

# East Hampshire and Havant Voluntary Sector Health & Wellbeing Forum

Support Services for Neurodivergent People

1-2pm Thursday 29 February 2024



## Programme for today...

## Support Services for Neurodivergent People

- Welcome and Agenda Angela Gill Community First & GVA Health Forum Facilitator
- > Tim Houghton, Chief Executive, Community First
- Monika Legg, Welfare & Wellbeing Commissioning Office, East Hampshire District Council & Ros Carvell, Community Graduate
- > Zoe Beasley, Autism Partnership Coordinator, Adults' Health & Care, Hampshire County Council
- ▶ Gemma Langman, Clinical Champion for Learning Disability and Autism, Hampshire & IoW Integrated Care Board
- > Ashleigh Spice, Services Manager, Autism Hampshire (Pre-recorded presentation)
- ➤ Date of the <u>next</u> East Hampshire and Havant Health & Wellbeing Forum Webinar
- Close of the Health & Wellbeing Forum Meeting/Webinars







## **Tim Houghton**

**Chief Executive**, Community First

## **Community & Voluntary Sector Update**

tim.houghton@cfirst.org.uk



## **Update**



#### **Community First**

#### 1. HCC Future Services consultation:-

https://www.hants.gov.uk/aboutthecouncil/haveyoursay/consultations/future-services-consultation

- > Proposed cuts to VCSE grants, including CVS, Community Transport, Homelessness services and Sexual Therapeutic services
- ➤ We need to demonstrate our impact and social value and keen to work with local partners to better evidence what we are doing works

https://socialvalueportal.com/

https://hact.org.uk/how-we-can-help/social-value/

https://socialvalueuk.org/social-value-self-asessment-tool/

Cooperation & collaboration must continue as we explore new ways of meeting the needs of people who need our help the most



## **Update**



### **Community First**

- 2. **HIVCA** (Hampshire & IoW VCSE Health and Care Alliance) <a href="https://actionhampshire.org.uk/get-involved/networks-and-forums/hivca/">https://actionhampshire.org.uk/get-involved/networks-and-forums/hivca/</a> HIVCA Leadership Committee includes Becky McGregor, Mountbatten; Helen Fisher, Energise Me; Natalie Webb, No Limits and Rob Kurn, Southampton Voluntary Services and representatives for our work/partnerships around children and young people, and mental health are; Sally Arscott, Solent Mind; Dr Kim Brown, Nature Therapy CIC; Clare Ansell, Motiv8 and Natalie Webb, No Limits
- 3. **Healthier Together website** is a valuable resource for families <u>Home :: Healthier Together (what0-18.nhs.uk)</u> Keeping your family 'winter strong' campaign and downloadable app. LCPs are effective cross-sector partnerships tackling the needs of families and children. For more information contact Debbie.Grace@cfirst.org.uk
- 4. Energise Me/HCC's **Hampshire Active Health** <a href="https://www.energiseme.org/funding-support/hampshire-active-health-programme/">https://www.energiseme.org/funding-support/hampshire-active-health-programme/</a>
- 5. Final round of **Household Support Grant** being allocated <a href="https://www.hants.gov.uk/socialcareandhealth/childrenandfamilies/connectforcommunities/communitygrants-overview/communitygrants-being allocated">https://www.hants.gov.uk/socialcareandhealth/childrenandfamilies/connectforcommunities/communitygrants-overview/communitygrants-being allocated</a>

## **Update**



#### **Community First**

- 6. **Live Longer Better** funding available to District Councils <a href="https://www.hants.gov.uk/socialcareandhealth/publichealth/livelongerbetter">https://www.hants.gov.uk/socialcareandhealth/publichealth/livelongerbetter</a>
- 7. **Public Health Mental Wellbeing Campaign** targeting men and ethnic minorities focuses on Five Ways to Wellbeing, signposting to <a href="https://www.hants.gov.uk/socialcareandhealth/publichealth/fivewaystowellbeing">https://www.hants.gov.uk/socialcareandhealth/publichealth/fivewaystowellbeing</a> Printable posters and digital ads are available. Contact <a href="megan.saunders@hants.gov.uk">megan.saunders@hants.gov.uk</a> for more info
- 8. Amparo offers an ICS-wide bereavement by suicide service <a href="https://amparo.org.uk/our-locations/hampshire/">https://amparo.org.uk/our-locations/hampshire/</a>
- 9. Community First continues to provide a range of wellbeing, sports and leisure activities from our centres at Clanfield <a href="https://clanfieldcentre.co.uk/">https://clanfieldcentre.co.uk/</a> and Leigh Park in Havant <a href="https://www.cfirst.org.uk/wellbeing/leigh-park-community-centre/">https://www.cfirst.org.uk/wellbeing/leigh-park-community-centre/</a> including a lunch club, Positive Pathways and a welcoming new space for Havant & East Hants Mind
- 10. Community First also provides affordable transport across Havant & East Hampshire via our Connect services which can help access health & wellbeing activities and benefit from social prescribing.
  - For more information <a href="https://www.cfirst.org.uk/community-transport/call-go-and-dial-a-ride/call-go-havant/">https://www.cfirst.org.uk/community-transport/call-go-and-dial-a-ride/call-go-east-hampshire/</a>



# Welfare & Wellbeing Strategy Refresh 2024-2029

Monika Legg, Welfare & Wellbeing Commissioning Officer Monika.Legg@easthants.gov.uk

Ros Carvell, Community Graduate

# Welfare and Wellbeing Strategy 2020-2024

## The Key Priorities in the Existing Strategy:

- Delivering Physical and Mental Wellbeing
- Supporting an Ageing Population
- Improving Community Connectivity and Sense of Place



## Where we are now in East Hampshire...

14.78% (14,475) adults registered with depression - this is higher than the national average.

Source: JSNA 2021.

58% of adults and 33% of Year 6 students were overweight/obese.

Source: JSNA 2021.

Citizens Advice East
Hampshire have seen
demand by individual
clients rise by 2,500
clients overall in the
last year.

30% of East Hampshire residents do not feel that there is a sense of community where they live.

Source: JSNA, Healthy Places 2022.

2,851 7–16-yearolds are estimated to live with a probable mental health disorder.

Source: JSNA 2022.

45.5% of East
Hampshire residents are
older than 50, compared
to 37.8% across
England.

Source: Census 2021.

## Our Vision

► To empower our residents to live healthy, fulfilling, and independent lives which will create supportive, well-connected and resilient communities.



BIG HEART, BIG IDEAS, BIG DIFFERENCE!



Why communities matter for health

Placing communities at the heart of public health can:



## Our PLAN for 2024-2029

#### Better Places

# Community Infrastructure Access to Open Spaces Climate Change Housing

## Better Living

Mental Wellbeing
Health Inequalities
Physical Health
Children and Young
People

## Better Ageing

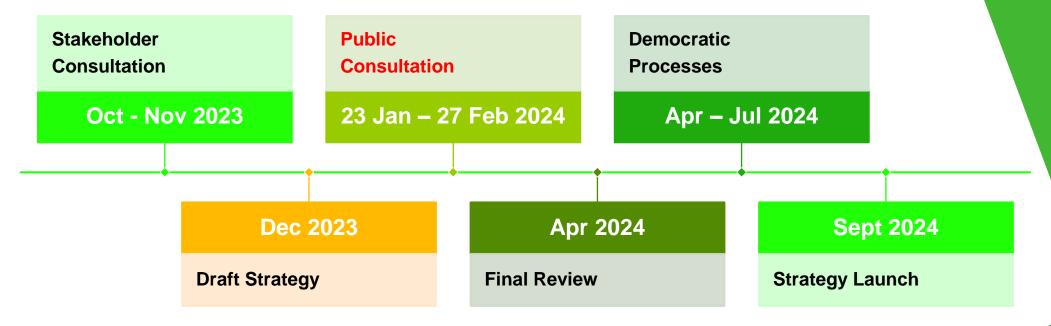
Living Longer
Resilient
Communities
Social Isolation and
Loneliness

## Better **N**etworks

Underrepresented Groups Financial Difficulties Planning for Emergencies



## **Timeline**



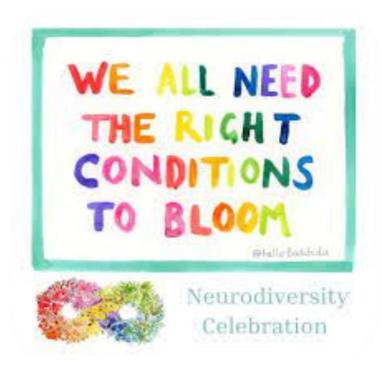


BIG HEART, BIG IDEAS, BIG DIFFERENCE!

# The purpose of Welfare & Wellbeing Strategy

- ► To set out a strategic direction for our services by defining the areas that will be prioritised over the next five years
- ➤ To identify evidence-based priorities for health and wellbeing for local populations and the approaches that will be taken to bring about improvements in these areas
- Work in partnership with organisations and communities to focus on delivery of these priorities
- To underpin financial decisions undertaken by officers (e. g., Welfare Fund, Supported Communities Fund)

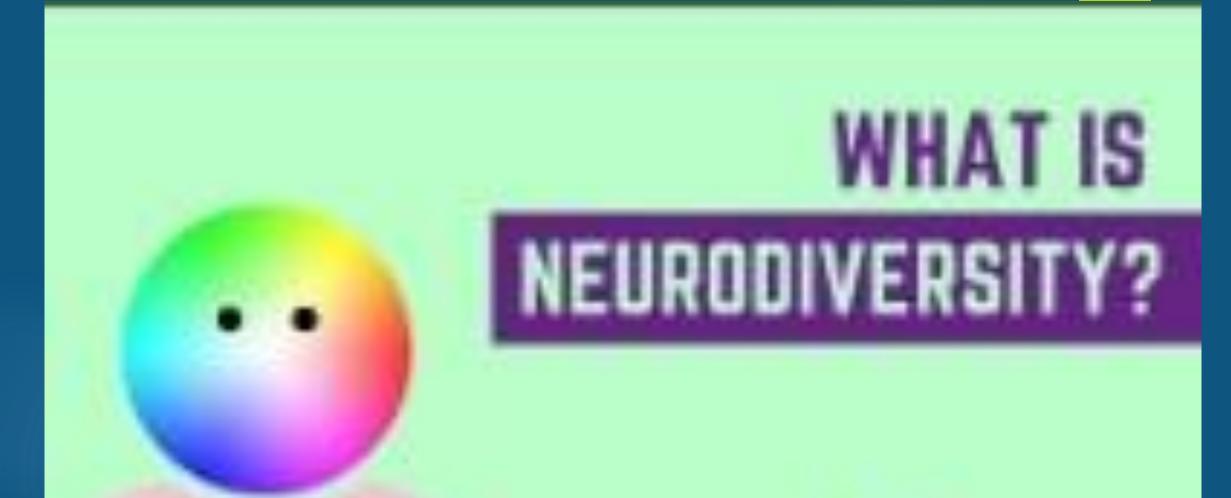


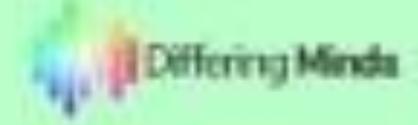


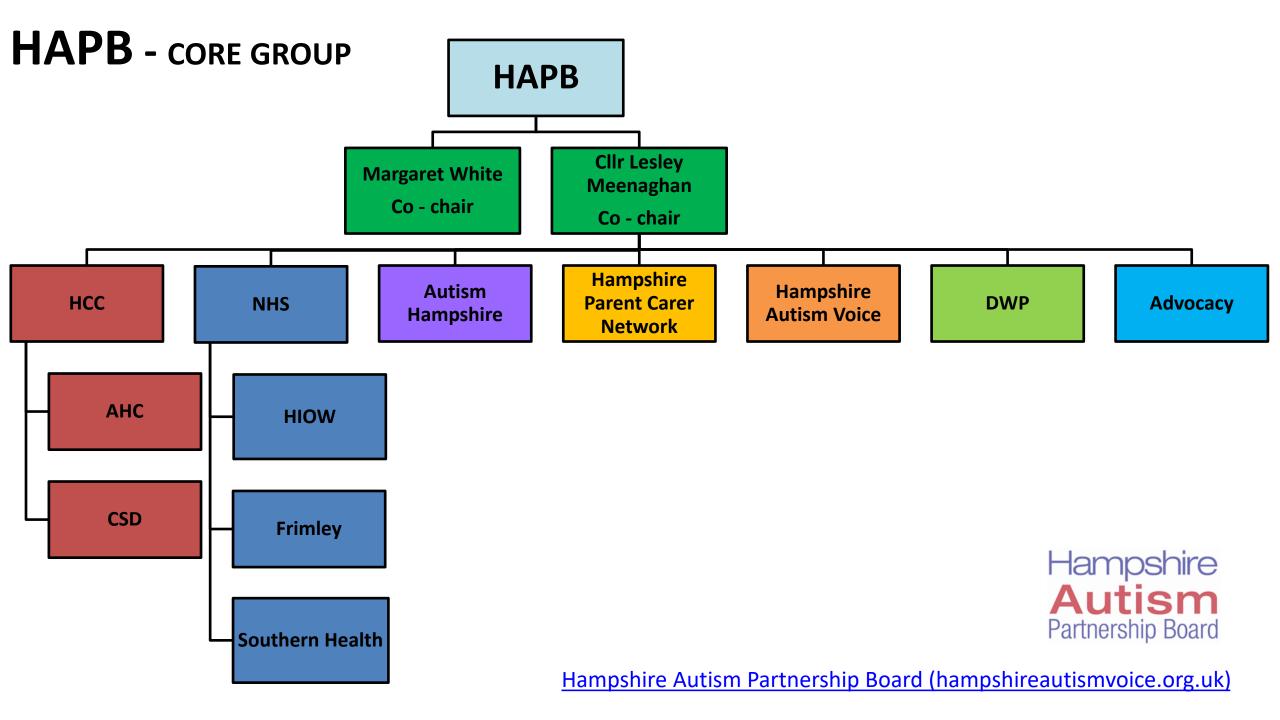
# Supporting Autistic Individuals

Zoë Beasley **Autism partnership coordinator** 









## **Hampshire Autism Strategy**

Work has been ongoing since December 2021 to review and update the Hampshire\* Autism Strategy to an all-age strategy, that will look to improve services for autistic individuals and those that support them.

The Strategy focuses on six priority areas, which mirror the National Autism Strategy priorities:



Improving understanding and acceptance of Autism within Society



Improving education and supporting transitions



Supporting more Autistic people into employment



Tackling Health inequalities

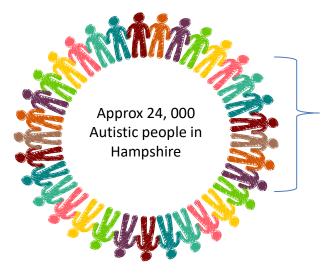


Supporting those in Inpatient care and building the right community support



Improving support in all aspects of the Criminal Justice System

## Autism demography in Hampshire





16.7% of all EHCPs show Autism as primary need

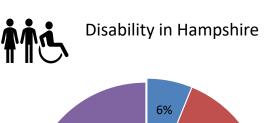
CYP with EHCPs suspension and exclusion rates are higher than national average (Autumn 22/23 term data)

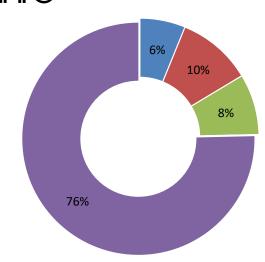
CYP with SEN support had 40.9% of permanent exclusions academic year 22/23 compared to 38.6% of CYP with SEN

**SEND & EHCPs** 

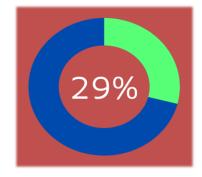


16.6% Hampshire population is over 70 years old, but autism will be very underrepresented within this





- Disabled under the Equality Act: Day-to-day activities limited a lot
- Disabled under the Equality Act: Day-to-day activities limited a little
- Not disabled under the Equality Act: Has long-term physical or mental health condition but day-to-day activities are not limited
- Not disabled under the Equality Act: No long-term physical or mental health conditions



Employment levels for autistic people (Nationally)

## Health and Care Inequalities for Autistic People

#### **Prevelance**

- Autism referrals have gone up by 200% since 2019
- Less than half of autistic individuals have been identified in Hampshire GP databases (based on the current prevalence)
- 30% of Autistic People have ADHD & 40% have a Learning Disability

#### Healthy life expectancy

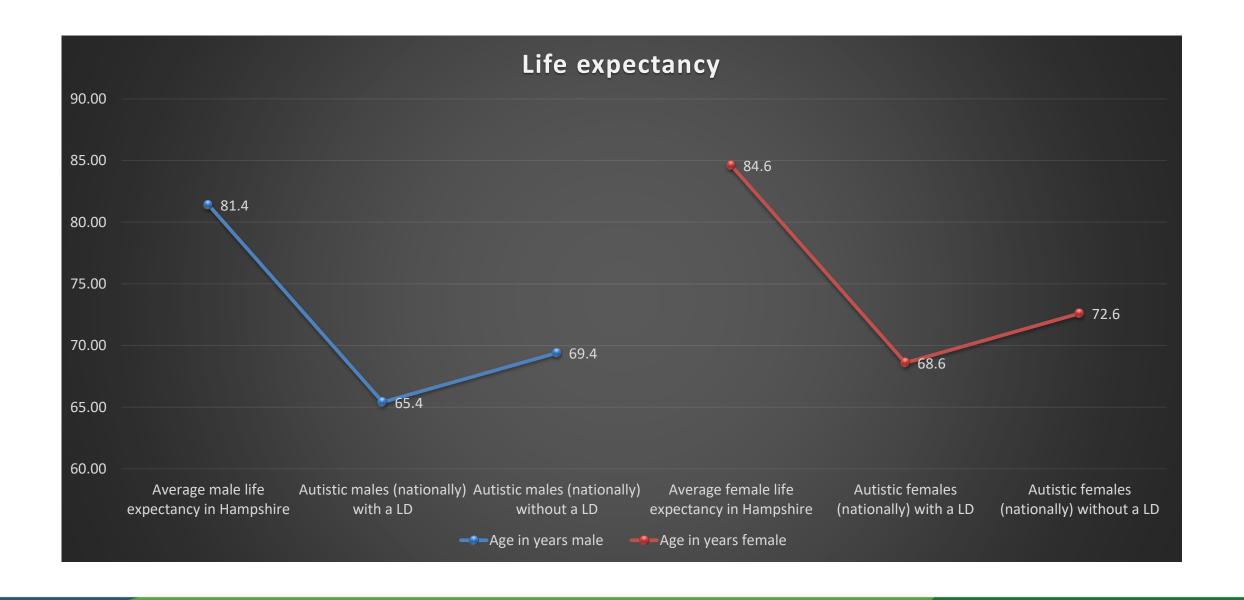
- Life expectancy is less in autistic people, with less time spent in good health
- Associated long-term health co-conditions including Epilepsy, Eating disorders, ADHD, Ehlers-Danlos syndromes/Hypermobility and Anxiety.

#### **Mental Health**

- 80% of autistic individuals will experience mental health issues during their lifetime.
- Autistic adults without a Learning Disability are 9 times more likely to die by suicide than the general population
- 15% of Autistic CYP have had suicidal thoughts
- Autistic people were 7 times more likely to be chronically lonely than the general population during Covid

#### Accessibility and Trust in Health Services

- 85% from our public survey felt being autistic was the main reason attending healthcare appointments was difficult
- Autistic people often feel dismissed, misunderstood, or not believed by clinicians at appointments.
- There are challenging sensory issues, such as noisy waiting areas and unpredictability over timings/who they see/location.



## Ways to improve accessibility and inclusion

Send out information prior to appointments with key information (inc. visuals)

Above all... be patient and ask where you can assist

Use Flesch Kincaid language level wherever possible on documents - Flesch Kincaid Calculator

Keep people updated re any delays

Ask if any adjustments may be required

Have clear information signs, with imagery

Clarify with the person – don't just assume

\* Professionals and training



★ Children and Young People











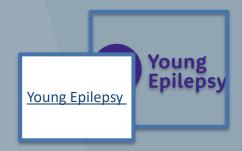




















\* Adults

























★ Parents/Families/Carers

























## Ways to support us

#### **Hampshire Autism Partnership Board**

- Hampshire Autism Strategy The strategy is due to be launched soon so please share and utilise.
- Inform us of any initiatives, projects you are working on that we can share at our meetings or to the community and/or any concerns that may affect autistic people (email autismboard.admin@hants.gov.uk)

#### **Autism Ambassadors**

 Being an Ambassador is a great way to be an ally to an autistic individual - <a href="https://www.ascambassador.org.uk/">https://www.ascambassador.org.uk/</a>

#### Mental Health Charter

 The Charter is based on four principles for supporting people who require care and support for their mental health - <u>Mental health</u> <u>consultation (shantsnas.org.uk)</u>



#### Hampshire Mental Health Charter

for people on the autism spectrum

Autism Consultation carried out by National Autistic Society South Hampshire Branch.

Our aim is for all organisations, which provide mental health services, to adopt this Charter, promote its; and then display it in their work place. Progress will be monitored by Hampshire Autism Patriership Boa "Wiffhout compossion and understanding, autistic people and families are at risk of bell soluted and developing mental health problems". National Autistic Society 2019

This Charter is based on four principles for specifically supporting people on the autism spectrum who re

#### rinciple 1: We will recognise and respond to your mental health needs, and

- Autism will not present any barrier to you when accessing mental health serv
- . Our organisation has a good understanding and knowledge of Autism
- · Your contact with all our staff is sensitive to your needs
- . Our organisation makes reasonable adjustments when providing you with a service
- We provide the support you need to manage your mental health to avoid escalation
- If you require another service for your mental health or wellbeing, we will work with y
  find the appropriate service(s)

#### Principle 2: We will recognise your strengths, expertise and knowledge to ensure that w

- Listen to you and your parent, carer and/or advocate without bias or prejudice
- Take your worries and concerns seriously alongside those of your parent, carer and/
- Take into account your personal needs and preferences.

#### Principle 3: We will communicate with you, your parent, carer and/or advocate in the varieties, to ensure:

Was an arranged to advance of the first control of the control of

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Principle 4: We op

Hampshire Autism Partnershin Board



Hampshire All-age Autism Strategy 2023



Southampton - Hampshire Isle of Wight - Portsmouth



#### Do you want to help your local community?

#### Make your business/organisation autism-friendly

'the smallest change can make the biggest difference'

#### Autism Ambassador

me launched by the Autism Partnership Boards of shire, Portsmouth, Southampton & Isle of Wight all our communities to become more autism-friendly.

For more information please visit: www.ascambassador.org.uk

introduced to the Ambassador role, receive autism awareness ow they will make a difference and meet fellow Ambassadors.

· interest to take part in this fantastic project, please email admin@ascambassador.org.uk

D Ambassadors already appointed - sign up now!





















What you can do to help me:	My name is:  I am years old I communicate by:	What is important to me:
What people like and admire about me:	Me Click to add a photo here	My strengths & talents:
My dream is to:	My fears / worries / things I don't like:	My favourite things:

#### My Health Passport For autistic people



WAYS YOU CAN

HELP ME UNDERSTAND

HOW TO PRESENT

CHOICES TO ME



Wha

If you are an autistic pers around them ur The 'know yo describe what such as how n time you spend

and how this changes, it's who may not

Healthcare staff, please consult this passport before you assess me or carry out any interventions.

Hospital staff, please keep this passport with my notes at the end of my bed and return to me when I am discharged.

Please look at the guidance notes before filling out your health passport the notes are at <a href="https://www.qutism.org.uk/health-passport">www.qutism.org.uk/health-passport</a>

Personal information	
Name:	
like to be called:	
Date of birth:	
NHS number:	

24 Too the and practical resources for solidic arous pages	ke the follow	ving person to be contacted:
34 Top tips and practical resources for authority young people		
What autism means for me		
My name is and I am autistic.	act in connec	ction with my treatment and care:
My special interests are	nship:	Phone:
Being autistic means I am a little bit different from other people.	nship:	Phone:
I have many strengths, but I also have challenges in some areas. In the boxes below I have listed these things so that you can understand me a bit better.	No	
Social interaction Social communication	ut me is:	
	Decision Makir	ng Profile

What might I need for support? \_ This tool is something you can bring with you to a youth group to help tell the youth group leaders what they can do to include you and make you feel comfortable. You can 🗸 tick options that you like and add your own. Things you must know about me

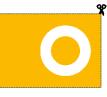
Parent/Carer contact detail	s:		
My diagnoses:	My medication:		
What to do during a	I like to be:	Please:	
mercown / snacown	left alone	let my parent or carer know	
	allowed to leave	let me move onto the	
	checked on by staff sat somewhere quiet	next activity let me play with a toy	
	sat somewhere quiet	other	
		other	
Behaviours to look out for	Things that show I'm upset:	other	
	Things that show I'm upset:	other	
	Things that show I'm upset: scratching not talking to anyone	looking scared covering my ears	
	Things that show I'm upset: scratching not talking to anyone leaving the room	looking scared covering my ears jumping around	
	Things that show I'm upset: scratching not talking to anyone	looking scared covering my ears	
	Things that show I'm upset: scratching not talking to anyone leaving the room	looking scared covering my ears jumping around	
	Things that show I'm upset: scratching not talking to anyone leaving the room looking angry	looking scared covering my ears jumping around	

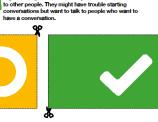
27 Top tips and practical resources for youth group leaders

To make your youth group truly accessible, you should A red badge means that the person does not want to have multiple options for communication such as verbally talking, writing responses on paper or a device talk to anyone, or only wants to talk to a few people. The person might talk to others if they feel able to, and that is okay; the approached people are welcome to talk back to and sign languages. Autistic people might be very good at expressing themselves, some may struggle to put them in that case. their thoughts together into clear sentences and some may use assistive technology or alternative methods A yellow badge means that the person only wants to talk

Some young people may struggle with starting conversations or may need reassurance that their communication preferences are known and respected This can be done with stickers, lanyards or badges that can be easily interchanged by the young person. Work with the young person to agree the rules of each colour badge and make sure that staff and other members know and respect these rules.







to people they recognise or prefer to have people start conversation with them. They may start a conversation with someone if they feel able to or prefer to have

A green badge means that the person wants to talk

someone start a conversation with them.



What's

'NORMAL'?





HOW I LIKE

TO GET INFORMATION

neans that I can

Resource
example

## Resources

#### Local Information websites

- Hampshire's Local SEND Offer: <a href="https://fish.hants.gov.uk/kb5/hampshire/directory/localoffer.page">https://fish.hants.gov.uk/kb5/hampshire/directory/localoffer.page</a>
- Autism central: www.autismcentral.org.uk/resources
- •NAS South Hampshire Branch: www.shantsnas.org.uk
- •Autism Hampshire: www.autismhampshire.org.uk/local-autism-directory & alert card: www.autismhampshire.org.uk/how-we-can-help/autism-alert-card

#### Education

- •AET: <u>www.autismeducationtrust.org.uk/resources/ Resources to Support Autistic Children and Young People (autismeducationtrust.org.uk) / Raising Peer Awareness During World Autism Acceptance Week & www.autismeducationtrust.org.uk/resources/transition-employment-toolkit</u>
- Ambitious about Autism: www.ambitiousaboutautism.org.uk/information-about-autism
- •Anna Freud: <a href="https://www.annafreud.org/resources/">www.annafreud.org/resources/</a> <a href="https://www.annafreud.org/resources/">Neurodiversity Celebration Week toolkit Secondary (mentallyhealthyschools.org.uk) / Neurodiversity Celebration Week toolkit Primary (mentallyhealthyschools.org.uk) & Mental health lead resource hub: Mentally Healthy Schools
- •Learning About Neurodiversity at School: leans recommended neurodiversity readings for educators.pdf
- •Sensory assessment checklist: AET Individual Sensory Checklist.pdf (locala.org.uk)

#### Health

- •Health Passport: My health passport (autism.org.uk)
- •CAMHS: https://hampshirecamhs.nhs.uk/nhs.uk
- •NAS: www.autism.org.uk/advice-and-guidance/topics/mental-health
- •MIND: www.mind.org.uk
- Mental Wellbeing: www.hants.gov.uk/socialcareandhealth/publichealth/mentalwellbeinghampshire

#### Communication, planning and accessibility tools

- Ambitious about Autism (<u>www.ambitiousaboutautism.org.uk</u>): your-normal-toolkit, what-autism-means-for-me & daily and session planners
- •NAS https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools
- •NDTI: www.ndti.org.uk/assets/files/f.-decision-making-profile-editable.pdf
- •Terminology Guide: www.autismeducationtrust.org.uk/sites/default/files/2021-11/terminology\_guide.pdf
- •Makaton: <a href="https://makaton.org/TMC/Free">https://makaton.org/TMC/Free</a> resources .aspx
- •The Spectrum: <a href="https://thespectrum.org.au/autism-strategy/autism-strategy-communication/">https://thespectrum.org.au/autism-strategy/autism-strategy-communication/</a>
- •Text Help: www.texthelp.com/solutions/creating-accessible-content/

Good books link - Jessica Kingsley Publishers | Jessica Kingsley Publishers - UK (jkp.com)

<u>Downloadable Resources | Autistic Parents UK</u>

<u>Challenging-Stereotypes-ImWithSam.pdf</u> (dimensions-uk.org)

Resources Archives - Gareth D Morewood (gdmorewood.com)

Communication tips (autism.org.uk)

<u>I am a professional supporting Autistics - Reframing Autism</u>

Hampshire Equality and Rights Advocates (EARA) | Hampshire County Council (hants.gov.uk)

Neurodiversity Celebration Week toolkit - Secondary (mentallyhealthyschools.org.uk)

Neurodiversity Celebration Week toolkit - Primary (mentallyhealthyschools.org.uk)

#### **Useful videos and blogs:**

Know your normal: <a href="https://youtu.be/ZLJACPxcojg">https://youtu.be/ZLJACPxcojg</a>

Autism Education Trust – what is autism: <a href="https://youtu.be/h-bc1CJlhbM">https://youtu.be/h-bc1CJlhbM</a>

The Neuro Bears - the autism experience: <a href="https://youtu.be/490q6LaHIY">https://youtu.be/490q6LaHIY</a>?

Young people explain what it's really like being autistic https://youtu.be/xTLUYda-008

Young people explain meltdowns and shutdowns: <a href="https://youtu.be/zseDI1V-BqU">https://youtu.be/zseDI1V-BqU</a> &

https://youtu.be/gztHLxesWII

NAS – sensory overload: <a href="https://youtu.be/aPknwW8mPAM">https://youtu.be/aPknwW8mPAM</a>?

NAS – barriers to work: <a href="https://youtu.be/GAehvcnFjml">https://youtu.be/GAehvcnFjml</a>

NAS - Diverted short film: https://youtu.be/GflKHWfnH-Y

Blog | Ambitious about Autism

Blog | Autism Education Trust

## Links for additional resources

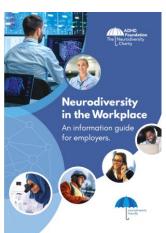
## Resources (click on pics for links)





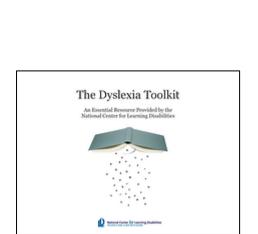


















# Thankyou



Zoë Beasley

**Autism partnership coordinator** 

Adults Health and Care, Hampshire County Council

Email: zoe.beasley2@hants.gov.uk Direct dial: 0370 779 6844



Isle of Wight - Portsmouth

2021-2022



## **Additional information**

- The following slides has information and video's that would be beneficial to look at and share with colleagues in your own time.

## Things people may have



Lanyards



Hidden Disabilities Scheme UK



## I am autistic

Please be calm

- Your behaviour may confuse me
- I may not respond in the way you expect



I am autistic card (autism.org.uk)





Autism Alert Card | Autism Hampshire

Alert Card Schemes | National Police Autism Association (npaa.org.uk)



## Things people may use



Sensory aids









PECS &
Electronic
communication
systems









## Neurodiversity



	Dyslexia	Dyspraxia	ADHD	Autism
Strengths	<ul> <li>Entrepreneurialism</li> <li>Creativity and cognitive control</li> <li>Visual reasoning</li> <li>Practical skills, visual-spatial skills and story-telling ability</li> </ul>	<ul> <li>High verbal comprehension ability</li> <li>Problem solving</li> <li>Empathy and people skills</li> <li>Tenacity</li> </ul>	<ul> <li>Creative thinking</li> <li>Visual spatial reasoning ability</li> <li>Hyper-focus, passion and courage</li> </ul>	<ul> <li>Memory ability, and other 'specialist individual skills' including reading, drawing, music and computation</li> <li>Innovative thinking and detail observation</li> </ul>
Challenges	Memory,organizational skills, time management, stress management, literacy     Workplace participation in terms of mental functions and social interactions     Cognitive functioning and social self-esteem	Difficulties with driving, self-care, organization, communication and self-esteem     Processing speed and working memory     Persistence of motor difficulties	Time management     Concentration, attention and self-regulation difficulties     Insomnia, depression, injury and absence     Maintaining employment     Difficulty with team work	Time management     Concentration and coping with more than one task     Social and communication difficulties     Need for routine
Source: The British Psychological Society, 2017				



Billie Eilish.png



Cara D...gne.png



Chris P...ham.png



Clay Marzo.png



Daniel...cliffe.png



Emma...tson.png



Whoopi...erg.png



Greta T...erg.png



Hannah...sby.png



Jack Monroe.png



Jessica-...ate.png



Keira K...tley.png



Ladyhawke.png



Will.I.Am.png



Lewis H...ton.png



Maggie...ock.png



Richard...son.png



Ryan Gosling.png



Satoshi Tajiri.png



Simone Biles.png



Tom St...man.png



#### Social understanding, Communication & Sensory processing

Autistic individuals can have varying levels of communication. Social situations can be difficult for Autistic individuals and cause great anxiety. Autistic individuals may find it more difficult to understand other's intentions and express themselves in the way society deems the 'norm'.

The theory the 'Double Empathy problem' by Dr. Damian Milton explains essentially it is not that Autistic individuals don't have social skills, they are just different to non-Autistic social skills. The double empathy problem (autism.org.uk)

Individuals may be Hypersensitivity or Hyposensitivity to certain senses and use stimming to regulate these.



### 'Autism rates and differences in ethnic minorities and links to social disadvantage' study

The study of more than 7 million children in the UK showed around one in 57 (1.76%) children in the UK is on the autistic spectrum.

The highest prevalence was found in Black pupils (2.11%) and the lowest in Roma/Irish Travelers (0.85%), with important variability across geographic areas.

26% of Black pupils and 38% of Chinese pupils were found to be much more likely to face significant social disadvantage. Pupils with a record of autism in schools were 60% more likely to also be socially disadvantaged, and 36% less likely to speak English.

Findings showed that pupils facing social disadvantage were more likely to be autistic.

Professor Fiona Matthews from Newcastle University stated:

"This study highlights the need for more attention to the unrecognised and differing needs of autistic children from disadvantaged and diverse backgrounds."

Task – pen and paper required --- warning of potential sensory overload

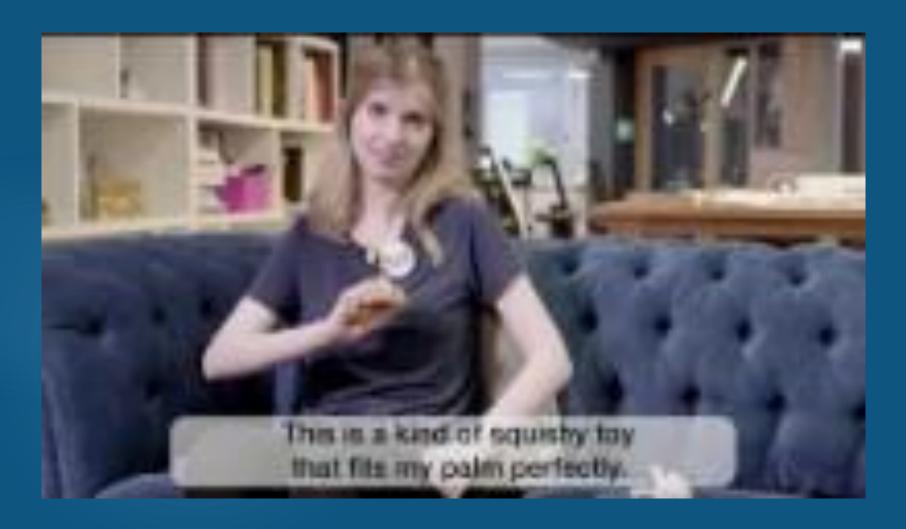


This is a video of the young Autistic individuals experience around communication



Reference: Young people explain communication | Ambitious about Autism - YouTube

#### Repetitive behaviours & stimming



Repetitive behaviours can be a major part of life for many Autistic people. They can be an essential way of regulating emotion and providing someone with a source of comfort or enjoyment that enables them to carry on with their day.

#### Meltdowns and shutdowns



# Inequalities in Individuals with Autistic Spectrum Condition

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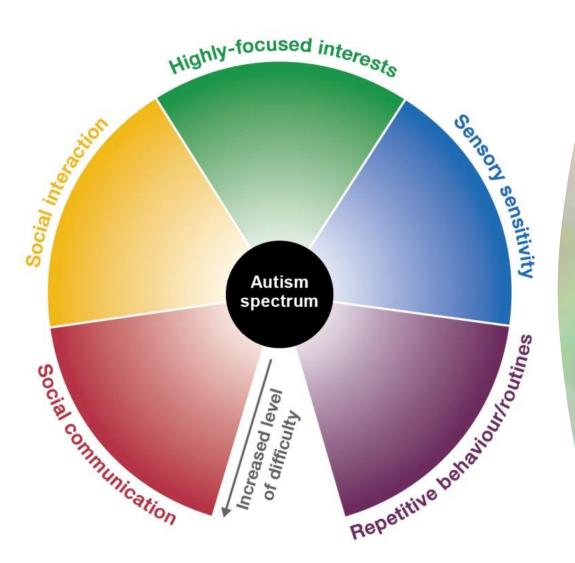


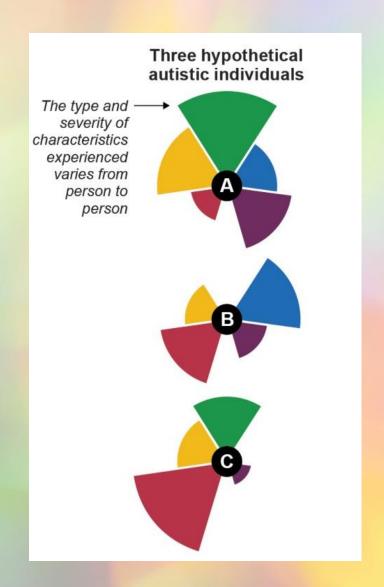
Autistic Spectrum Condition
(ASC) is a lifelong
neurodevelopmental
condition that affects how a
person relates to and
communicates with other
people

There are five different modalities that a person with autism may have difficulties with.....



#### A 'spectrum' condition





#### Prevalence of ASC

- Estimated to be around 700, 000 in the UK.
- 1 in 100 people are thought to have the condition.
- We haven't got a current good estimate of the prevalence in Hampshire and IOW.
  - But using the above figures, with an estimated 2 million people living within the HIOW ICB, there are at least 20,000 autistic people living in the community.
  - It is likely to be higher.

What is the Significance?

#### Mortality rates and outcomes

- There have been many studies that have shown that mortality rates are increased in ASC.
- There are also studies that suggest autistic people have poorer quality health outcomes and poorer healthcare generally.
- Therefore there is evidence to show an inequality in healthcare in those people with autism, with or without a learning disability (LD).

## Misconceptions of Autistic Spectrum Condition

- There is a general lack of understanding throughout society as to what ASC is and how it presents.
- This unfortunately extends into the NHS and Education systems.
- There needs to be more education in the NHS to highlight the possible individual needs of the autistic community.
  - Oliver McGowen training
  - How do we logistically implement this?
  - Is it enough?

#### **Education**

- Due to a lack of support, many autistic children are not receiving the education they need nor deserve.
- The National Autistic Society published their School Report in 2021.
- It reported:
  - Less than half of autistic children are happy in school
  - 26% or parents waited over three years to receive support for their child
  - 74% of parents said the placement their child had, did not fully meet their individual needs

#### **Education**

Exclusion rates vs home schooling

 What proportion of home educated children are autistic and have been pulled from school because their individual needs are not being met?

#### Work, Family and Impact on Society

- In England it is believed that nearly two-thirds of autistic adults do not have enough support to meet their needs.
- Fewer than three in 10 people with autism are in work; even less are full time.
  - This is a particularly low employment rate.
- With every autistic child, comes a family who also need support
  - And implications of non mainstream education.
- The impact of the lack of support and resources for autistic people on society is potentially huge.

#### **Mental Health**

- The Beyond Autism website quotes that 70-80% of children and adults with autism experience or have experienced mental health problems in their lifetime.
- These figures are huge.
- However, due to some autistic people's difficulties with communication and potential difficulties with describing their feelings, these mental health problems can be overlooked.
- Also autism itself can misinterpreted as other mental health conditions, such as personality disorder, and patient's end up on the completely wrong treatment pathway with an inaccurate diagnosis.

#### Falling through the gaps....

- I believe one of the biggest issues here in Hampshire though is when autistic people fall through the gaps of services.
- Autism is NOT a mental health condition.
- More often than not, autistic patients, and those awaiting their diagnosis, fall through the gap in mental health support.
- Whilst autism is not a mental health condition, their autistic traits make them more susceptible to mental health issues.
- However, often when secondary care teams see autism in a referral, patients
  are rejected on this basis as they do not have the resources and sometimes
  understanding of the needs of autistic patients.
- The impact of mental health problems in this population can cause issues in education, employment and generally functioning in society.

#### Falling through the gaps.....

- Case study in Hampshire
  - 7 year old awaiting autism assessment with Psicon.
  - Self harming and having suicidal ideation.
  - Major panic attacks with regards to schooling.
  - Goes to jump off a balcony.
- CAMHS assessed and said
  - "as her anxieties are due to her autism, the family should await autism assessment and await support from that service".

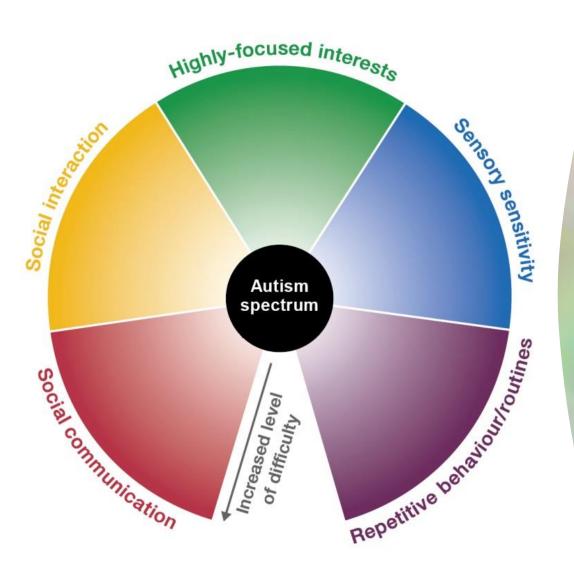
#### Falling through the gaps

- What support is there for that family?
  - From CAMHS?
  - From Psicon?
  - After an autism diagnosis?

As a GP, what can I offer that family?

#### A Neurodevelopmental Service

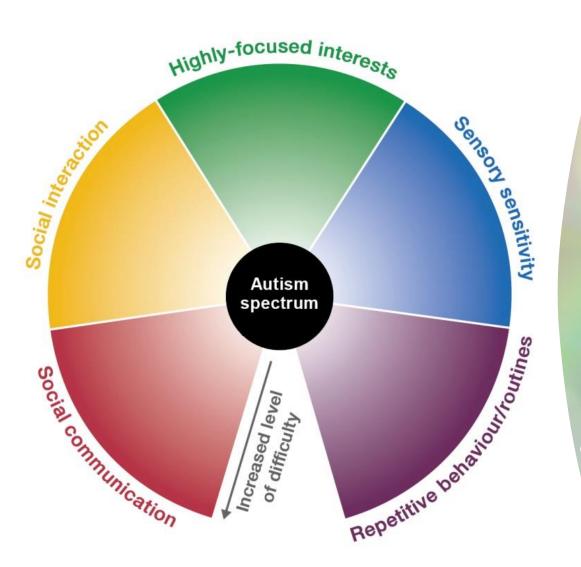
- In an ideal world, the NHS should provide a separate neurodevelopmental service for people with neurodevelopmental disorders (NDD) such as autism and ADHD.
- NDDs are NOT mental health conditions.
- But they are lifelong.
- And their impact on individuals can be huge and affect every part of a person's life.
- The service should include not only diagnostic pathways but support and help to individuals and their families.



#### Accessibility to healthcare

- Tailoring to their individual needs.
- Patients and carers are NOT trying to be difficult.
- They are trying to gain access that works for them.

#### Reasonable adjustments



 changes to remove or reduce a disadvantage related to someone's disability.

#### Reasonable adjustments

- ALWAYS acknowledge the person
- ALWAYS Show RESPECT
- ask how best to proceed
  - how can I best communicate with you today?
- LISTEN!
  - AND REACT TO WHAT YOU HEAR

#### Reasonable adjustments



We need to try to provide metaphorical ramps



#### Summary – moving forward

- Much more needs to be done for the HIOW autistic community.
- The evidence that their needs are not being met is extensive across the board.
- The inequalities in healthcare in this population I believe is unacceptable.
- Higher mortality rates and poorer health outcomes need to be addressed.

The impact of autism on the individual and society as a whole is huge.

We can be - and should be - doing better.

#### References

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- Autism Ambassador Southampton, Hampshire, Isle of Wight, Portsmouth Presentation slides
- <a href="https://www.gov.uk/government/news/new-review-to-boost-employment-prospects-of-autistic-people#">https://www.gov.uk/government/news/new-review-to-boost-employment-prospects-of-autistic-people#:~:text=People%20with%20autism%20have%20particularly,is%20aiming%20to%20change%20that.</a>
- Sources: GAO analysis of the Diagnostic and Statistical Manual of Mental Disorders , Fifth Edition (DSM-5) and the National Autistic Society





## Ashleigh Spice Community Services Manager



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## How would you make a glass of squash?



#### How would you make a glass of squash?

- Question your own knowledge, judgements and perceptions of a situation
- Ask questions and get clarity
- Check your own understanding and remember it may be different to someone else's
- Be specific and break things down simply

#### 1. Information, Advice, Guidance



- Free service (for people in Hampshire) to support autistic people, their parents, carers and professionals
- Access available pre, during and post diagnosis
- Open Monday-Friday 9-5

#### IAG offers 3 tiered levels of support:

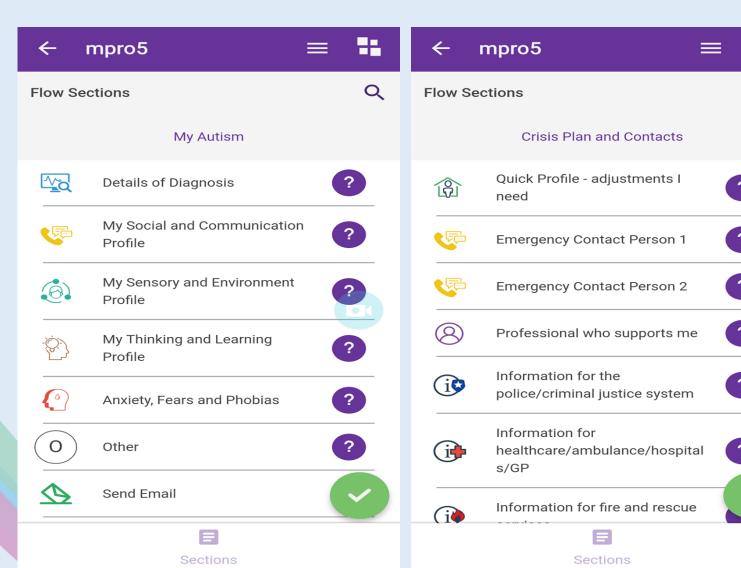
- Tier 1- When a question can be answered through an email or call
- Tier 2- When an appointment is needed or further research and guidance is required
- Tier 3- Ongoing regular appointments with an IAG Officer





#### Alert card and Autism Assistance App

Q





#### 2. Serendipity Community Groups



Our Serendipity groups are a great way for autistic adults to meet in a supportive and non-judgmental setting.

- Free online and in-person groups across
   Hampshire
- Facilitated by a our team and trained volunteers
- For autistic adults aged 18+
- No diagnosis needed
- Attend independently or with support if needed
- Most groups meet one to two times per month in a regular venue



#### 3. External Training & Consultancy



Empowering autistic people, their families and professionals by learning more about neurodiversity in an interactive way, using first-hand experience.

- High-quality, CPD-accredited training and consultancy
- Training courses are created, designed and, wherever possible, delivered by autistic people themselves using innovative and immersive exercises
- Consultancy includes workplace/environmental assessments and 1-1 interviews

- Being with Autistic People (3 hrs):
  An entry-level course
- Towards Understanding Autistic
   People (6 hrs): An intermediate-level course
- Understanding, Accepting &
   Accommodating Autistic People (6 x
   3 hrs): A longer course for parents,
   professionals, and anyone else who
   has frequent contact and interaction
   with autistic people.

#### 4. Specialist Mentoring Service



Our service aims to empower university students using specific strategies to help manage barriers to learning and life and encourage successful and independent management of lifestyle and studies.

- For students who are: autistic, have other neurodivergences or specific learning differences and/or mental health conditions
- Online or in person
- Funded by universities or Department For Education based on needs assessments
- Have dedicated time to set goals that help with challenges, reflect on their experience of university and celebrate achievements



#### How can you help us?



- We need more volunteers! Serendipity Volunteers alone donate approximately 960 hours of their time per year
- Attend our training courses it's made by autistic people with real lived-experience stories and a great way to learn from the experts in Hampshire (CPD accredited)
- Fundraise for us! A fun run, silly sock work day
- Spread the word we get such great feedback from people we support – please signpost and share information about our services to others so we can try to support as many people as possible









- \* Thank you to all who have supported &/or attended today's Health Forum Webinar
- ✓ The recording and PP will be saved on Community First's and GVA's webpages within a week
- > Dates of the 2024 East Hampshire and Havant Health & Wellbeing Forum Webinars/Meeting...
- Thursday <u>1-2pm 23 May, 1-2pm</u> (Webinar)
- Tuesday <u>1 October</u>, <u>12.30-2.30pm</u> (Networking & Showcase Event <u>Face to Face</u>)
- Thursday <u>21 November, 1-2pm</u> (Webinar)
- > Please feedback via Chat or email including re future Health & Wellbeing Forum theme or presenter ideas
- ➤ Health & Wellbeing related items will be circulated 4-6 weekly by Jane Bray
- Finally, if you aren't a Health & Wellbeing Forum member or know of a local health organisation that would like to join, please ask them to email Jane:- <a href="mailto:healthforums@cfirst.org.uk">healthforums@cfirst.org.uk</a>
- Have a Happy, Healthy Spring!

#### **Contact Details**



#### **Community First**

Leigh Park Community Centre, Dunsbury Way, Havant, PO9 5BG



https://www.cfirst.org.uk



healthforums@cfirst.org.uk



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