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

MINUTES OF THE ANNUAL GENERAL MEETING

Held on Saturday 27 November 2021
Via Video Conference

There were present: 45 Members

1. WELCOME AND ADDRESS BY THE CHAIR OF TRUSTEES

1.1 Dr Carol Homden CBE, Chair of Trustees, welcomed members to the AGM. Introducing the meeting, she said that after 10 years as chair of the board, this would be her final AGM but she was delighted to be able to introduce her successor, Dr Steve Ladyman.

1.2 Dr Homden gave a presentation reflecting on her 10 years in office. She made the point that her personal experience with her autistic son, from battling to secure school placements to finding the right provision for him as an adult, had underpinned her work. Her son is now supported by the NAS to live with as much independence as possible and is proud of his relationship with the charity.

1.3 Carol had joined the NAS just after the pioneering Autism Act had been passed and in time for the Society's 50th anniversary celebrations in 2012. In the 10 years since then, particular highlights had included:

- Building on Sybil Elgar's pioneering work in education by opening the first autism specific school in the 1960s, we had set up the NAS Academies Trust and opened three new free schools,
- We had developing the Autism Education Trust and campaigned to ensure that teacher training includes information about autism,
- The *Too Much Information* campaign had been a major success with films that were watched by 65 million people,
- Other initiatives included the introduction of:
  - Autism Friendly performances at theatres and cinemas,
  - World Autism Awareness Week,
  - Autism Hour for stress-free shopping,
  - The Autism Friendly Award for organisations that take the needs of autistic people into account.
- New channels to access information about autism had been developed with almost 5 million visitors to the website in the year.

1.4 Fundraising is a continuous challenge but significant progress had been made to increase individual giving while other initiatives ranged from sponsored bike rides to the Spectrum Ball. However, the funding was never sufficient to do everything we would like to do.

1.5 Most autistic children are educated in mainstream settings and with generous support from Peter Cullum we have been able to open three ‘Cullum Units’ at mainstream schools with two more under development. These provide the resources and support that allow autistic children to thrive while attending mainstream schools.

1.6 88% of our adult services are rated as good or outstanding by the regulators but maintaining and improving our services is a never-ending journey. We have successfully transitioned older, more traditional residential services to provide supported living in the community and we continue to develop services across all the UK nations. Nonetheless, given the financial pressures on local authorities, we face significant challenges to maintain and develop these services.

1.7 Branches play a key role in providing practical support and advice to autistic people and their families and we now have 116 branches that support some 17,600 people. One result of the Covid lockdown is that we now have virtual branches, including one that supports the Highlands and Islands in Scotland.

1.8 Looking ahead, the Autism Strategy for England promises to build on the Autism Act with funding to support diagnosis services, improve the public’s understanding of autism and to help move autistic people who are in inappropriate mental health hospitals to move out.

1.9 So, there is much to do but Carol thanked everyone for their support over the years and was now delighted to introduce the faces of the future and to wish everyone a successful 60th NAS anniversary.

2. PRESENTATION FROM THE CHIEF EXECUTIVE

2.1 The Chief Executive, Caroline Stevens, gave a presentation highlighting the successes and challenges of the past year. These included:

- Under the heading of ‘Transforming Lives’, the 2021 family survey had shown very high levels of satisfaction with NAS services.
- Conscious of fewer opportunities to exercise during the Covid lockdown, staff in adult services had organised the Spring Forward Challenge with 62 million steps walked. This was followed by a Summer of Sport, picking up the Olympics theme.
- Schools had done an amazing job through the pandemic with schools staying open but supporting students at home when necessary.
- Clear information relating to Covid was provided to autistic people and their families, both through the website and via branches. The specially designed Coronavirus website hub received over 600,000 visits.

- We worked to ensure that governments across the UK and major supermarkets understood the difficulties that some autistic people have with masks, noting their exemption from having to wear one.
- Following our *Left stranded report*, 11,326 people signed our letter to the Chancellor, calling on him to invest in support and services for autistic people.
- We set up a new Autism Inpatient Mental Health Casework Service.
- We helped persuade the Government to change the definition of 'mental disorder' in the *Mental Health Act* so it no longer includes autism.
- Our campaigning led to the Scottish Government committing to improving teacher training and autism awareness.
- World Autism Awareness Week went virtual and Training and Conferences moved online, both proving to be very successful in that format.

2.2 Summing up and referring to the upcoming anniversary, Caroline said it had been an extraordinary 60 years but the task now was to make the next 60 count.

3. MINUTES AND RATIFICATION OF NEW TRUSTEES

3.1 Moving on to the formal part of the meeting, the Chair invited those members who were present at the AGM held on 23 January 2021 to confirm via their online voting form that the minutes of that meeting represent an accurate record of the meeting. This was done and the minutes were approved.

3.2 The chair then invited the four new trustees to introduce themselves, noting that their appointments had followed a rigorous and thorough recruitment process and that all trustees are unpaid volunteers.

3.3 Introducing himself as the new chair elect, Steve Ladyman thanked Carol for all her hard work over the past decade. He referred to his experience as a Member of Parliament, during which time he had become aware of the difficulties that parents of autistic children in his constituency had had to battle through to obtain the support and education that their children needed. Talking to colleagues in Parliament, he had realised how common such cases were and had set up the All Parliament Parliamentary Group on Autism. After leaving Parliament, Steve had gone on to chair health authorities in Somerset and Wiltshire and his aim now was to build on the legacy left by Carol.

3.4 Each of the other prospective new trustees said a few words to introduce themselves.

- Olga Clayton lives in Scotland and has an autistic nephew. Her career has been focused on homelessness and the provision of housing and as chair of the NAS Scottish Reference Group, she will pressure the Scottish government to ensure that its commitments on autism support to the Scottish people are delivered.

- Sheila Norris is a consultant in social care, having previously worked in the Treasury and in local government, giving her a wide experience of the challenges in the social care sector. She has an autistic daughter who is now a young adult and would now like to support other parents and families.

- George Davidson has spent some 25 years in marketing and market research and has also been a deputy leader of a council and a director of an ambulance trust. He has an autistic son – the only one in his school class.

3.5 The chair commended these additions to the board and asked members to vote to ratify their appointment. This was done and the appointments were ratified with one vote against and one abstention.

4. PRESENTATION OF THE ANNUAL REPORT AND ACCOUNTS

4.1 Edward Caddle, Chair of the Plans and Resources committee, gave a presentation on the audited accounts for the year ended 31 March 2021. He introduced his report by described the year as having been extraordinary, thanks to Covid and the challenges the pandemic presented. The NAS had successfully navigated its way through these and remained financially strong. However, significant challenges lie ahead and difficult decisions are required now.

4.2 In common with other organisations that provide adult social care, staffing is becoming more challenging. We are dependent on the local authorities that provide the funding for adult social care and while the costs associated with the minimum wage and national insurance are set to rise, local authorities are struggling with their budgets. As well as staff costs, we also need to continue to invest in our properties to ensure they are fit for our service users to live in.

4.3 Edward confirmed that the NAS continues to be solvent with sufficient cash and reserves. Income and expenditure were both down when compared to the previous year but it should be noted that the results for the NAS Academies Trust are included. However, any NASAT reserves are ‘restricted’ and are not available for the NAS to invest in other areas. Excluding NASAT and one-off sales of properties that were no longer required, the NAS accounts show an operational deficit of £0.7m. Total assets had reduced over the year by £3.1m.

4.4 Looking forward, we anticipate further constraints on our income while costs are rising. To tackle this situation, we will:

- Optimise fundraising, legacy and grants.
- Review our operating model for Education and Adult Services
- Pursue continuous efficiency and cost reduction programmes.
- Reduce central costs through the leadership team and development of a shared service centre.

- ‘Sweat the assets’ by disposing of surplus assets and making best use of those we retain
- Invest in technology.

4.5 The chair thanked Edward and the members of the Plans & Resources committee for their work.

5. MEMBERS’ QUESTIONS

5.1 Several questions had been received ahead of the meeting and responses had been sent to the members asking the questions. Any questions that could not be answered during the course of the meeting would receive responses subsequently and all questions and answers would be posted on the website.

5.2 Questions asked during the meeting were:

Q. How was the crisis across the social care sector affecting the NAS?

A. Caroline Stevens agreed that the crisis in social care is becoming acute. She had met with the Secretary of State for Health and Social Care and along with other charities the NAS is campaigning to draw attention to the need for action. There is no doubt, however, that the coming months will be extremely challenging.

Q. Did the pressure on costs mean that the NAS was using volunteers to compensate for staff shortages?

A. Edward Caddle confirmed that while volunteers are highly valued, they are not professional staff and cannot be used as a replacement for trained and qualified staff members.

Q. Is the NAS involved in the work that is going on regarding autism and genetics?

A. Caroline Stevens said that it is known that there is a genetic element to autism and the NAS supports research but only provided it is of high quality, is respectful of autistic people and is co-produced with autistic people. Specifically, the NAS is not involved with the research programme recently announced by the Institute of Neurodiversity.

Q. Could Steve Ladyman please say more about his direct experience of autism?

A. Steve explained that as a Member of Parliament and as Health Secretary he had come across many autistic people. He found that during his constituency surgeries he would regularly meet parents of autistic children with massive files documenting their battles to get the services and support their child needed. Talking to colleagues he realised that this was going on all over the country and it led him to work with the NAS to establish the All Party Parliamentary Group for Autism. This in turn had introduced him to more autistic people and to professionals working in the field, an experience he had found to be inspiring.

After leaving Parliament Steve had chaired the NHS Foundation Trust in Somerset which had responsibility for autism services.

Q. A member observed that the level of debtors shown in the accounts had increased and wondered why this was.

A. Responding, Edward Caddle said that the accounts provide a snapshot as at 31 March so the figure might not be typical. He would, however, look into the question further and would provide a more detailed response off-line.

Q. Environmental issues are now a high priority for everyone and how was the NAS responding?

A. Carol Homden agreed with the point made, saying that all organisations, including the NAS, would increasingly need to be aware and to manage their environmental footprint.

Q. A member noted that there is a trend for celebrities to declare their connection with autism and was concerned that they are doing this to enhance their own careers, not to further the cause of autistic people. What is the NAS' view?

A. Carol Homden said that the NAS works with a number of people who have a public profile and these 'Autism Ambassadors' can be very helpful in getting messages across to members of the public who might otherwise not be interested. However, it is important to ensure that the profile of the NAS is not compromised by that of any individual. In this respect, the 60th anniversary celebrations will provide opportunities to promote the image and reputation of the Society.

Questions related to Scotland:

- **Why was there no autism hour in Aberdeenshire this year – I know they hold them in other areas of Scotland?**
- **Why has the national Autistic society not had any easy read information about autism for autistic adults on independent living or travel training?**
- **Why has the national autistic society not done any course about autism specifically for autistic adults rather than just for professionals?**
- **Why has national autistic society missed out on holding events in Scotland – they seem always to be in England**

- **Will we get any events in Scotland to celebrate the NAS 60th birthday?**

A. The Autism Hour had to be paused across the country during 2020 because of Covid. A statement on this was published on the website: (https://www.autism.org.uk/what-we-do/news/pausing-autism-hour).

We provide a range of services and activities for autistic people and families in Scotland which can be accessed wherever you live in the country. The key ones being:

- Online social groups - our programme of groups support more than 200 children, young people and adults each week by helping participants build social navigation skills, confidence as well as build friendships.
- Post Diagnostic Support programme - this supports young autistic people who have recently been diagnosed to better understand what that means and develop strategies and confidence accordingly.
- Education Rights & Transition Service - this provides case work directly to families struggling to get support for their sons and daughters in schools or who may be facing difficulties making the transition from school and collage into adult live.

We also have 15 volunteer led branches across Scotland providing localised support to autistic people and families. Unfortunately, we do not have one in Aberdeen.

In addition, we also offer a number of services in specific geographic areas including; information, advice and guidance services in Ayrshire, Glasgow and Highland, employment support in Glasgow as well as adult social care in Glasgow, parts of the central belt and Ayrshire.

There are more details about our services in Scotland here: https://www.autism.org.uk/what-we-do/scotland.

Questions relating to ageing and autism:

- **What is the NAS' policy towards the care of the elderly with ASD and when is and ASD person considered elderly?**
- **How many elderly autistic people are there and what is the average age at death and the main causes of death?**
- **What is the attitude of the NAS towards the promotion of the Personal Welfare Deputy provisions of the Mental Capacity Act 2005? How many PWD Orders have been made to the date of the AGM?**
- **Can the NAS publish the names of lawyers who actually are familiar and experienced with the work of the Court of Protection and can act for parents; and the range of costs applicable thereto?**
  - **What action is to be taken on the June 2019 decision of the CoP that the Guidance Code shall be revisited? Has the Code been**

revisited and with what result? And to which staff member enquiries re ageing etc should be addressed?

- **Whether it is proposed to republish the Scottish Society's booklet on dying? And update it? There seems to be no reference to dying or death on the NAS website.**

A. These are important questions as many people who have received an autism diagnosis approach older age. Due to a historic lack of NHS data collection, an issue on which we have been campaigning for several years, it is not possible to know everything about older autistic people's health yet. However, emerging research appears clear that autistic people across the spectrum are at significant risk of dying prematurely, often because their needs are not understood and met.

The National Autistic Society is involved in a research study with Newcastle University, which is hoping to design an intervention to support older autistic adults' health needs. This is funded by the Inge Wakehurst Trust. We hope to have the full findings of the research next year and we will be using the findings to influence the NHS. With a new autism team in the NHS looking at health inequality, this will be an important opportunity to make sure that autistic people of all ages are included in the team's work. In the meantime, the NAS attends key meetings in NHS England to check progress on work to tackle health inequality and will make sure that the issues of older autistic people are raised.

We support the use of Personal Welfare Deputyships and know how important they are for autistic people who lack capacity, whether that is financial deputyship or welfare. Our Policy Team has been monitoring an important legal case on the issue of Welfare Deputyships. We were not directly involved in this case as we did not have the particular insight on which the legal team needed evidence, but we were supportive of its overall aims.

The Government plans to refresh the Code of Practice to the Mental Capacity Act, though this has now been delayed several times. We have worked as part of the Complex Needs Consortium to engage with DHSC about this Code of Practice, which will also be important in implementing the new Liberty Protection Safeguards. We will take part in this consultation on the new Code of Practice and will promote it to our supporters.

We do not have access to data on the number of welfare deputyships to autistic people.

The legal profession is vast and so compiling a comprehensive list of specialists on individual topics is impracticable. There are many solicitors listed on our Autism Services Directory and the Law Society's website has a very useful search function. There are a number of legal experts in the area, such as barristers Alex Ruck Keene and Tor Butler Cole.

I am afraid we are not in a position to be able to indicate costs, though we do know that legal action can be very costly.

Enquiries about ageing can be directed to Tim Nicholls, Head of Policy.

In relation to advice on ageing and dying on the NAS website, we have an established process to review all available evidence in order to then build our online guidance. Given the limited resources of the organisation, we have to prioritise which topics will be addressed first, balancing people's need to know and demand. Reviews into ageing and death and dying are currently planned for 2023/24. We are currently focusing our resources on online information and guidance, which our audience insight tells us is what our supporters want to see more of.

We do not currently have plans to republish previous booklets.

Q. I am a parent of an autistic child in Northern Ireland. What priorities does the NAS have for Northern Ireland over the next year and beyond?

A. We have recently opened a new Day Centre in Northern Ireland and we would like to do more but it is a case of working within the resources we have available.

Q. I note that the organisation is working with EY and others to support Autistic staff. Is this to address their needs in any role, or is it to put Autistic people in some separate area?

A. We work with employers to raise their awareness of the needs of autistic employees so that they can then employ more autistic people. It is not intended that autistic employees will be separated away from other employees.

Q. I have a daughter aged 23 with Aspergers. On applying for many jobs nowadays, applicants have to complete an online questionnaire as the first part of the process. These contain questions clearly set by neurotypical individuals and are marked by an IT programme. Despite her intelligence she is repeatedly rejected by these companies which she believes is due to the way in which she thinks differently and answers questions from an autistic perspective. She feels this is a form of covert discrimination. Does the NAS have any experience of this and how to approach a solution?

A. This is indeed a known problem and is one that the NAS is addressing both through its Employment Support and more generally though its campaigning to raise awareness of autism and the needs of autistic people. The 'Too Much Information' campaign highlighted this specific issue but of course change comes too slowly and many employers are following practices that discriminate against autistic people.

Q. Closure of the helpline is already putting pressure on our branch. We are trying to recruit more volunteers, but this is challenging.

A. The NAS had little option other than to close the general helpline as it became increasingly challenging to fund it. Other, more specialist helplines, such as the Education Rights helpline, have remained open because they are supported by specific funding streams. That said, we have placed much more information online and while this is not the same as speaking directly with someone, it does mean that all the information is available. We very much appreciate the work that our branches are doing to provide direct support at the local level.

Q. Some BBC radio 4 programmes on "File on 4" (broadcast in 2019/2020) have reported considerable mistreatment of people with autism. Have the board of trustees discussed these programmes.? What action, if any, has the society taken, to support people in these circumstances?

A. This is an incredibly important question. It highlights the scandal in mental health support for autistic people and it is one of our charity's most important campaigns. In 2011, BBC's Panorama uncovered shocking abuse in a kind of mental health hospital called an Assessment and Treatment Unit. Further investigation also highlighted that these inpatient mental health units weren't appropriate for autistic people and people with a learning disability but too many people were stuck in them, often for years. The Government pledged through the Transforming Care programme to change this and reduce reliance on these hospitals.

However, their progress has been far too slow and there has been no significant reduction in the number of autistic people in these units. In fact, the proportion of people under Transforming Care who are autistic has increased. This is something that we have highlighted in our campaigning for several years.

Wherever possible, autistic people should get the mental health support they need in their own community. If someone falls into crisis and is admitted to hospital, it is essential that this is delivered by staff who understand autism - and in an environment that meets their needs – and for as short a time as possible.

Three things need to happen:
1. Make sure there are enough services in the community. There are not enough services in the community to meet the needs of autistic people. This means autistic people develop more significant needs and often mental health problems like anxiety or depression. Without mental health support that understands autism, many people reach crisis point. At that point, there is currently not enough support available other than being admitted to hospital.

2. Make sure the money is available for community services. At the moment, if you are treated in a mental health hospital your care is paid for by the NHS. If you move to somewhere in the community, councils generally need to take on the cost of your care. But many councils don't have the services or funds. This means there is a problem with how places are funded at the moment: to get someone from the wrong care to the right care means that the funding needs to be moved with them.

3. Make sure mental health law reflects the needs of autistic people. The overwhelming majority (90%) of people under Transforming Care are detained in hospital under the Mental Health Act 1983. This Act defines autism as a "mental disorder", meaning that autistic people can be detained when they do not have a treatable mental health illness. This puts them at greater risk of over-medication and restrictive practices. Often as a result of being in environments that are inappropriate, their behaviour escalates due to their distress, which results in further restrictions.

Following our campaigning, alongside many others, the Government has committed to amend the Mental Health Act so that autistic people cannot be sectioned long term just for being autistic. It has also committed to creating a duty on commissioners to have enough services in each area. We will keep putting pressure on the Government to make sure these things happen when the new Mental Health Act goes through Parliament next year. We are also part of key accountability meetings chaired by the Care Minister to make sure progress is made in getting autistic people out of hospital.

It is not only through our campaigning that we need to end this crisis. Last year, we set up our new Autism Inpatient Mental Health Casework Service. This advice service provides in depth support to families of people in inpatient units to help them challenge decisions and work towards discharge. This new service is under great demand and we are pleased that we have just secured two more years' funding for it from NHS England.

Q. The NAS is increasingly moving its activities and information on line and this is disadvantaging those who are not computer literate or who choose not to use computers. What can the NAS do about this?

A. By providing information online we are able to support many more people than we can reach on a face to face basis, wherever they live. This has been particularly true over the past 18 months with the impact of the Covid pandemic and restrictions on face to face meetings.

We do, however, also have a network of 117 volunteer run branches so that people can access face to face support in their local area. These branches provide a range of services, including social groups for adults.

The NAS has limited resources and it's always necessary to prioritise how we spend our money in order to meet as many needs as possible with the resources available. While we recognise the importance of face to face support and will maintain it wherever possible, it is also critical that we reach as many people as possible and there is no doubt that online services allow us to do this.

6. THANK YOU TO CAROL HOMDEN

6.1 Bringing the meeting to a close, Caroline Stevens read out a letter from the charity's patron, HRH The Countess of Wessex, expressing the Countess' appreciation for everything that Carol had done for the NAS during her time as chair. This was followed by a short film in which the NAS President, Jane Asher, also conveyed her thanks and appreciation.

6.2 Carol then said a huge thank you to everyone who had supported her through her time as chair, saying it had been a great privilege but she had been supported by a terrific team and she had been inspired by autistic people and by her fellow trustees.

6.3 The meeting was then closed.