

An Open Letter to The Royal College of Speech and Language Therapists (RCSLT)

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Thank you!

Thank you so much for downloading this pdf version; we are so grateful.

It was originally published online on 06 July 2023, but we know that sometimes having something to print is easier than reading online!

Introduction

The Royal College of Speech and Language Therapists (RCSLT) are updating their Autism Guidance for Speech and Language Therapists (SLTs). Speech and Language Therapists and the public were given the opportunity to comment on the draft guidance earlier this year. The guidance is due to be published in September.

A collective of speech and language therapists, Autistic professionals, academics, advocates, and allies wrote to the RCSLT directly, expressing concern and disappointment about the content of the proposed guidance. The copy of this letter outlines our concerns and provides suggestions for autistic-affirming and neurodiversity-affirming Speech and Language Therapy.

The response from RCSLT is also included for you.

Your comments

We welcome further conversations on this important guidance and are very grateful you have downloaded the information; **PLEASE SHARE IT!**

Please take it to team meetings, give to colleagues, email it to other SLTs you know.

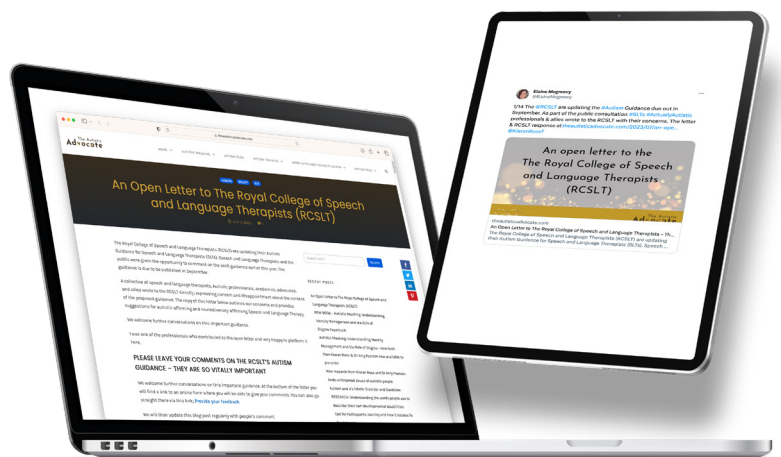
So far the blog post has had over 4000 hits and our Twitter post has reached over 112,000 people.

You can really help us make sure the RCLST takes notice, and action, by;

Visiting the original blog post (so that the clicks keep on growing and the RCSLT know this issue isn't going away); <https://theautisticadvocate.com/2023/07/an-open-letter-to-the-royal-college-of-speech-and-language-therapists/>

Sharing our tweets (on Twitter find <https://twitter.com/ElaineMcGreevy> and Elaine's [tweet about the letter on 07 July 2023](#)) so that we reach 200,000 people.

And leaving us your comments so that the RCSLT can really understand what SLT's are thinking (**this is vitally important**).



An open letter to the Royal College of Speech and Language Therapists in response to the public survey on the draft Autism Guidance (26 May 2023)

We are writing as concerned Speech and Language Therapists, Autistic professionals, researchers and allies, regarding the latest RCSLT draft Autism Guidance for consultation. We collectively represent a breadth and depth of expertise in this field, with many of us recognised as leading professionals within our respective areas of professional, academic, voluntary and advocacy work. In keeping with a growing awareness of the value of co-design and co-production with neurodivergent experts, we hope that you will invite further collaborations regarding the final version of the Autism Guidance so that it accurately reflects the needs and experiences of Autistic people and truly embraces the Neurodiversity Paradigm in SLT practice.

As you are aware, there were many public comments about this second draft on social media when this was shared at the beginning of May. This came both from SLT professionals and non-SLTs, as well as a large number of comments from the Autistic community and its allies. These views, overwhelmingly, shared dismay, disappointment, frustration, and anger about the nature of much of the revised content.

While we recognise some edits were made following the first draft of the Autism Guidance and note some improvements to the guidance as a result, we share those concerns and the distress of the Autistic community and colleagues. We outline those concerns below.

Despite some clear intentions to reflect a more neurodiversity-informed approach to SLT support for Autistic individuals, in our view, this document represents “Neurodiversity-Lite”. Neurodiversity-lite described by Shain Numeier ([2018](#)) as, “when neurotypical people, who either use the language of the movement in good faith or intentionally co-opt it, undermine its work by overlooking or outright contradicting its core concepts, including bodily autonomy and basic dignity. If anything, such inauthentic trappings of neurodiversity can allow charities, service providers, and caregivers to effectively disguise ableist stereotypes and harmful practices for audiences that aren’t aware of or attuned to them.” We would, therefore, urge RCSLT to carefully consider our concerns and suggestions to avoid these pitfalls.

For an organisation purporting to be neurodiversity-affirming, some of the language used in this document is not in line with this e.g., use of the terms ‘neurodevelopmental condition’ and ‘spectrum condition’. Please refer to this [Bottema-Beutel et al \(2020\)](#) as a guide. [NHS England](#) has also a helpful resource on language. In addition, the description of Autism as a spectrum and also as a wheel is confusing as one description negates the other. The wheel analogy would be more useful, in our view.

There are underlying tones of ableism throughout the document e.g. ‘employment is a desirable outcome’, ‘0.6 – 1 in 100 people having autism’. Furthermore, recommendations for interventions

aligned with a deficit model and reductionist approaches, e.g. [PACT](#). Interventions which have neuronormative goals, such as within the More Than Words programme do not align with neurodivergence-informed therapy [Chapman & Botha \(2022\)](#). These authors make the case for a “focus on neurodivergent flourishing rather than normalisation.”

Prevalence figures

Statistics on autism prevalence are notoriously varied, and the statement in the document about prevalence does not reflect this variation. Indeed, there is also some confusion in the document on whether Autistic people are considered a neuro-minority or whether autism is considered to be relatively widespread. Local statistics have not been included, such as the Scottish population statistics that show 15% of Autistic people have a learning disability ([Kinneer et al 2020](#)). The document cites a world-wide estimate of 0.6 – 1 in 100 (Salari et al 2022; Zeidan et al 2022). Other figures are important to be aware of such as the [CDC](#) figures indicate a prevalence of 1 in 36. [Northern Ireland statistics](#) show 1 in 20 school children are Autistic.

Regarding the Autistic people in Employment figures, these are flawed as in fact there are a number of estimations of these. These statistics are presented as a fact in the document without any caveat into explanations regarding the limitations of these figures.

Contemporary evidence base for neurodivergent-affirming SLT

The disappointing lack of neurodivergent-affirming research cited in the document is incongruent with the RCSLT opening statement regarding aspirations for a neurodiversity-affirming model. There is insufficient understanding of neuro-cultural differences. There is a brief reference to Double Empathy Theory (DET) and Monotropism Theory, but the impact of these theories on both the Autistic and non-autistic population is insufficiently reflected, as exemplified by the statement, “many Autistic people find certain theories i.e. the double empathy problem (Milton 2012) and monotropism (Murray, Lesser & Lawson; 2005), helpful when considering their own diagnosis.” This statement overlooks that these two theories more accurately explain Autistic experiences in a non-pathologising way, guide our support of the person, address the transactional nature of communication difficulties, and they are increasingly evidenced by empirical research. These theories along with the growing evidence base of the [Diversity in Social Intelligence](#) and the work of Professor Noah Sasson and colleagues (e.g. [Sasson et al 2017](#)) are core to the work of neurodivergent-affirming Speech and Language Therapists. This has not been explored in the guidance.

Here are some examples of the application to SLT: The DET underscores the importance of recognising the mutual misunderstandings that can occur between Autistic and non-autistic people ([Crompton et al., 2021](#)), and so it is important for a non-autistic SLT to be aware their own capacity for misunderstandings and assumptions about e.g. lack of cognition. The work of [Wood \(2018\)](#) is highly relevant for SLTs and highlights this phenomenon. Further research by [Wood \(2019\)](#) looked at incorporating the Autistic student’s interests to capitalise on their monotropic cognitive style, highlighting how this enabled their communication (and well-being etc.) See also [Pavlopoulou, \(2020\)](#), [Phung et al., \(2021\)](#). There is also empirical research on the social benefits of shared interests (noting in particular that these are Autistic modes of sociality) e.g. [Heasman & Gillespie \(2019\)](#).

We would suggest a complete rewrite of the paragraph referring to Double Empathy Problem and Monotropism, taking into account the broader applications of these theories, the evidence base, and their relevance to tailored SLT support for Autistic individuals. See [Monotropism](#) for a central resource. Such information would constitute vital guidance for SLTs and so we urge the RCSLT to demonstrate a greater understanding of the importance of these theories. It is our opinion that SLTs should have knowledge of Critical Autism Studies and we would hope to see the guidance leading on this.

PECS: a behaviourally-based requesting system

The value of listening to and valuing a diversity of Autistic experience needs to be emphasised, and on an ongoing basis. [Chapman & Botha \(2022\)](#) argue for a ‘standpoint epistemology’ in neurodivergence-informed therapy, with those closest to an experience having the greatest access to the knowledge around that experience. In their view, the focus of therapy should not be on ‘remediation, prevention and cure’, but instead on the exploration of neurodivergent pride and the relational impact of environments; it is not only sensory environments that can disable, but also stigma, discrimination and victimisation. A case in point is the apparent disregard for many voices in the Autistic community, Autistic professionals, and Autistic and non-autistic SLTs who advocate for a rejection of the use of PECS as a form of AAC due to its inherent limitations and behaviourist underpinnings. See [here](#) for a good summary of the problems with PECS. The paragraph relating to AAC suggests that PECS is useful for an Autistic person who can’t initiate communication. This recommendation highlights a lack of understanding of Autistic communication. There is significant concern that RCSLT have not understood the inherent harms or limitations within this method. This approach causes distress to many of us.

The need to consult with non-speaking Autistic people

SLTs find themselves working with a significant number of Autistic children and adults who are non-speaking. Autistic advocacy organisations such as [CommunicationFIRST](#), [Communication4All](#), [Zekwande Foundation](#), [NeuroClastic](#), and [Autistic Strategies Network](#), working directly with non-speaking Autistic people ask that professional bodies and researchers seek input and ongoing guidance directly from non-speakers, especially those who have motor disinhibition difficulties or apraxia which underlies their significant communication difficulties, described here by [Ido Kedar](#), “..it means I can’t get my body to do what I want it to do, when I want it to, with reliability and consistency. This is entrapment. It is not receptive and expressive language confusion, and most definitely not a lack of thought, emotions and awareness. In my opinion, this is like a paralysis of intentional responses. When it comes to self-stimulatory behavior, I often cannot get my body to stop moving to its internal impulses though I may desperately want it to, and at other times, such as when I lie in bed unable to move to my desire to pull on another blanket, I cannot get my body to listen to me at all.”

As we cannot represent the needs, views and experiences of non-speaking Autistic people, we ask that RCSLT hears directly from an advisory group of leading non-speaking Autistic advocates.

Gestalt language processing

We would ask the RCSLT to consider including guidance on gestalt language processing and the evidence base for the Natural Language Acquisition Pathway. [Here](#) is a summary of the evidence. The complete history, research and resources are available at [Communication Development Center](#).

Autistic masking

Masking and stigma are at the core of autistic experience. ([Chapman et al., 2022](#)) describe masking as “emotionally and psychologically rooted, which develops partially subconsciously within a social-environmental context. Participants described masking less as a choice or decision, but more as an anxiety-driven response to others’ behaviour and attitudes towards them, or to uncomfortable and inhospitable environments... masking is a response to not being accepted by the neurotypical world (Pearson & Rose, 2021).”

The lack of understanding of Autistic masking in the document is a major concern. The following guidance highlights this: “support an autistic person in social understanding work if this is something they want to engage in – both in anticipation of planned social interactions and reflecting on past social experiences, encouraging self-advocacy rather than masking.”

This recommendation fails to highlight the multi-faceted aspects of masking, which for many Autistic people is compounded by the impact of trauma, and of multiple intersecting stigmatised identities ([Botha & Frost, 2020](#)) The guidance is unclear on how the SLT would proceed, but the wording appears to legitimise teaching social skills, “if they want to engage,” without consideration of the longer term consequences of masking on mental health, development of self-image and identity. “..camouflaging autistic traits is associated with increased risk of experiencing thwarted belongingness and lifetime suicidality.” ([Cassidy et al., 2020](#)) We believe the guidance does not address the limitations and potential harms of teaching social skills and social scripting. If the SLT takes this approach, this will increase vulnerability for an Autistic person who has likely absorbed deficit-based narratives about themselves across their life. In essence, SLTs could be setting an Autistic person up to fail or to just continue to feel like they are in the wrong.

Secondly, there is minimal guidance on how to address masking and unmasking safely. The complexities of this area needs to be made clear, especially in relation to issues relating to a person’s race, gender identity and culture. Developing self-advocacy skills helps a person tap into their authentic self, helps them prioritise their needs, and eventually, they may be able to express those needs and boundaries. This is merely one aspect of supporting an Autistic person who masks. An Autistic person can’t be encouraged to unmask, if they haven’t been supported to build self-knowledge and if they are in hostile and unsafe environments. [Chapman et al., 2022](#) cite Thomas (2020) who “compares neurodivergent masking to the Finding Nemo character Dory’s strategy to ‘just keep swimming’ and concludes that, ‘No amount of swimming... [is] enough if the world will not also adjust to meet you’.” ([Chapman et al., 2022](#))

In summary, we need to show a sensitive understanding of an individual’s Autistic identity, as well as gain their insights into the impact for them of the wider environment (physical, social and cultural), rather than focus on unmasking as an objective. In short, we need to understand that “Autism + Environment = Outcome” ([Beardon, 2019](#)). This concept is again largely missing from the narrative in

the current document.

The potential for harm and increasing vulnerability is real. We ask that the RCSLT pause, review, and seek expert advice from Autistic professionals before publishing the guidance. We ask that the RCSLT consult with renowned experts, Kieran Rose, The Autistic Advocate, and Dr Amy Pearson, Developmental Psychologist, authors of some of the papers cited above, and the upcoming highly anticipated book: [Autistic Masking: Understanding Identity Management and the Role of Stigma](#).

The SLT as an expert, deciding “best interest”

The following pieces of guidance are a concern:

“Speech and language therapists can support the teaching of specific language and communication skills: • when it is in the Autistic person’s best interest, enhances quality of life and/or reduces risk. • when an Autistic person asks them to.”

“We have suggested that speech and language therapists can consider social skills training, PBS and PECS if it is in the best interest of a particular individual, enhances quality of life and reduces risk.”

We believe that the wording here, positions the SLT as an “expert” in deciding when it is in the “best interest” of an Autistic person to receive behaviourally based or neuronormative social skills training: the risks and harms of which we have outlined already. These statements suggest that the SLT knows best and can impose therapies which are not compatible with neurodivergent-affirming care. This expert positioning is something that sits uncomfortably with us. This recommendation erodes the espoused principles of neurodivergent-affirming and person-led care and negates neurodivergence-informed therapeutic practice [Chapman & Botha \(2022\)](#)

PBS has a very poor evidence base [Hassiotis et al \(2018\)](#) and according to Gore et al ([2022](#)) PBS is “...not intended for persons identifying as neurodivergent who do not have a learning disability.” The document has not addressed this evidence at all. PBS is an approach that uses ABA and we argue that it is not appropriate or safe for any Autistic person. There is much [evidence](#) to support our position. The Oireachtas Joint Committee on Disability Matters concluded that such behavioural interventions, “cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment.” [Aligning Disability Services with the United Nations Convention on the Rights of Persons with Disabilities \(oireachtas.ie\)](#) (paragraphs 58 - 60). [Ethical Standards and Guidance](#) (Autistic Self-Advocacy Network, 2021, p 22 - 28) is highly relevant for SLTs working in Autism services.

The drivers that lead Autistic people and their families/ carers to sometimes to seek out or accept ableist therapy such as ‘social skills training,’ PBS, and PECS interventions are complex. It is important for us to hear and acknowledge individual perspectives and preferences, however, to not clarify the potential for harm, clearly documented in ethically-driven research into these interventions summarised above, poses a clear risk to both therapists and the individuals we support. These interventions furthermore firmly sit within the medical model framework. We need to make it clear how neurodivergent-affirming support is different e.g. [AutisticSLT.com](#), [Therapist Neurodiversity Collective](#). This is another area that is insufficiently covered in the current document in our view.

Lack of inclusion, social justice, and equality

The guidance is minimal in terms of recognition of the impact of intersectionality. There is little reference to the needs of and considerations for Autistic people who are Black, People of Colour, ethnic minorities such as those from the Travelling community, and Trans people, nor the specific and changing needs of Autistic people across the [life span](#). This lack of attention to the impact of multiple marginalisation is a further weakness of the guidance. It is important that we take steps to address the dynamics of power and privilege when we consider the needs and experiences of Autistic people with varied and layered intersectional identities, who will be more likely to experience oppression and marginalisation in healthcare services, including SLT services. The contents of the current draft Autism guidance, as evidenced in this letter, represent a distinct lack of inclusion, social justice, and equality and exemplify how racist and ableist practice continues to exist through omission of racialised experiences. Indeed, the suggestions for good practice in this guide directly conflict with the ethics and morals demonstrated by the [board](#) of RCSLT, and we would like this disparity clearly explained.

Our colleague, Emily Price (Lees), also a signatory of this letter, was a supporting author for the Autism guidance, however, she had to withdraw because her views as an informed Autistic Speech and Language Therapist were dismissed by the leadership. Emily had expressed many of the concerns that are raised in this letter and she was not heard. Emily had previously written an article for the Bulletin regarding neurodivergent-affirming Speech and Language Therapy.

While we understand (but do not agree with for reasons of accessibility) the RCSLT's wishes to keep this consultation behind closed doors, for reasons of clarity and open discussion, the contents of this letter will also be published openly by us, in order to be inclusive to the many deeply concerned stakeholders who declared their concern via social media, but whose views will not be taken into account.

Recommendations

There is so much value that Speech and Language Therapy can offer Autistic individuals and the Autistic community. For example, the SLT role in facilitating equitable clinical services at all points of access and care, summarised using the acronym 'SPACE' in [Doherty et al \(2023\)](#) sets out how to meet 5 Autistic core needs in healthcare. Many of these elements are either missing or unclear in the current guidance. Given the substantial public opinion, and our feedback as summarised, we ask, that in order to ensure the guidelines are neurodivergent-affirming and take a human rights approach:

- The document be redrafted in light of our concerns and suggestions.
- Recognised Autistic specialist professional stakeholders, Autistic advocates and Autistic SLTs, are involved in co-producing the guidance. "Acknowledging Autistic people as the key stakeholders is an essential and fundamental step forward." Pukki et al (2022)
- Autistic-led documents are included as key frameworks such as [An independent guide to quality care for autistic people – National Autistic Taskforce](#) could be considered as a framework of support to complement the RCSLT 5 Good Communication Standards. See also [More than Words: Supporting Effective Communication with Autistic people in health care settings](#)

While this guidance is for and by Speech and Language Therapists, it is imperative to reflect on the

fact that Speech and Language Therapy does not exist in a vacuum. To prevent this guidance being an echo chamber of Speech and Language professional thought and to ensure that the profession meets the actual needs of the Autistic people, cross-field input and, more importantly, the input of Autistic specialist professional stakeholders, beyond tokenistic representation is vital. Involving a majority authorship from the Autistic community, and from within the SLT membership, from the outset would be preferable. “Autistic people must be involved in all decision-making that stands to affect Autistic people, from the highest levels of policy development to individual support planning; that is, they ‘deserve a full seat at the main table’ (Gernsbacher, 2007, p. 13). With this in mind, neurodiversity advocates assert that autism research and practice must be brought into line with the needs and priorities of the Autistic and autism communities.... (Milton, 2014b; Raymaker, 2020; Robertson, 2010).” ([Pellicano & den Houting, 2021](#))

We have an opportunity here to take a lead within health care, and for the SLT profession, both nationally and globally, on delivering ethical, neurodivergent-affirming support for Autistic individuals. Let’s not waste this opportunity. We want to see the RCSLT produce a robust document that is respectful and inclusive, one that can be a template for future policies on other neurodivergence going forward.

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This letter was also prepared with input from Dr Rebecca Wood of the University of Glasgow, and Kieran Rose, Consultant and Academic Researcher.

Response to open letter about the draft RCSLT autism guidance consultation.



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Response to open letter about the draft RCSLT autism guidance consultation

From the RCSLT autism guidance project working group 20th June 2023

We are grateful for the feedback provided in the letter dated 26th May 2023 and for the engagement with the consultation by RCSLT members and other stakeholders. The letter was shared with the project working group and the feedback was discussed when the group met on 7th June 2023.

The guidance is being developed by a working group of experts in line with RCSLT processes. However, this is the first time that RCSLT guidance has been co-produced. We would like to thank Emily Price (Lees) for her valued and welcomed input during the scoping phase of the project. When Emily left the group in December 2021 we were in the early stages of planning and organising the content. As a result of her feedback, the RCSLT took the decision to fully co-produce the work.

The project working group includes autistic professionals, autistic adults with service experience, and advocates for autistic people, including those advocating for autistic people with additional support needs. Recruitment for speech and language therapists (SLTs) did not require individuals to disclose whether they were autistic themselves or have autistic family members.

There is a breadth of experience and perspectives in the working group (as well as the wider project reference group) which includes all ages and wide-ranging experience of service delivery in a variety of settings, and across the four nations of the UK. In addition, both consultations were shared through various autism charities and organisations to reach as broad a range of people as possible and to hear different viewpoints.

We would like to reiterate the purpose of the two consultations. The first consultation in March was on draft guidance for SLTs, and the most recent consultation in May was on separate draft information for the general public. The draft shared in May was not a revision of the draft guidance shared in March. This was explained in both consultation surveys and related communications.

The guidance (both the SLT guidance and the public information) is now being revised based on feedback provided during the consultations. The working group has worked hard to listen to all viewpoints and develop information that is neurodiversity-affirming, balanced and representative of the wide-ranging needs of the autistic population. We recognise that there will be parts of the guidance that not all stakeholders agree with, and decisions have been made based on consensus and majority views where necessary. We have noted and considered the feedback about the drafts, including on social media. However, in both consultation surveys (which had 272 responses and 236 responses) there was majority agreement with all sections of both drafts – ranging from 83% to 100% for the SLT guidance, and from 76% to 92% for the public information.

The guidance will be updated based on the feedback received and we would like to thank everybody who took the time to provide this. We hope that the final published information will be a useful

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resource for SLTs, providing guidance on evidence-based practice and encouraging critical thinking and self-reflection, as well as providing information for the public about the important role of speech and language therapy in autism.

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If you want to be able to download a copy of the response you can do this on the original blog post.

YOUR COMMENTS ON THE RCSLT'S DRAFT AUTISM GUIDANCE

Your comments are vitally important and so please do leave your own thoughts (you can do this on the original blog post) or by [clicking here](#). Please ask your colleagues to leave their own comments.

"As a Highly Specialised Speech and Language Therapist and the parent of autistic child, I fully support this letter."

"As Head of the Specialist Teaching, Advisory and Resources Service (STARS) we support hearing and/or vision for those aged 0-25y. We would welcome consideration of Autistic children and young people with coexisting non-typical levels of hearing and or vision the arising complexities associated when attempting to follow guidance designed for all people with typical levels of hearing and/or vision."

"Absolutely agree with the response sent to the consultation in the open letter. What was the point of rcslt asking if they were going to completely ignore it! Thank you for doing this."

"I'm an autistic lecturer and I teach on a BSc Speech and Language Therapy programme. I applaud the signatories and authors! If I can help with this effort let me know - I'd be very happy to be involved."

"It is time for the RCSLT to respect & acknowledge their ND members & the clients & families we work with. They merely provide a tick-in-the-box response to any challenges relating to the equality of ND individuals. This needs to change. I am a member of the RCSLT, but as an autistic SLT, the RCSLT does not represent me as they refuse to make real change."

"I fully support the content of this letter both in my professional capacity as an SLT and personal capacity as mother of an autistic child. Please RCSLT listen and adapt accordingly."

"Please listen to autistic people. I was told my non speaking child wasn't ready for an AAC iPad device by a speech therapist, thankfully I didn't listen and went with my autistic instinct. My child can now communicate. There are no prerequisites for AAC devices. The fundamental mindset should always be presume competence. It's time now to listen to us."