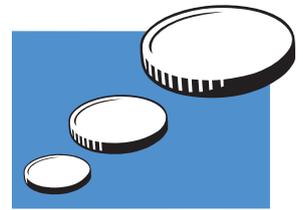


Changing lives



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A report on the autism voluntary sector

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The Clothworkers' Foundation

Changing lives

A report on the autism voluntary sector

Executive Summary

Over the past three years the autism sector has seen considerable changes in terms of: policy, funding, and within the sector itself. This report looks at these changes and explores the implications of this new environment for people with autism, autism charities, and funders looking to support and improve the sector.

Changing policy

The autism sector has seen several major breakthroughs, not least the Autism Act 2009 and the adult autism strategy. Government departments are paying more attention to the needs of adults with autism and awareness of the condition has grown.

The key question is what happens next. Autism charities are worried that weak guidance for local authorities and no new money for implementation means that the autism strategy may well fall down local government's list of priorities and jeopardise the strategy's potential to improve services for adults with autism.

Changes to other mainstream policy issues will also have an impact on people with autism. For example, over a third of autism charities that responded to our survey think academies will have a negative effect on education provision for children with autism, and only 9% think they will be positive. Charities are concerned that some children with autism will not get the specialist support they need and are at greater risk of being excluded. Even in mainstream schools, the government's plans to take a tougher stance on poor behaviour may penalise children with autism, especially where they have not secured a diagnosis or an official statement of their special educational needs.

Changing funding

Autism charities are feeling the squeeze as local government commissioners attempt to cut costs and reduce fees charged to deliver services, such as residential homes or specialist schools. The government recently announced in the Comprehensive Spending Review that cuts to local government funding will amount to at least 25% over the next

four years. The autism charity sector relies heavily on local government funding and so it will not escape unscathed. Nearly half of the charities surveyed for this report expected some decrease in their fee income, with 18% expecting over a third of their income to be cut next year. In some cases, this may force charities to close down altogether. One regional autism charity—the Sussex Autistic Society—has already become insolvent and our survey showed that at least another four organisations fear bankruptcy in the next year.

Changes to commissioning are adding further instability. The shift to GP-commissioning and the personalisation agenda, for example, are shifting commissioning away from large contracts towards more market-based models based on local area priorities or individual needs. Charities may be forced to completely restructure their services and develop new funding models to cope with potentially fluctuating demand.

These cuts and the added uncertainty will translate into tougher times for adults and young people with autism. 37% charities surveyed expect to cut front-line services in the next 12 months. Particularly vulnerable are services on the borders of government's funding remit, such as play and leisure services and respite care. These services often make the most difference to the quality of life of people with autism and their families, yet Aiming High for Disabled Children, a key funding stream in this area, looks set to end early next year.

A changing sector

Policy and funding are not the only areas that have seen changes. There have been many positive changes in the autism voluntary sector itself. People with autism have become more involved with the development of policy and services around their condition. The development and use of research is being encouraged, with many service-delivery charities more interested in the efficacy of their approaches. Autism charities have forged closer relationships with more partnership

working, particularly around the Autism Act, which has served as a rallying point for a historically fragmented sector.

However this progress may be put at risk by the funding cuts. Increased competition for contracts, for example, could undo some advances in partnership working. And long-term goals that build the capacity of the sector tend to be the first to go when money is tight and as more immediate goals take priority.

Priorities

Funders and charities need to work strategically to overcome some of the pitfalls that lie ahead and take advantage of the opportunities. In particular there are five main areas for funders and charities to think about:

- 1. Adapting to a changing environment:** charities are reassessing their financial models in light of the new funding and policy context. Funders can smooth this transition by funding core costs—giving charities valuable breathing space and time to adapt.
- 2. Maintaining lobbying work:** both nationally and also at local levels, where a push towards localisation is increasing the role of local authorities in developing and delivering government policies.
- 3. Networking and sharing good practice:** charities and funders need to continue to prioritise activities that allow the sector to come together and exchange ideas.
- 4. Developing pilot projects that fit with new government priorities:** funders should support charities' efforts to find ways to provide people with autism with services they need and that government will fund.
- 5. Maintaining non-statutory services:** such as play and leisure services. These are important in terms of improved quality of life for people with autism but do not receive guaranteed government funding.

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Introduction

Aims and approach

This report is an update to NPC's previous research into the autism voluntary sector, *A life less ordinary*, which was published in 2007.¹ Since then, the autism sector has seen considerable changes, including the passing of the Autism Act 2009 and the growing pressures of funding cuts. This new environment has significant repercussions for people with autism, autism charities, and funders looking to support and improve the sector.

In this document we pull out and analyse the main developments that have emerged over the past three years. This does not involve revisiting all of the specific themes and findings from the previous report—in many cases the situation on the ground has not markedly changed and the main recommendations are still valid.² Instead, the research focuses its attention on what has

changed and the issues that are helping shape the direction of the autism voluntary sector. This provides the context within which to understand challenges and opportunities for charities and funders. For readers new to the topic, see Box 1 for a short description of autism.

To inform our research, we drew on two main sources of information. First, we carried out a series of interviews with a selection of charities and experts from across the sector—representing a cross-section of services and activities. Second, we undertook a web-based survey of a much larger selection of autism organisations to help test and expand on some of the trends and hypotheses that had emerged from interviews. 155 organisations were invited to take part in the survey and it was completed by 39, making a response rate of 25%. The full results of this survey can be found in Appendix B, which is available to download from NPC's website.³

Box 1: What is autism?

Autism* is a lifelong developmental disability that typically creates difficulties in three areas of behaviour:

- **Communication:** such as an inability to speak, monotonous intonation, and a literal interpretation of words.
- **Social interaction:** including an inability to read facial expressions or body language, and difficulty understanding basic social rules.
- **Social imagination:** for example, lack of imagination, or inability to understand other people's emotions.

These difficulties are sometimes known as the 'triad of impairments'. Autism is a spectrum condition, which means that while everyone shares the same types of impairments, the severity and nature of these symptoms vary for every individual. On top of this, some people with autism also have learning difficulties (sometimes known as low-functioning autism). They may require extra care and support, such as residential care or supported living.

An estimated one in every 100 people has autism—which equates to over half a million people in the UK—and it is far more prevalent in men than women. There is no cure for autism but a range of interventions and activities focusing on learning and development can prove helpful at overcoming some of the negative aspects of the condition.

* In this report, we use the term 'autism' to refer to a full range of autism spectrum disorders, including classic autism and Asperger syndrome.

¹ Fradd A., Joy I., *A life less ordinary* (2007).

² See Appendix A for the Executive Summary of *A life less ordinary*.

³ See: http://www.philanthropycapital.org/publications/health/autism_update.aspx.

Structure

Our research highlighted three main areas of development that cut across the voluntary sector. These are helping to shape and structure the sector and the services and support available to people with autism and their families:

- **Changes in policy:** including autism-specific initiatives, such as the adult autism strategy, as well as new government policies, such as academies and changes to employment support.
- **Changes in funding:** this does not just include the level and nature of government cuts, but also the shift in how government commissions services.
- **Changes in the voluntary sector:** such as the recent trend towards greater collaboration and the increased emphasis on involving people with autism.

The report looks at these three issues in turn, analyses what they mean for the sector, and picks out the key points and repercussions. In many cases the full implications of these changes are not yet apparent and there are clear opportunities for charities and funders to shape and influence the outcomes by accentuating the positive trends and mitigating the negative.

The **conclusions and recommendations** pull together the main findings and lessons for donors and the sector as a whole. For while the sector has seen several improvements—such as a growing recognition of the importance of autism and better collaboration—the past year has also seen a fair amount of turbulence and uncertainty that threatens to derail some of this progress. A whole new raft of government policy is coming in while funding is being cut and rearranged. And while NPC was struck by the general optimism of the autism charity sector, it will still require concerted effort by funders and charities to ensure that the voluntary sector is able to develop and grow over the next year.

Changing policy

Government policy shapes the support and services that are available to people with autism and their families, from schools to housing support, employment programmes or diagnosis systems. How government organises, funds and delivers these services has significant repercussions for the way in which people with autism live their lives. And the past three years have seen significant developments in this area, most obviously through the autism strategy launched in March 2010, which provides a framework for coordinating and developing provision for adults with autism.

Yet while the new strategy is an important landmark, it is not the full story. The policy landscape has been changing across areas such as education and employment support. Almost all of these developments are likely to have some impact on people with autism—70% of children with autism in education attend mainstream school, for example.⁴ But rarely are the specific needs of people with autism (and other disabilities) taken into account and the full repercussions of these changes for people with autism are still poorly understood and often overlooked.

Work still needs to be done to ensure that the voice of people with autism is heard as part of the wider national policy debate. But influencing policy is only the first stage in the journey. Looking ahead, the key question to consider is: how will these policies be implemented? If they are not enforced, funded, or prioritised, this will reduce their impact on autism services and on people with autism. The push towards greater localisation means that local authorities play an increasingly important role, and there is a clear need for charities and funders to also target their efforts at a local level.

The Autism Act 2009

The Autism Act 2009 is probably the single biggest change in the autism sector in the past three years.⁵ It is also probably the single biggest achievement: the Act is the first piece of legislation aimed at helping a single impairment group and was passed after considerable lobbying from a coalition of autism charities. The Act requires the government to develop a strategy across England to ensure adults with autism have access to the services and support

they need, and to develop statutory guidance for local authorities and NHS bodies and trusts to implement it.

The autism strategy

The purpose of the autism strategy is to ensure that existing legislation and policies work much better for adults with autism. Autism does not fit neatly within existing health or social care structures. Responsibility for meeting the needs of people with autism is spread out across different departments and there is poor coordination between them, as well as a more general lack of understanding of the condition. The overall effect is that many people with autism do not receive the right support or services.

The strategy is therefore designed to provide a unified approach to delivering services for adults with autism through the existing system. Rather than involving major new funding streams, the strategy aims to make sure that existing legislation and policies work together so that awareness of autism is integrated at all levels—across all frontline staff, in diagnosis, and also across mainstream services (see Box 2). These efforts will often be supported by setting up autism partnership boards to consider how services can be improved at a local level, and by appointing individuals within local areas to take the lead on diagnosis and commissioning services.

The strategy, *Fulfilling and rewarding lives*, was published by the Department of Health in March 2010 following a consultation period with various stakeholders, including people with autism, their families and carers, and with input from an external reference group (ERG).⁶ This group included professionals, local authorities, people with autism and charities.

Reaction to the strategy has been largely positive. The charities that we spoke to and that responded to our survey appear relatively happy with the content of the strategy in terms of the needs identified; half of survey respondents said they are satisfied with the strategy. However, some organisations were, perhaps inevitably, disappointed that the scope of the strategy was not as broad as it could have been and that there are still outstanding issues that it fails to address.

⁴ Total number of children with autism in primary and secondary schools compared with those in specialist schools. Data taken from Department for Children, Schools and Families, *Special Needs in England: January 2009* (2009); see data table: www.education.gov.uk/rsgateway/DB/SFR/s000852/sfr14-2009_M.xls.

⁵ For the text of the Act see: <http://www.legislation.gov.uk/ukpga/2009/15/contents>.

⁶ Department of Health, *'Fulfilling and rewarding lives': The strategy for adults with autism in England* (2010).

Box 2: The autism strategy

There are five main strands to the adult autism strategy:

1. Increase awareness and understanding of autism among frontline public sector staff

All public sector staff should receive general autism awareness training. Health and social care workers, who come into contact more frequently with people with autism, should receive more in-depth autism training. Online and offline resources will be developed to help local areas develop their own training programmes.

2. Develop ‘a clear and consistent pathway for diagnosis’

The National Institute for Health and Clinical Excellence (NICE) will develop clinical guidelines that include model diagnosis processes. The strategy confirms that autism diagnoses should result in a community care needs assessment to determine whether there is any additional support the individual may require.

3. Improve access to mainstream services and support

The strategy reiterates the requirement that public bodies make adjustments to ensure services—including access to personal budgets—are available to people with autism. It commits to publishing guidance explaining the sort of adjustments that may be necessary.

4. Help adults into autism into work

The Department of Work and Pensions (DWP) is engaging with employers to better include adults with autism. DWP will also ensure that government schemes to help people into work—including services provided by Jobcentre Plus—are accessible to those with autism. It also sets out planned changes to employment support.

5. Help local areas implement the adult autism strategy

The strategy will mostly be implemented at a local level, and specifies ways to ensure that this is done effectively:

- The Joint Strategic Needs Assessment, which uses prevalence data for health conditions and disabilities to identify the needs of the UK population, will include the numbers of adults with autism in each area. This will help different areas understand local need.
- Regional implementation plans will be developed. These plans will also map existing autism services, including those provided by voluntary/third sector organisations.
- A manager or commissioner in each local area will be expected to develop a local commissioning plan, and participate in or set up local strategic partnerships boards as necessary. The strategy is explicit that this work should be done within existing budgets and highlights examples where a business case for investment in services for adults with autism have been successful.

Effects of the Autism Act

The charities we spoke to felt that the Act has successfully raised autism awareness among decision-makers, particularly at a national level. Autism now appears to be on the agenda of more government departments, especially the Department of Health, where there is now a dedicated team for autism. A cross-departmental programme board has also been established to look into improving services for adults with autism and implementing the strategy. Lobbying and campaigning efforts, as well as the passage of the Bill, means that awareness of autism among MPs is generally high. However, this has apparently declined slightly since the 2010 general election, which saw an influx of new MPs.

Beyond this the strategy has had two further effects:

- **Enshrined autism as a cross-party issue:** although both the Bill and the strategy were products of the last Labour government, the new coalition government appears to have thrown its weight behind continuing the efforts of implementing the strategy. This is thanks both to the fact that the Bill was introduced by a Conservative MP and that it received wide cross-party support in Parliament.
- **Boosted collaboration in the sector:** the shared goal of an Autism Act seems to have been a good way for the different parts of the sector to come together and work for a common cause. One of the criticisms of the sector in the past has been the lack of collaboration and communication. The Autism Act has helped to deepen and develop some relationships (this is discussed in more detail in Section 4).

What happens next?

The key question is what happens next. A strategy is of no use if nothing happens with it. Here we are still in the early stages: the first year of delivery is focused on getting the right infrastructure in place at local, regional and national levels and so impact on the ground is slight.⁷ Success will come down to two things: the implementation guidance for health and social care bodies and the money available.

Developing guidance

Responsibility for actually delivering the strategy is devolved to local government. Statutory guidance setting out how health and social care bodies should do this is currently being developed. The guidance will be published by the end of 2010 and, at the time of writing, a draft version had been put out to consultation.⁸ Once the final version is published local authorities and NHS bodies will be legally required to follow it. People with autism, their carers and representatives will be able to bring legal action against any body that fails to comply with the guidance. How the guidance is worded, for instance whether a local authority 'could' or 'should' do something, will have serious repercussions on the actual level of care provided.

There are encouraging signs at a local level that many local authorities are beginning to respond to the new strategy and are putting structures in place in readiness for the statutory guidance. There are also examples of local authorities making real efforts to set up structures that follow best practice. For example, Liverpool Primary Care Trust has set up a team to look at ways of ensuring that people with Asperger syndrome receive the services they need.

However, there is a worry that weak language in the draft guidance will mean that the strategy's objectives can be dismissed or ignored. This is something the charities we spoke to and the survey respondents are worried about: at first glance it tends to make suggestions and recommendations, rather than mandating particular actions or outcomes. For example, rather than obliging local authorities and NHS bodies to provide autism awareness training to staff, the draft guidance instead suggests that they '*should consider what autism awareness training is made available and...and how training can be prioritised*'.⁹

This has the benefit of giving more autonomy and flexibility to local areas—indeed the government has stressed that it wants the guidance to be

implemented locally and regionally in a way that makes sense to the area and builds on local strengths. While this makes sense, it also means that there are few safeguards against local authorities dismissing the guidelines. This could jeopardise the strategy's potential to improve services for adults with autism.

Charities and other autism organisations are responding to this and taking action on two fronts:

- Many have responded to the consultation document and are lobbying central government on beefing up the language in the draft guidance. The organisations that formed part of the ERG, for example, have submitted a joint response to the consultation document.
- They are also working to apply pressure to local health and social care bodies. For example, the NAS is supporting its local branches to lobby local decision-makers. This is much bigger job as campaigning efforts will have to be targeted at each local authority separately rather than directed at a single central government department. However, this work is crucial: how successful the strategy proves to be at improving services for adults with autism will be determined by how well it is implemented at a local level.

Funding

The second major concern around implementation is whether there will be enough money to carry it out. No new major funding streams are being introduced. Instead the strategy and the draft guidance make clear that the measures should be implemented using existing budgets and local authorities should make the business case internally for investment in autism services. This is concerning because without dedicated resources many autism charities are worried that local authorities will choose to implement the strategy cheaply, rather than effectively.

Existing pots of money are also likely to shrink (see Section 3). Local authorities are facing tough times, and are looking to cut back their spending drastically. In many cases they have already begun to reduce their expenditure. Front-line services will be affected by these cuts and, in such a climate, the autism strategy may well fall down local government's list of priorities. One charity we spoke to speculated that cutbacks will mean eligibility criteria for adult social care will be raised, meaning that many higher functioning adults with autism may no longer qualify for any support at all.

⁷ For more information about the infrastructure being set up to deliver the strategy, see: Department of Health, *Towards 'fulfilling and rewarding lives' The first year delivery plan for adults with autism in England* (2010).

⁸ Department of Health, *Implementing 'Fulfilling and rewarding lives': Consultation for statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy* (2010).

⁹ *Implementing 'Fulfilling and rewarding lives'*, p16.

Government policy changes

While the Autism Act was a real breakthrough, it is not the full picture. Initiatives and policy changes introduced by the new Coalition government and the previous administration do not appear to have taken the needs of people with autism into account. Yet many people with autism rely on the state for at least some support and they are likely to be considerably (and possibly negatively) affected by these reforms. In our conversations with charities, we picked up on two areas where there is particular concern: the changes to the education landscape and the shake-up of welfare-to-work.

Coalition government education policies

Charities are worried that certain aspects of the Coalition government's education policies will have a detrimental effect on education for children with autism. In particular, they highlighted some parts of the Academies Act 2010 (see Box 3), which will increase the number of schools outside local authority control, and government rhetoric around taking a tougher approach to poor behaviour in schools.

Box 3: Changes to the education system

Academies Act 2010

The Academies Act aims to confer greater freedoms to schools by making it far easier for any state-maintained school to become an academy. The Act also allows for the creation of 'free schools'.

- **Academies:** these are state-funded schools that have a greater degree of independence from local authorities and government. They can set pay for staff and have some flexibility around the curriculum.
- **Free schools:** these are state-funded schools set up in response to demand from parents, or at the initiative of voluntary groups or businesses. They will enjoy the same freedoms and flexibilities as academies.

Academies

Charities are anxious that extending the number of academies (see Box 3) will result in poorer education for children with autism. In theory, academies have the same obligations as ordinary state schools towards pupils with special educational needs (SEN) in that they should be as likely to get a place at an academy as at a state-maintained school and should receive the same level of support to meet their needs.

But charities that we spoke to are not yet convinced. Over a third of survey respondents think academies will have a negative effect on education provision for children with autism, and only 9% think they will be positive.

The causes for concern appear to be twofold. First, some academies will not be able to provide enough high-quality support for students with autism. Academies' greater independence from the state means that, rather than relying on teams provided by local authorities, they have to provide their own SEN support, which they may not have the skills to deliver. The speed of the policy changes is a factor here too; because some state schools converted to academies so quickly, they may not have had time to build up their own in-house team.

There is also a risk to the local authority specialist teams providing support to children with autism in state-maintained schools. The independence of academies means the funding that local authorities were using for these teams is now going straight to the school, making these teams less financially viable. This has the potential to weaken provision in mainstream schools that, according to our survey respondents, is already very poor (see Box 4).¹⁰ And although funds allocated to specialist teams will remain in place for one year, it is not clear what will happen after that.

The second area of concern is around access and exclusions. This was summed up well by one survey respondent: *'We also have concerns that the admissions and exclusions guidelines will not apply to academies in the same way as they will in other schools. This means it may be harder for children with autism to access a place in an academy and it may be more likely that they are excluded if their special educational needs are not met'*.

Free schools

In many ways, free schools provide an opportunity for charities (see Box 3). Where there is demand but no provision, charities and parents of children with autism can take action and establish a school for themselves that caters to their children's needs—this is what the parents who founded TreeHouse did.¹¹ One county-wide charity, Autism Concern in Northamptonshire, is already preparing proposals with a group of parents to set up a new free school. For it, free schools will *'unleash parental innovation and energies, and enable more meaningful partnerships between parents and professionals'*.¹²

However, local authorities' apparent reluctance to refer children to expensive specialist schools (discussed in more detail in Section 3) raises doubts about the viability of a new network of specialist autism free schools. The implications of this are expressed by one survey respondent:

¹⁰ 63% respondents to our survey described provision for children with autism in mainstream schools as poor or very poor.

¹¹ See: <http://www.treehouse.org.uk/us>.

¹² Quotation taken from survey response.

'[it] could encourage a two-tier system where those who can afford a place in a specialist school, or have the means to fight for one, will be able to access them, while those who can't will be left in local authority maintained special or mainstream schools with diminished resources to meet their needs'.

Behaviour and discipline in schools

Research by TreeHouse found that 43% of children with autism were excluded from school over a 12 month period.¹³ Several charities are apprehensive that government plans to take a tougher approach to poor behaviour in schools will make this situation worse. Lower tolerance of poor behaviour was a Conservative party pledge from the 2010 general election campaign and the Coalition government looks set to give teachers new powers to discipline pupils.¹⁴

Children known to have autism and who have an SEN statement may not be especially affected. But securing a diagnosis of autism or accessing an SEN assessment can be difficult and take a long time. The Lamb inquiry from 2009 showed that many parents face considerable barriers to securing recognition of their child's special educational needs.¹⁵ This means there is a risk that children with unidentified autism or SEN are unfairly penalised by tougher discipline measures that do not take into account the impact of their autism or SEN on their behaviour. Children may end up being excluded because of, what one charity described as, a simplistic interpretation of this behaviour where the focus is on the behaviour itself, rather than looking at what a young person is trying to communicate.

Helping people with autism into employment

A second major area of policy change is the new approach to welfare-to-work schemes. This was introduced by the Labour government and remains in place under the Coalition government for the time being. Even when these policies are specifically targeted at people with disabilities, such as the new Work Choice programme (see Box 5), it still appears that commissioning arrangements, the targets that are used, and even the referral process continue to pose problems and are unlikely to overcome or reverse the staggeringly low levels of employment for adults with autism.

1. Continued lack of autism-specific support

Changes to the way services are being contracted may make it less likely that people with autism will receive specialist support. Instead of contracting directly with a number of providers, DWP is instead contracting with a smaller number of providers, often pan-disability organisations. These 'prime providers' are then meant to sub-contract services to smaller organisations, particularly those with expertise in particular areas.

However, these prime providers have a great deal of discretion to decide how they sub-contract to other organisations. There is nothing to stop them providing the majority of these services in-house, or sub-contracting just to other general disability organisations and only calling on specialist organisations for particular interventions or support. In some areas there are indications that charities providing employment support for people with autism, for example ASpire run by Autism West Midlands and Prospects run by the NAS, may not be receiving as many contracts as they first expected.

Box 4: Jan and Luke's story

Luke was not diagnosed with autism until he was ten. According to his mum Jan: *'The picture had never been put together for us up until that diagnosis. Before that, Luke had always been labelled as naughty and disruptive.'*

It was another year before Jan managed to get a statement of special educational needs for Luke, just days before he started secondary school. The teaching assistant assigned to Luke was not trained in helping someone with autism, and even with Jan's help, secondary school did not go well. Jan received almost daily calls about Luke's behaviour and on a few occasions he was excluded from school. In Luke's words: *'School was a horrible place for me. I didn't understand what was going on...I couldn't get involved in the usual banter so I got left out.'* Luke was bullied and after one incident, when he reacted badly, he was expelled from school.

Under pressure from Jan, the local education authority eventually found a new school for Luke. It wasn't a specialist school for young people with autism, but instead helped children with emotional and behavioural problems. Luke found his new school hard at first, but he soon got used to the clear rules and reward system. He found that staff were able to help him because they understood his condition.

After just one year, Luke passed eight GCSEs and started acting as an ambassador for the school, giving speeches about autism. At 18, Luke is now a mentor to other children at the school. *'Every day is still very tiring — certain things do not come naturally to me. But I have good friends now and a good outlook on life.'*

Jan believes that so much more could be done to help families like hers. *'There is a gap between what people are saying and what's actually happening on the ground. I've received no help with Luke and have had to fight all along the way. The new Autism Act does set out what help families should receive but it is frustrating because while we wait to see what happens, many families are struggling to cope.'*

¹³ TreeHouse, *Disobedience or disability? The exclusion of children with autism from education* (2009)

¹⁴ See: The Conservative Party, *The Conservative Party Manifesto 2010*, (2010); see also: <http://www.bbc.co.uk/news/education-11476802>.

¹⁵ Lamb, B. *The Lamb inquiry: Special educational needs and parental confidence* (2009)

Even if sub-contracts are made, there is a danger that the level of funding will be insufficient to cover the complex and long-term needs of people with autism. One charity told us that the changes in contracting arrangements will mean they work with fewer people in a more limited and superficial way.

Box 5: Work Choice

Work Choice is a government programme that aims to help people with disabilities into employment. It is made up of three modules:

- **Work Entry Support:** up to six months of support to help people develop work-related skills and prepare for employment.
- **In-Work Support:** two years of support following a person getting a job.
- **Longer Term In-Work Support:** to help individuals progress in their job or move further towards unsupported employment.

Work Choice was introduced in October 2010 and is a replacement to three smaller employment support programmes: WORKSTEP, Work Preparation, and the Job Induction Service. The new programme has also considerably changed how services are commissioned.

The programme was developed by the previous Labour government but, so far, the new Coalition has backed the reforms. However, the new government is planning a more fundamental shake up of the welfare system in the near future, with the introduction of the Work Programme. This will support all jobseekers in need of employment support (apart from those with the most complex levels of disability, who will remain on Work Choice). The programme is still being developed, and so the details of how it will work remain to be seen.

2. Targets and outcomes may exclude the harder to reach

A second potential problem is the effect of the incentives and targets used as part of the new programme. Organisations delivering Work Choice on behalf of the DWP will be paid by results. NPC believes that this model has many benefits as it encourages providers to focus on the sustained outcomes achieved for the user. However, it only works if the outcomes measured are appropriate, and there are some concerns that this is not the case. The standard measure of success for Work Choice is someone doing 16 hours of work per week for a number of weeks.¹⁶ For some people with autism, especially those with higher support needs, 16 hours a week is an unrealistic target. Providers may end up ‘cherry picking’ those people who will meet the targets, rather than those who would benefit most from the support. Adults with autism could potentially miss out.

This situation is accentuated by the fact that providers are paid the same amount for each client, irrespective of their level of needs. This pushes providers away from helping people with autism who are further from the workplace and so are more expensive to help. There are encouraging indications that the Coalition government may improve this by introducing ‘differential pricing’, which will mean that providers will receive more money for working with harder-to-reach clients.¹⁷ However, contracting arrangements are not due to be published until 2011 so the details will not be known until then.

3. Opening up access to employment support

A third potential area of concern is around the referral process. At first glance, this is one of the strengths of the new system as Work Choice will provide more opportunities for people with autism to be referred onto the scheme. As well as the more traditional route through Jobcentre Plus, people will be able to be referred via other statutory agencies, such as health and social care services. This may pick up those who would not normally access employment support, such as individuals not on benefits. But there is also a risk that health and social care workers, who are not experts in assessing work readiness, may end up referring people who are unsuitable for the programme. With budgets tightening across the public sector, cross-referring may end up as a way to shift responsibility for a person with autism onto someone else. This is especially the case for people with Asperger syndrome for whom health and social care may have little to offer.

Key points and actions for funders and charities

Over the past three years the autism sector has seen several significant policy developments. This is both a cause for celebration—not least the introduction of a new national autism strategy—but also a cause for caution. For one thing, it is still too early to see the impact that these policy changes will actually have on the lives of people with autism. Even good policy might not translate into strong provision unless there is the will and the money to back it up. General shifts in policy focused on mainstream issues, such as education and welfare, may have particular repercussions for people with autism that are overlooked and not clearly understood.

Box 6: Kieran's story

Kieran was diagnosed with autism in 1999. Before that, he had suffered with depression and struggled to cope with the demands of a job: *'I only worked for short periods of time—usually seasonal jobs and short term contracts. I struggled to keep work, as my anxiety and depression were too severe.'*

It was Kieran's mother who encouraged him to contact the NAS's autism employment service, Prospects. *'At the time, I didn't have the initiative—I could scarcely tie my own shoelaces'*. The staff there helped Kieran with his CV and to prepare for job interviews. They taught him coping strategies and gave him advice about how to handle anxiety and to build his confidence.

This support helped Kieran to get a job at Stirling Council, working with other people with autism wanting to find work. During this time Prospects were still on hand: *'They'd pop in and see how I was doing...They always said if anything was a problem, to give them a call'*. Kieran now works for Prospects and supports around 12 people—meeting up with them regularly and helping them improve their social and interview skills. He says, *'Work gives people dignity, and gives them back their self respect'*.

Kieran believes that the right employment support can have a really positive influence on people with autism: *'Just knowing that someone cares about them and wants to help them, can make all the difference'*.

Two issues stand out. First, there needs to be increased and continued lobbying of local government. With the statutory guidance due to be published at the end of 2010, how well it is implemented will determine the impact of the strategy on the lives of adults with autism. This is part of a broader trend towards increasing localism and devolution where local authorities are the ones developing policy and practice in their areas. In an environment where local authorities are cutting back on services, autism may fall down the list of priorities or be overlooked.

Second, charities need to continue to push and prioritise autism at a national level. This is the case for ongoing issues relating to the autism strategy and also in ensuring that the needs of people with autism are understood and taken into account in mainstream policy areas, such as education and welfare policies.

Both funders and charities have a vital role here. Charities can help ensure that the needs of people with autism and their families are understood and prioritised. At a number of different levels, from national advisory groups to work with local commissioners, the charity sector can help to shape and influence the debate. Cooperation between charities is key here, ensuring that there is a clear and coordinated message, a theme that is returned to in Section 4. But to do this lobbying work requires funding, particularly more flexible unrestricted funding, to ensure that charities have the time, the resources and the staff to engage and work with local and national government effectively.

Changing funding

A changing funding landscape makes up the second major area of development in the sector. This reflects two main trends: first, the impact of a changing economic environment over the past three years, as reduced government spending has led to significant spending cuts across the board. Entire funding streams are being cut, and there is an increased emphasis on cost-cutting and value for money. And second, there has been a more long-term shift in how government funds and commissions its services. A trend for localisation and personalised services has put power into the hands of individuals, GPs and schools.

These shifts in government funding are recalibrating and restructuring the voluntary sector's funding environment. To cope with this, services are being cut or streamlined, and charities are drawing on their reserves; some have already become insolvent. All organisations have to change how they operate and pay greater attention to their financial stability. While some organisations see potential gains from this new government funding environment and an increased ability to help people with autism, others do not and are increasingly looking to voluntary funding for the answer.

Box 7: Comprehensive Spending Review

In October 2010, the Coalition government announced a series of measures and reforms designed to reduce public spending by £81bn by 2014-15. The full ramifications of this spending review are hard to predict but some of the implications for people with autism and their families, as well as for the autism voluntary sector, are beginning to emerge.

People with autism who rely on government for services and support are likely to feel the full force of the reforms and reductions to public spending.¹ Cuts across different services and benefits are likely to have a cumulative effect that the NAS is worried 'could push whole families to crisis point'.² Of particular concern are:

- The abolition of funding for transport for people living in residential care (part of the Disability Living Allowance), which is likely to reduce their independence and ability to get around in their local community.
- A new medical assessment for the Disability Living Allowance, which charities worry may exclude people with autism, particularly Asperger syndrome, who are perceived as needing less help.
- Cuts to local government budgets are likely put adult social care services at risk. Some disability charities are worried that, despite the government's announcement of an extra £2bn for social care, this will not be enough to plug the gap.³

There are also some positive changes. Government plans to expand personal budgets in social and health care may lead to more tailored support for people with autism. And the pupil premium, which will provide extra support for children eligible for free school meals, will benefit young people with autism from disadvantaged backgrounds.

Autism charities will also be affected by the spending review, with ACEVO—an umbrella body for charity chief executives—predicting that the whole voluntary sector's funding will be hit by up to £4.5bn.⁴ Autism charities deliver many government services for people with the condition and cuts to welfare or support budgets will inevitably have a knock-on effect on their funding. Autism charities providing living or residential services, for example, are likely to be hit by cuts to the Supporting People programme and the removal of ring-fencing in this area.

In order to help the voluntary sector cope with these changes, the government is introducing a £100m Transition Fund. Small and medium autism charities delivering front-line services will be able to apply for grants to help them adapt to the new funding environment.⁵

¹ See: Demos report, which identified people with disabilities—including people with autism—as facing the worst of the cuts. See: www.demos.co.uk/files/Destination_unknown_-_web.pdf?1286894260.

² See: www.autism.org.uk/News-and-events/Media-Centre/Media-responses/Media-responses-2010/Media-response-Comprehensive-Spending-Review.aspx.

³ See: <http://www.mencap.org.uk/page.asp?id=20506>.

⁴ See: http://www.charitytimes.com/ct/Comprehensive_Spending_Review_sector_verdict.php.

⁵ See: <http://www.biglotteryfund.org.uk/transitionfund.htm?regioncode=-uk>.

Cuts: where and how much?

Cuts to local government spending announced in the Comprehensive Spending Review are predicted to amount to around 25% over the next four years (see Box 7).¹⁸ As the autism charity sector relies so heavily on government for funding—70% of charities that NPC surveyed received at least some of their funding from local authorities—it will not escape unscathed.

Squeeze on government contracts

Autism charities are feeling the squeeze as local government commissioners attempt to cut costs and reduce fees charged to deliver services, such as residential homes or specialist schools. This could be either by looking for similar services at reduced costs or by looking for a less intensive package of care. So instead of paying £80,000 for year-round adult care they would offer £60,000; or instead of paying for 48 weeks of schooling they would cover 32 weeks.

Charities that NPC has spoken to are particularly worried because commissioners were already being quite aggressive in reducing their costs even before the Comprehensive Spending Review. More contracts are being put out for tender which increases competition and puts extra pressure on price. Some autism charities are worried that slicker private organisations or larger more generic disability organisations will be better placed to take advantage of this new funding environment.

Nearly half of the charities surveyed for this report expected some decrease in their fee income, with 18% expecting cuts of over 30% next year. Even small cuts to fees can have huge repercussions for charities; one major autism organisation said that every 1% reduction in fees costs it £800,000. Uncertain demand for specialist autism services from commissioners.

For some charities a further issue is not just a question of local government fees being squeezed, but also more general instability in demand from commissioners for specialist autism services, which makes it harder for them to properly plan and budget. A big part of the reason for this is increased 'mainstreaming'. Within the sector there is a philosophical and practical debate about how much people with autism should be included within specialist care. This has led to an improvement in mainstream services on the one hand, but also a growing unwillingness to refer people with autism to specialist services on the other. For example, adults with autism needing residential care may be provided with generic living services from a pan-disability provider, rather than a specialist autism organisation.

In some areas this trend appears to be accelerating, and not always for the right reasons. Dedicated services for people with autism tend to be expensive and so there is a strong temptation to provide cheaper generic services instead. For example, local authorities are increasingly choosing the less expensive option of placing children in state schools. Some charities running specialist schools are reporting lower demand for their services and are anticipating empty places in their schools over the next few years. This could put the entire service at risk, for example in 2009 Autism West Midlands shut down its specialist school because of a fall in demand for places.¹⁹

However, this picture is mixed and a drop in demand does not appear to be the case across the board. One charity told us that it has seen a resurgence in demand as a result of the abolition of the Building Schools for the Future investment programme.²⁰ This scheme would have seen the development of specialist units within mainstream schools that could provide support to pupils with autism. Now these are no longer being built, local authorities are turning to autism education charities for alternative provision.

General uncertainty around government funding

More general funding uncertainty also exists: 74% of the charities surveyed reported that they felt insecure or very insecure about their funding from government. Government grants and tenders are often short term, normally between one and three years. They may not then be renewed. In the current funding environment whole funding streams for particular areas in the sector could come to an end. Currently there is extremely little information on the extent of the cuts. As a result, some of the charities we spoke are highly resistant to committing to any new project or spending until the situation has stabilised. One organisation had even turned down a short-term contract for running a service, because it would be too destabilising when it came to an end.

In particular, there are few protections against cutbacks for services on the borders of government's funding remit, for example respite care, employment schemes, play and leisure services and transition support. These areas are therefore extremely vulnerable. The charities we spoke to, for instance, have little idea as to the fate of Aiming High for Disabled Children, a key funding stream in this area (see Box 8). Nor had they any clue as to when they might find out.

On top of the uncertainty about funding levels was a further worry about how changes in policy and commissioning structures would affect the

¹⁸ See: <http://www.guardian.co.uk/society/2010/oct/28/blackburn-darwen-council-cuts>.

¹⁹ See: <http://www.malvern gazette.co.uk/news/4198150>.

²⁰ See: <http://www.bbc.co.uk/news/10514113>.

security of funding. The personalisation agenda is shifting commissioning away from large contracts towards a more market-based system driven by the demands of service users in control of their own health and social care budgets. Charities are unsure how this will affect their organisations, and how they will cope with potentially fluctuating demand for their services. It may require organisations to develop completely different funding models and restructure their services.

The move to GP-commissioning as well as increasing numbers of academies and free schools will further shift established commissioning structures and relationships. There is a danger that these new local commissioners will not know much about autism or prioritise it.

Charities even spoke of the impact that cuts and restructuring will have on commissioning from within traditional adult social services; numbers of commissioners will be cut giving them less time to develop specialist knowledge of autism, or properly evaluate funding bids.

Effect on the autism sector

Cuts will have an impact across the whole autism voluntary sector:

- **Greater financial instability:** the impact of cuts is not limited to a particular project, it can destabilise an entire organisation. A major regional autism provider, Sussex Autistic Society, recently became insolvent because it lost one of its local government contracts, which was worth 35% of its income.²¹ It is not alone; four organisations that responded to our survey said they risked bankruptcy next year due to funding cuts. Many charities are considering scaling back services or even closing them down, and 37% of survey respondents expected to cut services in the next 12 months. Others are eating into their reserves, which will limit their ability to respond to the tough times ahead.
- **More unmet needs:** if charities are forced to scale back services it will reduce already patchy provision (see Box 9). Even where services remain, the shift from specialist to generic support may result in poorer standards of services for people with autism. General disability charities tend to cater for people with physical and sensory disabilities or learning difficulties. They may not have specialist knowledge of working with individuals with autism to overcome their social communication difficulties. In schools, more children may struggle within a mainstream school before reaching crisis point and being placed in a different school.

Box 8: Aiming High for Disabled Children

Aiming High for Disabled Children (AHDC) is a £430m government programme that aims to provide greater support for disabled children and their families. It does this by funding a range of services, from leisure activities and short holidays for children, to respite breaks for their families, and transition support from children's to adults' services.

Launched in May 2007 by the then Department for Children, Schools and Families and the Department of Health, AHDC was envisaged as a three-year programme, running from 2008-2011. With the change of government in May 2010, the Minister for Children and Families, Sarah Teather, confirmed the new Coalition government's commitment to the programme.

However, the Comprehensive Spending Review in October 2010 has put the future of AHDC after April 2011 at risk, although what will happen still remains to be seen.

- **Loss of specialist skills and knowledge:** many specialist services have taken a large amount of time to emerge. If charities are forced to scale these back, valuable skills and knowledge will be lost. This will also reduce the ability of charities to respond to future opportunities for specialist work. For example, one charity said that the current lack of demand from commissioners for their employment services could result in the project being closed down. This will make it harder for them to respond to any opportunities to tender for employment support contracts in future.

NPC's impression has been that many charities are showing remarkable determination in the face of funding cuts. Several organisations we spoke to are restructuring their organisations in order to better respond to the new climate. For instance, some are choosing to shift the focus of their work onto less-intensive services by scaling down residential care and increasing the amount of supported living they provide. Others are shifting their provision towards areas where there is less pressure on fees, for example support for those with higher care needs.

Many charities were upbeat about the opportunities that the new climate presents. One survey respondent explained, *'we also see many opportunities for the organisation to broaden its offering through the New Schools programme and setting up micro-social enterprises that will offer gainful employment to people on the autistic spectrum. We are also in discussions around partnering with a comparable Autistic Spectrum Disorder non-profit organisation in the USA, which should enable us to access American trusts and foundations'*. These are encouraging signs but whether autism charities are able to capitalise on these opportunities remains to be seen.

²¹ See: www.autismconnect.org.uk/news.asp?section=00010001&itemtype=news&id=6547.

Box 9: Dorothy and Michael's story*

Michael was diagnosed with autism in 2003, when he was 38 years old. His mum Dorothy says she was not surprised at the diagnosis: *'I knew something was wrong. Michael was always very upset, he would smash things up and get very hyperactive. It made sense when they told me'*. Michael says he was shocked when he found out, *"I didn't realise I had Asperger's. I just knew I had always felt like this and found meeting people and being in a group very hard"*.

Michael is unemployed, having lost his job four years ago. He recently started going to sessions run by the charity, Resources for Autism, that he hopes will build his confidence. *'The first time I was in a group with new people I found it very intimidating and scary. I hope I will get more help now because I really lack confidence and my self-esteem is very low. I'm hoping to go back to work but it's difficult to find anything at the moment because of all the job losses'*.

Apart from the sessions with the charity, the family have received no help since Michael's diagnosis. Dorothy is very worried about the future: she is 77 years old and has diabetes. *'Sometimes he gets very hyper and I don't know what to do...I have no help and I'm very scared but I try my very best...I worry all the time about what will happen to Michael, he often goes out and I don't know where he is or if he will come home'*.

* Names have been changed.

Increasing role of voluntary donations

With so much government funding under threat, the sector is looking to other sources to meet the shortfall. Historically, there has been little in the way of voluntary income going into the autism sector. Our research in 2007 found that only about 7% of the sector's total income came from donations and grants. NPC has not looked in detail at current levels of voluntary income for this research but our impression is that levels are still low.

Over the next few years voluntary donations are going to play a key role in helping charities weather the financial storm. As one charity put it: *'Funding from the government is drying up... That means that if programmes are to continue they must continue through trust and foundation funding and community fundraising events.'*

Charities have recognised this and are ramping up their fundraising activities. The NAS, for example, has developed an ambitious new fundraising strategy, with the aim of more than doubling its current net fundraising income. However, under-investment by some charities in this area over the past decade will make this a considerable challenge and success is not guaranteed. Autism charities' ability to fundraise may be further limited by the effects of the spending cuts on individual donors; there is a worry that donations will drop as they feel the pinch. As one charity summarised it: *'Everybody is going to have less disposable income, resulting in smaller, or less, donations.'*

Many charities we surveyed appeared pessimistic about prospects for increasing their voluntary income: 68% of survey respondents expected their voluntary income to decline or stay the same over the next 12 months, with a further 16% unsure about what will happen.

Key points and actions for funders and charities

As a large proportion of the sector's income comes from government, unsurprisingly the autism sector will be significantly affected by government spending cuts. The squeeze is likely to affect both core statutory funding and also shut off specific government funding streams. On top of the funding cuts, changes in how government funding will be structured add a further layer of instability. Reductions in income and considerable uncertainty is taking its toll on charities, with many dipping into their reserves, cutting front-line services or even facing closure altogether.

In this environment, charities have to be aware and careful about their finances, both in terms of short-term cash flow and long-term financial viability. It is unlikely that voluntary funding can simply plug the gaps left by government. Current levels of voluntary income are too low to start with, and are also likely to be reduced by the wider economic environment.

All charities will need to examine their financial model to ensure that it remains viable. There may have to be specific investment in adapting existing programmes and approaches to fit new government priorities and new sources of funding, as well as a strengthening of their financial systems and management.

Voluntary funding, as a source of unrestricted income, can play an important role in helping charities adapt to this new environment. It can help them develop their tendering and procurement systems and adapt to a new commissioning environment. At a basic level, contributing to reserves or providing short-term loans to cover immediate cash flow problems can be extremely valuable.²²

A changing voluntary sector

Changes to the autism voluntary sector make up the third major area of development over the past three years. NPC's previous research into autism highlighted a number of weaknesses in the sector, including a lack of coordination, poor measurement systems and a reluctance to share best practice and data. All of these stood in the way of an effective and efficient voluntary sector. During our conversations with charities this time round, we noticed positive shifts in three areas: collaboration and coordination in the sector has increased; the involvement of people with autism has grown; and research efforts have become stronger.

All of these developments play an important role in strengthening and expanding the impact of the sector. The success of the autism strategy is partly testament to a greater sense of collaboration, as are the more practical examples on the ground. Ensuring that information is shared, and that people with autism are put at the centre of the sector will also help improve the quality of provision and services in general.

Yet this is not to suggest that the initial problems are already overcome. Collaboration is still an issue. The autism strategy provided a focal point for collaboration, but this progress may be undermined by increased competition between providers. And although efforts to develop mechanisms to share best practice are still promising, as are improved research and measurement initiatives, it will require sustained and consistent effort to ensure that they continue to progress in a positive direction.

Collaboration and coordination

Charities appear to have forged closer relationships, with more partnership working, particularly around lobbying and campaigning activities, and sharing best practice. Our previous research showed that the autism charity sector lacked coordination and was fragmented. Our conversations with charities suggest that, although the sector remains very diverse, the situation has improved over the past three years. Networks have grown stronger. For example, Dame Stephanie Shirley, a philanthropist with strong ties to the autism sector, has convened a group of chief executives to promote partnership working.

The NAS has also undergone a strategic review with a strong focus on partnership working and how it can build a stronger autism charity sector.

The Autism Act has provided opportunities for joint campaigning

The campaign to secure the Autism Act 2009 was spearheaded by the NAS in partnership with a coalition of 16 autism charities.²³ In such a diverse sector, it has historically been difficult for charities to develop a common campaigning voice, as there have been few points of agreement. The campaign to secure the Autism Act was an exception and has provided an opportunity for many organisations in the sector to come together. Coalition members went on to sit on a Department of Health ERG, which provided extensive input to the strategy. As the implementation of the autism strategy gets going, the focus of campaigning work has moved to a local authority level. There are encouraging signs here that autism organisations are continuing to work together. For example, the NAS Central regional team and Autism West Midlands are hoping to work together to lobby local decision-makers about the strategy.

The key question is what happens next. The autism strategy provided a rare rallying point for the sector, and it is not immediately obvious how this collaborative approach will be sustained beyond the strategy or extended to other issues. There are, however, a couple of encouraging signs. The organisations that make up the Autism Alliance are considering how they can do more joint campaigning and influencing work. Another very positive step is that the ERG, which is no longer under the auspices of the Department of Health, has decided to continue as an independent group facilitated by the NAS. The group has jointly responded to the consultation on the implementation guidance for local authorities. It is now considering how to take the group forward and common areas of interest that might be suitable for future campaigns. This has the potential to provide a platform for campaigning for other areas of common ground, such as more autism training for public sector workers.

²³ The coalition was made of 16 national and regional charities: Autism in Mind; Autism Anglia; Autism Education Trust; Autism Initiatives UK; Autism Research Centre; Autistica; Autism West Midlands; The Children's Society; Hampshire Autism Society; the National Autistic Society; Research Autism; Staffordshire Adults Autistic Society; Sussex Autistic Community Trust; TreeHouse; the Wessex Autistic Society; and the Wirral Autistic Society.

Sharing best practice and partnerships

Stronger networks in the sector are also contributing to better information sharing and general exchange of good practice. Forums such as the Autism Alliance continue to provide opportunities for members to exchange information and ideas, which can then feed into services. At present, the Autism Alliance runs bi-annual events for the chairs and chief executives of the 13 member organisations. There are also events for other staff members, such as for those responsible for delivering training programmes. Other more ad hoc arrangements for sharing knowledge and best practice also exist. For example, the research charity Autistica (formerly Autism Speaks) has helped Kingwood, a charity providing residential and supported living services, to put together a programme of lectures for family carers and their own staff to increase their understanding of autism.

Websites, particularly the one developed by Research Autism, are also helping to share information about autism and effective interventions among charities, autism professionals, and people affected by autism. The NAS's new strategy—in particular the Centre for Autism—should also help boost information sharing. The aim is for the Centre for Autism to be a hub of collaboration for the sector, and a place where information about autism and best practice can be gathered and shared between charities, practitioners, professionals, people affected by autism and the public more broadly.

Stronger networks and greater information sharing in the sector may lead to more instances of collaborative and partnership working. This is beginning to happen in a few cases. For example, the NAS is currently working in partnership with the Wessex Autistic Society (TWAS) to provide advice and support to people affected by autism via a telephone helpline. Calls received by the NAS from Dorset and the south west of England are now rerouted to helpline staff at TWAS, who combine their local knowledge of autism provision and services with the NAS's information and resources. Another example is TreeHouse, which is offering other autism organisations the opportunity to use its building and facilities. NPC has heard that some commissioners are increasingly looking to fund total packages of support for individuals, rather than buying in different services from a range of providers. This may provide a further opportunity for partnership working in the future, as charities with different specialisms work together to provide a holistic package of support.

Although many of these examples are promising, few are properly established and, in an era of reduced funding, there may be less money available to support collaboration and partnership. There is also a danger that increased competition for a limited set of government contracts will scupper growing cooperation as individual organisations become more reluctant to share information that could undercut their competitive advantage.

Greater involvement of people with autism

Charities NPC spoke to admitted that in the past the autism sector has failed to include people with autism in their governance, strategy development, advocacy and campaigns. The involvement of parents in many organisations was seen as sufficient representation and there was a sense that the difficulties around involving users made the idea impractical. However, increasingly charities are recognising the benefits and the fundamental importance of ensuring their work is more inclusive. And as the sector has become more established, involving people with autism has taken on a higher priority. In part this is due to the concerted work of several user-led groups that have begun their own campaigning work.

Increased role of people with autism in charities

Increasing efforts to involve people with autism in the governance, activities, and overall direction of autism charities represents a marked change in the sector since NPC's previous report. Since then the autism sector appears to have woken up to the growing trend of service user involvement. One charity described it as a stage in the evolution of a sector that has tended to be led by strong personalities and small groups of parents. It has also taken time for organisations to develop and test different models of user involvement.

There is also a growing recognition among charities that involving people with autism not only improves the effectiveness and design of their services, but also embodies the basic ethos of the sector's work—ensuring that people with autism are involved, respected and listened to by their communities and wider society. If charities, which are meant to promote the rights and the talents of people with autism, are not doing so themselves, this is likely to undermine and weaken their efforts.

Charities appear to be involving people with autism to different degrees and at different stages (and to varying levels of success). For example, some use surveys and focus groups to help them set their priorities, while many charities use feedback forms to help evaluate and review services. Other organisations have involved people with autism in designing their services and there are also examples where people with autism are delivering training. The NAS is doing some interesting work involving people with autism in its campaigning work. Its most recent campaign, which highlights the mental health problems experienced by children with autism, is drawing on a young campaigners group to develop its key messages. They are also acting as the face of the campaign and spoke at this year's party conferences.²⁴

Growth of user-led organisations

Some people with autism—especially those with high functioning autism and Asperger syndrome—remain very sceptical about autism charities truly representing their views, even with increased user involvement. They feel that charities are not in a position to speak about their needs and experiences, since most staff do not have any direct experience of the condition. They also have strong reservations about user involvement initiatives, whether by charities or other bodies. The concern is that unless they have connections to the rest of the autism community, the people involved do not represent those with the condition as a group, and can only really reflect on their own experiences.

This feeling among some people with autism has led to the establishment of user-led campaigning groups. These groups really came to the fore in 2009, around the same time as the adult autism strategy. They feel that people with autism have not been adequately represented during the development of the strategy or the statutory guidance, because representation has been restricted to charities and individuals with autism or carers. As one autism rights group put it: *'The whole thing—Act, strategy, and its implementation—has not been led by autistic-led and controlled organisations, from start to finish. Nor are we represented at all on the autism programme board, or on the NICE group [that is developing clinical guidelines on autism]'*.

These user-led groups therefore aim to effectively represent people with autism, as summed up in their motto: *'Nothing about us, without us'*. The movement is still very young and at present there are only a handful of user-led organisations in the UK, fronted by the Autistic Rights Movement UK (ARM-UK) and the London Autistic Rights Movement

(LARM), which act as umbrella bodies. Most of these groups are still in the early stages of development. They have very little funding and are run by dedicated volunteers. Their activities to date have primarily involved vigorous campaigning for involvement in various strategic and consultative groups. The movement was represented on the ERG and it hopes to play a greater role in the implementation of the autism strategy.

In future ARM-UK hopes that the user-led movement will branch out into providing services, particular in advocacy. It believes that people with autism are well placed to provide this kind of service as they better understand the needs and difficulties experienced by people with the condition. This feeds into a broader debate within the sector about how best to represent people with low-functioning autism. This is a complex area and some charities have reservations about assuming that people with higher-functioning autism are always best-placed to represent their entire autism community. Various models of engagement need to be tested before coming to conclusions about what it is appropriate.

Stronger research

A third development within the autism sector is the growing use of research and data. NPC's previous report highlighted the need for greater investment in research and a greater emphasis on measurement and evaluation, as this could help develop the evidence base in favour of different services and therapeutic approaches and help organisations refine and develop their work. In this area there are already indications of positive developments. Mainstream charities are developing their research and measurement capabilities and partnering with universities and academics, while the specialist research charities have strengthened their operations and are helping to channel increasing amounts of money into autism research. Although the current levels of funding into this area are still woefully small, the sector is already starting to see the practical applications of better research and better knowledge.

More charities involved in research

A positive development in the past three years is that more charities providing direct services are taking an interest in research and testing the efficacy of their approaches. Some are commissioning research around their existing services and interventions, while others are developing relationships with academics and research organisations and facilitating more studies, often closely linked to their own services.

²⁴ See: <http://nas-education-update.blogspot.com/2010/10/nas-heads-to-labour-and-conservative.html>.

For example, the NAS is in the process of developing its own research strategy. Although the NAS does not see funding research as part of its role, it plans to encourage and facilitate more research in the sector, particularly around developing improved interventions. It recently collaborated with the University of Birmingham on a study looking into self-injury among pupils with autism at three NAS schools. TreeHouse is also doing work in this area and is developing an evidence base for education interventions as one of its strategic priorities.²⁵ It has developed the Centre for Research in Autism and Education (CRAE) in partnership with the Institute of Education with the aim of improving education outcomes for people with autism.²⁶

Much of this work is also helping charities understand the effectiveness of their own work. For example, the NAS hopes to conduct an evaluation with the Institute of Education evaluating the approach of its EarlyBird programme, which supports parents and carers of young children with autism. Similarly, research by CRAE into which interventions produce the best results for people with autism, will help it evaluate and develop the effectiveness of its own approach. These measures are helping to address a weakness within the autism voluntary sector identified by our previous research, namely that few charities were measuring their impact.

However, despite developing good practice, there is still work to be done in this area. NPC's sense is that autism charities could do more to systematically capture and collate their outcomes. There are also some concerns about the quality and rigour of some of the research being produced. This could be improved by greater coordination and information sharing between charities, which would create more opportunities for encouraging robust peer review and discussion of results. Autism charities may want to consider pooling resources and expertise to develop a shared approach to measurement.

Stronger research organisations

The two dedicated autism research charities, Research Autism and Autistica (previously Autism Speaks), have both become more established in the past three years, albeit in different ways. When NPC was last conducting research into the autism voluntary sector, both were still relatively new and under-funded. Although funding challenges remain, both charities appear to have matured and are now on a sounder footing.

Research Autism funds research into interventions that overcome negative aspects of autism. In the past it has been strongly associated with the NAS. However, this appears to be changing with the recent recruitment of its first full-time chief executive and its plans to launch a new strategy next year, both of which will help define its purpose and direction. Also significant is the launch of the Research Autism website in 2007. This contains a wealth of information about autism and interventions for the condition and appears to have become a well-regarded and trusted resource: the website currently receives around 25,000 visitors every month.

Autistica, which funds biomedical research into autism, has also experienced change in the past three years. In January 2010 it changed its name from Autism Speaks, and ended its formal partnership with its American sister charity—Autism Speaks Inc. This was as a result of the two organisations developing in different directions: whereas Autism Speaks Inc. is highly active in advocacy work, the UK charity has remained focused on funding and promoting biomedical research. As well as the organisational changes, the charity published its science strategy in 2009, setting its priorities until 2014.²⁷ To date Autistica has directly channelled £2.6m towards biomedical research, and has leveraged a similar amount through third-party sources. Another encouraging development has been Autistica's open call for research proposals put out in 2009—the first ever such call by a UK charity using its own unrestricted funds.²⁸

Increasing focus on practical applications of research

Autism research is increasingly focused on developing effective interventions and therapeutic approaches that can help people with autism overcome the negative aspects of their condition. This is partly the result of greater engagement and involvement of other non-research charities with research. However, this is also the case even with biomedical research, which increasingly has greater potential for practical application. For example, recent research has identified a potential role for biomarkers and brain scanning techniques in diagnosing autism.²⁹ Furthermore, as this research throws more light on the biological factors underlying autism, this will be something that government decision-makers and autism charities will have to take into account when developing new methods of diagnosis, interventions or policies.

²⁵ See: <http://www.treehouse.org.uk/promoting-change/centre-research-autism-and-education>.

²⁶ See CRAE's website: <http://www.ioe.ac.uk/research/28033.html>.

²⁷ See: <http://www.autistica.org.uk/research/pdf/strategy.pdf>.

²⁸ See: http://www.autistica.org.uk/research/research_we_fund.php.

²⁹ See: <http://www.guardian.co.uk/science/2010/aug/10/autism-brain-scan>.

There has also been greater recognition of the need for interventions based on solid scientific evidence. Research Autism's website, which contains detailed information about the effectiveness of different approaches, has helped to debunk myths about more unconventional therapies for autism, particularly among parents and carers. This has been further helped by evidence pointing to the role of genetics in causing autism. The discrediting of research from 1998 that linked autism to the measles, mumps and rubella (MMR) vaccinations has also been significant. Andrew Wakefield, the physician behind the research, was struck off the medical register in May 2010 and The Lancet retracted the original research paper.³⁰

Key points and actions for funders and charities

Over the past three years, the autism voluntary sector appears to have strengthened and developed by: building stronger networks; sharing good practice; involving people with autism; and encouraging the development and use of research. These are all to be applauded, and are the result of a significant change in the overall mindset of the sector. However, it is important to note that these areas are often quite new and poorly established. They are at the mercy of recent changes in the sector and will be affected by greater competition between individual charities due to reduced levels of government funding.

Often, it is these areas, such as research or partnership work, which are the first to go when money is tight. Immediate goals take priority and more tangible services attract the funding. Increased competition can distract organisations from sharing their work and cooperating. This is short-sighted and instead the sector should work on maintaining and building on the positive progress that has been made to date. This can even help charities adapt to the new environment as partnerships can help charities win contracts and developing shared research approaches can lower costs. It does not just need willing, but also concrete funding to encourage and support these efforts. Even when giving money to specific projects funders should encourage efforts in this area by designating part of their grant for monitoring and evaluation, and then sharing the outcomes.

³⁰ See: <http://news.bbc.co.uk/1/hi/8695267.stm>.

Conclusions and recommendations

The autism sector has experienced significant developments over the past three years involving changes in policy, funding, and the structure of the voluntary sector. Many of these developments have been positive, and are to be supported and encouraged, such as better collaboration, a more integrated national strategy, and increased levels of user involvement. Yet the current environment and the rapid changes to policy and funding are putting the sector under pressure and could put some of the more recent positive developments at risk.

The uncertain situation underlines the importance of charities and funders continuing to work strategically and thoughtfully to overcome the pitfalls that lie in the way and take advantage of the opportunities. This will require charities to adapt the way they work and operate. It will also require voluntary funders to support charities in these efforts. This will particularly be the case over the few next years as the government's plans and funding approach becomes clearer, voluntary funding will play an increasingly important role in ensuring that the positive developments are sustained and strengthened.

In particular there are five main areas for funders and charities to think about. These are:

- 1. Adapting to a changing environment:** many charities we spoke to are having to make considerable changes to their organisational and funding models. These changes are time-consuming and expensive, especially for charities that do not have large reserves to fall back on, but are vital if they are going to do well in the new environment. All charities should reassess their financial models and their organisational structures in light of the changing funding and policy context. Funders can smooth this transition by funding core costs, giving charities valuable breathing space and time to adapt.
- 2. Maintaining lobbying work:** government is the single biggest funder of autism services in England. However, it is becoming increasingly important to target both national and local government, particularly in light of

the pronounced push towards localisation and the impact that local authorities have on how policies are actually delivered on the ground. Local campaigning will require considerable extra effort from charities in order to target every local authority in England, rather than just a single government department.

- 3. Networking and sharing good practice:** while there are encouraging signs that the sector is coming together and exchanging ideas, progress so far is fragile and risks being set back by increased competition over funding. Charities need to continue to prioritise the overall needs of the sector. Funding can be used to encourage the sharing of good practice and to develop partnerships between organisations.
- 4. Developing pilot projects fit with new government priorities:** charities need to find new ways to provide people with autism with the services they need and that government is prepared to fund. However, many local authorities want proof of concept before they are prepared to put up the money. Funders should support charities to pilot new ways of working, this can include projects that help people with autism to organise and commission personalised services. In all cases, it is vital that the impact and the value for money of these services are tracked, in order to make a compelling case for future funding.
- 5. Maintaining non-statutory services:** this is a final and perennial area for voluntary funders to support. Some areas are on the borders of government's funding remit, and if they have been funded by government, this is only out of a discretionary and temporary pot of money. Play and leisure services are a prime example, for while these are important in terms of improved experiences and quality of life for people with autism, they do not receive guaranteed government funding. Lobbying and campaigning work is another example of an area where voluntary funding has a specific role, which is unlikely to be fulfilled by other sources.

Appendix A: Executive Summary for *A life less ordinary*

An estimated one in every 100 people in the UK has autism. This means roughly 540,000 people have problems communicating and interacting with others. Some will have repetitive behaviours and narrow interests. People with autism are more likely to have sensory problems, learning difficulties, mental health problems and epilepsy.

Autism and charities

Charities are improving our understanding of autism; helping individuals with autism; and improving their environment. They do so in different ways and can look quite different. Although 86% of the sector's funding comes from government, private donors can make contributions that add enormous value to the sector.

The role of a donor

Donors have many opportunities to have a real impact. Finding the best option involves donors asking themselves a number of questions: the type of activity they want to fund; the group they want to help; at what level they want to operate; and what issue they want to tackle. Underlying this is the need to find effective charities that have a real impact.

Helping the individual with autism

Diagnosis: the earlier someone is diagnosed the better as children with autism need specialist help. Without this, they can become stuck in repetitive routines, lose their skills and become depressed and anxious. Diagnosis helps individuals have their needs recognised so that they are eligible for support. Charities are devising better diagnostic tools to identify more people; they are working with government to improve the process; and they are providing help and advice to parents and individuals along the way.

Education: education is the only intervention commonly accepted to be successful for children with autism. It helps them overcome impairments and develop strengths. Yet for too many children with autism, school is part of the problem rather than part of the solution. At school they become bullied, excluded and depressed, and they often leave unprepared for later life. Charities are working to improve all points of the system. They are running specialist schools, training teachers, advising parents and lobbying government.

Employment: only 6% of adults with autism are in full-time employment. While work will never be an option for many people with autism, there are others who are missing out. Lack of employment leaves people poor, depressed and isolated. Charities are preparing people for employment and helping them find and keep jobs.

Housing and support: half of adults with autism are unhappy with where they live. Either they are deemed too capable to require support, or so incapable that they often have little choice over how they live. More effort is spent controlling their behaviour, rather than tackling the root of the problem. Charities are helping people live how they want and putting the right support and encouragement in place.

Friends and leisure: taking part in social and leisure activities helps people with autism develop skills; enjoy themselves; make friends and feel less isolated. For many, autism and public attitudes are barriers to having a fulfilling social life. Charities are helping develop social skills, improve existing social opportunities and run specialist programmes.

Addressing the wider picture

Families: although each family is different, they all have to care for their relative with autism; fight for better services and support; and deal with emotional repercussions. Parents of children with autism are twice as likely to have mental health needs as parents in general. Charities help families to cope by providing information and advice, practical help and access to emotional support.

Government: government plays a central role in people's lives. It is responsible for their health, safety, education, housing and care. Autism does not fit easily into existing government structures or funding streams and often falls through the gaps. Charities are making sure that government does not overlook autism and has the necessary information and commitment to provide better support and services.

Public attitudes: poor public understanding adds to the challenges that people with autism face. If doctors, police officers, or the general public have little awareness or knowledge of autism, it makes it harder for people with autism to live their lives and be part of their local community. Charities educate people about autism, teaching police officers and GPs about the condition and how to respond to it.

Research: knowledge is power. Research provides the knowledge to address the effects of autism, ranging from genetic research to developing practical strategies, for example, effective education and employment schemes. Charities not only raise money for high-quality research, but also influence other funders. They improve capacity and communication between researchers and those affected by autism.

Conclusions: arguments can be made for addressing many of the areas in someone's life. However, NPC has identified four priorities where we feel that a donor can have the greatest impact: research; transition from school to adulthood; supporting adults with autism and normal or high IQs; and equipping parents and individuals with autism with information and advice.

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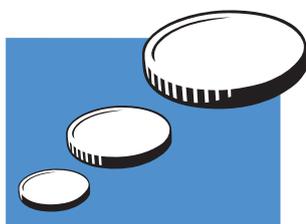
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