

**“True support is having acceptance, warmth and help from everyone in my life”**

Exploring post-diagnostic support  
for autistic young people

Emily Niner  
Winston Churchill Fellow 2019

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**Ambitious  
about Autism**

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## About the author

Emily Niner has been the Participation Programme Manager at Ambitious about Autism since early 2017. She manages the participation programme for young autistic people aged 16-25, delivering a national youth council, the online Ambitious Youth Network, the [Autism Education Trust](#) young persons' panel and external consultancy projects. The most recent participation projects have been the [Include Autism Toolkit](#) which provides advice and resources for making youth groups accessible and [Know Your Normal](#) which focusses on the mental health experiences of young autistic people. In 2020 Emily was nominated for an Autism Professionals Award in the 'Someone who changed my life' category. Prior to working at Ambitious, Emily delivered participation contracts for local authorities, housing associations and schools.



## About Ambitious about Autism

Ambitious about Autism is the national charity for autistic children and young people. We provide services, raise awareness and understanding, and campaign for social and policy change. Through TreeHouse School, The Rise School and Ambitious College we offer specialist education and support. Our ambition is to make the ordinary possible for autistic children and young people.

## About our Youth Patrons

Ambitious about Autism works with a wide group of autistic young people to shape everything that we do; we call them our Youth Patrons. Some of these young people sit on our Youth Council, on advisory boards for the work we do with external partners or are members of the online Ambitious Youth Network. They volunteer their time and expertise to help make the ordinary possible for other autistic young people through the projects and campaigns we run.

If you're interested in the work of the Youth Patrons or would like to know how to get involved email [participation@ambitiousaboutautism.org.uk](mailto:participation@ambitiousaboutautism.org.uk)

## The principle of co-production

At Ambitious about Autism, we are led by the principle of ‘nothing about us, without us’ and engage our Youth Patrons, a group of autistic young people aged 16-25, in every area of our work through co-production.

The Social Care Institute of Excellence has several definitions of co-production on their website:

*A way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all. The approach is value driven and built on the principle that those who use a service are best placed to help design it.<sup>1</sup>*

Co-production is not only important, it makes sense. Who better to decide on services or resources that need to be created, than the people who would use them themselves? Each year our Youth Patrons choose a campaign topic, create resources and run events. The topic of post-diagnostic support was one which kept arising and which the group felt very strongly about due to the poor experiences the majority had had. This project and Fellowship would not exist without the Youth Patrons and their desire to improve outcomes for other young people like them.

## What is autism?

Autism is a processing difference that can have an impact on many areas of a person’s life. Autistic people can often experience differences in how they process information, their sensory environment and how they interact with other people.

While autistic people share some similar characteristics, they are also all different from each other. This is because autism is considered a spectrum. The autism spectrum is not linear from high to low but varies in every way that one person might vary from another.

Autism is lifelong condition; autistic people are born autistic and autism can be identified at any point in a person’s life. You can’t see if someone is autistic just by looking at them and some people might not have been diagnosed as autistic when you meet them.

Many autistic people also have co-occurring conditions which can make their needs more complex. Autistic people may also have attention deficit hyperactivity disorder, anxiety disorders,

 **One in 100**

**children, teenagers  
and adults in the  
UK are autistic.**

<sup>1</sup> [National Occupational Standards \(undated\) SFHMH63: Work with people and significant others to develop services to improve their mental health., https://tools.skillsforhealth.org.uk/competence/show/html/id/3833/](https://tools.skillsforhealth.org.uk/competence/show/html/id/3833/)

depression, mental health issues, learning disabilities, physical health conditions and communication difficulties. Officially, autism is considered a disability, but some people do not identify in this way. Autism can be viewed as a disability or disabling due to the impact autism and co-occurring conditions can have on daily life.

Being autistic is not a bad thing and does not make someone 'less' than others; autistic people have a lot of strengths that balance the challenges and difficulties they may face. Some of these strengths may include: having exceptional attention to detail, having an increased interest in a topic that brings them joy and the ability to offer different perspectives to questions.

**Most importantly, while there are similarities amongst autistic people, when supporting an autistic individual, the best approach is to ask the person what they like and don't like for support.**

## How do we talk about autism?

When you meet an autistic person, they might use different terms to describe themselves:



**People have different preferences of what they like used when describing them and autism, so it is always best to ask the individual themselves what their preference is.**

There are also different labels used when talking about an autism diagnosis; some are no longer used, and some are new. Some autistic people may have been diagnosed with: Asperger's syndrome, Autism Spectrum Condition or Disorder, Pathological Demand Avoidance, Atypical

Autism, Pervasive Developmental Disorder or High Functioning Autism. These are all autism but have been used to mean slightly different ideas or profiles of autism.

In this report I have used the term autistic, as identity first language is the preference of the Ambitious about Autism Youth Patrons and they have co-produced this project.

## Executive Summary

Currently in the UK, after you receive a diagnosis of autism as a young person, you are very unlikely to be offered any sort of post-diagnostic support that is catered to you and your needs. Although the NICE guidelines on autism<sup>2</sup> recommend a follow-up appointment within six weeks, a personalised autism plan and a key worker who will support you, most autistic people will be given a simple leaflet or told to look online for more information.

This isn't because post-diagnostic support is seen as unimportant; on the contrary, we know that good support after a diagnosis can make all the difference in understanding yourself, valuing your identity and ultimately improve your overall wellbeing. But with waiting times for a diagnosis increasing all the time and the focus being on the experiences of parents and carers, so far post-diagnosis support specifically for autistic young people has been forgotten.

In the past few years, autism and awareness of it have come to the forefront of society with the government and NHS prioritising autism-specific work. It was therefore the opportune moment to research best-practice in post-diagnostic support services abroad and come back with information and examples that could be a catalyst for work in this area in the UK.

This Fellowship showed that the term post-diagnostic support is imprecise and has no clear definition, content or method of delivery. Instead, it uncovered the key principles that organisations must consider and include if the service or resources are going to be of benefit to autistic young people. These include but not are exclusive to: support being realistic but positive, having key people they can rely on, meeting other autistic people and the opportunity to thrive rather than just survive. Ultimately, we want to ensure that after their diagnosis, no young autistic person feels alone.

Shortly after my return from my Fellowship travels, the Covid-19 pandemic began. Using my learning from Australia and New Zealand allowed me to quickly and safely set up online peer support sessions for young autistic people across the country. It has allowed us to create new services with the input of more young people than ever before and has given us the space to co-produce the resources that young people were asking for. The past year of pandemic life has shown me that the principles I'd outlined for post-diagnostic support are also key to navigating uncertain times and that having a supportive community and safe space is priceless for young autistic people – something that we will continue to prioritise in our work going forward.

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<sup>2</sup> [Recommendations](#) | [Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) | [Guidance](#) | [NICE](#)

## Background to the project

Getting an autism diagnosis can take a long time, but rather than being the end of the journey, it is really the start. For young people in the UK seeking support for a newly received autism diagnosis - or who want more information about a diagnosis made in childhood – there are often very limited opportunities to access help and advice.

Many of the autistic people I support through leading the Participation Programme at Ambitious about Autism were diagnosed as teenagers or young people. However, they tell us they struggled finding post-diagnostic support that was tailored to them rather than their parents or carers. Their diagnostic reports are deficit based - based on a series of milestones they haven't reached – which can compound an already low level of self-esteem or a feeling of being burdensome. Too often late-diagnosis and lack of understanding can lead to problems in their education, family or personal lives; they lose confidence and their mental health suffers as they struggle to understand their identity without support.

We know from our own research that 4 out of 5 young autistic people have mental health conditions<sup>3</sup> and that as many as 79% percent of autistic people feel isolated<sup>4</sup>. We also know that only 16% of autistic adults are in full-time employment<sup>5</sup> which begs the question, why are people sent away with little more than a label?

Since 2016 the median reported waiting time from referral to diagnostic assessment has increased from 16 to 30 weeks and there has been a 40% increase in the population-based rate of diagnoses<sup>6</sup>. Guidelines for waiting times are not being met and this subsequently impacts on the capacity to provide support after the diagnosis is given.

The NICE Quality Standards for Autism<sup>7</sup> recommend that people receive a follow-up appointment within six weeks of a diagnosis and a personalised autism plan is developed that includes any post-diagnostic support, they may need, but we know that this is happening in very few places. Of our group of fifteen autistic Youth Patrons, only one young person had received any support, and this was privately through university.

However, all our Youth Patrons felt like they would have benefitted from post-diagnostic support and would still benefit now. Their asks aren't difficult; they want relatable information from autistic peers to help with self-acceptance and understanding what autism means for them. They want to

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<sup>3</sup> Crane, Pellicano, Harper, Welch and Adams, 'Know Your Normal' – mental health in young autistic adults, June 2017 and Ambitious about Autism Coronavirus and Autism survey 2020  
<https://www.ambitiousaboutautism.org.uk/sites/default/files/reports/files/Coronavirus-and-lockdown-report-2021.pdf>

<sup>4</sup> Sense, 'Someone cares if I'm not there' – addressing loneliness in disabled people, 2017

<sup>5</sup> National Autistic Society, 'Too much information', 2016

<sup>6</sup> Public Health England, Autism self-assessment exercise 2018: executive summary, June 2019

<sup>7</sup> National Institute of Clinical Excellence, Autism spectrum disorder in under 19s: support and management, <https://www.nice.org.uk/guidance/cg170>

learn about coping strategies, co-occurring conditions and reasonable adjustments. Ultimately, they want a place or a person that answers their questions.

For one young person their diagnosis “felt like everything [they] had ever known had gone”<sup>8</sup> and searching for answers online only made this feeling worse. Just because you have a diagnosis doesn’t mean you suddenly understand yourself or the new terms that come with it. Learning about the terms that matter, like camouflaging, masking and stimming and finally having the vocabulary to explain your experiences could make all the difference.

2019 was a year where autism was much more on the national agenda, both in government and the NHS.

- A consultation was launched on mandatory learning disability and autism training amongst health care professionals after a petition around reducing avoidable deaths
- The NHS launched its long-term plan with a priority to improve healthcare outcomes for autistic people and those with a learning disability and launched the Autism and Learning Disability Programme, of which post-diagnostic support is a key strand
- In April 2019, The Secretary of State for Health and Social Care, Matt Hancock announced his intention to run a national autism awareness campaign
- The government called for evidence on extending the Autism Strategy to children as well as adults and this should be published in Spring 2021

These initiatives suggest it is the right time to push for more and better services for autistic people and therefore the right time for this Fellowship. Sadly, the coronavirus pandemic throughout 2020 and into 2021 has meant that whilst Government’s policy intention is evident, publication and implementation has been delayed.

## What is post-diagnostic support?

In the UK there is a dearth of post-diagnostic support available for autistic young people and there are regular calls for this to change. But the term itself doesn’t seem to have an official definition. The NICE guidelines recommend a follow-up appointment after six weeks, the development of a personalised autism plan and the appointment of a named key worker to coordinate the care and support detailed in the plan itself. However, the recommendations go no further than this and so post-diagnostic support remains a nebulous idea. When asked what they considered it to be, the Youth Patrons responded with a range of services, resources and programmes that they saw being delivered by both statutory and voluntary agencies. It is a classic case of one-size definitely doesn’t fit all. And yet at the same time, it was also evident that they would have been happy with any sort of service marketed to them compared to the current resource desert.

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<sup>8</sup> Youth Patron quote, Bella

There is also the consideration of what you need the support for. Depending on when you receive your diagnosis, your family situation, your educational provision and a range of other factors, you will be looking for different answers to different questions – all autistic people are different.

Is the support you're looking for directly linked to being autistic and needing to unpack everything that has led to receiving the diagnosis? Do you want to understand your autistic traits and meet others like you or do you want to “learn to manage life with a diagnosis that can be hard to accept”<sup>9</sup>? And when we break it down, are these things really competing needs?

We regularly hear stories of young people being turned away from support services because they are considered to be too complex a case, when in reality complex is quite often the norm<sup>10</sup>. If we focus on post-diagnostic support through the lens of the social model of disability, does the support you receive ultimately need to show you that it is the system, and not you, which needs to change?<sup>11</sup>

It seems that many services could be delivered under the banner of post-diagnostic support and yet there also services that would never consider themselves such but do indeed fit the gap. So as well as identifying best practice in three areas of post-diagnostic support: peer-led, 1:1 and online, this Fellowship became an exploration of the definition of post-diagnostic support – not just the method of delivery but the key principles a service had to offer in order to be of benefit to young autistic people.

## Why was I initially interested in the different forms of support?

When it came to researching support services, both in the UK and abroad, it was evident that there were a wide range of options available. We know that all autistic people are different and therefore will have differing needs and communication styles. Whereas some people are willing to meet others face-to-face, either in a group or 1:1, others prefer online communication from the safety of their own home. Alongside this, I was interested in the ‘proof’ behind the delivery methods – was there any evidence that these methods were successful, and if so, was one better than another?

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<sup>9</sup> Youth Patron quote, Bella

<sup>10</sup> ‘In addition to experiencing physical co-occurring conditions, up to 70% of autistic children have at least one co-occurring mental health condition’ Simonoff E, e. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population derived sample. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/18645422>

<sup>11</sup> Nick Hodge, Emma J. Rice & Lisa Reidy (2019): ‘They’re told all the time they’re different’: how educators understand development of sense of self for autistic pupils, Disability & Society, 2019

## 1:1 or mentoring

Mentoring or 1:1 support was of interest because it is a halfway point between clinical services and group support. The relationship doesn't have to be formal or authoritative and can be beneficial to both parties. Rhodes, Spencer, Keller, Liang, and Noam (2006) proposed that positive mentoring relationships can promote: a) social and emotional development, b) cognitive development, and c) identity development<sup>12</sup>; three areas which match with Youth Patron requirements for support. Mentoring also gives you an element of choice and control; you can choose your goals and the area you want to work on which empowers you, but you are also guided and supported to achieve it.

## Peer-led and groups

Group-based activities and projects are what we run at Ambitious about Autism, so I was keen to see if there was evidence that this method works, rather than just anecdotal feedback. Mee and Sumsion have said that “engagement in a meaningful group-based activity has been found to positively impact adults experiencing mental health difficulties by providing a sense of purpose, structuring time, and a sense of belonging”<sup>13</sup>. As 4 out of 5 autistic young people have mental health support needs, this method seems to fit. We also know that for the Youth Patrons meeting other autistic people is of key importance and had reduced their sense of isolation; one young person stated that coming to Ambitious about Autism's Youth Council was like “finding my people”.

## Online

Lots of young people first turn to the internet in order to understand their new diagnosis. However, as well as the information being primarily written for parents/carers of autistic young people, there can also be huge controversy and arguments over autistic identities. The growth of Facebook groups, Twitter and Instagram has meant that there is a large and ever-growing community of #ActuallyAutistic people online who use the internet to find support and like-minded individuals. Unfortunately, these online settings are also the site of regular ‘attacks’ on opposing views of what autism is and who autistic people should be, which can deter young people from accessing support.

Although the Youth Patrons had all used the internet to research more about themselves, they also felt that they “shouldn't have to rely on the free support and understanding of under-resourced autistic people online”<sup>14</sup> in the place of funded services.

I was therefore interested in how online services could be curated as ‘safe spaces’ and technology used for good; to connect people, to facilitate conversations and to be a trusted source of information. If technology is a way to reach isolated young people, then there needs to be more focus on utilising it to the best of its abilities

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<sup>12</sup> Jill K. Ashburner, Natasha I. Bobir & Kate van Dooren, Evaluation of an Innovative Interest-Based Post-School Transition Program for Young People with Autism Spectrum Disorder, International Journal of Disability, Development and Education, 2017, p4

<sup>13</sup> Ashburner et al., Evaluation of an Innovative Interest-Based Program, p5

<sup>14</sup> Youth Patron quote, Georgia H

## Why Australia and New Zealand?

First and foremost, I wanted to learn from countries that believed in the social model of disability and where I could visit programmes that were about empowerment and dismantling societal barriers, rather than focusing on autistic people as the problem. Although services and practitioners who subscribe to the medical model of disability will always likely exist, it was important that I was going to a country that broadly aligned with my views and that of the organisation I work for. Due to the imperial past, Australia and New Zealand have similar governmental and legal structures which would hopefully allow ease of replication in the UK regarding services.

Australia was a particular interest as so many of the programmes I was looking into were evaluated and had supplementary research papers, which gave me actual, rather than anecdotal evidence to work from. Both countries are currently moving forward in their practice; Australia has recently published its first national guideline on autism<sup>15</sup> and New Zealand has the world's first Living Guideline<sup>16</sup> which is added to and revised each year by a group of experts. These documents are current and modern rather than basing services on outdated statistics or outdated views of autism and autistic people.

At the same time, although often grouped together, Australia and New Zealand are very different in their approaches to support services due to the level of funding available, the differing communities they serve and of course their geography and population. As well as comparing with the UK, it was also interesting to see how two countries with so many similarities, delivered services so differently and the relationship between state and voluntary sector service provision.

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<sup>15</sup> <https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline>

<sup>16</sup> <https://www.health.govt.nz/our-work/disability-services/disability-projects/autism-spectrum-disorder-guideline/living-guideline-group-keeping-asd-guideline-date>

## Aims and objectives of the project

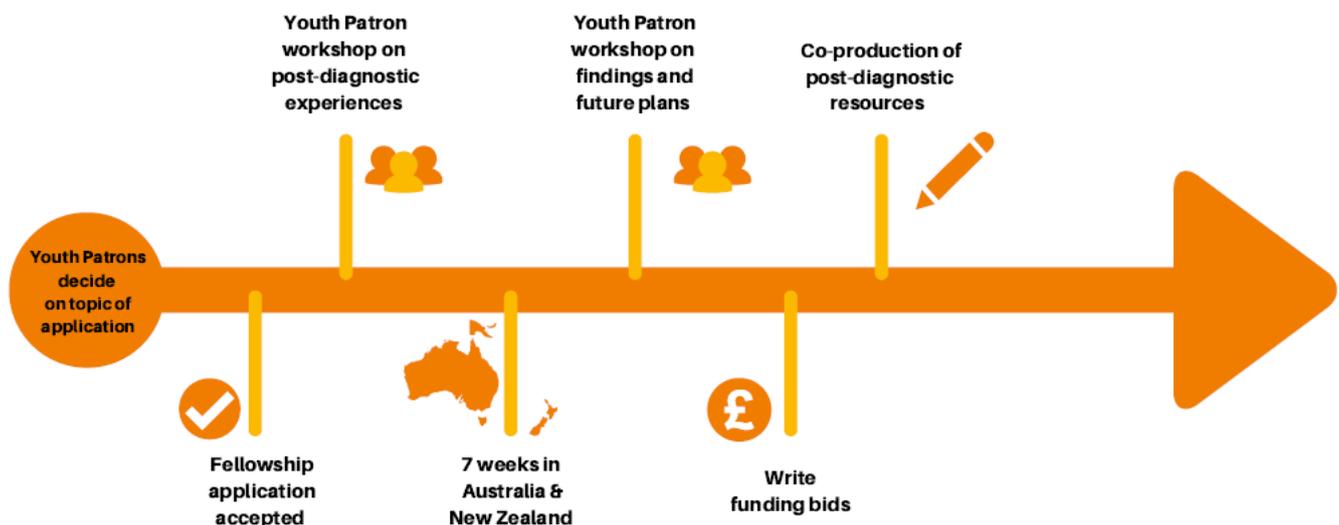
### Short-term objectives:

1. Identify best practice in three areas of post-diagnostic support: peer-led, 1:1 and online, including gender-specific, age-specific and common interest services.
2. Work with the Ambitious Youth Patrons to create tangible resources such as a toolkit, website or pilot peer-mentoring group.
3. Work with partners in the autism and health sectors to devise the widespread dissemination of the report and resources across the UK.

### Long term:

1. Influence professionals who are responsible for diagnosis to implement post-diagnostic pathways and utilise the resources.
2. Provide positive and practical support to young autistic people around the country which in turn will reduce the isolation, stigma and fear around a diagnosis.
3. Campaign and work towards making the NICE Quality Standards for Autism a reality, with post-diagnostic and emotional support within 6 weeks of a diagnosis.

## Methodology



To ensure this Fellowship and any resulting resources and services are co-produced, I have been working with the Ambitious about Autism Youth Patrons throughout. Before I left for Australia and New Zealand, I ran a day-long workshop with the Youth Patrons (15 young autistic people aged 16-25) in order to understand their experiences, what they would have wanted after their own diagnoses and support with deciding which organisations to visit abroad. Upon my return, I ran

another workshop to share my findings and use these examples of best practice to decide on our priorities going forward. The group decided they want to create empowering post-diagnostic resources to be hosted on the Ambitious about Autism website and start planning a peer-support programme for schools, based on the I-CAN Network.

With the COVID-19 pandemic, the initial plans for the peer-support programme in schools had to be delayed. However, moving engagement online meant that we could work with a much larger group of young people from the Ambitious Youth Network to create the resources for the website. We planned these resources through online and interactive planning sessions where the young people both suggested and voted on the topics they most wanted to see content on, allowing us to prioritise which pieces we focused on first. We also gained funding to pay the young people for the time and expertise they had given in sharing their stories through videos and writing articles.

### **Initial questions asked of the Youth Patrons:**

- *How old were you when you were diagnosed as autistic?*
- *Were you offered any post-diagnostic support?*
- *If yes, what way was the support given?*
- *If no, do you think you would have benefitted from post-diagnostic support?*
- *What method of support would work for you?*
- *What would be your aim with post-diagnostic support; what would you like to gain from it?*
- *If you were diagnosed when you were younger (11 and below) do you think you would still benefit from post-diagnostic support now? e.g 'making sense of my autism'*
- *Where would you expect to find this support?*
- *Have you ever experienced peer-mentoring? Would you be interested in a service like this?*
- *Is there anything else you'd like to say about post-diagnostic support?*

From these questions I gathered the following responses:

## Youth Patron requirements for post-diagnostic support



## Recommendations

Combining the feedback from consultations with the Youth Patrons and findings from my Fellowship, I have produced the following recommendations. Rather than recommending the commissioning or creation of specific methods of support, I have outlined the components that must be included in services in order to best meet the needs of autistic people and fill the gap identified by the Youth Patrons.

These recommendations can be used by services that already exist in order to improve their offer or they can be used as a best practice charter to follow when designing new services or resources.

**Prioritise** autistic people and their experiences when designing and commissioning support – all services, resources and programmes need to be co-produced with autistic young people as standard to ensure they are fit for purpose and meet the needs of those who will access them.

**Acknowledge** the needs of everyone – post-diagnostic support should be delivered directly to autistic people but should also be holistic to encourage wider awareness and acceptance. Parents, carers, siblings, families, peers and professionals need to be educated as well, in order to wholly support the young person.

**Create** a positive autistic identity but without being unrealistic or ‘sugar-coating’ the reality of growing up and everyday life. Don’t minimise the challenges that young autistic people face but do work with them to “get the best out of their autism”<sup>17</sup>, reach their potential, and learn to value who they are.

**Ensure** that young autistic people can meet others like them in a safe and supported way. Your differences aren’t different when you meet people like you and can create a sense of solidarity, pride and belonging that isn’t possible to recreate elsewhere.

**Embed** these programmes early – lots of services come too late in the day for young people; rather than making up for a lack of support before, create a kinder, more accepting environment from the beginning. School is the key place for this work to begin and ultimately help support a happy transition to adulthood.

**Evaluate** continually – post-diagnostic support services should be iterated, evaluated and improved to ensure they are consistently meeting the needs of young people and to prove worth to commissioners and funders whose support you need. Services and resources need to be adaptable to the changing times and take advantage of developing technology to stay relevant and user-friendly.

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<sup>17</sup> Youth Patron quote, Josefina

## Challenges to implementation – key questions to consider

Whilst this Fellowship has shown me incredible examples of best practice in service and resource provision, it would be remiss to assume that they can be easily translated to a UK context. Below are questions that I believe are key to consider when thinking about post-diagnostic support services and can be used in the same way as the recommendations above: both by organisations or individuals designing new services and those who want to assess the impact of their existing service and how it can be improved.

### Geography

- How can we design the best delivery mechanisms for services?
- Can we utilise modern technology to reach young people across the UK?
- How can we ensure that support can be adapted to fit to local need?
- How do we encourage or design local support that is led by local people?

### Funding

- Who will fund or commission these services?
- Do we need a business case of long-term costs for local and national government to act?
- Once running, how do we prove worth to funders and commissioners?
- Can we quantify the benefits of post-diagnostic support?

### Voluntary and statutory

- Devolution in the UK and within England means that there is already a postcode lottery of services. Is there any way can we ensure consistency of service across these organisations?
- How do we embed services and resources across the lifespan?
- Does the government need to legislate on this for action to be taken?
- How can we implement the NICE recommendations?

### Clinical and informal

- Who will be delivering these programmes?
- Can we work together to meet needs rather than competing for funding?
- How do we find the balance between clinical professionals and community services?
- How do we step away from pathologising autism in clinical services?
- How do we design services with the lifespan in mind - are there key points when people need more support?

### Diversity

- Who do existing programmes target?
- Can universal services meet the needs of the autistic community?
- Are we considering the diversity of the autistic population? One-size-doesn't-fit-all.
- How do we consider co-occurring conditions when designing services?
- How do we consider cultural diversity and the stigma of autism in differing communities?

## What are the key principles of post-diagnostic support?

Exploring post-diagnostic support services and resources has shown me that there are multiple ways that support can be delivered and that it can be both simple and incredibly innovative. What truly matters is the content and the underlying aims. Whilst the case studies in this report focus on the method of delivery of post-diagnostic support, this section focuses on the principles of what should be included, based on examples I have seen and the evaluated evidence of services that work. Each heading has been identified by the Youth Patrons as something they would have wanted after their diagnosis and is accompanied by a quote in their own words.

### Support to be realistic but positive

*“I would have wanted... something honest, learning the good and the hard without sugar-coating.”<sup>18</sup>*

Post-diagnostic support should be there to help you make sense of the diagnosis you have received and how you can move forward with this knowledge. For some people, the diagnosis is reason to celebrate and an affirmation of what they already knew and felt, but for others it can be confusing and fraught with uncertainty. Feelings regarding an autism diagnosis are not always constant; life events and new experiences can mean that your perspective can change and aren't consistent.

The Youth Patrons told us that when they did look for support, they wanted it to be **realistic but positive**. They found that the professionals and services they had encountered were either entirely focused on their perceived deficits and the things they couldn't do or painted autism as a 'superpower' without any hurdles. Neither is helpful.

Autistic young people want support that is honest and doesn't 'sugar coat' the truth. Being autistic can come with challenges and there are areas of life that can be undeniably more difficult. Professionals, be they educational, clinical or therapeutic, shouldn't be scared to acknowledge these difficulties and then work together with the young person to identify how they can be overcome using their strengths. This support should be focused on the priorities that matter to them, whether that is academic, social, emotional or personal. Simple methods such as asking: what are you good at, what do you want to do, how can we get there?

Currently lots of programmes to support autistic young people are framed as 'interventions' – but post-diagnostic support shouldn't be trying to 'intervene' and change the person. Instead, we should focus on early support that can provide young people with the knowledge, skills,

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<sup>18</sup> Youth Patron quote, Josefina

confidence and motivation to live their life in the way that suits them. It should give them 'tools' that they can use when they need them and put them away when they don't, such as coping strategies or scripts for certain situations. One Youth Patron said that they 'feel like [they're] constantly playing catch-up' because they missed out on understanding themselves and developing a strong sense of self from a young age. Being misunderstood and poorly supported meant they haven't mastered skills or gained knowledge that their neurotypical peers have, such as how to socialise or engage in spontaneous conversation. The NICE recommendation for a personalised autism plan would allow young people to outline their goals and ensure that the team around them were dedicated in supporting them to achieve them.

Validation is also key – societal norms mean that autistic young people have likely spent most of their lives trying to conform and 'fit-in'. "The effort required by autistic [young people] to regulate and control themselves, putting on a 'façade' of 'being normal', is... exhausting"<sup>19</sup> and can make them feel as if they are failing. Post-diagnosis support should step in and validate them and their identity; they shouldn't have to mask their true selves in order to fit-in and they aren't being wilfully difficult – "[Finding out I was autistic] meant I am not wrong or naughty or a problem"<sup>20</sup>. Knowing that there is no 'right' or 'wrong' way to feel can be liberating for young people who have regularly been disbelieved for their reactions and emotions.

Support should also be transparent in its aims. If there are objectives of sessions, activities or therapies then these should be openly discussed. There is no point attending a service or using resources that are aiming to reach a goal that you don't share. Whether being delivered in a group or 1:1 everyone should be on the same page – the young person needs to be able to trust those delivering the service and know that they are being valued and respected for who they are, not for an outdated stereotype of what autism is.

Ultimately, support should equip young people to be able to face the challenges of life and this isn't possible when the information or support they receive is 'sugar-coated'. This isn't about lowering expectations for autistic people but giving high levels of support which enable them to tackle and overcome obstacles.

A great example of a support service and resource that allows young people to be supported in a practical and positive way is Autism Queensland.

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<sup>19</sup> Pellicano, Dinsmore and Charman, 2014, p6

<sup>20</sup> Youth Patron quote, anon.

## Case Study: Autism Queensland



Whilst in Australia I attended three of the Autism Queensland programmes: Studio G, Make a Meal of It and The Hangout. These programmes are 10-weeks long and begin with a meeting of the individual and their support network and an Autism Queensland practitioner, to go through their goals of attending. There are informal check-ins throughout the project, and they get a report each term on their project and personal goals. Although there are specific aims for each programme; for example, to budget for, buy and cook a meal, there is also a positive overall effect on emotional wellbeing, through creating an opportunity to mix with like-minded people<sup>21</sup>. For example, a participant of the Studio G tech skills programme stated “I love Studio G. This is my place... my sanctuary”.

As part of the pre-meeting, the Autism Queensland practitioners use the Adult and Adolescent Goal Setting Tool (AAGST). The tool is made up of 72 different cards that have been developed, designed and evaluated by autistic people, families and professionals<sup>22</sup>. The cards are sorted according to the person’s goals and are prioritised and personalised into what each goal means for them. A planning sheet then allows them to create an outline of the steps required to achieve the goal and set review dates to track progress or update their goals.

The AAGST has proven that it works to help determine goals, but I think this tool, or this style of tool, could be used with young people to help them understand more about themselves. Through sorting and prioritising, the cards prompt conversations and reflections on skills and struggles that the young person may have. This could help identify certain problems they are facing or even identify something they hadn’t previously recognised in themselves. For example, prioritising learning to use public transport but identifying that a barrier to that is noise and odours. This tool is incredibly versatile and could be used by any young person, parent or practitioner – educational provision being a key area – and could be used immediately in a UK setting with very little adaptation.

The AAGST combined with the social participation and skills-acquisition of the programmes seems to be the perfect mix of the formal and informal. For young people who have left school with low self-esteem, who feel disenfranchised and unsure of their own capabilities, this method works. The participants can navigate the programme themselves, curate their own goals and pathway but access the support of skilled professionals when needed.

***“AAGST enables people on the spectrum to exercise choice and control over their lives, and therefore has the potential to substantially improve their quality of life.”<sup>23</sup>***

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<sup>21</sup> Ashburner et al., Evaluation of an Innovative Interest-Based Program

<sup>22</sup> Ashburner, J., Jones, J., Tomkins, V., McLucas, R., Bobir, N., Taylor, J & Lister, J., The development and evaluation of a goal setting tool for adolescents and adults on the spectrum, Co-operative Research Centre for Living with Autism, 2019

<sup>23</sup> Ashburner, J., et al, ibid

## Demystifying and destigmatising autism

*“Any information I found was either vague or harmful” “Unfortunately most of us are tricked by stereotypes.”<sup>24</sup>*

If 1 in 100 people are autistic, then you are statistically likely to know someone on the spectrum. However, society is awash with stereotypes about what this means. Stereotypes such as autistic people not experiencing empathy, only boys being autistic or autistic people being savants, continue to persist despite consistent efforts to debunk these myths. These stereotypes can be difficult to unpack and have led to autistic people being ‘missed’ and misdiagnosed. It is also difficult to ignore the pervading ‘negative societal beliefs’<sup>25</sup> around disabled people in general, centred around the idea of ‘abnormality’ or being ‘disordered’. In order to support young autistic people to understand themselves and value their identity, we need to step away from focusing on deficits and **destigmatise being autistic**.

When young people receive their diagnosis, one of the first places they turn is the internet. The online world hosts a wealth of information about autism and technologically literate young people are adept at finding it. However, with no guarantee on the quality or the source of the information, young people report that a lot of the resources they find are both **vague and harmful**.

*“It was presented to me as an entirely negative thing that meant you were something bad, a burden, something deserving of being called horrible names. This held back my true understanding of my autism for years and harmed my self-confidence greatly.”<sup>26</sup>*

Early education is one way in which we can destigmatise and demystify autism. Being openly autistic shouldn’t be “like walking around with a target on [your] back”<sup>27</sup>. Rather than being ashamed of being autistic and knowing that the label will incite bullying, we need it to be affirmative. By teaching people from a young age that we should value difference and that being autistic is not something negative, we can raise a generation to foster a kinder environment and be more inclusive. This works for both young autistic people and the people around them; the onus should not be on autistic young people to educate others but everyone to try to understand and accept.

We also need to consider the diversity of the autism community when we think about addressing stigma. Different cultures can view disability and autism in varying ways and for some, there is real shame attached to an autism diagnosis. This means these communities may not be able access

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<sup>24</sup> Youth Patron quotes, Kieran and Josefina

<sup>25</sup> Ashburner et al., Evaluation of an Innovative Interest-Based Program, p4

<sup>26</sup> Youth Patron quote, Kieran

<sup>27</sup> Youth Patron quote, Kieran

services that are currently on offer or that existing resources don't relate to their personal experiences. We must also remember to acknowledge intersectionality when thinking about support services and ensure they are accessible and appropriate for autistic people who are marginalised in multiple ways due to gender, race or class. Therefore, any resources or services that are designed need to be co-produced with members of differing communities, to ensure they are sensitive to all needs.

So, when we talk about demystifying and destigmatising autism, we need autism to be humanised. Rather than pathologising it and providing young people with a list of traits they may or may not have, we need real and representative resources. Young people need to be able to see themselves in the world and this means taking into account the diversity of the autistic community and the range of needs this presents.

The I-CAN Network school programme achieves this goal by bringing diverse young people together in mainstream school settings to unpack and demystify autism and break down the pervading stigma they have felt around their diagnosis.

## Case study: I-CAN Network



The school programme is a 10-15 week course that runs once a week for an hour in mainstream schools. It brings together a group of autistic students from different year groups and covers a range of modules, whilst remaining informal and fun. It also includes a talk to parents and the rest of the school about autism to ensure support is extended outside the peer group. The programme is run by autistic adult mentors, a large proportion of whom who have accessed I-CAN services, meaning they understand the needs of participants and can support their journey.

Having observed the school programme at Pine Rivers State High School, it is obvious that it creates a strong peer network in mainstream schools, with younger students looking up to older members and going to them for advice and support. It also creates a sense of pride in being autistic by demystifying and therefore destigmatising their diagnosis through the sharing of experiences. The feeling in the room was that of joy and solidarity. A lot of the older participants were also keen on becoming mentors and using their new-found knowledge in helping others on their journey.

***“I was introduced to the I CAN Network through my school when I was in Year 7 and signed up straightaway. Being a part of I CAN has opened me to experiences and challenges I would not have had otherwise. I have also met many great people on the spectrum who I can share my passions with and who understand me in a way that others can’t.”***

Because of this, the I-CAN school programme is the service that the Youth Patrons would most like to see replicated in the UK. One Youth Patron said that having a programme like this “would have helped me detoxify the harmful mindset that school peers had instilled in me”<sup>28</sup> and that by including parents and the rest of the school, it could help an overall environment of acceptance. If school has long been recognised as a critical site of development for the self<sup>29</sup>, we need to ensure that it is inclusive and values difference. Rather than focusing on helping the pupil ‘fit-in’ to the neurotypical school, these programmes need to champion autistic pupils and examine the environment in which they are teaching. Only by approaching support in a holistic way will we be able to fully demystify and destigmatise being autistic.

### How could the UK deliver this model?

- Ensure that any support, resources, or groups you are putting in place are meeting the needs of the young people by asking pupils what support they would like to see before you begin.
- Have clubs, societies, or networks available to autistic pupils that are kept safe and moderated.
- Train staff in autism awareness and understanding so they can support pupils with trusted information.
- Run autism awareness sessions in your settings with input from autistic pupils if they are interested in educating others.
- Work on creating an inclusive environment for all young people where difference is celebrated through PSHE lessons.

## Meeting other autistic people

*“For the first time in my life I didn’t feel alone. I finally felt like I belonged on this strange planet.”*

Meeting other autistic people is one of the easiest ways of supporting people to understand themselves and their identity, but many of those we work with had never engaged with autistic peers before. For the most part, this was due to not feeling comfortable being open about their diagnosis at school or feeling wary of groups or activities catered specifically for those with additional needs. For the girls in our group, many reported not wanting to go to ‘autism-specific’ offers as they were often the only girl and the activities didn’t interest them, being based on stereotypical special interests. There is also the challenge of growing up in isolated or rural areas where groups or activities aren’t on offer and the additional costs which not every family can

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<sup>28</sup> Youth Patron quote, Kieran

<sup>29</sup> Harter, S. 2012. *The Construction of the Self: Developmental and Sociocultural Foundations*. 2nd ed. London: The Guildford Press, p3

afford. However, we know from running our youth panels and groups that meeting like-minded people can have incredibly positive effects on wellbeing and self-esteem.

***“My differences weren’t different when I met other autistics. They were uniting similarities.”<sup>30</sup>***

Nearly every programme I visited in Australia and New Zealand centred around promoting relationships with other autistic people. After being ‘othered’ and socially isolated for so long, meeting people who are like you and have similar life experiences is validating and creates a sense of belonging. After spending a lifetime being compared to others and having your differences highlighted, you can find those all-important similarities and common ground. Yellow Ladybugs, a social group for autistic girls, has created a strong identity for young people; some of them may be too young to understand autism and what that means for them but can see that they are like the other Yellow Ladybugs at the groups they attend, and they are proud to be so. For many young people, meeting others like them gives them permission to like themselves and be open about their interests as well as sharing their struggles.

Although national groups can work, as the Ambitious Youth Council does, having a service in your local area that you can go to and who understands you is incredibly empowering. The Youth Patrons regularly talk about their wish to have a Youth Council in each of their local areas. With the devolution of service provision across the UK and within England, having local support means having knowledge of your area and what is available. Local groups also allow young people and their support circles to create a network that is easily accessible and creates a real sense of community, that perhaps they haven’t been included in before.

As well as supporting young people with discovering, accepting and valuing who they are, meeting other autistic people can aid with core understanding of autism and how it affects them in a practical sense.

***“They [other autistics] have helped me figure out how autism manifests in me and the co-occurring conditions that autistic people sometimes have.”<sup>31</sup>***

Co-occurring conditions and links with autism are often misunderstood and overlooked. Autistic people are more likely to have co-occurring conditions than the general population with learning disability, anxiety disorder, epilepsy, anorexia and hypermobility conditions being most common. 3 in 10 autistic people have epilepsy, 70% have a mental health problem and 1 in 3 has a learning disability<sup>32</sup>. Meeting other autistic people provides a forum whereby people can share health experiences and support others to see the links in their own medical history. Autistic people can therefore provide relatable advice about navigating the world in general, also considering any co-

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<sup>30</sup> Autistic adult quote, Sarah

<sup>31</sup> Youth Patron quote, Josefina

<sup>32</sup> <https://www.autistica.org.uk/what-is-autism/what-is-autism>

occurring conditions and particular experiences. Advice on education or employment will be much more helpful if it comes from someone who experiences the world in the same way as you.

Support from autistic peers can be delivered in a variety of ways; through a 1:1 mentoring relationship, the creation of all-autistic peer groups or engaging in autistic online spaces. Whatever the method of delivery, it is important that autistic people are involved and respected as the experts. At the same time, we need to ensure that support is facilitated in a way which benefits all those involved and considers the differing needs of autistic people. We need skilled, enthusiastic and empathetic people to run and monitor these groups to ensure they are achieving their aims and that the space is and remains safe. The right setting for young people to explore their identity means that not only can they find others like them but also discover who they are themselves.

Alongside I-CAN Network as an example of all-autistic group work, the Sylvia Roger Academy at Autism CRC in Brisbane runs a programme called Future Leaders.

## Case study: Future Leaders Program



The Future Leaders Program is a course that builds leadership capacity for autistic adults. It was designed to empower autistic adults with leadership potential who want to make a positive impact in their communities. Although targeted to an older cohort than the one I work with, I was interested in this programme due to its design and delivery by autistic people, the structure of the course with face-to-face and online opportunities and the limited time-frame of 9 months.

The Future Leaders can further develop their leadership skills through a series of training and development initiatives including:

- completing online training modules
- attending a 3.5-day/3 night residential workshop
- undertaking a 50 hour voluntary placement with a community or corporate organisation
- being mentored by an autistic leader or Project Team member
- being part of a community of emerging and established autistic leaders who learn from, encourage and support each other

Autistic people often find themselves framed as disordered, abnormal and different<sup>33</sup> but this leadership programme highlights and champions autistic people and their strengths. By empowering autistic adults to become leaders in their communities, the programme is also helping to create a group of role models for autistic young people to look up to and model themselves on. The evaluation of the first Future Leaders Program <sup>34</sup>shows that most of the participants have gone on to mentor other autistic people, run programmes or give back to their communities, creating a full circle of support and acceptance.

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<sup>33</sup> Nick Hodge, Emma J. Rice & Lisa Reidy (2019) 'They're told all the time they're different' p5

<sup>34</sup> Haar, T., Rodger, S., & Brewer, J., Evaluation of a leadership program for young autistic adults

***“Future Leaders was my introduction to the world of advocacy and the opportunities that exist for autistic adults to be leaders and to have an influence.” – Jac, Future Leaders Participant***

The all-autistic environment is also something that needs to be prioritised in post-diagnostic support services. Jac told me that programmes like this need to have a warning about *“how amazing it feels to be in all-autistic spaces”* and that *“you’ll never want to go back to a neurotypical world”*. Ultimately the formula for success with Future Leaders makes use of all three methods of post-diagnostic support. You have online training and can communicate with other participants online, have a group face-to-face residential and the 1:1 mentoring relationship. You are surrounded by like-minded people whilst being supported to learn and upskill yourself. This combination could improve our current Youth Patron offer, or any social group, by providing tangible skills development, rather than just anecdotal improvements in confidence and self-esteem. It will also provide a solid base from which you can develop and self-support after the programme or group has finished due to age restrictions.

### **How could the UK deliver this model?**

- Create all-autistic spaces in educational settings, as mentioned in the I-CAN case study, or workplace networks for autistic employees.
- Leadership programmes in education and in the workplace to consider the needs of autistic participants, through conversations about support needs and reasonable adjustments.
- Autism charities to provide upskilling, campaigning or advocacy opportunities for autistic young people.

## **Know what autism means for me**

***“I’m not alone, I’m not broken. Finding out I was autistic helped me be nicer to myself.”<sup>35</sup>***

Receiving a diagnosis of autism doesn’t suddenly unlock understanding about yourself, if anything, it can raise more questions. If ever a young person reads their diagnostic report, they will discover everything they cannot do, all their perceived deficits and the milestones they haven’t reached. One Youth Patron reported being so upset by his diagnostic report that he burned it.

The use of clinical language and medical jargon means that it can be hard for the young person to recognise themselves when reading about autism or even their own diagnostic report – it is so far removed from their experience. Terms such as functioning labels can be difficult to comprehend; a young person could be labelled as ‘high-functioning’ but struggle with daily tasks, whereas someone ‘low-functioning’ could live independently. These labels ignore both peoples’ struggles

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<sup>35</sup> Youth Patron quote, Georgia H

and their strengths and makes young people question whether they are ‘autistic enough’ or too complex. It also makes it difficult to access services when you don’t fit neatly into a group. For example, in New Zealand, it was only in 2014 when you could apply for services whilst ‘just’ autistic i.e not with a learning disability.

So, we need to ensure that we are equipping young people with the knowledge and the vocabulary they need to be able to understand themselves and the terms being used about them. One Youth Patron stated that she was “*diagnosed aged 9 but was 16 and online before [she] found out what sensory differences were ... and they’re the thing that affect [her] the most!*”<sup>36</sup>. Although she had been diagnosed at a relatively young age, having no support to unpack what that diagnosis meant she still wasn’t confident as to how it affected her on a day-to-day basis. She didn’t have the vocabulary to explain her experiences nor the knowledge of what autism could ‘affect’, putting her on the back-foot in her own life.

Post-diagnosis support should fill this gap. It should equip young people with the knowledge they deserve to have about themselves and empower them to be able to use it. Rather than sterile leaflets that list traits and dehumanise autism, we need to give young people the opportunity to work through their strengths and weaknesses and ask questions. Terms such as masking, camouflaging, meltdown and shutdown are regularly used in educational or healthcare settings, but not always explained to the young person they are referring to. Language is power and giving a young person a word to describe the experience they are having, and perhaps one they thought only they struggled with, is empowering.

***“Once I was actually aware of my diagnosis, I had already had my understanding of autism corrupted and polluted by the vast amount of harmful, toxic and offensive misinformation that I had seen.”***

We must also consider that by the time a young person receives their diagnosis or begins to explore a diagnosis given when they were younger, they may already hold negative feelings about the term. Rather than relief they may feel scared. Rather than being happy they may be confused. And this is before we consider cultural stigma and intersectionality. Young people need to know that there is no right or wrong way to react to a diagnosis and that it is a different process for everyone. Every autistic person is different and so post-diagnostic needs to be personal.

Altogether Autism, a national autism charity in New Zealand, aims to provide personalised support by running a government funded information and advice service.

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<sup>36</sup> Youth Patron quote, Georgia H

## Case study: Altogether Autism



Altogether Autism runs an information and advice service that allows people to ask their questions about autism in a safe environment through phonelines, online chats and emails. Rather than receive blanket information that may not be relatable to them, each question or query is individually researched by their team of experts. The service is free to access and can be used as much as you need. The person you are talking to introduces themselves and their team is profiled on their website if you would like to know more about their expertise and skillset.

We know that there is a wealth of information online about autism, but it is indeed hard to know what to 'trust'. As one Youth Patron said of their search online in the UK, "all the information I found was either vague or harmful"<sup>37</sup>. Where young people have used social media to access support or find information, there has been mixed results; the online community can be very polarised and using this as a means of understanding yourself can be quite troubling<sup>38</sup> - being rejected or 'told-off' by the group you finally felt a part of. Youth Patrons also noted that they shouldn't be relying "on the free support and understanding of under-resourced autistic people"<sup>39</sup> when there should be funded services in their place. So, the 'trusted information' service seems to fill this gap.

When discussing the idea of the Altogether Autism service in the UK, the Youth Patrons had differing opinions. Some liked the anonymity of the service and felt they could open-up more if they remained anonymous, whereas others wanted a closer relationship with the person they were talking to. For a group who have experienced statutory services more than most, they felt that the word 'trusted' was a big claim – they had been misled before or given conflicting information, so what would stop this service repeating those mistakes? However, the consensus was that having a single place where you can access advice and chat to people with expertise and training, would be highly beneficial. They liked that a large majority of the population who have a device can access the service and that it isn't limited by geography. The opportunity to be signposted to services in your local area, if available, was also a key feature as they felt you can often be overwhelmed by searching and deciding what was a 'safe' opportunity.

### How could we deliver this model in the UK?

- The trusted advice service that Altogether Autism delivers is government funded and therefore it would require funding in the UK and for a charity or organization to be commissioned.
- The service would have to be able to give advice and information pertaining to each of the four nations and their differences in legislation and entitlements.

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<sup>37</sup> Youth Patron quote, Kieran

<sup>38</sup> Ortega, F. 2013. "Cerebralizing Autism within the Neurodiversity Movement." In *Worlds of Autism*, edited by J. Davidson and M. Orsini, 73–97. Minneapolis: University of Minnesota Press.

<sup>39</sup> Youth Patron quote, Georgia H

- The service should employ autistic advisers and those with genuine expertise to provide the advice.

## Key people I can rely on

***“I want professional support that doesn’t force me to seem neurotypical but instead helps me to make the most out of my autism.”***

Key to the right support is the right people delivering it. The Youth Patrons regularly reference the one key person they have been able to rely on; the one teacher, the one nurse, the one doctor, who has made a difference in their lives. The services that work are the ones delivered by people who care, both autistic and non-autistic. These people need to be skilled and have a genuine interest in seeing young people succeed and be able to create a holistic circle of support around the young person.

If the aim of post-diagnostic support is about living comfortably with yourself, you need everyone around you to be on the same page. Rather than a competition of needs between parents and carers and siblings and the young person, families need support to navigate the system together. Some of the best services I have seen bring in the whole family or circle of support; they work through goals together and foster an environment where the young person is getting the same support at home and at school or at work.

Services also need to stop working in siloes; autistic children become autistic teenagers who become autistic adults. Although their age and needs might change, there will always be a need for support. As one Youth Patron said *“I know how to be an autistic teenager, but I don’t know how to be an autistic wife or an autistic mother.”*<sup>40</sup>

When services are cut or age restrictions apply, young people can lose their key person and the support they had fought to receive. There is also a huge loss of knowledge as the transfer between services means you can lose key information about young people and their needs, making it harder to build rapport and provide effective support going forward. The loss of a key person can also lead to crisis situations if there is no further support available.

So, the one ‘key person’ needs to become ‘key people’ for support to be consistent and helpful. Young autistic people shouldn’t have to wait for one person to see them for who they are or to fight for one person to truly care about them. They need support to be delivered by teams of people who understand autism and who are person-centred. They need to be involved in the commissioning of services and support pathways that they know would work for them and that provide the right amount of support when they need it.

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<sup>40</sup> Youth Patron quote, anon.

***“It would be so useful to have one point of contact who could co-ordinate the support you require and receive.”<sup>41</sup>***

At the same time, the NICE guidelines recommend that local autism teams should provide a “*case manager or key worker to manage and coordinate treatment, care and support*”<sup>42</sup>. Rather than being one key person, this role would help young people and their support circles navigate the system, know their entitlements and not be overwhelmed with the vast amount of knowledge you must pick up post-diagnosis.

This is exactly the role that the ASD Co-ordinators and Needs Assessment Service Co-ordination (NASC) fulfil in each New Zealand district.

## Case study: ASD Co-ordinators & NASC

New Zealand is split into 20 District Health Boards and each employs an ASD or Developmental Services co-ordinator to whom you can be referred after diagnosis. This person can support you and your family for two years beyond your diagnosis, refer you to services, provide you with training and work with you and your supporters on your priorities. The two-year time frame means that the workers can really get to know the young person, their families and carers and their needs, which is incredibly rare. The ASD Co-ordinator is a holistic role that steps away from sterile clinical services and champions person-centred practice.



Each region of New Zealand also has a Needs Assessment Service Co-ordination (NASC) which can assess your needs, support you with service planning and help you apply for money and resources. Some NASCs also have Local Area Co-ordinators who support you to access services in your local community and can help you make links with your neighbours to create a support network. Again, this service gives people the support and guidance they need to make informed decisions around their lives.

Although both services are national initiatives, they can be contracted to and delivered by different organisations or based in different teams meaning there is still a postcode lottery of sorts. Funding opportunities can be different in different regions and there aren't always services that can be signposted to, or the services on offer are of varying qualities.

Whilst this set-up and role would be a utopia of sorts and would fulfil the NICE guideline recommendation of a key worker, replicating it in the UK would be incredibly challenging. Devolution to local authorities and clinical commissioning groups would make it hard to guarantee

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<sup>41</sup> Youth Patron quote, Lily

<sup>42</sup> Autism spectrum disorder in under 19s: support and management, Clinical guideline [CG170], National Institute of Clinical Excellence, 2013

consistency of service and budget cuts mean there is often very few services that can be signposted to. The other challenge is of course, population. The ASD co-ordinator in the Hutt Valley, Wellington, receives on average 10 referrals a month from a population of roughly 110,000; for comparison, the London Borough of Camden alone has a population of 240,000. However, it remains that a key worker or case manager providing local and tailored support would be the ultimate ask of most autistic people and their support circles.

### How could we deliver this model in the UK?

- NHS England are currently piloting a key worker service for young people with additional needs which is similar to the role of ASD Co-ordinator.
- Some local authorities do have care co-ordinator and key worker roles in place, but demand is greater than capacity.

## To thrive not just survive

*“We need to empower autistic people with the knowledge and practical support they need to thrive.”<sup>43</sup>*

Unfortunately, we know that overall, society doesn't allow young autistic people to be their true selves. With support services often trying to make autistic people conform to societal norms and fit-in, young people aren't helped to understand and value who they are. Misconceptions of autism and capacity mean that they are often infantilised by services and patronised by professionals with people talking to their parents or carers instead of them. It can also be exhausting to constantly have to tell your story and explain your autism to each new professional, in order to prove your worth or that you need help. Daily life can feel like a constant battle and with the lack of services that currently exist and with low levels of autism acceptance, some young people are barely surviving.

Support services need to have higher aspirations for autistic people and help them feel seen and heard and valued. We need to teach agency, independence and resilience and enable access to society and everything that entails. Outdated understanding of autism means that young people are told what they cannot do and have their choices restricted; the right support should mean they are empowered to have the same life opportunities as their neurotypical peers. As previously mentioned, this doesn't mean removing obstacles but teaching young people how to face and overcome them.

We also need to ensure that the circle of support around that young person is thriving. People are often fighting for support for their loved ones and play a key role in their lives, helping them navigate the system. We must acknowledge that everyone has support needs and that a young

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<sup>43</sup> Youth Patron quote, Kieran

person cannot thrive if the circle around them is constantly firefighting. This means that agencies must work together and join the dots between parents and carers, siblings and young people.

Lots of post-diagnostic support services are time limited and short-term but young people will benefit from different types of support at different times and by different people. By giving young autistic people the knowledge, they need to understand themselves, providing spaces where they can be surrounded by like-minded individuals and delivering services that cater to them individually, we can empower them to take their lead in their own lives. This again fits with the NICE guidelines on autism which recommend local autism teams making arrangements to “*support children and young people with autism and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.*”. Post-diagnosis support is an ongoing process and services need to be responsive to changing needs.

Finally, we need to ensure that with all post-diagnostic support services and resources that we are placing the young person’s quality of life, happiness and wellbeing at the centre. Funders, commissioners and government need to switch their mindset when it comes to ‘successful outcomes’. So often, services focus on the outputs of what they are delivering and quantify success against measures that are artificial and unhelpful. Instead, the aim of support should be to help young autistic people be happy, well and thriving, in whichever way that means for them.

## Conclusion

This Fellowship has shown me that the question of post-diagnostic support is both more complex and yet easier than I previously imagined, with even the term itself being incredibly nebulous. So many of the services I found seemed to be common sense, like tailored support that meets individual needs and holistic working, but putting this into practice with a large population, an increasing rate of diagnosis and rapidly shrinking budgets is incredibly difficult.

As with any country the UK has pockets of best practice when it comes to post-diagnostic support services, but these aren't being replicated in any meaningful way and the NICE recommendations of a follow-up appointment within six weeks, a personalised autism plan and a key worker, remain unimplemented. To achieve these recommendations, we need government level buy-in, consistency of services across local authorities and a properly funded system that focuses on the wellbeing of autistic people rather than artificial goals.

Post-diagnostic support is an ongoing process and a lifelong journey. Autistic people will need different levels of support throughout their lives and for the young people this project focuses on, this centres around the transition years from primary to secondary school and secondary school to further or higher education, training, employment and adulthood. The idea of an ongoing process doesn't mean that short-term programmes don't have their place. We know these programmes are incredibly effective in empowering young people in the journey to self-acceptance, but we do need to embed these programmes early on in a young person's life.

Rather than having to unpack harmful stereotypes and stigma around autism and making up for a lack of support before and the damage that can cause, we can empower young people to understand and value themselves from the point of diagnosis. The support should be practical and relatable, deconstructing negative perceptions and misunderstandings of autism and giving young people the answers to what being autistic truly means for them. This means that professionals need to step away from the medical model of disability and the pathologising of autism and autistic traits. Without this shift, young people will start their journey post-diagnosis with a negative perception of autism rather than the positive autistic identity that we know is key to wellbeing.

Meeting other autistic people will always be key to post-diagnostic support. All the programmes I visited abroad had autistic young people at the centre and encouraged friendships to blossom and mentoring relationships to develop. The impact of meeting others like you cannot be underestimated. It provides a sense of belonging, solidarity and the opportunity to share experiences that many autistic people previously believed they were alone in having.

We know that being autistic can be hard, being a parent or carer can be hard and being a sibling can be hard, especially when you are having to fight for the support you need and deserve. Each group faces its own legitimate problems, but this shouldn't mean a competition of needs when everyone needs support. We need to make sure everyone works together to help the young

person reach their potential but also ensure that each group is getting what they need to thrive. The young person will always be at the centre but the cogs around them need to work. This means seeing diagnosis as part of a bigger picture and making sure support is holistic rather than exclusionary.

We also need to acknowledge that society has its part to play in supporting young autistic people as well as those closest to them. Post-diagnostic support cannot exist in a vacuum and the onus cannot solely be on the young person themselves; they need everyone around them to be empowered in understanding and accepting autism. This covers more than just their family and friends but anyone they will meet throughout life. The programmes that had the most impact abroad were the ones who involved their families, their educational provision and, if applicable, their workplace – a full circle of support.

Although autism awareness might be at an all-time high in the UK, autism understanding is still behind. If the general population were more accepting and valued difference, young people wouldn't need to fight so hard for the right to be themselves and could be confident that being autistic wasn't going to hinder them. They could be confident in the knowledge that they were safe and accepted in all areas and therefore weren't restricted in their life choices.

This means that all agencies need to work together. When I asked the Youth Patrons where they expected post-diagnostic support services to be hosted, they covered a range of bodies, both statutory and voluntary. Learning from Australia and New Zealand shows that a variety of agencies can provide services and resources that work if, and only if, they are person-centred and autism aware. So autistic young people must be involved in the design and delivery of services that are catered to them with co-production engaging the entire diversity of the autistic community. Whichever sector and whichever organisation, those in charge need to acknowledge that autistic young people are the experts on what works for them and their community and prioritise their voices and experiences. Without their ongoing input, these services and resources won't be accessible or useful to those who need them.

Ultimately, post-diagnostic support, in whichever form it is delivered, can be the key to a happy autistic life. Support shouldn't be considered a bonus but part of the diagnostic pathway; understanding and valuing who you are is the foundation of all your experiences and without it, life can be confusing and at times even seem pointless. Getting post-diagnostic support right is imperative if we want young autistic people to be afforded the same rights and opportunities as their non-autistic peers and have the chance to thrive in the lives they choose.

***“True support is having acceptance, warmth and help from everyone in my life.”***

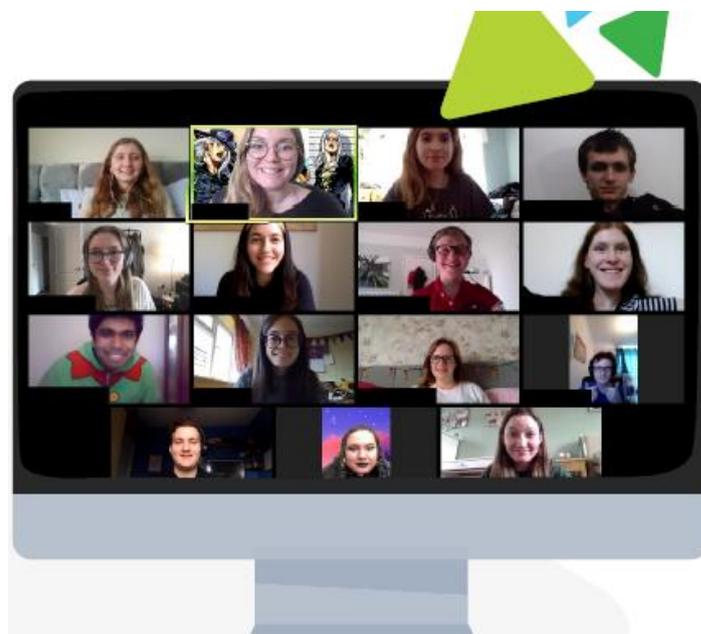
## One year on: what are the next steps?

We know that the right resources can make all the difference when it comes to searching for information about your autism diagnosis. There is a wealth of information out there about autism and a huge online autistic community, but different resources speak to different people and wading through negativity and things that don't relate to you is incredibly time consuming and exhausting.

We also know we need to find a way to provide empowering and relatable resources in one space. That's why our Youth Patrons have begun creating resources for young autistic people like themselves. *So, you're autistic?* is a collection of content that discusses diagnosis, autistic identity and everything that surrounds it in an affirmative and relatable way. Young people have shared their stories around diagnosis in video form and have also written articles together that they would have wanted to read when they were diagnosed. Creating these resources has been made possible by extra funding that allowed us to pay the young people for their time and effort.

We are also committed to continuing the online peer support sessions that we set up as a pandemic response, based on the work of the I-CAN Network in Australia. The past year of working online during the lockdown has allowed us to improve our offer to young people, learn about how to successfully run online support and reach more young people across the country. The impact of these sessions on the young people can be best communicated by them:

***“After finding out about the online chats and being able to speak to other young autistic people that know how I’m feeling, I don’t feel alone in all this anymore. Seeing their familiar faces and hearing their voices is more powerful than you would ever know right now. It’s little things like knowing that they care about me, hearing them say that they are struggling too but also what they are doing to cope. We can share our feelings and advice in a safe space full of honesty, kindness and support. Thanks to the participation team I’m making it through this when I didn’t think I could.”***



*Online peer support session*

Working online has also allowed us to co-produce new webinars and training sessions for professionals about understanding autism. Thanks to funding from Mind and the Department of Health and Social Care we were able to co-produce and co-deliver sixteen webinars on

'Understanding autism and mental health' to over one thousand professionals. We've also started running 'Autism Explained' webinars for corporate professionals and are developing training for healthcare professionals in the NHS. All of these opportunities are paid and have included more young people than we ever thought possible. Without the learning from the Fellowship, these endeavours would have been pipe dreams.

***“Being part of [co-produced webinars] has truly been an amazing experience for me. Actually feeling part of something tangible that could make a real change in the world was so incredibly empowering; getting to share my story, and, even better, receiving actual feedback from people and knowing that what I was saying had impact, had worth....it has made me so determined to fight for more change and improve things for autistic people struggling with their mental health. I want to use my negative experiences and this project showed me I can be heard, which is something I haven't understood before”***

The Participation Programme has been approached to share this learning as an example of best practice in online and inclusive engagement, in both conferences and in a new book chapter called 'Ambitious about co-production: adapting a participation programme during the pandemic to meet the needs of autistic young people'<sup>44</sup>. Our success in this area has resulted in funding which is allowing us to invest in an online platform to further expand our capacity to support young autistic people.

Through this platform, we are also hoping to start an online peer-support programme to unpack what autism means for young people and support them in their journey to self-acceptance. The modules will be designed and delivered by the Youth Patrons across the Ambitious Youth Network, based again on the work of I-CAN Network in Australia. They hope this programme will allow young people to find pride in their diagnosis, so no-one must fight to fit-in or be valued. Ultimately, we want to extend the peer support and post-diagnostic support services into schools and other educational provision based on the recommendation about embedding these services early.

All the work the Participation Programme does going forward will be based on the recommendations of this report. The resources and support course have and will have young autistic people at the heart, prioritising their experiences and points of view in both the design and running of the programme. They will help create and promote a positive autistic identity and ensure that young autistic people can engage with one another in a safe environment. They will be evaluated in-depth by the young people they are designed for and we will make improvements

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<sup>44</sup> 'Ambitious about co-production: adapting a participation programme during the pandemic to meet the needs of autistic young people' written by Emily Niner and Kerrie Portman (young person) will be published in Policy Press' Rapid Responses series called 'Covid-19 and Co-production in Health and Social Care Research, Policy and Practice.'

with each cohort of the support course, listening to all feedback. As a team and an organisation, we will continue to acknowledge the need for holistic post-diagnostic support that reaches everyone around the young person, and we will continue to push for early and targeted support.

We will continue to share our expertise in accessible and inclusive engagement and continue providing a platform for autistic young people to meet one another, share their views and influence change.

## About the case studies

### Autism Queensland, Australia

[Autism Queensland](#) is a state autism association that delivers a range of support groups and programmes for autistic people across the lifespan. The organisation also runs autism-specific education provision and conducts advisory visits to around 1200 young people in mainstream schools across the state. During my time in Australia, I was able to visit two of their schools, Brighton and Sunnybank and observe three of their programmes: Studio G, Make a Meal of It and The Hangout.

### I-CAN Network, Australia

The [I-CAN Network](#) is a social enterprise which delivers a range of projects in education, mentoring and advocacy across Australia. I-CAN was founded and is run by autistic people, providing mentoring in 1:1 settings, school groups, summer camps and online services. They also deliver professional development training, consultancy and run campaigns that celebrate the strengths of people on the spectrum.

### Sylvia Roger Academy – Future Leaders, Australia

An initiative of the [Autism CRC](#), the [Sylvia Rodger Academy](#) delivers nationwide programmes in Australia aimed at empowering autistic adults to contribute to policy and practice impacting upon their lives. The Academy also works to build the inclusive capacity of the broader community to recognise and engage the strengths of those on the autism spectrum. One of these programmes is Future Leaders, designed to empower autistic adults with leadership potential.

### Altogether Autism, New Zealand

[Altogether Autism](#) is a national charity that offers free, nationwide autism information and advisory service in New Zealand. They strive to provide information that meets the needs of each specific request and ensure their responses contain a wide range of relevant, evidence-based material. They supply information to autistic people, to parents, educators, support workers, GPs, police and any other professional working with adults or children on the autism spectrum. They run a Professional Advisory Group and a Consumer Advisory Group to ensure their knowledge is up-to-date and based on lived-experience.

### Autism Spectrum Disorder Co-ordinators, New Zealand

Across New Zealand each District Health Board has an ASD Co-ordinator. The ASD co-ordinator service provides support to young autistic people and their families to help them access community support agencies and ensure that any recommendations in the child's assessment plan are actioned. With familial input, the ASD coordinator develops a service plan outlining the

agreed actions to be taken and planned follow up dates. Depending on the needs of the young person and family, they can access support for up to two years.

## **Needs Assessment Service Co-ordination, New Zealand**

NASC services are contracted by the Ministry of Health or District Health Boards to serve disabled people, people with mental health issues and older people needing age-related support. NASCs are generally required to do three things: facilitate needs assessments, service planning and co-ordination and resource allocation within a defined budget. Some NASCs also offer Local Area Co-ordination which help signpost to and support people into mainstream community groups and services.

## **Glossary**

### **Alternative and augmented communication (AAC)**

This is an umbrella term which covers the different communication methods that may be used by people to communicate or aid communication. These can range from picture cards, symbols and gestures to computer software.

### **Anxiety**

Anxiety is a condition which means you worry more than normal about things. Anxiety can be mild or very difficult to live with and can change dependent on the situation and support available. There are many causes for anxiety and different ways it can present and it doesn't always make sense to the non-anxious person.

### **Burnout**

When an autistic person over-stretches themselves by doing too many tasks, too much socialising or making their brain work too hard they can burnout. Burnout is similar to when you are ill, tired and need a rest but are unable to do so.

The autistic person might not act like themselves because they aren't able to think as clearly as they did before a burnout started.

### **Learning difficulty**

Unlike a learning disability, a learning difficulty does not affect intellect. Examples of learning difficulties are: dyscalculia, dysgraphia, dyslexia, dyspraxia and language and social communication disorders.

### **Learning disability**

A learning disability is a reduced intellectual ability which may result in difficulty with everyday activities or taking longer to develop new skills. Learning disabilities are lifelong and can be mild, moderate or severe. With the right support people with learning disabilities can lead independent lives.

Some people can be autistic, have a learning disability or both.

## Masking

Masking or camouflaging is when an autistic person acts to appear less autistic or not autistic at all. They may change how they present, how they talk and their behaviours. Too much masking can lead to a burnout.

## Medical model of disability

The medical model of disability says people are disabled by their impairments or differences. The medical model looks at what is 'wrong' with the person, not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their lives<sup>45</sup>.

## Meltdown

A meltdown is a response to an overwhelming situation such as sensory overload or high stress. The response can be very loud and sometimes physical. The person needs time to recover after a meltdown as it is a full-body experience.

## Neurodiversity

Neurodiversity is the idea that the way we think is not always the same. Instead, it recognizes that all variations of human neurology should be respected as just another way of being, and that neurological differences like autism, attention deficit hyperactivity disorder (ADHD), dyspraxia and dyslexia, among others, are the result of natural variations in our genes.

## Neurotypical

Someone who is not autistic or not neurodiverse.

## Sensory processing and sensitivity

Sensory processing is how we take in and perceive sensory information. This may include hyper (high) or hypo (low) sensitivity to the five senses, as well as balance and body awareness.

## Shutdown

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<sup>45</sup> Scope, <https://www.scope.org.uk/about-us/social-model-of-disability/>

Shutdowns are similar to meltdowns but are not as visible or loud. A person may withdraw instead of being their usual self.

### **Social model of disability**

The model says that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets. Or they can be caused by people's attitudes to difference, like assuming disabled people can't do certain things.<sup>46</sup>

### **Special interest**

This is an intense and passionate level of focus on things of interest on a specific subject. For some people this can be a game or TV show, a type of animal, a type of machine or a country. Special interests are varied and bring the person joy.

### **Stimming**

Stimming is short for 'self-stimulatory' behaviour. Stimming can be a repetitive movement, repeating words, hand movements and making noises. Some stims are barely noticeable and some are very visible. Stimming behaviours are a way of self-regulating and shouldn't be stopped or reduced as they are an autistic person's way of managing a situation.

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<sup>46</sup> Scope, <https://www.scope.org.uk/about-us/social-model-of-disability/>

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