

Children and Young People’s Autism Strategy 2021-2026

Minutes from Parent and Carer’s Listening Event – Wednesday 5th October 2022

<u>Part of the Listening Event</u>	<u>Notes</u>
<u>Presentation: Our Vision</u>	<p><u>Age Range:</u></p> <ul style="list-style-type: none"> - Queries on the age range of the strategy, reflecting that Mental Capacity Act applies at age 16, Adulthood is considered at age 18, but the SEN legislation is 0-25. Also noted that the National Autism strategy is all-age. - ACTION: Officers to raise this with Seniors. <p><u>Language:</u></p> <ul style="list-style-type: none"> - The use of person first language raised concerns with some attendees, preferring identity first language ‘autistic person’. Some attendees explained that autism is not an accessory but something that the person is autistic. It was noted that the national autism strategy uses identify first language and it was felt that DCC should align to that. - Emily explained the slides were a draft version, some attendees noted that the slide refers to ‘people with autism’ and ‘children’, there needs to be consistency, as ‘people’ could include adults. Emily noted that the slide should read children and young people, but this relates to the question about the age range of the strategy. <p><u>Our Vision and accompanying bullet points:</u></p> <ul style="list-style-type: none"> - Parents reflected that these should apply to all people and what autistic children and young people need is opportunities when they need them, at the point in their life that is right. <p><u>Development of the Strategy:</u></p> <ul style="list-style-type: none"> - A parent questioned how the strategy had been developed to date and what the purpose of the session was. Officers outlined that the strategy had been developed in 2022 but based on parent feedback there were significant gaps. The development of the strategy was therefore paused to enable engagement with parents and carers. Further engagement will be needed in Torbay and Plymouth and with Children and Young People. -
<u>Presentation: What we think we know</u>	<p><u>Differential Diagnosis:</u></p> <ul style="list-style-type: none"> - Vicky explained what a differential diagnosis is. A parent expressed that a diagnosis is essential to access any support. <p><u>Resource Challenges:</u></p> <ul style="list-style-type: none"> - A parent expressed that there is a lack of therapists and treatments and funding, without these fundamentals a re-drawing of the pathway will not work. Frustration was expressed that from 2018 onwards the pathways have got worse for people. - Officers explained that the introduction of Integrated Care Boards are breaking down the barriers between health and social care, and while that’s in its infancy, it should be beneficial in the future. <p><u>Neurodiversity:</u></p>

	<ul style="list-style-type: none"> - While this today is focusing on an autism strategy, it was expressed that unless the view if on neurodiversity there will not be an understanding of the support needed for autistic people with ADHD as an example. This means that support provided will not meet the needs of the person. Professionals explained that there is a National expectation to have an Autism Strategy and that needs to be delivered, but it has to be meaningful for Devon and in Devon there is a drive to think about neurodiversity and traits. - A parent reflected on the need for a neurodiversity pathway rather than an autism pathway and a separate ADHD pathway. They reflected that for adults you will be put on an internal list for assessment for ADHD or Autism following your initial diagnosis of one or the other, but this doesn't happen for Children and Young People. <p><u>Community:</u></p> <ul style="list-style-type: none"> - Parents reflected that neurotypical people need to adapt and change if we aim for a change for all the community e.g. shopkeepers, cinemas etc.
<p><u>Round up and next steps</u></p>	<p><u>Voice of Children and Young People</u></p> <ul style="list-style-type: none"> - Parents questioned how children and young people would be engaged to co-produce the strategy. Parents had some ideas on how to achieve this. They were asked to submit their ideas via the evaluation for the PCFD will send out after the event. <p><u>Key Messages:</u></p> <ul style="list-style-type: none"> - Should not be restricted to Autism - The strategy needs to be flexible to adapt to changes that might happen e.g. a new national strategy. - The strategy <u>has</u> to be delivered and improvements should not wait for its publication. Officers stressed that improvements are being made now. <p><u>Local Area SEND Inspection:</u></p> <ul style="list-style-type: none"> - Attendees were asked if feedback from today's session could be used to inform the SEND Improvement Plan which has a significant section on autism. All agreed. <p><u>Final Questions:</u></p> <ul style="list-style-type: none"> - What research is being used? Green et al. Families requested that research by autistic people was also used e.g. Dr Luke Beardon - Resources: workforce and money are both a significant challenge. The Safety Valve Project was referenced.