

Autism/ Neurodivergence Project

September 2022





Introduction

“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.”

Veronica Price – Chair,
Portsmouth Autism Community
Forum

Portsmouth Autism Community Forum (PACF)

PACF is an open forum for autistic people, carers and professionals. This project was carried out on behalf of and with full participation of PACF.

Purpose of PACF;

- 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


The Project

Seeking to understand;

- How Autistic and Neurodivergent (ND) people are experiencing public sector services
- Where there are gaps in support
- The level of demand for potential or reconfigured new support
- What support might look like
- What level of resource might be required
- Priorities for new Strategic Plan
- Links to other Autism/ND work



Data



There is no accurate data due to under diagnosis particularly in certain groups however this is the data we have;

- The estimated range of the prevalence of Autism is between 1-2% of the population
- There are 1010 active adult patients with an Autism (or similar) diagnosis on SystemOne
- There are 75 active ASC clients with an Autism or ND diagnosis

Local data from January 2022



Preventing worse health

- Autistic people are at double the risk of dying early due to virtually every cause of death
- Autistic adults who do not have a learning disability are nine times more likely to die from suicide, increasing to 14 times for women ([Suicide - Autism | Autistica | Autistica](#))
- The average cost of one suicide is £1.7m
- It is currently hard for Autistic people to access help for their health because of a standardised NHS offer



Employment

- The Office for National Statistics (ONS) published data in February 2021 that shows just 22% of autistic adults are in any kind of employment.
- The Disability Employment Gap is wide, with around half of disabled people in work, compared to over 80% of non-disabled people.
- Of all disabled people this research shows that autistic people are the least likely to be in work.

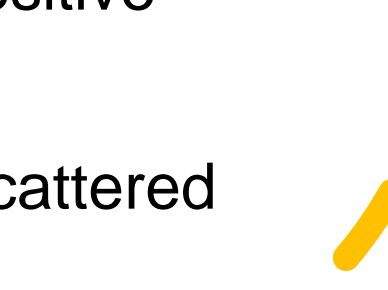
[New shocking data highlights the autism employment gap](#)

Legislative and policy context

- The Autism Act 2009 is the only disability specific legislation
- The Care Act 2014 is very clear about the obligation to offer assessment and support particularly around prevention and wellbeing
- National strategy for autistic children, young people and adults: 2021 to 2026
- All Party Parliamentary Group on Autism report
- NHS Long Term Plan 2019
- NICE Guideline

Despite the above most local authorities have struggled to implement the legislation and the policy recommendations due to a lack of investment and the impact of the pandemic.

Existing Service Offer

- Diagnosis – there is often more than a two year wait
 - Autism Hampshire – varying experiences were reported
 - Adult Social Care – small numbers of people being supported adequately, more not getting good support
 - Adult Mental Health no reported positive experiences
 - Community – pockets of support scattered across different organisations
- 

Headline Findings

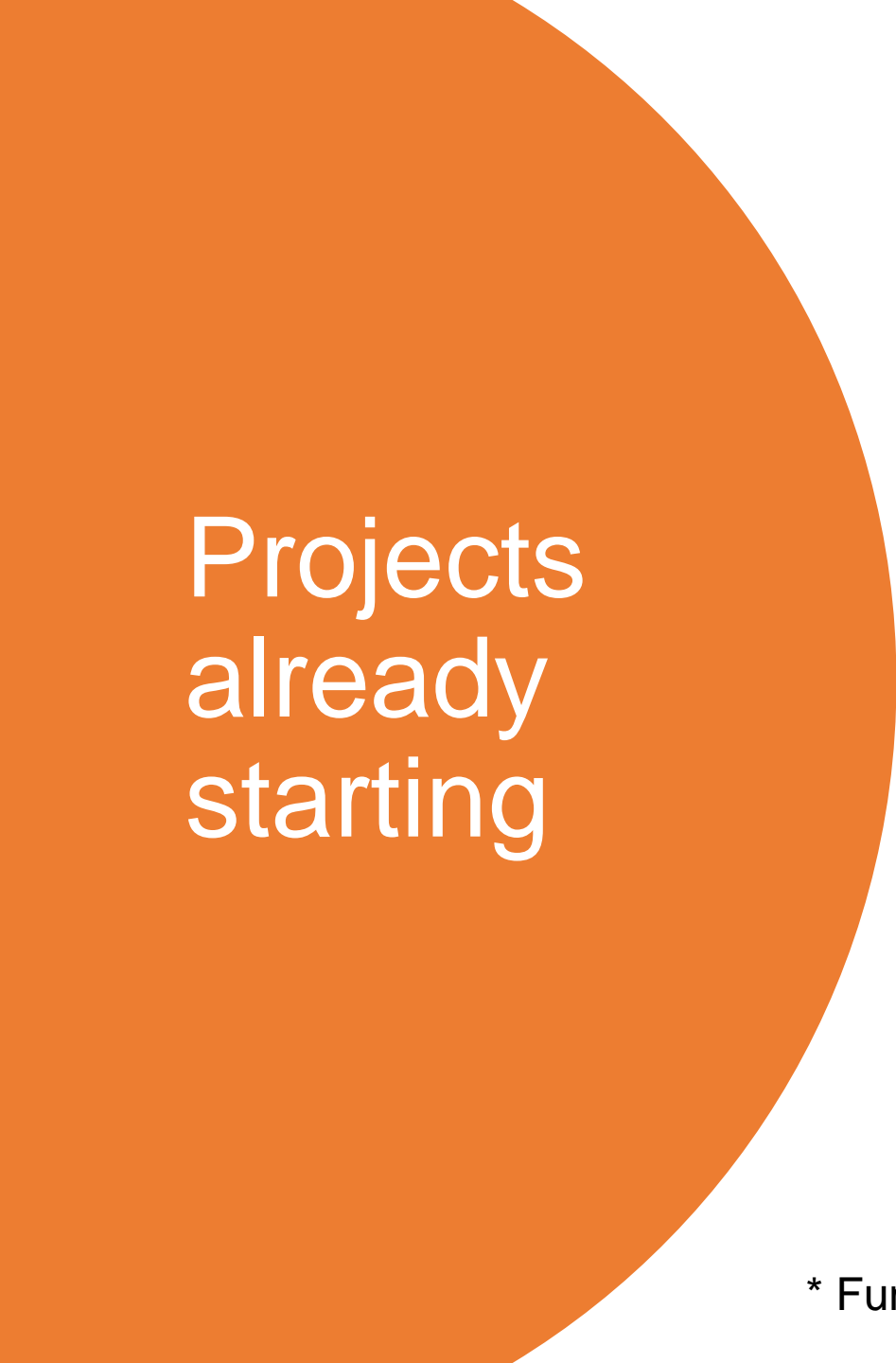
"People's lives are blighted by
being subjected to services"

Autistic person



Themed recommendations

- **Transition** – including support for unpaid carers and strategic alignment between adult and children’s services
- **Support** – including specialist ASC support, building staff networks, reviewing commissioned support and establishing a psychoeducational offer
- **Workforce development** – developing a comprehensive offer
- **Building public knowledge** to improve understanding and acceptance
- **Health** – improving access to health support particularly mental health
- **Research** – this piece of work is a starting point to build on



Projects already starting

Support into Employment *

Training for professionals (development
of video resources) *

Peer group support**

Serendipity Group**

Ko Create art sessions**

Charles Dickens Community Centre –
room to act as a community hub*

* Funded for 1-2 years

**run by volunteers

What next?!

**Thinking about how we can all be
the change**

**Supporting the development of a
new strategic plan**

Ideas for you

- Improve your own knowledge, understanding and acceptance
- Ensure people you know or manage gain knowledge, understanding and acceptance
- Scrutinise your service areas, are they accessible to neurodivergent people, those with sensory and communication needs



Thank you

Clare Rachwal

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