



**Notes of the Autism Norfolk Forum (ANF) Meeting
Held on: 22 March 2023**

Venue: Online via Zoom

Please note: These notes represent an overview summary of this meeting rather than a verbatim transcript.

Name of Attendee	Organisation and/or Role
Lee Gibbons	ASD Helping Hands, Norfolk Autism Partnership Co-ordinator
Karen Dures	Strategic Business Lead - Autism Adult Social Services (NCC)
Adrian Grant	Norfolk Autism Partnership Co-Chair
Robert Cooper	Commissioning Programme Manager Mental Health (NCC) Guest Speaker
Nicola Cogdell	Independent Advocate (PohWER) Guest Speaker
Members of the public (7)	

Agenda Item 1	Welcome and Introduction
1.1	Welcome and introductions made: <ul style="list-style-type: none"> • This Forum was held using Zoom • Communication prompts and their use explained. • Acknowledged a note taker is provided. • Norfolk Autism Partnership Board's (NAPB) Code of Conduct and Coproduction principles introduced and explained.

Agenda Item 2	Update from the Board
2.1	Lee Gibbons gave the forum an update on the work of the Norfolk Autism Partnership since the last forum (last forum held on 14/12/2022)
2.2	The Norfolk Autism Partnership has been working with the library champions and the library service to set up social and support events in each of the 47 libraries in Norfolk. While most of the libraries have

	<p>something set up for their clusters there are still some libraries working on the offer.</p> <p>All groups with dates and times can be found on the Norfolk Autism Partnership website under the 'What's On?' section</p> <p>https://www.norfolkautismpartnership.org.uk/whats-on/</p>
2.2	<p>An update was given on the co-production of the new early support service and members of the forum were incited to complete the questionnaire based on the found themes that had emerged from the co-production events.</p> <p>The questionnaire can be found on: https://tinyurl.com/bdfc3mmm</p> <p>This is open until the 9 April 2023.</p>
2.3	<p>An update on the diagnosis working group was given explaining that they are focusing on the following three points:</p> <ul style="list-style-type: none"> • Decreasing waiting times • Post diagnosis support Adult and Children • Pre diagnosis support Adult and Children
2.4	<p>An update on the forward working task and finish group was given.</p> <p>Lee explained about the creation of a steering group being led by Autistic people and how this will influence the agenda of the Autism Partnership Board. The aim of the steering group is to ensure that the voices of Autistic people is directly the work of the Norfolk Autism Partnership.</p>
2.5	<p>Lee explained the different ways that people can get involved with the partnership and the different levels of membership.</p>

Agenda Item 3	Guest speaker 1 – Robert Cooper
3.1	<p>Robert Cooper join us to talk about the Advocacy services commissioned and available though Norfolk County Council as well as the types of Advocacies there are.</p>

3.2	<p>Advocacy is about:</p> <ul style="list-style-type: none"> • Express their views and concerns. • Explore choices and options. • Access information and services
3.3	<p>Advocacy is about empowering people, giving them more confidence and control. It is about making sure that people can be fully involved in decision about then and support them to defend their rights and responsibilities.</p>
3.4	<p>There are many different types of advocacy some of them are:</p> <ul style="list-style-type: none"> • Self-advocacy – advocating for yourself. • Advocacy through family and friends – when a friend or family speak on your behalf • Peer advocacy- someone who is not in your family but advocates for your using their skills and knowledge • Citizen advocacy – a member of your community supports and advocates for you on your behalf
3.5	<p>Community Advocacy. There is no legal requirements to provide these. The Norfolk Advocacy partnership is available in Norfolk more information on this can be found through NCAN (Norfolk Advice Network Helpline 0333 996 8333 or email helpline@ncan.co.uk).</p>
3.6	<p>There are two types of statutory advocacy services:</p> <ul style="list-style-type: none"> • Instructed advocacy – where someone is able to say what their views and wishes are. • Non–instructed advocacy – where someone is not able to say clearly in a given situation what their needs and wishes are.
3.7	<p>Types of statutory advocacy are:</p> <ul style="list-style-type: none"> • IMCA – Independent Mental Capacity • IMHA – Independent Mental Health • ISCA – Independent Social Care • NHS Health Complaints (The provider for NHS complaints advocacy in Norfolk is PohWER)
3.8	<p>Instructed advocacy</p> <ul style="list-style-type: none"> • The advocate will get up to date information to help service users make informed choices but will not give them advice.

	<ul style="list-style-type: none"> • The advocate will listen to the service user and discuss their options but will not force their views or opinions on the person. • The advocate will talk to and write to professionals with the individual's permission but will not make decisions or choices on behalf of the service user. • The advocate will give the individual's views and wishes but the advocate won't take action without the agreement of the individual that they are supporting. • The advocate will agree a plan with the individual that they are advocating for.
3.9	<p>Non instructed advocacy is when a service user cannot give clear instructions, an advocate will take time to get to know them.</p> <p>They will make note of what they like and dislike and their routine</p> <p>The advocate will look for other ways to communicate with the service user so they can express their views and choices.</p> <p>The advocate will make sure the person's human rights are respected and upheld.</p> <p>The advocate will challenge decision makers in NHS or care authorities and service providers to follow a person-centred approach.</p>

Agenda Item 4	Guest Speaker 2 – Nicola Cogdell
4.1	Nicola Cogdell introduced herself as an independent advocate from Pohwer who has recently been diagnosed with Autism.
4.2	Nicola mentioned that a large number of complaints are relating to language used. It is the consensus of the Norfolk Autism Partnership to use identify first language unless other wise directed by an Autistic individual.
4.3	Nicola has been an advocate for 13 years in both NHS complaints and in community advocacy services. She has recently moved to Norfolk where she know works with PohWER managing their NHS complaints.

4.4	Current trends in NHS complaints are around waiting times for assessment and diagnosis.
4.5	It was explained that if PohWER receive advocacy services for those with ill mental health or Learning disabilities they would be referred to Equal Lives and for those over the age of 60 they would be referred to Age UK.
4.6	<p>Nicola explained that she believes advocacy should be:</p> <ul style="list-style-type: none"> • About empowering people to take control of any complaint they may have • Full inclusive looking at different ways of communicating with people and working with their preferences. • An advocate should not assume someone can or can't do something. • Should be person centred and holistic in its approach.
4.7	<p>Nicola asked the group to feedback on two questions:</p> <ol style="list-style-type: none"> 1. What does advocacy look like to you and what advocacy services do you need? 2. How would you like advocacy services to interact and communicate with you? <p>This questions where discussed in the open discussion agenda item.</p>

Agenda Item 5	Open Discussion
5.1	Permission was given to pass and additional questions through to Nicola if they raised after the meeting
5.2	<p>A public member of the forum raised that they would of found some advocacy support after they received a diagnosis for their child very helpful. They explained that after receiving he diagnosis they felt lonely and had to find additional information and support services themselves. An advocate would of helped relieve some of this pressure.</p> <p>Families can face pressures such as work commitments other children. So, someone to guide them through the process of finding and securing support would have been very helpful.</p>
5.3	Tina Allen (Autism Service Norfolk) talked about the post support offered through Autism Service Norfolk and stated that it was three sessions and the final one was about finding and signposting to additional support service once they had been discharged form Autism Service Norfolk.

	She commented that community advocacy was lacking and improvements in this area would be a great help to Autistic people especially those who had just received a diagnosis.
5.4	<p>Question: Was equal lives just commissioned to support with NHS complaints?</p> <p>Answer: Equal lives are a community advocacy service so will take on additional cases and not just those with a NHS complaint. Equal Lives are very busy so the call for more community advocacy services was made again.</p>
5.5	<p>A member of the public shared with the forum that their daughter was creating a directory of services for Autistic people and encouraged people to visit and share within their networks : www.an-autistic-directory.com</p> <p>They are keen for feedback and to be linked with other organisations to join the directory. This is UK wide and not just Norfolk based.</p>
5.6	In relation to the second question posed. One member commented that this was a very subjective question as it entirely depends on the person. So the advocacy services need to be adaptable not just at the beginning but throughout the process and may need to change how they communicate and interact with the person.

Agenda Item 6	Any other business
6.1	There was not any other business brought to the forum.

Date, time, and location of next meeting	
<p>The next Autism Norfolk Forum will be held on: Tuesday 11 July 10:30-12:30</p> <p>Sign-up details will be posted to the Partnership's webpage and sent to members. The topic of this forum has not yet been decided.</p> <p>Future Forum meeting dates: 13 December 2023, 13:00-15:00. Venue TBA</p>	

Glossary

ANF:	Autism Norfolk Forum
ASD:	Autism Spectrum Disorder
ASB:	Autism Service Norfolk
CCG:	Clinical Commissioning Groups
EHCP:	Education, Health and Care Plan
FOIA:	Freedom of Information Act
GDPR:	General Data Protection Regulations
NAP:	Norfolk Autism Partnership
NAPB:	Norfolk Autism Partnership Board
NAS:	National Autistic Society
NCC:	Norfolk County Council
NCH&C:	Norfolk Community Health and Care
N&SFT:	Norfolk and Suffolk Foundation Trust
SEND:	Special Educational Need and Disabilities
UEA:	University of East Anglia
WAW:	World Autism Week
WG:	Working Group
WG Lead:	Working Group Lead

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