

National Lottery Community Fund

1 Plough Place, London EC4A 1DE

16<sup>th</sup> May 2019

**Re: Review of the National Autism Strategy 'Think Autism': call for evidence**

The National Lottery Community Fund is the largest community funder in the UK - we are proud to award money raised by National Lottery players to communities across England, Scotland, Wales and Northern Ireland. Every year we distribute over £600 million to communities across the UK, making circa 11,000 grants.

We recently produced an internal report detailing what we have funded, what has been achieved and what we have learned through our funding to support autistic people and their families. The report was prepared on the basis of extensive literature and funding reviews, and consultations with our own staff and representatives of organisations that work with autistic people. Some of our insights may be of value to the present review of the National Autism Strategy.

Over the past five years (2012/13 to 2016/17), the National Lottery Community Fund has invested £76.1 million into projects that support autistic people and their families. This makes up 1.9% of our total funding within the same period. Our projects have directly supported at least 13,400 autistic people and 9,000 families affected by autism.

We have funded projects that have helped autistic people into employment, provided support and development services to autistic people and their families, and worked to tackle loneliness and isolation through activities and social groups.

Because autism affects each person and each family in very different ways, projects that consider the whole person, not just the condition, have the greatest impact. A whole-family approach is also important, providing everyone affected by autism with support and advice. We have also learnt that 'putting people in the lead' will look different for each project, depending on the skills, needs and abilities of project participants.

We would be happy to organise visits to projects across the country who we know are doing great work supporting autistic people, their families and carers, providing the opportunity to see these projects in action and hear from some of the people involved.

We would also be very happy to meet with ministers or officials to discuss these areas or any other aspect of the work we are doing that may be of interest.

Yours sincerely

**Jane Edbrooke**

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# National Lottery Community Fund submission to the review of the National Autism Strategy ‘Think Autism’: call for evidence

May 2019

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## What have we funded?

### Total funding

Over the past five years (2012/13 - 2016/17), the National Lottery Community Fund has invested £76.1 million into projects that support autistic people and their families. This makes up 1.9% of our total funding within the same period.<sup>1</sup>

Two thirds (65%) of the projects in this dataset were designed to work specifically with autistic people and/or their families. The rest of these projects worked with autistic people as well as those with other conditions or disabilities, so it is possible that not all of the projects included in this figure benefitted people affected by autism. However, because autism is so diverse, and is often diagnosed alongside other conditions,<sup>2</sup> these projects are likely to have supported autistic people as well.

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<sup>1</sup> Estimated figures based on funding data from our funding reporting system and annual reports. Projects have been included in these figures based on key search terms. Our data search may have missed out some grants that we have funded because they have used different terminology in their applications.

<sup>2</sup> National Autistic Society (2017) Related Conditions. [online] Available at: <https://www.autism.org.uk/about/what-is/related-conditions.aspx> [Accessed 20 Dec 2018]

## Funding across the UK

The National Lottery Community Fund awards money to communities across England, Scotland, Wales and Northern Ireland.

Over the last five years, we have awarded 710 grants to projects working in this field. The average grant size (excluding large programme grants) was £84,710.

**Total funding** awarded to projects working with those affected by autism in the last 5 years: **£76,170,942**

England: £58,184,877 (76% of overall funding of this group), 521 grants

Northern Ireland: £8,681,167 (11%), 46 grants

Scotland: £ 8,171,158 (10%), 86 grants

Wales: £858,437 (1%), 30 grants

UK-wide projects: £275,302 (0.3%), 27 grants

Relative to overall funding, **Northern Ireland**<sup>3</sup> has invested most into these projects. They have awarded funding totalling £8.7 million, making up 11% of our total funding in this area.

- Northern Ireland's [Reaching Out: Supporting Families](#) and [Empowering Young People](#) programmes in particular attracted a lot of applications from projects working with autistic people and their families. This explains why Northern Ireland have funded the largest percentage of projects working with autistic people relative to their overall funding.
- Over £4 million of funding was awarded through Reaching Out: Supporting Families. This early-action programme offered grants of £500,000-£700,000 over five years, often to projects working with the parents and wider family of an autistic child, improving their knowledge of autism and teaching them practical skills.
- The Empowering Young People programme awarded over £3.8 million to projects that provide training in employment and life skills to young people with an autism spectrum condition or other disability.

**Scotland** contributed 10% to the total figure.

- [Investing in Communities: Life Transitions](#), a programme that supports people at key times of change in their lives, awarded £2.3 million. It funded projects that worked with people with complex needs, including autistic people, to help them into employment through skills training and confidence building.
- The [Investing in Communities: Supporting 21st Century Life](#) programme invested £2.2 million into projects that aim to build stronger families and communities through early action. This included projects tackling social isolation, supporting parents who are autistic or who have a learning disability, and wraparound support to families affected by autism.

**Wales** has funded 33 projects over the past five years, investing £858,400. This is a smaller number of projects, due to a lower application rate (72 applications compared to 139 for

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<sup>3</sup> There were three Northern Ireland projects that were incorrectly allocated to Scotland's portfolio rather than Northern Ireland's which are not reflected in the stated figures: Banbridge Amateur Boxing Club, £900; Belvoir Women's Family Support Group, £4,085; Team Aspie, £5,000.

Northern Ireland).

However, Wales has invested £10 million into the [Engage to Change](#) programme, which works to help autistic people and people with a learning disability into employment. Because this was funded through Dormant Accounts, it was not included in this data. There is more about this project in the next section.

**UK-wide** funding makes up 0.3% of the total, investing £275,300. The majority of projects came through the [People's Projects](#), which gives the public the opportunity to vote on which local projects receive funding. Many delivered activities for autistic children and their families.

## Funding trends

On average, we invest £15 million per year into projects working with people affected by autism. Applications have been steadily rising since 2013, which may be because of an increase of autism diagnoses and awareness of autism.

In 2016/2017, we received the highest number of applications (363) in this period, and funded a record number of projects. Over half (54%) of applications are successful, close to the average success rate (55-60%) across programmes and countries.

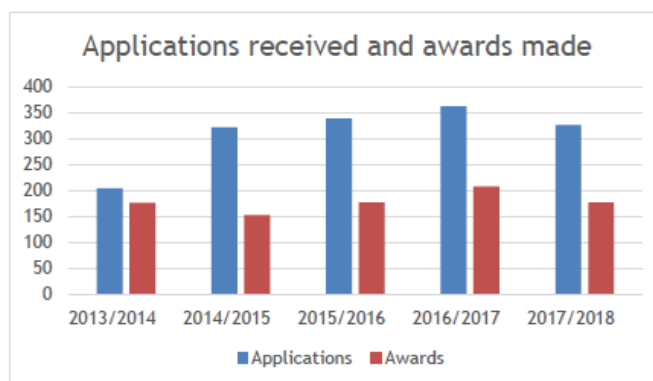


Figure 1. Applications for projects working with those affected by autism received and awards made.

## What have our grants achieved?

### 1) Our grants have supported thousands of autistic people through a diverse range of services and support.

Projects we have funded have supported at least 13,400 autistic people.<sup>4</sup> A further 4,200 people have been supported by projects which work with autistic people, as well as people with other conditions.

The projects we fund are diverse, providing different types of support and activities to autistic people and their families or carers.

The largest amount of funding (31%) has gone to **support and development projects**

<sup>4</sup> This figure was calculated by totalling the number of beneficiaries that projects stated they would work with in their project applications, therefore they may not accurately represent how many autistic people have benefitted from projects funded through our standard grants. It has been used to give the reader an idea of the impact that projects funded through our standard grants have made. It does not include beneficiaries from our Awards for All funding stream or strategic/third party funding as these figures are not readily available on our funding reporting system.

designed to develop the skills and confidence of autistic people and/ or their families. Many deliver workshops to improve communication and social skills, or practical skills such as healthy cooking, which help participants to become more independent. Others aim to improve the wellbeing of autistic people and their families through peer support groups, regular activities, or workshops. These projects tackle issues such as isolation or low confidence by enabling autistic people and their families to meet new people and try new things. Others have delivered regular workshops for parents or autistic adults, where they can receive advice or support.

Nearly a third (28%) of projects we fund provide **one-off events or regular activities**. These projects deliver a wide range of programmes, from weeklong camping trips for the whole family to regular sessions in music, gardening and drama. Like the support and development projects, these offer opportunities to develop skills and improve wellbeing. They also offer both autistic people and their families the chance to meet new people who understand their needs, in a safe and supportive environment. Residential and regular workshops for those with high support needs can provide respite for carers, while those that are open to the whole family offer them the opportunity to spend more time together.

Purchasing **specialist resources** makes up 14% of our funding in this area. Many schools have used the funding to build a sensory room or garden - a special space designed to engage and develop a person's senses, using lighting, music and tactile objects. These spaces can be therapeutic for those with communication needs, as they provide relaxation and enjoyment, as well as stimulating senses and encouraging people to engage in their surroundings. In [this video](#), you can explore the [Bristol Sensory Truck](#) funded through People's Millions. Other organisations have used the funding to buy additional equipment, such as cameras or gardening tools.

## 2) Our funding helps autistic people to reach their potential through employment projects.

We have funded 59 employment projects that work with autistic people to help them learn new skills, provide them with access to voluntary and paid employment opportunities, and build their confidence and self-esteem. Because autism affects each person differently, many projects offer **intensive, individually tailored support**. Projects often work on a one to one basis with participants, creating a personalised development plan, helping them to access training, volunteering and paid employment opportunities, and providing in-work support. Projects also **work closely with employers**, to ensure that they understand the support needs of each individual employee.

### *Example*

**In-work support leads to sustainable employment opportunities for autistic people.**

[Engage to Change](#) is a five-year employment programme that started in 2016, delivered by Learning Disability Wales. The programme received a £10.4 million grant through Dormant Accounts to help 1,140 young people with a learning disability and/or autism into employment.

This project takes a supportive, personalised approach to ensure that employment is both **fulfilling and sustainable**. Each service user is assigned a job coach who gives them pre-employment support, such as an assessment of their skills, qualifications, likes and dislikes; travel training; CV writing and interview training.

Once the person has secured a work placement, the job coach will accompany them at work, providing them with daily one-to-one support. Job coaches also work with the employer on understanding their employee's needs, helping to implement any adjustments to the workplace or training for their colleagues. Support will gradually

reduce and then withdraw as the employee and employer become more confident, but the job coach will return to the workplace if needed.

This long-term approach means that autistic people can get access to work opportunities that they enjoy, that play to their strengths and are sustainable. Two years into the project, 186 young people have undertaken short term unpaid work placements or volunteering roles, with 145 young people progressing into paid work placements.

### **3) Raising awareness of autism in the workplace and supporting employers to hire autistic people.**

We also fund a number of employment projects that **raise awareness around autism in the workplace**, and **support employers** to feel more confident in hiring people with autism or other disabilities. One project that is taking this approach is [PADD](#) (People's Awareness of Disability Discrimination), a group of young people who came together in 2015 as part of [Talent Match Humber](#), and work in partnership with [This Ability](#).

#### *Example*

##### **Helping employers to become 'disability confident'**

PADD works to improve employers' knowledge about autism and other 'hidden disabilities' by offering practical support and advice in hiring people with disabilities.

Members of PADD and the National Lottery Community Fund's Talent Match programme team worked with Sheffield Hallam University on the Making Our Business Yours (MOBY) pilot project which offers free mentoring to employers who take on a young person with a disability or learning difference. They found that it improved employers' confidence in hiring and working with disabled people. The project is now delivered across the Humber region.

PADD work with many organisations to help make their recruitment processes more accessible, such as the Hull Clinical Commissioning Group, East Riding Clinical Commissioning Group and MPH Fulfilment.

The group was also involved in a Green Paper consultation event with the Department for Work and Pensions (DWP), about supporting small businesses in recruiting and retaining employees with a disability.

Following discussion with the Welsh Government, Engage to Change can now use funds from the [Access to Work scheme](#) to support internships. Support for internships had only been available through the Government's Access to Work scheme in England until now. Having access to this funding will provide more support for employers looking to hire neurodiverse and disabled interns.

Although the impact of this work is taking place on a small scale through localised activity, these projects are raising awareness of autism in the workplace and helping employers to better support autistic people. This **empowers employers to diversify their workforce**, as well as helping autistic people into employment.

### **4) Supporting families affected by autism to build resilience together.**

We have awarded grants to projects that have supported at least 9,000 families and carers<sup>4</sup> affected by autism, providing them with the tools they need to best support their child and become more resilient as a family.

Many families who care for an autistic child struggle with everyday tasks and challenging behaviour. In addition, parents often find themselves 'fighting' to get support for their child,

this can include getting a diagnosis, the right treatment, or support at school. Not only does this affect the child's development and wellbeing, it can put a real strain on the rest of the family.

Over the past five years, we have funded 68 projects that support families with an autistic child, by providing them with practical tools and support to manage their child's behaviour, play and socialisation. These projects often support siblings of autistic children too. The [RAFT](#) project, run by Autism NI, provides this type of support.

### *Example*

#### **Empowering parents through early intervention and specialised support**

RAFT provides an early intervention service in Carrickfergus and Newtownabbey in Northern Ireland, offering up to six one to one sessions within the family's own home. These may include:

- The use of a visual structure to help a child communicate and understand.
- Structuring the home environment.
- Setting up and maintaining positive routines.
- Daily living skills and play skills.
- Organisation skills, such as homework schedules.

Individualised support from RAFT empowers parents with tools to support their children, and offers a non-judgemental, listening ear. This is important, because Autism NI have found that not knowing where to start is the biggest challenge for parents, even after their child receives a diagnosis.

Three years into the five-year project, they have provided one to one support to 275 families, with positive outcomes including improved parental wellbeing, calmer and less anxious children and the continuation of effective communication with their child.<sup>5</sup>

Studies have found that parents of children with disabilities can experience high levels of **psychological distress** and difficulty that often goes unacknowledged and unsupported.<sup>6</sup> To tackle this problem, [Scope](#) used a £684,000 Reaching Communities grant to set up a Face 2 Face befriending service in East London.

### *Example*

#### **Non-judgmental peer support for parents**

The Face 2 Face befriending service was delivered across East London for three years until 2017. Scope recruited parents who were caring for a child with a disability or additional needs and provided them with 40 hours of training as a volunteer Befriender. They were then matched with another parent and offered them **emotional support** and advice at regular meet-ups.

As with other Scope Face 2 Face services across the UK, Face 2 Face East London found that a large percentage of the parents who accessed the service had an autistic child.<sup>7</sup>

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<sup>5</sup> Autism NI (2018) End of Year reports that can be found on FMS attached to Agreement Number: 31010886. [unpublished]

<sup>6</sup> Bray, Lucy et al. (2014) *Evaluating the Scope Face to Face scheme in Alder Hey Children's NHS Foundation Trust - Executive Summary* [unpublished]

<sup>7</sup> Dickinson, Penny. Face 2 Face, Scope. 26 June 2018. Telephone interview. Graham, Jo and Elton, Karen (2013) *Face 2 Face Befriending: Evaluation of Scope's service*.

The project supported wellbeing and emotional resilience by creating a safe space to offload negative emotions in a **non-judgmental environment**. Through the service, parents had reduced feelings of guilt, shame and failure, and had a boost in confidence in their own abilities as a parent.<sup>8</sup>

Most other sources of support or intervention focus primarily on the child. What parents find important about Befriending is that the focus is on them. *“When Maureen comes round mine she doesn’t turn round and say how’s Scott doing? She comes round and says how are you doing, what’s going on with you? I think sometimes you need that.”*<sup>8</sup>

*“I think that the scheme is **unique**... In a way, that’s what was missing within a parent’s journey, if you like. They could be referred to counsellors; they could even have a sympathetic GP or a sympathetic health visitor, but that that would not mirror the support another parent could give them.”* **Face 2 Face Befriender**

## **5) Raising awareness of autism and giving autistic people opportunities to have their voices heard.**

Many autistic people and their families find that autism is widely misunderstood by the public, including by professionals such as teachers,<sup>9</sup> whom they rely on for support and advice. We fund 55 projects that work to change this by providing training and support to autistic people, giving them the skills and confidence to advocate for themselves.

### *Example*

#### **Providing opportunities for autistic people to speak up**

[Advocacy for All](#) received a £329,110 Reaching Communities grant for the ‘Speaking Up Together’ project, which delivers advocacy-based activities for people with a learning disability and/or autism. The project gives its members the opportunity to have their voices heard by the local authority, delivers workshops about issues such as [mate crime](#) (when someone takes advantage of a vulnerable person by pretending to be their friend), holds one-to-one advocacy sessions, and puts on member-led social events. Members of Advocacy for All write and design a regular newsletter, illustrating Speaking up Together’s range of activities. The project works with people across the spectrum, ensuring that everyone is able to participate fully, no matter their abilities or additional needs.

The Sutton branch have a ‘Partnership Board’, a self-advocacy group made up of members, which gives them the opportunity to meet with local councillors to voice their concerns about issues such as housing, healthcare, and safeguarding. In 2017, members of the Kent group advised the council on the design of flats for autistic people, making recommendations on their sensory and security needs.

These types of projects ensure that services supporting autistic people are serving their best interests and have a better understanding of the challenges they may face. Self-advocacy projects also **improve people’s confidence and wellbeing** by giving them the opportunity to learn new skills, socialise, and engage with their community.

## **6) Tackling loneliness and isolation among autistic people.**

Research suggests that autistic people are among the most lonely and isolated in the UK and

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<sup>8</sup> Graham, J. and Elton, K. (2013) Face 2 Face Befriending: Evaluation of Scope’s service.

<sup>9</sup> Lepkowska, D. (2008) Special educational needs: Why don’t you understand? *The Guardian*. [online] Available at: <https://www.theguardian.com/education/2008/nov/11/special-needs-autistic-children-education> [Accessed 20 Dec 2018]



are four times more likely to be lonely than the general public.<sup>10</sup> While many autistic people want to socialise they can face challenges in achieving this. Negative experiences, such as bullying, may have put them off socialising; they may not have the social skills they need to build relationships with people; or their anxiety may stop them from trying something new.

Over **200 of the projects** that we fund offer autistic people opportunities to socialise, learn new skills and take part in activities with other autistic people:

- [Project Aspie](#) is run for autistic people, by autistic people. The project was founded by Graeme Croton, who saw for himself, after his late diagnosis of Asperger's Syndrome at the age of 25, how little support was available for adults with autism. It began as an online advocacy and support forum, and has now grown into a grass roots organisation that aims to raise the profile of autism and improve people's lives.

Their project '[Alphabet 12](#)', which received a £10,000 Awards for All grant in 2017, brings people with Asperger's Syndrome and autism together at monthly workshops to socialise, learn new skills and build their confidence. Guest speakers deliver talks about autism, providing participants with a better understanding of their condition and the support they can access. The workshops also enable participants to socialise with their peers and the wider community to create and establish support networks.

- We fund a number of friendship and dating membership agencies for people with a learning disability and/or autism, such as [Dates-n-Mates](#) in Glasgow. This provides opportunities for people to connect, make friends, and build meaningful relationships through a regular calendar of social events in a safe, comfortable and inclusive environment.

Dates-n-Mates ensures that its members are proactively involved in the running of the project, with regular Coffee and Cake Committee meetings for members to propose new ideas and offer feedback. Members also have the opportunity to volunteer as a 'Friendly Face' at events, helping new members feel comfortable and included and offering volunteers the opportunity to learn new skills and build confidence.

Projects like these not only help to **fight against loneliness and isolation**, but improve the confidence of beneficiaries, leading them to **living lives that are more independent**. It opens up opportunities that can lead to volunteering roles and even employment. People have often used the phrase "**life-changing**" when talking about the impact of these projects.

## Challenges we have identified

The following points are core challenges identified by conversations with grantholders and National Lottery Community Fund staff. They highlight issues for us with funding projects that work with those affected by autism, but also for charities themselves in delivering services and activities.

### 1) Many autism therapies and interventions are under researched, making it difficult to make decisions on some applications.

Many different interventions have been developed to support autistic children and adults, yet there is a lot that is still not known about their effectiveness, as very few have been sufficiently evaluated.<sup>11</sup> The fact that autism is such a complex, diverse condition also means that what may work for one person, may not work for another. This can make it difficult for us to know how effective certain interventions are, which can be challenging for our

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<sup>10</sup> National Autistic Society (2018) Hidden crisis: Autistic people four times more likely to be lonely than general public. [online] Available at: <https://www.autism.org.uk/get-involved/media-centre/news/2018-04-25-hidden-crisis-autism-and-loneliness.aspx> [Accessed 20 Dec 2018]

<sup>11</sup> National Autistic Society (undated) Position statement: therapies and interventions. [online] Available at: <https://www.autism.org.uk/get-involved/media-centre/position-statements/interventions.aspx> [Accessed 14 Nov 2018]

decision-making.

In England, the National Institute for Health and Care Excellence (NICE) has produced clinical guidelines for interventions for autism in adults<sup>12</sup> and children,<sup>13</sup> and in Scotland the Scottish Intercollegiate Guidelines Network (SIGN) has one set of guidance for people of all ages.<sup>14</sup>

## 2) Cost effectiveness of projects

Projects that work with autistic people, or anyone with complex support needs, can seem expensive but it is reasonable that they take more time and resources to deliver than more generalist services. Autistic people often need intensive support, particularly when they first start to use a service, so we as a funder are mindful that this will affect the total number of people a project can work with.

Some grantholders have said they feel some funders focus too much on how many people the project has worked with. They think this is unfair, as successful projects can be life changing for individuals. We have concluded this should be taken into consideration when assessing applications and evaluating results. Therefore:

- while we should ensure that a project is cost effective, we need to be realistic and accept that projects working with people with complex needs will be more expensive than generalist services; and as
- evidence is lacking on what works when supporting autistic people, it is in our interest and the interests of the autism sector as a whole to support organisations to evaluate their projects and interventions effectively.

In 2017, the National Autism Project evaluated the cost effectiveness of a wide variety of autism interventions<sup>15</sup> and found that, in general, the following types of services are cost effective:

- supported employment,
- family training and support, and
- Cognitive Behavioural Therapy (CBT) for autistic people with anxiety.

If planned and delivered effectively, these projects can be good value for money in terms of impact versus cost. That does not necessarily mean that other projects, such as social support projects, are not successful or cost effective, just that there is not sufficient research currently to prove this.

## Our learning – what works?

Our investments have identified a number of key lessons around ‘what works’ in supporting people with autism and their families.

1. ‘People in the lead’ will look different depending on the needs and the abilities of people the project is working with.
2. It’s important to take a whole-family approach when supporting those affected by autism.

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<sup>12</sup> National Institute for Health and Clinical Excellence (undated) Autistic spectrum conditions in adults. [online] Available at <https://www.nice.org.uk/guidance/cg142/documents/autistic-spectrum-conditions-in-adults-final-scope2> [Accessed 28 Nov 2018]

<sup>13</sup> National Institute for Health and Clinical Excellence (2013) Autistic spectrum conditions in under 19s: support and management [online] Available at <https://www.nice.org.uk/guidance/cg170/chapter/1-Recommendations#specific-interventions-for-the-core-features-of-autism> [Accessed 21 Dec 2018]

<sup>14</sup> Scottish Intercollegiate Guidelines Network (2016) Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline [online] Available at: <https://www.sign.ac.uk/sign-145-assessment,-diagnosis-and-interventions-for-autism-spectrum-disorders.html> [Accessed 14 Dec 2018]

<sup>15</sup> National Autism Project (2017) The Autism Dividend. [online] Available at: <http://nationalautismproject.org.uk/the-autism-dividend> [Accessed 14 Nov 2018]

3. Autism affects people in very different ways, meaning a person-centred approach is essential.

4. To help autistic people achieve fulfilling, long term, and sustainable employment, projects must provide support beyond the job application stage.

### **1) 'People in the lead' should be defined around the needs and abilities of people the project works with.**

At the National Lottery Community Fund we believe that when people are in the lead, communities thrive. People understand what's needed in their communities better than anyone.

A strong user-led approach is vital to us, and we must adapt this to the abilities, skills and needs of the project's participants. Projects that work with people with milder autism traits could involve them in the planning, delivery and evaluation of projects; for example, through a buddying or peer support system, regular opportunities for people to decide on the kind of activities the project provides, or recruiting participants as volunteers to help deliver the project.

However, projects that work with autistic people who have more complicated needs, such as severe challenges with communication, may not be able to take part in the planning or delivery of a project in the same way. Instead, the project may have to take a more supportive approach to their involvement or give them more defined ways of getting involved, sometimes with their family or carer supporting or advocating for them. This can include contributions to the planning of activities, in which the participant does this with the support of a family member or carer, rather than taking part in focus groups.

Nevertheless, we should not underestimate the role that those who have challenging support and communication needs can play in steering and leading projects.

#### *Example*

##### **Putting people in the lead**

Advocacy for All used a grant to provide training to people with a learning disability and/or autism to deliver awareness training on safeguarding and abuse to their peers. With the help of a support worker, not only were the members able to bring their own experiences to the awareness training, they also learnt new skills. Some participants' confidence improved beyond recognition.

The group use creative tools to get feedback to ensure that everyone is able to have their say no matter their abilities. These include visual tools such as putting markers on a happy or sad face.

Building enough confidence to start taking a bigger role takes time, so it is important that all participants have appropriate support to enable them to steer or help deliver a project.

### **2) Take a whole-family approach to working with autism.**

Autism affects both the person diagnosed with the condition and their parents, siblings and extended family. Therefore, it is important to consider whole-family approaches. Consider the following:

- **Plan time and allocate resources to building a good relationship with the parents from the start.**

It is important to listen to and address parents' concerns, keep them in the loop about their child's progress, and potentially link them with other parents, to offer support and reassurance. As well as improving the parent's wellbeing, developing that trust can improve

the whole family's engagement in a project.

Many parents find it difficult to put their child's wellbeing into someone else's hands, particularly when their child has complex needs. Some may have had negative experiences with other services in which their child's needs were misunderstood or their wellbeing was at risk. Because of this, grantholders have found that some parents can be overprotective of their children and can be wary of allowing them to take part in a project.

The [Engage to Change](#) employment project assigns a support worker for every family. As well as supporting the young person, they will work with their family to reassure them that they will cater for their child's needs throughout the programme, from initial meeting to employment.

- **Give families access to advice and practical support.**

If a project cannot provide families with the support they need, it should be able to signpost them to other organisations that can. Peer support groups are a great way to provide emotional support and advice to family members, from people who understand what they are going through. Autism NI signposts all parents to a [local family support group](#), which offers advice and support.

It is important to remember that wider family members may also need support. [Resources for Autism](#) have found that play groups for siblings of an autistic child are beneficial for the whole family. These groups help participants to feel special, build up their resilience, and help to stop family breakdown as the family unit works together.

Family members may also need practical support around issues such as employment, health and finances. Engage to Change found that parents who had spent decades as a full time carer for their child needed additional support once their child began working. This includes support for parents in preparing for and finding employment or for families who are worried about how their child's employment affects their household's benefits. Engage to Change works with parents to offer them advice about benefits and to assure them that employment is the best thing for their child and their family, even if they receive less in benefits as a result.

### **3) Person-centred approaches are essential.**

Something that has come across in all aspects of these projects is that a holistic, person-centred approach is essential in meeting the needs of autistic people. Projects must be prepared from the outset to invest time into understanding and meeting each person's individual needs.

Autism NI takes this approach with the [RAFT](#) project, where support sessions are personalised around the specific needs of each family, enabling them to work on the issues where they need most help.

An essential part of this approach is ensuring autistic people play a key role in steering projects. This improves project engagement, not only because the projects are more likely to meet their needs, but by helping autistic people feel at ease and better understood. [AutAngels](#) used National Lottery Community Fund funding to run a course called 'Exploring Being Autistic', which offered autistic adults the opportunity to explore how autism affects them with a group of peers. The fact that an autistic person led the course was an important aspect of the project. One participant, Caroline said, "She really knew what she was talking about being autistic herself and you felt like you could open up much more to her, than if it was someone who wasn't autistic. You felt happier about sharing that part of you, when you haven't talked to anyone about it before."<sup>16</sup>

For some autistic people, having a say is very empowering, as there are many things in their

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<sup>16</sup> AutAngel (undated) Feedback from Exploring Being Autistic. [online] Available at: <https://www.autangel.org.uk/feedback-from-exploring-being-autistic.html> [Accessed 14 Nov 2018]

lives that they have not had control over. [Triple A's](#), a social group for autistic young people, run by autistic people say it best: *“The Triple A’s believe very strongly that autists need to be allowed to develop freedom of choice - many of us have had it taken away from us, either through bullying and anxiety, or through people restricting our options through concern. One of the main things that we therefore attempt to encourage in people is the willingness (and ability) to make their own choices.”*

#### **4) To help autistic people into fulfilling, long term, and sustainable employment, support must be provided beyond the job application stage.**

The majority of employment projects we fund tend to focus on getting an autistic person into employment. Support often ends once they have secured a job.

In Wales, the Engage to Change project works on the basis that to achieve *sustained* employment, support needs to continue after they have started their new job. This has multiple advantages:

- The job coach can implement specialist training, enabling individuals to achieve their full potential, independence, and integration within a workplace.
- It is often only after starting a job that it becomes clear what adjustments in the workplace are necessary. A job coach makes it easier to identify and make these adjustments.
- The job coach can support the employer through the transition process, giving them the knowledge and confidence they need to work effectively with their new employee.
- Building a strong relationship makes the employer more confident to go back to the project if they need additional support or training, making the job placement sustainable.

Job coaches can reconnect as and when needed. For example, if the employee’s task changes or they wish to move into a new position within the organisation.

It is common for the individual’s carer to feel overprotective and concerned for their child’s wellbeing in a new job. This can be another barrier to securing work. The job coach scheme provides the autistic person’s family with reassurance that their child’s needs are recognised and understood.

While the job coaching method is expensive, it is effective in helping individuals to achieve long-term, sustainable employment. This saves money in the long run.

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