

If not now, when?

Autism and neurodivergence in Portsmouth:
Evidencing the need for change



Cover Artwork by Jon Adams

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About this report

This report contains the findings of a project to understand the gaps in adult social care and community support for autistic and neurodivergent (ND) adults who do not have a co-existing learning disability, and the recommendations for a way forward.

It has been produced on behalf of, and with input from, the Portsmouth Autism Community Forum. **Portsmouth Autism Community Forum** is an open forum for autistic people, carers and professionals.

The purpose of the forum is to:

- work together to improve support for autistic people
- monitor and share progress against the autism strategy
- publicise and celebrate success for services and individuals
- identify areas for improvement and take positive action
- work with key decision-makers to improve services
- discover and share evidence-based best practice.

Language

We have used the terms 'autism' and 'ND', to be inclusive of anyone diagnosed or suspected of having any of the diagnoses listed below. We have used identify-first language (e.g. "autistic person" rather than "person with autism") as this is the preference of most PACF members, and we encourage others to adopt the same approach.

Neurodiversity is a recognition that not all brains think or feel in the same way, and that these differences are natural variations in the human genome. A group of people are neurodiverse, an individual is not.

Neurodivergent refers to an individual who has a less typical cognitive variation such as autism, ADHD, dyslexia, dyspraxia etc.

Neurotypical refers to individuals of typical development and intellectual/cognitive functioning.

Acknowledgments

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Foreword by Veronica Price, Chair of the Portsmouth Autism Community Forum



This is from my perspective as an unpaid volunteer who has 'dipped her toe' into Portsmouth's autistic world: as a GP working in Southsea for 29 years, as a mother of a 30-year-old autistic son and as a mentor for two young autistic adults.

Society's prevailing narrative of autism has been largely informed by so-called 'experts' from the non-autistic world who have perpetuated partly or completely inaccurate, misleading and dismissive views.

Autism is NOT a disorder, it is a different normality which co-exists with the predominant neurotype: neurotypicals. These co-existing normalities are not hierarchical but part of an overarching state of what it means to be human.

Diversity: as in the fields of gender, sexuality, culture and ethnicity, should never be considered in terms of 'the norm' and deviants from that norm. The majority is not the norm and being in the majority does not entitle superiority.

Autistic people are stigmatised in multiple ways inhibiting their ability to identify to themselves and to others.

Autism is not binary: it is complex and nuanced and takes time and effort to fully comprehend. It is also lifelong: you cannot 'grow out' of your own brain!

Autism + environment = outcome

Since autism is unchangeable, it is our responsibility to produce appropriate environmental adjustments to achieve desirable outcomes.

Introduction

We know that at least 10% and possibly up to 20% of the population are neurodivergent, which means their brain functions and processes information in a way that is different to what society usually expects from a neurotypical brain. For many neurodivergent people, these differences present both strengths and challenges, challenges which are often exacerbated by having to function in a world designed by neurotypical people based on an idea of what the average person wants and needs.

Many, but not all neurodivergent people, fit into the diagnostic box of one or a number of conditions, for example: autism, autistic spectrum disorder, pathological demand avoidance or sensory processing disorder, attention deficit hyperactivity disorder (ADHD) or attention deficit disorder (ADD), Tourette's syndrome, dyslexia, dyspraxia, dyscalculia. Conditions such as post-traumatic stress disorder, rejection sensitive dysphoria, schizophrenia and bipolar are sometimes considered as neurodivergent conditions or closely aligned. It is important to take a broad view of neurodivergence to ensure that support can be offered to those who need it rather than those who have a particular diagnosis.

Since the implementation of the *Autism Act*¹ in 2009 there has been a slow but marked shift away from the deficit/disorder viewpoint and towards better understanding and acceptance of neurodiversity and neurodivergence, prioritising people and not their diagnosis. To achieve meaningful change, leadership is needed from autistic and ND people to steer health and social care towards better models of support.

History of autism work in Portsmouth and the strategic context

The *Portsmouth Autism Strategy & Action Plan 2017–2022* replaced the previous document, *Whole Life Strategic Plan for Portsmouth: Implementing Strategy and Guidance for People with an Autistic Spectrum Condition and Their Families*.

This current strategy covers all ages and expires this year. Most of the actions and aims of the strategy in relation to adults did not have funding or staff attached to them. Due to this lack of capacity and insufficient buy-in, it has been impossible to provide essential services, resources, and support. The impact of the coronavirus pandemic since early 2020 has only exacerbated this. Access to support has relied upon a formal diagnosis by recognised accredited professionals. Waiting times for diagnosis have increased significantly during the pandemic and the only commissioned support for autistic and neurodivergent (ND) adults, provided by Autism Hampshire, has been affected by the staffing and practical challenges brought about by the pandemic. The system has so far failed, despite the *Autism Act* and the *Care Act*, to adapt social care approaches and systems to accommodate the needs of neurodivergent people.

As well as this lack of specialist support, most general support services lack specialist expertise and the ability to flex their offer. There is an almost total absence of useful, appropriate, meaningful training for health and social care staff, and the result is that autistic and ND people regularly receive inappropriate, often dismissive and damaging responses from health and social care. This can have a significant impact on their health and quality of life.

The Portsmouth Autism Community Forum (PACF) replaced the previous Autism Board and has developed into a strong, positive force for change, with members working both locally (see Appendix A for an overview of current work) and nationally to provide support for individuals and in the development of research and policy. PACF is a proactive group, but many members are frustrated by the lack of progress at system level.

PACF and Portsmouth adult social care are now seeking to address this lack of progress and achieve a shift in thought and action, fulfilling the vision of Portsmouth as a city that is autistic and neurodivergent friendly. This report has been commissioned to build on the previous work of PACF, addressing gaps in understanding local need, providing a view of how autistic and neurodivergent people are experiencing public sector services, and what support could be developed to promote healthier, happier lives.

Principles

The Portsmouth Autism Community Forum has produced a set of principles based on the feedback gained through this project. These are:

- **We must develop understanding and acceptance** – awareness isn't good enough
- **We recognise that neurodivergence/autism is a rapidly evolving topic** in terms of research and public debate and we commit to taking a broad viewpoint which prioritises people and not their diagnosis
- **Most autistic and ND people are a mix of different neurodivergence, come from a range of backgrounds, and identify in different ways.** We must recognise diversity and accept individuals for who they are, including those who have not sought or been offered diagnosis
- **Autistic and ND people are more likely to have multiple physical and mental health conditions than neurotypical people.** This is due to a combination of poor recognition by the individuals, late presentation, and poor management by health professionals, leading to significantly worse outcomes and earlier deaths². It is vital that we work to address these health inequalities
- **Where an autistic or ND person has more than one condition/diagnosis these should be viewed as distinct from autism** unless it's useful to think of them together
- **Co-production and collaboration are key** – services must be jointly led by those who use or have an interest in them and work together where an autistic person needs access to several services e.g. mental health, physical health, social care
- **Eligibility for support must be considered broadly to ensure wellbeing and prevention are at the core of our thinking** – all too often autistic and ND people are left to reach crisis before support is offered

The project

In the summer of 2021, the project lead was asked to take on this piece of work over a six-month period on behalf of PACF and adult social care.

The project sought to understand:

- how autistic and ND people experience public sector services, especially health and social care
- where there are gaps in support
- what autistic and ND people would like support to look like
- the level of demand for a potential new support service
- what level of resource might be required
- priorities for a new strategic plan
- links to other autism/ND work.

The method for this work was developed in partnership with PACF members and involved:

- qualitative research – defined in the broadest sense, this involved conversations with autistic and neurodivergent people and those who support them
- review – of the current strategy, the local landscape around this agenda, what support looks like now
- desk-based research – national strategy, legislation, prevalence data, key studies.

Moving forward with the recommendations of this project it is imperative that new services are designed in co-production with autistic and ND people.

Demographic data and types of challenges

It is difficult to determine an accurate prevalence of autism and other neurodivergent conditions due to under-diagnosis, particularly in certain cohorts of the population including: women, BAME individuals and those from lower socio-economic groups. Accepted prevalence data indicates that 1% of the population are autistic, however recent studies are now indicating a higher prevalence rate of 2% rising to 3% in certain communities. The 1–2% prevalence equates to 2,071–4,142 people (all ages) in Portsmouth (based on 2011 census data).

Portsmouth has a shared client record system called SystmOne which is used by all health and social care teams excluding the acute hospital. SystmOne records show only 1,010 adult patients in the city who have an autism diagnosis which falls into the quality outcome framework 'cluster' of diagnoses, this figure includes those with a co-existing learning disability.

The number of autistic people known to adult social care, but not allocated to the Integrated Learning Disability Service, was 75 in January 2022.

SEND data from 2018 identified 67 children with autism in Portsmouth primary schools, 114 in special schools and 52 in secondary schools who will require support through the transition from childhood to adulthood, including eligibility assessments for access to adult services.

The data above demonstrates the underdiagnosis and under-recording endemic in our health and social care system, particularly for people who do not have a co-existing learning disability. When we extrapolate from population-level data we can assume that at least 1,200 and possibly nearer 4,000 people across Portsmouth are persistently experiencing:

- being disabled by a world designed by and for neurotypical people
- becoming overloaded by the amount of sensory input in the environment
- struggling to process information – different neurodivergence can lead to problems processing information in different formats
- not being given the opportunity to acquire the learnt aspects of human communication; one person said, "I don't have the same inbuilt handbook or operating system for non-verbal communication"
- multiple barriers to living in a way that works for them and keeps them well (such as not being able to communicate through the channels expected of them, not being able to navigate public transport and struggling to get the support needed)
- exclusion from meaningful occupation, paid or voluntary: nationally only 22% of autistic people are in any form of paid employment³ and this statistic does not reflect the barriers experienced in maintaining employment.

The public sector is difficult to access for autistic people – this leads to public sector staff thinking that autistic people are 'hard to reach'. When an autistic/ND person does become 'known to' a service it can be hard to secure engagement due to the standardised, inflexible

communication methods often used in the public sector. If autistic/ND people are not seen to be accessing services, then there are significant challenges evidencing the need for services and support. If we wait until there is more evidence before accepting the need to change then we will never reach that point.

"The double empathy problem is that autistic people often lack insight about neurotypical perceptions and culture yet it is equally the case that neurotypical people lack insight into the minds and culture of autistic people. One way of overcoming this is to acknowledge it is a relational problem, a two-way street, and not an inevitable deficit of being autistic."

Damian Milton, Academic⁴

Co-occurring conditions

The National Institute for Health and Care Excellence (NICE) estimates that around 70% of autistic people have an additional condition, which is 'often unrecognised'. The main conditions that co-occur more frequently in autistic people compared with the general population include mental health and neurodevelopmental conditions.

'Autistic people have been found to have an overall risk of early mortality more than double that of the general population ...[and] are at increased risk of dying younger from virtually every cause of death.'

Autistica⁵

Mental health conditions

Research suggests that:

- more than 70% of autistic people have a mental health condition
- 40% have two or more mental health conditions
- autistic people are up to four times more likely to have anxiety disorder
- autistic people are twice as likely to have depression
- suicide is a major cause of early mortality in autistic people, with two-thirds reporting suicidal thoughts in one study.⁶

Autistic adults who do not have a learning disability are nine times more likely to die from suicide, this increases to 14 times for autistic women⁷. The average cost of suicide in working age adults is £1.67million. There are often multiple attempts at suicide prior to a completed suicide, it is hard to estimate the costs of attempted suicide due to multiple variables, but it is estimated that costs averted are £66,797 per year per person of working age where suicide is delayed.⁸

Autism is a neurodevelopmental condition, and it is common for autistic people to have other neurodevelopmental conditions. These can include:

- general learning disabilities (affecting around 40% of autistic people)⁹
- specific learning difficulties (such as dyslexia and ADHD)
- epilepsy
- delays in language development.¹⁰

When life is difficult, Samaritans are here – day or night, 365 days a year. You can call them for free on 116 123, email them at jo@samaritans.org, or visit [samaritans.org](https://www.samaritans.org) to find your nearest branch.

The causes and impacts of physical health conditions in autistic and ND people are not well understood. Autistica's report on premature deaths states 'multiple studies have found that most autistic adults are at a significantly increased risk of most medical conditions, including cardiovascular disease, diabetes, stroke, circulatory and respiratory conditions.'¹¹

Further reading around mental health and autism

- G. Harper, E. Smith, E. Simonoff, L. Hill, S. Johnson, I. Davidson, *Autistica Action Briefing: Adult Mental Health* (Autistica, 2019) <https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Adult-Mental-Health.pdf>
- E. Simonoff, A. Pickles, T. Charman, S. Chandler, *Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample*, *Journal of the American Academy of Child and Adolescent Psychiatry* (2008) https://www.researchgate.net/publication/51419327_Psychiatric_Disorders_in_Children_With_Autism_Spectrum_Disorders_Prevalence_Comorbidity_and_Associated_Factors_in_a_Population-Derived_Sample
- E. Cage, J. Di Monaco, Victoria Newell, *Experiences of Autism Acceptance and Mental Health in Autistic Adults* (London: Royal Holloway, 2018) <https://link.springer.com/article/10.1007/s10803-017-3342-7>
- *Autism and autistic traits in those who died by suicide in England* (Cambridge University Press, 2022) <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/autism-and-autistic-traits-in-those-who-died-by-suicide-in-england/04367C4DD9D8B4B3375A0D25C4764A54>

Legislative and policy context

'The Autism Act 2009 is currently the only disability-specific legislation in England. The Act requires the Government to introduce and keep under review an adult autism strategy. The initial strategy was published in 2010 and refreshed in 2014.'

Autism – overview of policy and services¹²

Since the Autism Act was published there has been an increased awareness of the dearth of research and good practice around autism and ND. Understanding of the legislation, policy and its implications is still very limited.

Policy

Following a comprehensive review of the 2010 strategy that resulted from the Autism Act, the government published its National strategy for autistic children, young people and adults: 2021 to 2026.¹³

The strategy describes a vision for the next five years based around six areas of change:

- improving understanding and acceptance of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

A report from the All Party Parliamentary Group on Autism, The Autism Act, 10 Years On¹⁴, was informed by 11,000 autistic people and their families and made 16 key recommendations covering a range of subjects including workforce development, improved access to social care and improvements in data collection. Of particular interest to this project are the following two recommendations:

- Commit to establishing well-resourced specialist autism teams in every local authority in England
- Establish an autism social care commissioning fund for councils to use to set up and run new autism services and support

The report contains a section titled '*Deeply concerning levels of unmet need in adult social care*'. Of the 11,000 people surveyed, 46% said that with more support they would be more independent.

The *NHS Long Term Plan* (2019)¹⁵ has several objectives for people with autism, including: the introduction of a 'digital flag' in the patient record by 2023/24 to ensure staff know a patient has autism; ensuring reasonable adjustments are made so wider NHS services can support people with learning disabilities or autism; and piloting the introduction of a specific health check for people with autism.

The *NICE Guideline – Autism spectrum disorder in adults: diagnosis and management*¹⁶, was published in 2012. Many of the recommendations reflect the lack of evidence that was available 10 years ago, but the Guideline does include the useful recommendation of the establishment of local specialist teams:

'In each area a specialist community-based multidisciplinary team for autistic adults (the specialist autism team) should be established. The membership should include clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists, support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).'

It goes on to recommend that *'the specialist autism team should have a key role in the delivery and coordination of...'* and lists a comprehensive range of types of services and support including diagnosis, care and support, and training other professionals.

Legislation

Both the *Autism Act 2009* and the *Care Act 2014*¹⁷ give a strong legal basis from which to proactively offer support to autistic and ND adults. The following is a summary of the key points.

Following diagnosis:

- information should be shared between diagnostic services and adult social care services about adults diagnosed
- people should be informed of their right to a social care assessment and, where relevant, a carer's assessment.

The *Care Act* requires local authorities to conduct a social care needs assessment where it appears to the authority that the adult may have need for care and support.

This assessment may be triggered either by the individual requesting it or if the local authority believes community care services may be necessary. This duty applies to people with autism and is not dependent on them having been formally diagnosed as having autism.

Social care assessments should be carried out by trained practitioners, taking full account of the potential communication needs of adults with autism.

Assessment of eligibility for care services cannot be denied on the grounds of the person's IQ. This is particularly important for some people with autism, including those with Asperger

syndrome, who may face very significant challenges in their everyday lives, despite having average or above average IQ.

Advocacy

Under the Care Act local authorities must provide access to an independent advocate to enable the individual to participate in the assessment and support-planning process. In particular where a person with autism would have difficulty in understanding the process of assessment including retaining information, and/or would not be able to meaningfully contribute their views, wishes or feelings and there is no appropriate person who knows them to support them in fully engaging in the process.

Transition

Autistic young people are identified by the Care Act's Care and Support statutory guidance¹⁸ as a group whose members may not have received support as a child but who may have care and support needs in adulthood. Local Authorities must offer a Care Act assessment which looks at potential care and support needs after turning 18. This duty applies to all young people with autism, not just those with an *Education Health and Care plan*.

"There is no single defining version of autism but instead an overlapping multiplicity of minds. The term spectrum is a poor way of capturing the sheer diversity of our experience – it's too linear, too fixed. When I imagine us I think of a constellation instead, or perhaps a Galaxy, millions of different stars shining, each expressing their fire in a different way."

Katherine May, Author¹⁹

How things are now

Currently efforts to implement any of the above legislation and policy are extremely limited in Portsmouth. The vast majority of autistic and ND people in Portsmouth are not being proactively offered assessment and support in line with the legislative requirement and there are damaging consequences from that lack of support.

The findings presented here are from the 90 people who have fed into this project via individual and group conversations. The sample includes: autistic and ND people, friends/family members, and professionals, many of whom are, or have a close friend or family member who is, autistic or neurodivergent. A broad range of experiences were described but some strong common themes also emerged. These have formed the basis of the recommendations and areas for development.

How autistic and ND people are experiencing services

“People’s lives are blighted by being subjected to services.”

Autistic person

Overall, the general experience of support from the public sector is poor. Statements such as the above are sadly representative of most people the project lead spoke to. Where useful support was accessed, it was often fragmented into limited areas of specialism (e.g. employment), and autistic and ND people are left to navigate their way to support using their own communication resources. Trying to find support whilst keeping on top of life admin can present a challenge which is either unachievable or has a detrimental impact on wellbeing.

Social care

None of the autistic people the project lead spoke to had been offered a social care assessment even though some of them had been supported in special schools as a child and were therefore known to children’s services. Several of them had been through the diagnostic pathway for adults in Portsmouth including a post-diagnosis referral to Autism Hampshire. The majority would warmly welcome an opportunity to have a useful conversation with a social care professional.

Professionals and Carers reported pockets of good practice in adult social care where communication and support had been carefully tailored by skilled, knowledgeable social workers and other professionals. However, even in these cases, there is a lack of comprehensive, appropriate support for social workers to link someone into.

In August 2021 a deep-dive was conducted into the records of 10 autistic adults who are known to adult social care to learn from the types of interactions and support being accessed through the health and social care system.

The key findings were:

- the amount of adult social care input was minimal
- each case had a higher-than-average number of case notes representing high numbers of contacts with a range of services
- seven of them were also allocated to Adult Mental Health services
- six were frequent visitors to their GP practice
- on four of the records there was no recorded preferred method of communication
- five of the clients reported chronic sleep issues
- four had challenges around managing hygiene and three around maintaining a habitable home
- six of the clients had a history of not responding to attempts to contact them
- five reported that they had suicidal thoughts.

The Social Care Institute for Excellence report *Autism: Improving access to social care for adults*²⁰ analyses some of the reasons that autistic people struggle to get support from adult social care:

'Individual professionals may be extremely helpful, but the system itself is seen as ill-informed, complex and set up in ways that exclude or alienate people with autism.'

'Social care assessors sometimes lack sufficient awareness of autism to do the job of establishing the needs of people with autism properly. The paperwork used – assessment forms, or resource allocation systems in England – can be too blunt to pick up the complex needs that people with autism sometimes have. They can also rely on good communication skills, and the insight, willingness and confidence to disclose personal details.'

The following case study illustrates how some people are experiencing attempts to secure support. The name has been changed:

In September 2021 the PACF coordinator received a call from Michelle, a young autistic woman, who had been given his number by a social worker.

She had been diagnosed autistic and was waiting for an ADHD assessment. Michelle was in great personal distress from her domestic and financial situation and was suffering from poor mental health. She had been advised to "try Autism Hampshire" but didn't get a useful response to her request for practical help, advocacy, and social group contact.

In the absence of support from any of the social work teams, the PACF Coordinator contacted the PACF chair/volunteer Serendipity group leader to see if she could offer voluntary support, and signposted to the Serendipity social group and to Solent Mind.

The volunteer Serendipity group leader was unable to contact Michelle.

In October of 2021 Michelle contacted the PACF coordinator again. She was experiencing intense difficulties living with a controlling, abusive father who imposed severe restrictions on phone use, social contact and access to money.

Michelle felt trapped, having to choose between accessing domestic abuse support and autistic support. Due to her communication needs she did not have the resources to pursue both and was unable to make progress to access support for either issue. At this time the Job Centre Plus also expected Michelle to be looking for work.

Both Solent Mind and adult social care attempted further contact with Michelle but were not successful.

There are a number of ways that Michelle could have been better supported:

- If she had been proactively offered support at a time when she wasn't in crisis she may have felt better able to engage.
- If she had a named worker who would build a rapport with Michelle, they could help her manage risks and support her to engage with help.
- That named worker could have advocated on her behalf particularly with regard to contacts from the job centre who may not have fully understood Michelle's needs.
- Michelle originally had contact with a non-specialist social worker who was not able to offer support. Had Michelle been offered personalised support at that first contact she may have had increased confidence in the service and been better supported to engage with it.

The potential to prevent worse outcomes

All the autistic people who contributed to this project talked about the cumulative impact of the various challenges they face. For some people, that impact manifests as worse physical health, but for all it manifests as worse mental health and an inability to live life to the full.

Thinking broadly about risk will be imperative in supporting better lives for autistic and neurodivergent people. There is a lack of hard evidence about what works. PACF recommends that Health and Care Portsmouth broadly commits to adopting a person-centred and non-standardised approach to supporting people in a way that will be effective for them.

Improving support through transition from children's to adult services

Many people described the feeling of falling off a cliff edge in the transition from children's to adult services, with the impact on young people and their families being extreme. Transition is a critical time and good transition can promote better lifetime mental, physical and economic health.

"The drop off from children's services has been really mentally draining. My son has been left and it's not fair. It has affected my physical health [fibromyalgia] and depression... I can't leave my [younger child] in the same room [as my older autistic child] because of his mood."

Parent of young person with autism

Work in progress

1. A new adult social care transition manager has been recruited and the recruitment of two specialist social workers for autism, ND and transition is underway. It will be important that these workers are able to link effectively into a range of appropriate services and inform the direction of commissioning intentions in response to the needs of those they are supporting.

Together this team will:

- work with young people (and those who are important to them) from the age of 14 through to 25 or such a time that social care support is no longer needed or there is a more appropriate team to provide support
 - be a named worker for young people as they transition to adult services
 - establish close links with the children's service's multi-disciplinary neurodivergence team to support the development of effective transition arrangements
 - act as experts for other professionals working with autistic and neurodivergent people.
2. Funding has been obtained to carry out a specific piece of work with young people aged 16–25, and their families, planning individually and as a collaborative group with a focus on housing and support models.

Lack of understanding and tailoring of offer from a wide range of public services including Primary Care

Every autistic person, family member, friend and professional who contributed to this project expressed frustration, and at times despair, at the lack of understanding routinely displayed by the public sector. The examples given were diverse, from systems-based

issues like only being offered a phone call when the person is unable to communicate by phone, to many examples of individual staff ignorance. Sadly, this is unsurprising – the public sector continues to operate in a highly standardised way, leaving little opportunity for personalisation.

The project lead looked into the availability of training for health and social care staff and found that the following training is available locally:

- E-learning on autism awareness, provided by Autism Hampshire
- PowerPoint presentation developed by the learning disability nurses at Portsmouth Hospitals University Trust.

However these were not developed with meaningful input from autistic and ND people. Feedback from the autistic and ND community, some of whom have viewed this content through their work or through PACF, was extremely poor.

There had been the development of a PowerPoint presentation for Portsmouth City Council by the learning and development team, but changes in staffing resulted in this being shelved shortly after the development phase.

There are training and workforce development resources available nationally, online, for staff with the time and motivation to seek them out, but given the pressure on staff in the health and social care system it is unlikely that these would be widely taken up.

In Primary Care, there is a Royal College of GPs toolkit available with some useful information, although the project lead has not been able to establish if this is something that local practices are aware of and actively using.

Staff working for Solent NHS Trust have no access to formal training through their organisation.

It is clear that staff across the public sector are not being given the opportunity to learn about what it's like to be an autistic person, the range of needs that might encompass, and what approaches and techniques will support engagement with services.

Work to form the basis of workforce development and training in Health has taken place nationally. Skills for Health have developed the [Autism Capabilities Framework²¹](#), which could be built upon locally.

Work in progress

[Autek²²](#) are a local organisation employing neurodivergent and disabled people to make public spaces and services more accessible. They are developing an online training package for professionals to be based on clips of Portsmouth autistic adults talking about their lived experience. Initial filming completed in February 2022.

Lack of support for independent living, advocacy, practical skills, navigating services, and finding appropriate housing

The project lead spoke to more than 40 Portsmouth-based professionals and found high levels of specialist knowledge, expertise and commitment to supporting autistic and ND people. These professionals reported a lack of flexibility around how services operate, and the constraints of working in time pressured services, which are structured to work separately rather than together, presenting one of the main challenges to better support.

Autistic and neurodivergent people should be proactively offered a social care assessment where there is an appearance of need or the possibility that needs may develop in the future. This is not happening in Portsmouth and when people do get into the social care system they are often not able to access the support that would make a difference.

"Children's and adult services are so separate, both are rigid in their thinking and there is extreme risk aversion."

Parent carer of adult sons

"As long as they realise that in a way it's like teaching someone who's blind to see, or someone who's deaf to hear. There has to be real understanding that our brains are differently designed so we really can't spot body language fast enough, etc."²³

Autistic adult

Work in progress

1. The new adult social care transition manager and small specialist team will take an approach which puts the person at the centre of their assessment, care and support, rather than allowing systems and processes to lead.
2. PACF employment and housing projects (please see Appendix A for more information).

Lack of support for physical, mental and emotional health

There is consistent evidence and acknowledgment through national policy, that autistic and ND people and family/friend carers are suffering from significant health inequalities and are at considerable risk of early death.

"My son had previously been diagnosed with anxiety and depression by CAMHS but once he'd been diagnosed with autism as an adult, Mental Health services dropped him, meaning he could not get a medication review until he threatened to complain. Then his meds were reviewed and found to be wrong. The mental health Crisis team said they shouldn't take him despite suicide risk due to his autism."

Parent carer

Need for better knowledge and understanding for autistic and ND people and their friends and family

"My mental health has been so much better since understanding I may have autism, I came off my anxiety and depression medication. I have given up trying not to appear different."

Autistic person

All of the autistic and ND people that the project lead spoke to described the challenge of knowing "there is something wrong with me" and having to go through a lengthy process of learning about autism/neurodivergence and what it means for them as an individual. For some people who feel they are "left hanging" following diagnosis, being able to accept and understand their diagnosis becomes impossible. In cases like this it is even harder to access necessary support.

There is growing evidence that peer-led learning and support at this time is a highly effective way of helping newly diagnosed autistic and ND people build understanding of themselves and how their brain works.

The Scottish Autism National Post Diagnostic Support Service²⁴ 'aims to support newly diagnosed people across Scotland to understand and embrace their identity as an autistic person.' The service runs peer-led groups, one for autistic people and one for family and friend carers. Each group follows an eight-week, semi-structured programme of learning and discussion, which helps people to understand autism, what it means for them, and facilitates connection to other autistic people and their communities.

Problems with interactions with mental health services, standardised approaches, potential misdiagnosis or not being able to access support due to autism diagnosis

"Adults with a learning disability have their needs met, too many [autistic] adults [who don't have LD] end up in the mental health system. Lots of people have a mental health diagnosis when they are potentially autistic. It's too easy to give people medication rather than help."

Parent carer

70% of autistic people have a mental health condition, which would be an estimated 1,449 autistic people in Portsmouth who also have a mental health condition (of all ages).²⁵

We know that a third of autistic people have had suicidal thoughts, which is potentially as many as 966 people in our local community who are very often not able to access help when autism is cited as the cause of their mental health condition, and for those who do get through to help what is offered is designed for neurotypical people.

The project lead spoke to several people who had been denied mental health support because of siloed approaches to which teams and services can provide support to an autistic person and outdated views of autism and what autistic people need. Ultimately these experiences can be traumatising and lead to people disengaging from health and social care altogether.

The mental health system, Primary Care and social care must change urgently to prevent the further worsening of mental health amongst our autistic and neurodivergent community.

Stigma around autism and neurodivergence

Many of the people the project lead spoke to are active in the autism and neurodivergence community, and reported externalised experiences of stigma, despite finding the process of being diagnosed enlightening and helpful.

One autistic young person described how he hates that he is autistic and that he hasn't had the opportunity to explore these feelings in a way that works for him. He said: "I haven't opened up enough, I put it all in a bottle that then cracked." For him this manifested as depression and self-harm.

Many people experienced feelings of stigma in relation to their work lives:

"My son will not tell his employer that he has Asperger's as they will look at him differently."

Parent carer

This can be a real barrier to being able to find and maintain employment.

Data from the Office for National Statistics shows that 'just 22% autistic people reported being in paid work'²⁶. This is thought to be the lowest employment rate amongst all disabled groups.

The National Autistic Society's report, *The Autism Employment Gap*²⁷, explores the reasons behind this low employment rate, stigma being one of them:

'Our YouGov survey of employers exposed some of the myths that employers may believe, which could cause bias against autistic people both in recruitment and in the workplace. For instance, 34% said they thought an autistic person would be unlikely to fit into their team, and 28% said that an autistic person would be unlikely to be a team player.

'As part of our separate study we were also shocked by some of the distressing experiences of autistic people at work. Roughly half of our respondents with experience in the workplace reported bullying or harassment (48%) or other discrimination or unfair treatment (51%) due to their autism.'

The Autism Employment Gap

Employers' attitudes are likely to echo those present in society.

Accountability and co-production

For too long: autistic and neurodivergent people have been ignored, the challenges that often come with being autistic have been belittled, and public services have not taken responsibility, despite the legal and policy framework in place.

The development, governance and delivery of a new autism and ND strategy must be shaped by people with lived experience, through an expert-by-experience group, and a range of inclusive participation options. The strategy must receive the attention, ownership and commitment to action that are well overdue.

The continued shift towards health and social care integration provides an opportunity to ensure meaningful responsibility is taken to better support autistic and ND people across the system.

The *Autism Act Guidance*²⁸ states: 'Health and Wellbeing Boards have a crucial role to play in overseeing implementation of the Adult Autism Strategy. As a local health and wellbeing system leader, bringing together partners from NHS England, CCGs, HealthWatch and Local Authorities, the Health and Wellbeing Board is central to ensuring the needs of people with autism are addressed locally.'

The *NHS Long Term Plan* states: 'Sustainability and Transformation Partnerships (STPs)²⁹ and Integrated Care Systems (ICSs)³⁰ will be expected to make sure all local healthcare providers are making reasonable adjustments to support people with a learning disability or autism.'

What does good look like? – examples of best practice

There are a small number of examples of specialist autism services and support options across the UK.

Examples include:

- **Scottish Autism**³¹ provides a comprehensive range of support for adults, children, families and professionals and across Scotland including diagnosis, 1–2–1 and group support, information and advice, training, day and vocational opportunities and crisis support
- **Autistic Nottingham – Supporting Autistic Adults**³² founded and run by autistic people – provides post-diagnostic support, access to personal assistants, advocacy and social opportunities
- **Avon and Wiltshire Mental Health Partnership**³³ provides every autistic person with six weeks post-diagnostic support, from which peer support groups emerge naturally
- Wales, Leicestershire, Gloucestershire and Cornwall all provide a **'Gap' service** for autistic people who may fall through the gaps between other services
- A number of areas have **peer support groups** supported through the voluntary sector, local authorities or Clinical Commissioning Groups.

There are pockets of good practice more locally, including support and services that are being developed and implemented through the recent *Surrey Autism Strategy*³⁴ and in *West Sussex*³⁵, where support is available through peer groups, low level support in the community, and support for employment. However there seems to consistently be a disconnect between support provided through the voluntary sector (including local authority commissioned services) and support provided by health and social care.

In summary, there is no one example of what excellent looks like, there are pockets of good practice, but they tend to be separate from social care and health and fragmented in the support they can offer.

Project recommendations

The following themed findings and recommendations are for the consideration of the adult social care senior management team, the Clinical Commissioning Group, and wider colleagues in health, social care and the public sector.

The recommendations cover new or developing areas of work which are not currently covered or well linked to other workstreams.



Not included in the recommendations is the upcoming recommissioning of diagnostic services (due to be recommissioned at ICS level) and post-diagnosis support, but these developments will take into consideration the findings and recommendations from this report and ensure full engagement with autistic and ND people.

There are several projects specific to autistic and ND people that are in the early stages of development and implementation. Please see Appendix A for an overview of those projects. All projects have temporary funding and if successful will require ongoing funding to ensure the gains made are not lost.



The planned 'community hub' is in the early stages of being established and will provide a space for some of these recommendations to revolve around.

All those the project lead spoke to were asked, "what would perfect support look like?" Responses can be found in Appendix B.

Key






-  Adult Social Care
-  Strategy
-  Clinical Commissioning Group




Theme 1: Transition from children's to adult services

-  Ensure that family members or other people who are important to the young person are supported through the transition phase including with support from the Carers Service where needed - recognising that change can be challenging to manage for all parties.
-  Build transition elements into new autism and ND strategy ensuring it dovetails with the children's services' neurodivergence strategy, wherever possible.


Theme 2: Support

-  Specialist adult social care team offering *Care Act* assessment and acting as Lead Professional for the individual. This should be in place on a pilot basis for two years.


-  Review of commissioned support services to enable short or long-term care and support for autistic and neurodivergent people, including review of contracts currently with narrow eligibility criteria.
-  Establish a virtual team/staff network across health, social care, criminal justice, voluntary sector providers, advocacy, acute settings and primary care to share knowledge, working practices and foster better cross-organisational working.
-  Ensure community-based provision (Community Hub/commissioned diagnosis and support services) are seamlessly linked with the specialist adult social care team and the virtual team/network.
-  Consideration should be given to using the model developed by the National Autism Implementation Team for staff and autistic people to determine what level of support would be most appropriate.
-  Explore whether advocacy is available when needed in health settings and in interactions with social care and address gaps in provision.

-  A psycho-educational offer (both group and 1-2-1) should be developed for both autistic and ND people and their family/friend carers including group programmes and structured one-off sessions.
-  The ASC specialist and virtual teams should make regular use of tools and resources to support individuals to understand their challenges/diagnosis and what it means for them as an individual.
-  Support for autistic and ND people to find and maintain employment, to include support for employers to understand their obligations under the Equality Act.

Theme 3: Workforce development

-  Development of a comprehensive programme of workforce development for public sector, voluntary and community sector staff. Training resources and sessions must be led or co-facilitated by autistic and ND people, building on the initial work of the PACF training project.

Theme 4: Building knowledge of what is needed

-  Undertake further research to extend the information gathered during this project including the development of a survey which would aim to provide us with an understanding of the experiences and needs of a wider range of autistic and ND people.



Pilot work should take place to secure a better understanding of the demand for various support services and what works.

Theme 5: Communications



PACF and the new strategy to consider a communications campaign raising awareness of autism and ND and supporting acceptance of neurodiversity in all forms considering:

- branding
 - target audiences
 - how to tailor the message for different audiences.
-

Theme 6: Health



Involve Public Health and CCG colleagues in the development of the strategy enabling further consideration of health support and interventions for autistic and ND and their efficacy including access to mental health support.



Ensure that the mental health transformation work (Community Mental Health Framework) includes the needs of autistic and ND people and how mental health services can provide better support, including awareness around self-harm and eating disorder prevalence.



A *Making Every Contact Count*³⁶ approach should be taken with all interactions in social care and partner organisations including blurring of traditional boundaries between roles to take responsibility for supporting good health.



Explore the potential for targeted work around suicide prevention, including workforce development for adult mental health staff.



Workforce development in Primary Care to ensure that GPs have a good understanding of the mental health risks around autism and ND and know how to refer to support services.

Closing statement from Jon Adams



Autistic people often miss out on the support and advocacy they really need because people assume they don't need it. Primarily this is down to stereotypes and myths that have haunted autistic people for over 50 years. Often these are born out of observation and not conversation, imagination, and not listening to lived experience. Autistic people simply wish to be accepted as part of society and not apart from it but often the support we need to do this is absent. Many autistic people who have tried to engage on 'other's terms' have ended up hurt, in burnout, or worse. Autistic people are not inherently broken but it's often society or systems that break us and when we come to ask for help to mend what we need is often not what we receive.

Real change needs involvement not just inclusion and to not be born out of pity or distress, but from a sense of natural justice. Autistic and neurodivergent people are not lesser or broken but innately human and creative. Without even our limited engagement the world would not be as rich as it is now but let's have more so we can shine and everyone benefits from what we can bring.

Change needs acting upon urgently as anything less now could be seen as perpetuating the 'status quo of exclusion' and if this continues many of us will stay damaged, isolated or simply absent ourselves from the hurt of not having been given an equal or equitable chance to contribute. I believe with the right support autistic people should be able to thrive in a society, not just to simply survive but in one that accepts who we are. I feel we need to see this as a holistic challenge not just view autism as a word on paper that trigger people's prejudices.

I am not the word

or the letters

and the spaces in-between

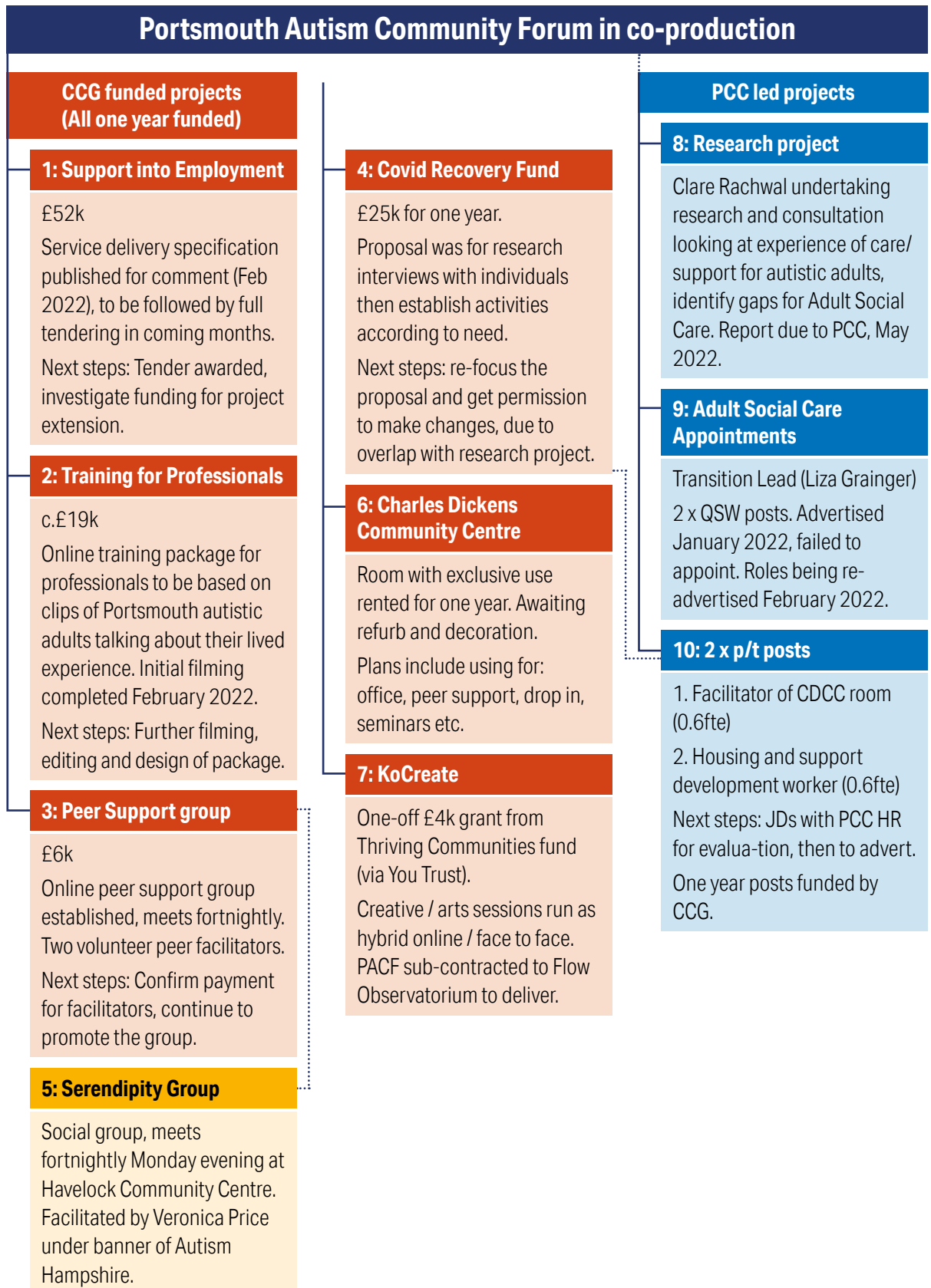
Or the person in your imagination

You think I should have been

I am Autistic I am human Embrace and accept our differences – if not now when?

Jon Adams, Artistic Director of Flow Observatorium³⁷

Appendix A: Overview of current work [as of February 2022]



Appendix B: Survey responses

What would perfect support for autistic people look like?

Talking more about life without feeling nervous

Problem solving in all sorts of areas

Would like a regular opportunity to talk i.e. weekly

Something that is not labelled an Autism service

Autistic person

A shop front where people know where to go

Support for basic things like going to the shops

The service would need to be visible

Less medication and more help - so many people are taking huge amounts of medication

Carer

Coaching

Problem Solving

Sense checking decisions

Needing to be there at a moment's notice

Knowing how to de-escalate a situation

Carer

Advocacy that prevents deterioration

Health and wellbeing services

Help with issues at work

Help with phone calls

Autistic person

Based on what people can do and what matters to them

Full check of where someone is at, what the gaps and solutions might be

Local (the Hampshire part of Autism Hampshire may put people off)

Supporting employment

Autistic person

Prevention including health checks

Good supported living which can support sensory needs i.e. sound proofing

Good assessment meaning you can get to the bottom of what is really needed

Flexible response solutions

Carer

Help to feel on top of things

Help with finding housing that doesn't make me feel worse

Feeling included in the transition from childrens to adults

Help to work out how to approach things differently

Autistic person

Providing social opportunities

Help to navigate social and work situations

Help with 'life admin' letters, bills, decisions

Listening and translating challenges to a way he can understand

Carer

Ongoing - not short term

Someone to pop over - building a rapport

Someone who understands what the challenges are - brother might say he can handle everything on his own

Someone with an excellent understanding of Autism

Valuing having someone to help outside of the family

Help him understand and accept his diagnosis

Coaching and mentoring

Help him to navigate challenges and take risks with relationships

Carer

Help when communication is stressful

Information overload makes it very difficult to recall what's happened

Auditory processing disorder tools and techniques to help

Independent living skills including finances

Understanding the impact of physical health conditions

Support with self-awareness, coping skills, support items and practical solutions

Understanding relationships

Autistic person

Would like to build skills in making and maintaining friendships

Training for family members on understanding autism and ADHD

Autistic person

Transition from 14

Vulnerable adults team

Help with work

Application forms

Help to access services like a GP phone call

Better understanding - named worker

Constellation peer support model

Valuing the enabling work - prevention

Employer responsibility

Carer

Help to be comfortable with himself

Help with independence

Able to link up with support that exists in the community

Getting rid of the "cliff edge" from EHCP to adults

Link with AMH - son has self harmed

Long term support "don't just leave them"

Carer

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