

Dr Anita Z. Goldschmied – Written Evidence (AAC0194)

Introduction

I am Dr Anita Z Goldschmied and I am submitting this brief account of evidence from various perspectives, including the voices of others. I present it as an individual, as other contributors have chosen to remain anonymous. My evidence arises from various roles that are often inseparable. When it is possible and meaningful to note the source, I will do so. While my experience encompasses the full spectrum of autism, this evidence has revealed a particular pattern and group of individuals on whom I will predominantly focus: adults with late diagnoses and aspirations for meaningful everyday activities and life.

1. I am Hungarian-born British who came to the UK in 2009. I received a late diagnosis of autism during my final year of undergraduate studies at the age of 40.
2. I am a learning disability nurse and social worker working predominantly with autistic people and with people with learning disabilities (intellectual disabilities) with and without autism.
3. I have organised focus groups to listen to the voices of autistic people who are not affiliated with any organisations, including autistic people with other autistic family members.
4. Since 2015, I have been a member of Multiagency Autism Groups, delivering on government strategies first in Wolverhampton (2015-2022) and currently in Sheffield (2022-present).
5. Since 2015, I have been actively involved in autism at various levels, including research (both as a researcher and a participant), teaching, projects, events, support groups, and numerous other activities.

Evidence

Initially, we considered your questions separately; however, apart from a few inquiries into actual numbers and statistics, we have found it challenging to separate them, as “all questions feed into another”.

A. *The Autism Act 2009, the Government’s autism strategy and the statutory guidance*

This account reflects my personal experience as a member of various boards and working groups over the past ten years, striving to transform the strategies into pragmatic outcomes. The Autism Act 2009 and the associated strategies indeed ‘forced’ local governments, the NHS, and commissioning groups (CCG, ICB) to take autism into account and develop plans. I have mixed experiences regarding the work and the outcomes.

What went well:

- Autism has become an integral part of the agendas and daily responsibilities of key players (LA, NHS, ICB (previously CCG)). There are boards and subgroups with all associated tasks.
- Autistic people and organisations are increasingly involved in planning and can express their voices.

- There has been a general improvement in diagnosis across all the areas covered by the strategies.

Areas for improvement:

- The voices heard do not reflect the spectrum of autism, nor do they represent the needs of a large group of people, their carers, and families.
- Local Authorities and other authorities are managing autism rather than proactively making a difference. I used the term 'it was forced' on them.
- The previous point is further complicated by autism being a diverse group, with many contradictory needs and voices. The struggle within the community is apparent, as is the officials' inability to navigate it.
- While the initial aim was to support adults, specifically two generations who were overlooked and 'let down', the focus very quickly turned back to children, if it turned away from it at all. The idea that we must prioritise adults has not reached the desired level.
- The strategy is extensive, covering every area of life, with nearly impossible goals and aspirations to achieve. Our delivery plans are lengthy and complex, yielding very few tangible outcomes aside from elements that can be delivered or evidenced as part of other projects. There is a lack of fresh and creative initiatives.
- The signposting began well; that is, councils created a page with information, but to put it bluntly, it is mostly ineffective. There is a lack of ownership, updates, or any meaningful system behind it other than the mandate they were obliged to fulfil. Databases require constant management and promotion.
- We have large meetings that are sometimes patronising, other times about signalling, and rarely meaningful, dominated by individuals employed by the authorities. It is still driven by their interests rather than those of autistic individuals. The Boards, in their current form, are not functioning as well as they should or could.

B. *Health and Social Care*

Autism and its separation from the rest. As a professional with a duty to care for many individuals, not just those with autism, having legislation and strategies focused solely on one condition is very problematic. I often hear people saying, "only Autism has an Act". Groups like Learning Disability, with and without autism, Autism and All Age Autism, have already complicated matters and created confusion, particularly when planning training, campaigns and other activities. At the Board, we also encounter comments like, "Yes, do an Autism Festival but only for people without learning disability; they have their Board and awareness week."

What went well:

- Creating medical categories lies outside the government's purview and is beneficial for diagnoses. It provides individuals with a clearer understanding of their unique profiles, and we require specialised health and social services.
- A single action can speed up processes and bridge gaps, as it is mandatory and well-received in autism. At the end of the day, I likely received my diagnosis over 30 years late due to the Act and the strategies.

- We have improved diagnostic pathways, specialised training and a range of services, among other improvements.

Areas for improvement:

- On the one hand, conditions like autism and learning disabilities include a heterogeneous group of individuals with very diverse needs and abilities; hence the constant 'struggles' and 'fights' at meetings. On the other hand, if allowed to meet and mix, those conditions share many characteristics and experiences. Organising every aspect of life according to pathological medical categories remains a considerable problem.
- Although this call seeks evidence from experts based on experience, it is guided by the same top-down, pathology-led thinking that perpetuates separation and fragmentation.
- We need to reconsider when the pathology should come first and when the experience should take precedence. We have reached the limits of what we can achieve regarding inclusion and progress if we base all our laws, policies, and services on a pathological medical category perspective rather than on activity and experience. It is a significant assumption that issues of loneliness, isolation, or lack of activities can and should be addressed by considering pathological groups instead of through other pragmatic and creative means. This is particularly true for higher-functioning individuals, who, if I had to translate to an IQ, would be 55 upwards.
- I am not convinced that the Autism Act and the strategies should continue in their present forms, especially since both diagnostic manuals (APA, ICD) from 2013 and 2017 allow for the dual diagnosis of Autism and ADHD. This is another significant topic and issue that I will not be able to expand upon here, but it must be taken into account.

C. *Evidence about autistic people and what they need*

Autistic people's experience, predominantly adults who receive a late diagnosis, typically between the ages of 25 and 60. This account also includes my personal experiences.

What went well:

- Finally receiving the diagnosis and a clearer picture brings some relief, answers and new opportunities.
- Enhanced awareness and reasonable adjustments in certain areas.
- Numerous organisations and charities are trying to do some good work.
- There is much better signposting.

Areas for improvement:

- The lack of post-diagnostic support, aside from perhaps a GP and other follow-ups, is concerning. Additionally, as individuals transition to adult life, services and support tend to diminish. The few that do exist usually come from non-governmental organisations, often established by

individuals affected by autism, either as autistic individuals or as family members of those who are autistic. Whilst they do their best, they do not cater to 'higher' functioning people as diversely as the rest of the autistic community.

- Females remain more misunderstood, as much of our tools and understanding are based on autistic males.
- There seems to be a gap for autistic people who do not wish to embrace the autistic identity and be identified as autistic persons in every area of their life, yet want to get on with their autistic lives.
- Building on the previous point, isolation and the need to connect with like-minded individuals—where connection is not necessarily rooted in the pathological medical condition of autism—remain significant issues. The group of autistic individuals who wish for a fulfilling life are often too quiet to ask for support or seize opportunities from others, particularly those with greater needs. They struggle to advocate for themselves, which leads to increased feelings of withdrawal. Moreover, they are disproportionately affected by the internal struggles of the autistic community, with changes in benefits and supports resulting in losses on all fronts.
- Finding and keeping a job alongside loneliness is a priority for many individuals with autism who aspire to lead fulfilling lives. Our success largely depends on the managers and leaders we encounter, as well as their understanding and attitudes towards autistic individuals. Many of us have previously lost jobs, despite working diligently, due to the person in charge who either failed or refused to engage with us. This extends to so-called diversity and equality heads and experts. While autism can present challenges, it often proves to be immensely rewarding when initial efforts are invested.
- Most of us with late diagnoses overwhelmingly share the sentiment that we are uncertain whether an earlier diagnosis would have been better or made a positive difference. Speaking from personal experience, I feel I am resilient and very skilled because I was not given a 'green card' at an early age to use as an excuse for anything I am unable to do or do not wish to do. While the two do not have to come together, unfortunately, it often does, and this does not help autistic children and young people develop skills. The impact of unfair treatment on my mental health did not appear to change with the diagnosis. What changed is the narrative, but not the influence of workplace challenges on my mental health.
- The individuals I spoke to were neither students nor board members, and they did not belong to any organisations. I believe they represent a large number of autistic individuals, and then the few vocal ones are the minorities. There seems to be a significant gap in our understanding of their needs. Their voices remain unheard.

D. *The Government's priorities*

Other general comments addressing key areas that frequently arise in all forums and discussions regarding autism.

Reasonable adjustment

- Universities and workplaces have embraced a universal approach that has devolved into a mere tick-box exercise. Non-universal does not refer to pathological medical conditions but rather to individual needs.

- It appears that funds and resources are in place; however, in practice, they seldom function effectively. Moreover, there is no evidence of how these are followed up or whether they are effective. The number of people responding to surveys is minimal and they represent a specific group. For instance, many autistic individuals find interviews challenging and struggle to demonstrate their talents. Yet, a 10-minute interview remains the primary access point to jobs and training.
- A lack of clear guidance, expectations, and consequences.
- Rigid systems that lack a shared best practice and creativity

Public understanding and acceptance

- Whilst most people felt that the public attitude needed improving, no tangible ideas emerged on how to achieve this. The press does not help with its sensational articles especially when they feature headlines like "Everyone is autistic" or "What an autistic savant has achieved". It seems that the more this is pushed onto people, the greater the resistance and negative effects we experience.
- The current political climate and stark divisions do not help, as people often prioritise their ideology over the needs of autistic individuals. This is not the first time a voiceless group has been sacrificed for political reasons; the same applies to individuals with learning disabilities. For example, we do not offer a wide range of living options, such as large homes, remote gated communities, and apartments, because some have decided on behalf of others that many of these options are incompatible with their ideology. Most of our actions remain top-down, with autistic involvement often remaining symbolic and tokenistic.
- Social media was mentioned frequently, underscoring the divide. There are also some valuable support groups that people find helpful. Many of the conversations there appear to reflect the climate of the autistic community, the broader societal division, and the challenges they face rather well.
- The recent pick-up on the word and movement of neurodiversity seems to have had a further negative effect on the autistic community. This is expected when we must give 15 minutes of fame to all those individual pathological medical conditions and various other groups. Organisations operate from a checklist of the days and weeks they need to fit into a calendar, ticking one off and moving to the next. I was informed that the Autism Festival organised with the council cannot be advertised because just two weeks ago, we had substantial coverage for Neurodiversity Week. This only changed when I appeared on television and radio with a councillor. Autism Day and week take place in early April, while Neurodiversity Week coincidentally falls at the end of March. One wonders whether other conditions, primarily dyslexia and ADHD, have deliberately 'hijacked' Autism Day. This, in itself, should suffice to prompt a reconsideration of my earlier points on pathological condition-led thinking, conflicts within and between disabled communities and actions. Most of the activities presented by the authorities during autism month were no different from the mandatory training and activities they typically conduct anyway. Refer to previous comments on the Boards as well.

Who is truly autistic, genuinely autistic, and more autistic enough to speak up?

- As hinted earlier, the competition is on who represents autistic people on boards, in meetings, etc. This also emerges as an issue in everyday life. For instance, autistic parents often compare their children to other autistic individuals. When such parents and autistic people occupy roles as managers, team members, heads of disability, or lecturers, it can have significant adverse effects on other autistic people who do not conform to their expectations and aspirations. This also happens as a result of training creating 'autism experts'.
- For instance and referring back to the authorities' inability to navigate the autistic community, I observed how a woman of 60 years old, who was diagnosed late, was eventually pressured off the board by younger autistic individuals who disagreed on who should be recognised as autistic.
- I am concerned that this call for evidence will not reach a group of individuals who should share their stories with us. I only managed to contact a dozen people who would not have heard about this call otherwise. Based on my experience, I am wary of trusting some non-profit organisations' claims regarding the size of the population they serve. Many of them focus heavily on ideological debates about language or models, for instance, while avoiding actual pragmatic actions and engaging meaningfully with no more than 10-20% of their mailing list.
- How often have we all heard phrases like "this is my autistic experience, so you are wrong", ironically, the total lack of or unwillingness to see other perspectives.

Training

- A top-down approach to managing autistic people, box standard PowerPoint presentations, and awareness-raising efforts aim to showcase diversity but achieve the opposite effect, creating numerous experts simply because they have attended a three-hour presentation. Similar to public awareness campaigns and sensational articles, these methods tend to have an inverse negative impact.
- Most of our tools convey an impression of autism, a rather rigid, old-fashioned version of it. If you do not fit the mould, you are dismissed.
- Whilst most are familiar with the slogan that if you meet one autistic person, you meet one autistic person, we still struggle to put this into practice. We currently lack the tools or, rather, we are reluctant to pursue solutions that seek to simplify and categorise, but not in outdated, tired frameworks. Ultimately, someone's voice and ideology frequently overshadow individual needs. A recent example is the Oliver McGowan training, which, as commendable as it is that we have finally reached this point, underscores the unfortunate reality that few voices have significantly influenced what we actually teach and how, once again, missing opportunities.

Summary

Overall, the Autism Act and its strategies appear to deliver some justice for autistic individuals, particularly for those generations who grew up believing they were 'bad kids' and felt that the failures they faced in school and employment were solely their fault. However, after 15 years, the limitations are also evident. Autism has lost direction and purpose. It no longer knows what it is and what it does. Escalation, separation, and ever more fragmentation is among its effects,

not only outside the autistic community but now within it as well. Whether it should continue and how, I do not know. But unless we begin working with communities, events and activities that are not organised around pathological medical conditions but instead embrace the myriad aspirations and hopes we humans possess, it will fail to meet our aims and continue to deteriorate. I have begun exploring the concept of Joy in pursuit of something greater than narrowly defined ideologies, which may provide us with a renewed opportunity to reconnect and piece together what is currently more fragmented, separated and divided than ever before. The people who truly pay the price for this are those whose voices will remain unheard. When being disabled, autistic and neurodiverse etc. becomes something people strive for, are proud of, and compete over, we know there is a problem. I am autistic. It is neither my making nor my choice. I am neither proud of it nor do I identify with it. All I know is that there is nothing sexy, funky, or cool about it. It is what it is, and I must get the most out of life, keeping in mind that another 67 million Brits and 10 billion other human beings want exactly the same. Unless we find new ways of negotiating and reestablishing a level of common sense, the status quo will remain.

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