

# **Autism/ Neurodivergence Project**

March 2022



# 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

# 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



UofG

Neurodiversity

LANGUAGE

### **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.



UofG

Neurodiversity

# LANGUAGE

## IDENTITY FIRST

Many neurodivergent people prefer identity-first language (neurodivergent person) because their neurodivergence is an inherent part of their identity.

## MEDICALISED LANGUAGE

There is a growing shift away from pathologising medical models of disability to recognise that many mental differences need not be classified as disorder, deficits, or dysfunction. Try:

- condition *versus* disorder
- with/without intellectual impairment *versus* high/low functioning
- traits/aspects *versus* symptoms
- has [X] *versus* suffers from [X]




# 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

# Existing Service Offer

- Diagnosis – there is often up to 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
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# 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.





# 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

# Headline Findings

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

Autistic person




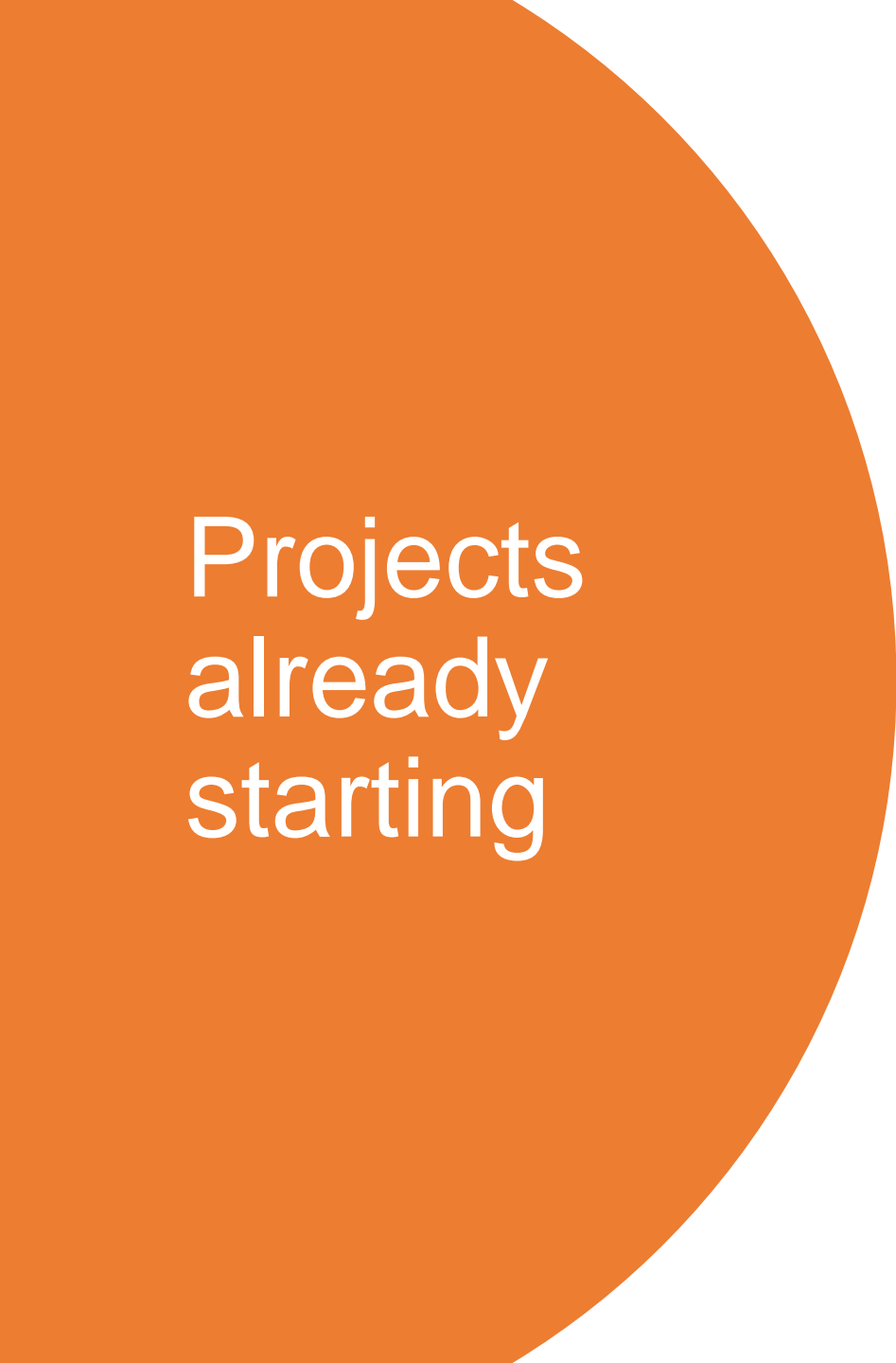
# Themed findings

- We need to improve support through transition from children to adult services and beyond
- Lack of understanding and tailoring of offer from a wide range of public services including Primary Care
- Lack of support for a wide range of things including independent living, advocacy, help with practical skills, help to navigate services
- Lack of support around achieving and maintaining good physical, mental and emotional health



# Themed findings

- Lack of support around achieving and maintaining good physical, mental and emotional health
  - Need for better knowledge and understanding about Autism and other neuro-divergent conditions for Autistic and Neuro-divergent people and their friends and family members
  - Problems with interactions with mental health services, standardised approaches, potential mis-diagnosis or not able to access support due to Autism diagnosis
  - Stigma around Autism and Neuro-divergence
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# Projects already starting

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Support into Employment

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Training for professionals (development of video resources)

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Peer group support

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Serendipity Group

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Ko Create art sessions

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

# Adult Social Care Response

Recruiting a small specialist team who will work with autistic and ND people and young people who are moving from children to adult services

Seeking to establish a larger virtual team from existing staff with expertise

Planning to establish a staff network for people working with Autistic and ND people

Commitment to provide better to staff and improve understanding and acceptance



# Next steps

- Development of an action plan which PACF will lead
- Development of a new Autism and Neurodivergence Strategy (CCG and public sector wide)
- Sharing findings as widely as possible to start improving understanding and acceptance



Thank you

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