

# Summary of workshop discussions

## National Autistic Taskforce Forum

### 23rd September 2021

#### **High Quality and Effective – The Future of Autism Care**

##### Introduction

The long-delayed forum took place by Zoom for an invited group of 43 participants. The NAT website has videos of the introduction and closing summary by Dr Ian Ragan, plenary presentations by Professor Sara Ryan and Dr Yo Dunn, and interviews of people asked to contribute their views on the ten recommendations of the NAT Guide to Quality Care for Autistic People. These presentations are not summarised here, but this report tries to capture the main points that were raised during the workshops.

##### Recommendation 1 – Respect and Support Autonomy

The concept of “autonomy” is greatly preferred to that of “independence” because of the suspicion that a label of “independence” might be used as an excuse to reduce support particularly these days when resources are so inadequate. No-one is truly independent, and some autistic people do not have enough of a support network for their wellbeing. We all need interdependence.

Gaining autonomy is not trivial – autistic people placed in a stressful environment where they are expected to express their abilities and needs to a service provider may be unable to do themselves justice and are at risk of allowing the person on the other side of the table to make decisions. Autonomy therefore has two aspects. First, autistic people: they need help to develop self-advocacy and decision-making skills. This needs to start in schools and involve parents (even of young adults) to help autistic people to cope with and support their development of autonomy and risk taking. Second, providers: they must recognise that expecting people to do things they struggle with can be very detrimental to their self-confidence. Providers must focus more on a person’s needs and less on outcome measures that do not address these needs, they must respect the right of autistic people to make their own decisions, and understand that support is not incompatible with autonomy. Training is key and greater involvement of autistic people as trainers would be a step forward.

##### Recommendation 2- Support Communication

Communication is the basis of care and therefore any assumption that there is a sector of autistic people who cannot be heard needs to be stopped. The means of communication should always be that which is needed and wanted by the autistic person and the role of the arts in communication and expression can be important. IT can be a powerful aid but provision is very poor in some settings and will always be subject to resource restraint. To do alternative communication well (i.e.

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ensuring that all staff working with an autistic person are fully trained and competent) is extremely expensive and the Autism Strategy funding is derisory. There is a scarcity of speech and language therapists. Whatever communication tools are used, it is important to ensure the availability of communication partners (someone to talk to) and meaningful things to do (because otherwise you do not have anything to talk about). However, there seems little awareness in service provision how changes in communication style can be really helpful.

#### Recommendation 3 – Provide Care that is Autistic Person-Centred

Systemic change is needed. The term “person-centred” is widely used without any clear definition of what it means, risking inconsistency in provision. It can be interpreted as what someone thinks an autistic person needs so terms such as “autistic person-led” might be better and help avoid assumptions about what a “good life” looks like for autistic people. It is really important to change provider mindsets and promote respect for the person’s autistic perspective about what is good for them. However, it should be noted that service providers are sometimes approached only at the last minute to respond to a crisis that is well underway.

#### Recommendation 4 – Tackle Environmental and Other Stressors

While the emphasis of this recommendation is on sensory needs, we should remember that there are other potential stressors such as “other people”, unpredictability and autism-unfriendly buildings.

Recognition of sensory needs is currently inadequate. It is not enough to say that the world is full of sensory stimuli and autistic people just need to get used to it. Sensory overload impairs function and causes distress and people have the right to retreat from that source of distress, so they must have access to a safe environment to recover from sensory overload. People may not know their sensory needs or be able to explain them. If they do, providers need to listen to them and believe their sensory experiences. External expertise from an autistic person who understands sensory needs can help make sense of what a person needs and explain it to providers (see for example the NDTi report on sensory needs in inpatient services and in community housing:

<https://www.ndti.org.uk/resources/publication/supporting-autistic-people-flourishing-at-home-and-beyond-considering-and-meeting-the-sensory-needs-of-autistic-people-in-housing>). There is a lack of understanding that reasonable adjustments need not be expensive or complicated and it is important that realistic expectations are communicated to service providers.

#### Recommendation 5 – Remove Barriers to Access

Discussion focussed on the difficulties both physical and mental that autistic people experience in accessing healthcare. These include using the telephone or grappling with the organisation and planning needed to make and keep appointments. On the other side, the realisation that simple reasonable adjustments (or perhaps “person-led” adjustments) could make a difference is often lacking. There seems to be a culture in service provision of risk aversion or a tendency to assume that theoretical knowledge of autism is sufficient to deal effectively with autistic people. A suggestion was made to turn the NAT Guide into a moderation standard that services could apply for. NAT currently does not have the resources to undertake this alone but is open to discussion.

#### Recommendation 6 – Fight Stigma and Discrimination

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An issue central to fighting stigma is that of “strengths”. While it is essential that we move away from considering only what autistic people cannot do, focusing on their strengths has its own pitfalls. Strengths must be defined in a person-led way and certainly not judged by a person’s earning capacity. In addition, an emphasis on what autistic people can do risks reviving Rain Man thinking and downgrading of support provision. Seeing highly intelligent autistic professionals in the workplace does not necessarily help those with learning difficulties although any platform for the autistic voice is going to be valuable. At a practical level, we need to ensure that commissioners are actually listening in a non-tokenistic way to autistic people reviewing the services they are funding, particularly those who are connected to the wider autistic community. Advocacy must be independent and free from discouragement by employers (cf Winterbourne View). In this, families have important information and need a meaningful platform to contribute. Just saying “listen to families” is not enough. Finally, there is the important and difficult issue of multi-factor discrimination (e.g. being both autistic and black). There is a real need for more engagement from BAME organisations.

When commissioning services, it is vital that contracts require equality, making sure that all services include provision for autistic people as standard. At present, it is not unusual for services e.g. CAMHS, to exclude autistic people and refuse to take on referrals of autistic people. Commissioners must require that services meet autistic needs and do not exclude or discriminate against autistic people.

#### Recommendation 7 – Recognise Behaviour as Stress

Someone commented “this is everything, this is fundamental”. Professionals need to step down from pathologizing language and recognise that “challenging behaviour” (or more correctly “emotional dysregulation”) has become pathologizing in itself. We need to move away from the idea of the person being the problem. As soon as people focus on “behaviour” they are not seeing the needs of the person and lose empathy. As for restraint, this should be seen as failure to provide appropriate support. It would help to have autistic people in the professional team to understand what is going on for an autistic person who is less able to advocate for themselves, and especially to help identify the whispers before the shouting happens. Giving autistic people choice and control applies equally to their choice and control over how much sensory overload they are willing to be subjected to. But in addition, there must be much greater sympathy to the possibility that behaviour may be a result of inappropriate medication for those in institutional care. We should also not ignore that stress in care givers can transactionally affect those in their care (emotional contagion).

#### Recommendation 8 – Ensure Better Transitions throughout the Lifespan

Mishandled transitions for autistic people cause distress and precipitate crises, at a time when financial cutbacks have led to a decrease in specific autism provision to more general care, and reaction to crises. Ongoing specialist social work support, such as having a named social worker, has disappeared and “episodic” care has come in, leading to a real deterioration in planning and continuity for individuals. A particular issue arises for elderly autistic people for whom there seems to be almost nothing in place, no research, plans, accommodation, strategies, or funding. When autistic people make the transition into care homes, their autistic needs become invisible, and they just become an elderly person. There is not a great understanding of this problem but a real need.

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#### Recommendation 9 – Ensure Ongoing, Practical, Autism-specific Staff Training

The worker needs to be more the focus of training, which is not just training about autism but training on how autism affects the person they care for, how to be a good support worker and how to manage their own stress. The best way to achieve this would be if practitioners spent time with a range of autistic people and had ongoing support from a colleague who really understands the issues, such as an autistic person. However, many autistic professionals feel unable to disclose because of the extent of the stigma they may experience. Training, however appropriate, is not enough in itself; it is how it is implemented and supported in practice. It requires follow up training, communities of practice, and regular supervision to embed the training which should include human rights, mental capacity, safeguarding and genuine empathy with autistic perspectives.

#### Recommendation 10 – Accept Difference and Support Positive Autistic Identity

Someone commented that this is the toughest one to tackle with commissioners because of their obsession with outcomes. It requires the service provider to be pragmatic, flexible, and not focussed on “fixing autism”. Autistic staff working in social care services would help provide a more rounded picture of autistic identity.

#### Conclusions

Whichever recommendation was being considered, discussion kept on returning to the same underlying issues of the inadequacy of training and resources for meeting the needs of autistic people. These are the common themes: people don’t listen, and if they do, they struggle to understand, and even when needs are understood, the resources to meet them do not exist.

It was inevitable in a meeting such as this that the focus would be on what is wrong rather than what works. It should not detract from all the genuine efforts that service providers make to enhance the quality of life of autistic people. But good efforts are frustrated by the simple fact that the system is hugely underfunded and unhelpfully focussed on “behaviours” rather than needs and quality of life.