill LLP as Auditors of the Society until the conclusion of the next Annual General Meeting (note: due to statutory changes, the appointment of Auditors would now cease to be a matter for the annual general meeting of Members).

6. AMENDMENTS TO THE MEMORANDUM AND ARTICLES OF ASSOCIATION

- 6.1 A poll having been declared, the following special resolutions were considered and passed by not less than 75% of the Members voting in person and by proxy (actual percentage figures are given in brackets below):
1. To alter, by Special Resolution, the Memorandum of Association to include a new clause 9 as follows:

9. *Nothing in this constitution shall authorise an application on dissolution of the property of the charity for purposes which are not charitable in accordance with any statutory provision in force in any part of the United Kingdom. For the avoidance of doubt, the system of law governing the constitution of the charity is the law of England.*" (99.58%)

2. To alter, by Special Resolution, the Articles of Association as follows:

To amend the heading immediately before Article 90 to read:
NOTICES AND OTHER COMMUNICATIONS (99.15%)

To amend Article 90 to read:

The Society may, subject to the requirements of the Companies Act 2006 (as may be amended), communicate with Members electronically and may send or supply notices, documents or other information to Members by making them available on a website. Any notice to be given to or by any person pursuant to the Articles shall otherwise be in writing and delivered to the registered office except that a notice calling a meeting of the Directors need not be in writing. (97.88%)

To amend Article 91 to read:

Subject to any statutory constraints, the Society may give notice or provide any document or information to a Member either personally, electronically (including by way of making it available on a website) or by sending it by post in a prepaid envelope addressed to the Member at his registered postal address or by leaving it at that address. A Member whose registered postal address is not within the United Kingdom and who gives to the Society an electronic address or a postal address within the United Kingdom at which a notice document or other information may be given to him shall be entitled to have it given to him at that address until that permission is changed or withdrawn by the Member, but otherwise no such Member shall be entitled to receive any notice from the Society. (98.02%)

To amend Article 93 to read:

Proof that an electronic message containing a notice document or other information was properly addressed or that an envelope containing such was properly addressed, prepaid and posted shall be conclusive evidence that the notice document or information was given at the expiration of 48 hours after the electronic message was sent or the envelope containing it was posted. (96.89%)

To add a new Article 94 (and to renumber existing Articles 94 and 95 to 95 and 96 respectively, as follows:

Any notice document or information sent or supplied electronically by a Member to an electronic address specified for that purpose by the Society shall be validly sent or supplied. (98.02%)

The poll was formally closed.

7. MEMBERS' QUESTIONS

- 7.1 Garry Williams, a Member from Windsor, suggested that there was always a debate to be had as to whether it was better to buy or to lease property out of which services were to be operated, with some people being inherently suspicious of leasing. He asked whether the trustees had views on this. The Treasurer replied that it was an important question. She was aware that it had for many years been the custom of the charity to own much of the property it used, and that was still the case, but perhaps decreasingly so. Her view was that the charity needed to be open-minded about the issue, and to review critically the relevant facts and circumstances upon each occasion. Colin Barrow, Chairman, agreed saying that there was no doubt that the decision of previous trustees to purchase buildings for schools and adult residential care services had served the charity very well indeed, but there were risks inherent in purchase, by mortgage or outright, just as there were risks in renting or leasing. He agreed that the touchstone should be to explore on each occasion what was the best way to improve services to people with autism, whilst at the same time seeking to ensure stability and security for the future.
- 7.2 There being no further questions of a financial nature, and before seeking general questions from the floor, the Chairman reported receipt of one written question, from Elizabeth Hugo, a Member from Harrow, who asked:

Could the Chairperson and Committee describe any action currently being taken or planned to be taken, by the NAS or its affiliates or other providers to promote awareness of the difficulties and needs of adults who have Asperger syndrome or High Functioning Autism, or to secure provision to meet those needs.

The Chairman responded that the recently launched *Think Differently About Autism* campaign aimed to raise general awareness of autism and used people living with autism to get the charity's messages across. It covered all age ranges, and a number of the spokespeople were individuals with Asperger syndrome, or what was known as high functioning autism. The second stage of the campaign, being launched in February (slightly later in N. Ireland) would focus specifically on the social care and health needs of adults with autism, including those with Asperger syndrome/High Functioning Autism. The aims of the campaign were based on information received from adults with autism and their families/carers, 1700 having replied to the survey of Members asking about their experiences. Local Authorities and PCT's had also been surveyed to see what action they were taking to provide services for adults, as well as in-depth interviews with adults having been conducted in order to inform the campaign messages.

- 7.3 The Chairman added that no one should be left with the impression that the charity preferred one sub-group over another, but it had to be recognised that maintaining equality was a difficult course to steer, as what was true about one sub-group was not true about another. This might seem at first sight to be a valid argument for splitting the charity into two (or even several) different charities. However, the reality was that the majority of individuals fitted neither into a "high functioning" group or a "low functioning" group, but were in-between – indeed they often and perhaps regularly

switched from one to another, dependent upon internal and external influences. The charity had recently agreed that it was important to stay as one, representing the whole spectrum, and there was no intention of revisiting that decision, nor of favouring one group above another.

- 7.4 Elizabeth Hugo, being present, said that she had raised the question because it was apparent that local authorities would not willingly make provision for individuals with Asperger syndrome and her local NAS branch was not interested in campaigning for the needs of individuals with high functioning autism. She had consequently felt the need to set up another pressure group. Larry Arnold, a Member from Coventry (also a trustee, and a person with Asperger syndrome) applauded this initiative, saying that he believed this was exactly how it should be – the more people that were campaigning the better, and it was often more weighty when parents and individuals with autism made their points themselves than when a large organisation did; the key was to collaborate and ensure messages were consistent and therefore strengthened, rather than weakened by being divergent. Local authorities would inevitably play off one against another if given the opportunity.
- 7.5 Another Member said that she had two sons with Asperger syndrome, both of whom had been excluded from school as young teenagers; she had had to fight for any support and the impact on the rest of the family had been very severe, including on a sibling daughter who had dropped out of education as a consequence. The lack of services at an early stage not only created a huge problem for individuals and families at the time of acute need, but also created a chronic and often wide-ranging problem later. The Chairman agreed that this was exactly the issue – the lack of effective intervention led not only to family disruption but often to mental health issues, resulting not only in serious personal cost, but also potentially enormous long-term financial cost to the state. This was a message the charity was determined to get across to central government, local authorities, PCT's, and Health Trusts – at present many still seemed not to understand there was a problem, let alone prepared to do something about it.
- 7.6 Elizabeth Hugo said that she felt that the 2002 NAS report *Ignored and Ineligible* had gone some way to creating an understanding and asked if the campaign would follow-up on that. Benet Middleton, Director Communications, said that the adult campaign would be driven by those considerations, and the report to be launched in February would build on that earlier report – it looked across the spectrum, but very much acknowledged that many higher functioning individuals fall through the gap between care and mental health services.
- 7.7 Another member with Asperger syndrome said that he accessed a local Alcoholics Anonymous group, not because he was an alcoholic, but in order to gain the support he felt he needed to avoid becoming one, in the absence of a proper service addressing his needs as an adult with autism.
- 7.8 Another member with Asperger syndrome said that the new era of person-centred and individual-driven care had important implications for the charity. His condition was not relevant to a mental health service, in which he was expected to be treated and get better – he didn't and wouldn't "get better". He firmly believed that individuals like him needed to be supported to support themselves. The Chairman agreed and said that

the Society did seek to influence and educate decision-makers and professionals to ensure that individuals with autism did not inappropriately become clients of mental health services, and to make the point that if such individuals did not get the support they needed, there was strong evidence to indicate that many would by default suffer illness as a result not of their autism, but of being failed by the state.

- 7.9 Garry Williams made the point that the government was abolishing patient and public forums, substituting a much looser consultative process called Links, whilst at the same time the central regulator for registered social care, the Commission for Social Care Inspection, was being wound up and absorbed into yet another quango. Both measures were being heralded as advances, but it was difficult not to conclude they were cost-cutting exercises that could lead to less consultation and prejudiced quality. A close eye needed to be maintained.
- 7.10 John Kedar (a Member from Berkshire, and a trustee) made the point that Branches could be assisted to evolve and develop their services to families in their locality, and to campaign, by regional staff. Certainly this happened in his locality and he hoped that all regional officers saw supporting branches as a priority. The Chairman agreed, adding that it was certainly the intention of trustees that this should be the experience of volunteer members nationwide. To this end the trustees had recently approved a major investment to ensure regional teams were strengthened on the ground.
- 7.11 Sharon Jones, a Member from South Wales and a NAS councillor for Wales, said that it was good to hear that the number of salaried regional staff was being increased, but she agreed with the earlier statement that parents must not rely unduly on others. When her severely disabled son was newly diagnosed many years previously, professionals said that he was the only child with autism known to them. She had made it her business to prove them wrong. Parents should not leave everything to staff, but work with staff through the branch network – often parents could say and do things with an intensity and conviction that was not possible for salaried staff.
- 7.12 A local Cardiff member said that he had real problems getting a diagnosis for his son and wondered if this was still a general problem, and if so what was being done about it. Vernon Beauchamp, Chief Executive, replied that this was much less of a problem than it was, but when it was experienced individuals needed to ensure that the NAS was informed in order to ensure appropriate pressure was applied. The ideal however was to move towards a position where services were built on needs, not on a diagnosis, in order to ensure that individuals were not inappropriately excluded, as was currently the case. People did move across the spectrum and a label could prove as much of a hindrance as a help. That said, he recognised that getting a diagnosis, even sometimes an incorrect one, was often the only gateway to getting any services at all. The Member agreed, saying that it seemed that individuals in residential care got all the help they needed, but there was very little for those who lived independently.
- 7.13 The Chairman said that it was certainly not the case that individuals with Asperger syndrome did not need residential support; many NAS services included individuals with a diagnosis of Asperger syndrome or high-functioning autism, and there were supported living flats in Lancashire, Cambridgeshire and elsewhere – indeed trustees had just approved the development of further “move-on” accommodation from Hayes Hospital (Bristol) to a community based and more independent model of care.

- 7.14 Russell Stronach, a Member from Tyne & Wear, a trustee and a person with Asperger syndrome, said that he felt the language of high and low functioning was unhelpful, as it forced people to think in terms of poles, forgetting that autism is a spectrum condition – there was an enormous variety of individuals who had a diagnosis of Asperger syndrome. Such language was potentially divisive, but more importantly it tended to make people forget about the many in the middle, quite apart from the fact that a very significant percentage of individuals with autism responded to stimuli and moved frequently from one sub-group to another.
- 7.15 A Member asked if work was being undertaken to create a better understanding amongst decision-makers of the entitlement of individuals with Asperger syndrome to benefits. Benet said that his team was well apprised of the need and the adult campaign would increase an existing focus on educating decision-makers. Also, a new Welfare Rights Adviser post had just been created at City Road, and families could book an appointment to discuss issues with him, by their preferred form of contact.
- 7.16 There being no further questions, the Chairman spoke about the recent flurry of correspondence in the Independent, originating from a letter from *Treating Autism*. The issue of biomedical interventions was one that created high emotions and was potentially divisive, and he wanted Members to be aware of the charity's position. There were a lot of people in, particularly, America who believed in a chemical solution to autism – that treatment ranging from the application of vitamins to the removal of heavy metals by way of chelation, held the key to a cure. At the other extreme there were those who firmly believe that autism should be prized and valued, and not extinguished. In between there were hundreds of thousands of individuals and families for whom the impact of autism ranged from being either not entirely negative to not entirely positive – for whom autism involved a varying degree of physical and/or emotional pain. All deserved to have authoritative information about which interventions and treatments worked and which didn't work, and where they worked for some, the probability of them working for any given individual, so that an informed decision could be made as to whether or not to pursue a particular intervention. The NAS was not a medical charity, and didn't have the resources to gather or the expertise to evaluate the evidence in order to form its own opinion. It had therefore set up Research Autism, which was dedicated to gathering and disseminating relevant academic and scientific research. That was all that the NAS could reasonably do. He appreciated that such a stance would not please everyone, and sought views.
- 7.17 Larry Arnold said that he agreed that was an appropriate stance for the NAS; it was essential that the Society did not add its voice to those who were prepared to rely on anecdotal evidence and poor science.

There being no further observations or questions, the Chairman brought the formal part of the meeting to a close.

AFTERNOON SESSION

The afternoon session was introduced and chaired by Vernon Beauchamp, Chief Executive.

Jane Hutt, Welsh Assembly Minister for Children, Education, Lifelong Learning and Skills gave Members a brief outline on how the Assembly was developing its powers and on the implementation of the All Wales Autism Strategy, which she initiated when Minister for Health and Social Services (1999-2005) and which was currently awaiting publication. This recognised that the issues related not just to education, but equality of access to whole life opportunities, so that every individual with autism in Wales would be enabled to achieve his or her full potential. The Minister also drew Members' attention to the work the Assembly was doing with regard to teacher training, before seeking questions.

A local Welsh member said that his son's local school had no understanding of the nature of autism, but that he had been fortunate enough, after much personal research, to find a school in Cardiff where his son had since made remarkable progress. However, the attributes of the school (which he named) appeared not to be well known, nor was there any apparent sharing of best practice across Cardiff, yet alone the whole of Wales. The Minister replied that she was not aware of the school's expertise, but would make enquiries; she agreed that the sharing of good practice was an issue for the Assembly.

Genevieve Edmonds, a person with autism, who had been hoping to give a talk entitled *Living with Asperger Syndrome*, was indisposed and unable to attend.

Marie James, who lives in West Wales, is a member of the Welsh Assembly's Cross Party Group on Autism and a very active member of the Carmarthenshire NAS Branch, then gave a *Parent's Perspective* on the life of and with her son, now aged 21, who has tuberous sclerosis (a genetic disorder characterized by abnormalities of the skin, brain, kidney, and heart), and autism – the latter being the major barrier to her son's development, particularly as he was brought up in a Welsh speaking family and environment. One point that Marie made strongly was that whilst she agreed with what the Minister had said with regard to the value of and the need to focus resources on, early intervention, access to early intervention services could only be via a formal diagnosis, and getting a diagnosis in Wales was extremely difficult when her son was young, and to her knowledge still was. The family had also suffered, as she knew had many others, from the dogma of inclusion and the associated closure of special schools. Getting the support to which her son and the family needed, and to which they were entitled, had proved an almost constant battle.

Joe Powell, a service user from the NAS adult residential service in Newport, spoke about his autism, and how it did and did not affect him, recognising that all individuals with autism were different. He had gone through a long period as a young man when he was almost mute, but with support he had been able to develop his own personality and capabilities. He gave a most entertaining talk about his life.