

Report containing the responses to our survey to Ascertain the Expectations and Needs of the Autistic Community re: the Content and Delivery of the Oliver McGowan Mandatory Learning Disability and Autism Training for All Health and Social Care Staff

Introduction

Autistic UK is an Autistic-led Community Interest Company, with 6/7 of our Directors being Autistic (many with additional neurodivergences) and 1 being otherwise neurodivergent.

While we welcome the news that mandatory training is being introduced to ensure Autistic people’s and Learning Disabled people’s needs would be met within healthcare services, we share the concern expressed by our community on social media in the reported implementation. The [statement written by two of our Autistic directors](#) highlights our position.

As a result, we launched the first in what will be a series of surveys regarding this training to ensure that our community’s voice is heard. This report has been written using the answers received.

Demographics

While Autistic UK seeks to uphold the views of the Autistic community, the survey was open to Autistic individuals, Learning Disabled individuals, parent/carers, and professionals. As the social media reaction to the training announcement was markedly different depending on the individual’s demographic, we were interested to see if this would translate into our results.

We had a total of 92 respondents, however there was a drop-off due to the length of the survey (which has been noted for future requests) and the total number of people who completed the survey was 66.

The following tables contains details of the demographics:

Answer Choices	Responses	
Autistic	82.61%	76
Learning Disabled	6.52%	6
Otherwise Neurodivergent	29.35%	27
Neurotypical	1.09%	1
A Parent/Carer of an Autistic Person	41.30%	38
A Parent/Carer of a Person with Learning Disabilities	4.35%	4
A Parent/Carer of a Person with Other Neurodivergencies	16.30%	15
An Autism Professional	13.04%	12
A Learning Disability Professional	5.43%	5
A NHS Professional	3.26%	3
A Local Authority Professional	3.26%	3
A Care Sector Manager/Worker	4.35%	4

A Care Service Provider	2.17%	2
Other (please specify)	14.13%	13
Answered		92

Responses to 'other':

Other (please specify)
I may be autistic
Community leader
I am an autistic advocate running my own project
I'm both the parent of two autistic sons and a professional who supports autistic adults
Elected councillor
Self-diagnosed autistic, looking to be referred for ASC diagnosis
Early childhood development educator
Might be autistic
Possibly autistic
A happily married autistic person married to another autistic person for over thirty years - I am his carer because he has physical disabilities and not because of him being autistic. I am the parent of an adult autistic person and he is also well adjusted and married and both my husband and son run their own businesses. I say this not to boast but because I think it is important to bear in mind that while being autistic is always going to add a layer of difficulty to a person's life that is mainly because of the way the world is set up and some of us are able to 'pass' in society and appear successful etc but eventually the strain of masking takes its toll in such things as high blood pressure and comfort eating etc.
Supervisor (primary school)
Developmental Psychology student
A museum educator with an interest in SEND, married to an autistic person

As we are an Autistic-led organisation, many of our followers are Autistic. Therefore, it is unsurprising that Autistic people are highly represented in the respondents to this survey. This is a unique position, as many surveys conducted by parent-led autism organisations will have an overrepresentation of parent/carers and professionals.

We are pleased to have received responses from six people who identify as Learning Disabled, however as the training contains an autism element and a learning disability element, we will endeavour to gain more responses from the Learning Disabled community in future surveys to ensure their community is fairly represented.

A high percentage of our respondents identify as female (67.47%), however we had responses from a range of genders, including agender, non-binary, and genderqueer. This is particularly important in surveys which discuss the needs of Autistic people, as Autistic people are highly represented within these demographics.

Our respondents ranged in age from 13-17 bracket through to 65+. Most respondents sat within the 35-44 and the 45-54 age brackets both when filtered for Autistic respondents and all respondents, whereas the majority of

Learning Disabled respondents sat within the 55-64 age bracket. We highlight this as there is a tendency within neurotypical society to infantilise both Autistic and Learning Disabled people, and there is still a significant number of people who believe autism is something you “grow out of”. Our figures demonstrate that Autistic and Learning Disabled people over the age of 35 want to share their opinions and expertise, yet they are not often given a seat at the table.

We would have liked to have received more responses from the BAME communities, however we have been informed that there is a lot of (understandable) mistrust due to the way their communities are treated. It is worth considering that as a trusted Autistic-led company that as we struggle to obtain a good number of responses, it is likely that any consultations arranged by parent-led organisations and healthcare providers themselves are likely to have even less BAME representation. Autistic UK will work with these underrepresented communities to ensure their voices are heard – we suggest you do the same.

Answer Choices	Responses	
White British	48.19%	40
White Welsh	4.82%	4
White Northern Irish	3.61%	3
White Irish	4.82%	4
White Scottish	2.41%	2
White English	14.46%	12
Any other White Background	9.64%	8
Black British - Caribbean	1.20%	1
Mixed - Asian & White	1.20%	1
Mixed - Any other Mixed background	1.20%	1
Any other ethnic group	1.20%	1
Prefer not to say	7.23%	6
	Answered	83

Most of our respondents (75.9%) consider themselves to be disabled, with 84.62% of those respondents being Autistic. Over half of disabled respondents have a chronic illness, and over 30% have Neurodivergence other than being Autistic.

It is imperative that person-centred approaches are taken at all stages of this training. Consultations must ensure that they are accessible, and that all needs are accounted for.

Answer Choices	
Autistic	84.62%
Other Neurodivergence	30.77%
Physical Disability	35.38%
Sensory Disability	23.08%
Learning Disability	7.69%
Chronic Illness	50.77%

Other (please specify)	20.00%
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Other (please specify)
Too many to name all
PTSD OCD Borderline personality disorder
Nil
Mental illness
Depression and anxiety
self-diagnosed autism (I don't like to tick autistic w/o diagnosis)
Bipolar
Celiac
Physical injury
Social Anxiety, General Anxiety, Depression
A.B.I
Untreated after effects of trauma

Understandably, there were some defensive responses to this element of the survey. We feel that this highlights the distrust the disabled (particularly ND) communities feel towards organisational surveys, particularly if they are unaware that they are Autistic owned and led.

We also asked our respondents to indicate whether or not they are carers. There was an almost 50/50 split between those who identified themselves as carers, and those who did not. 100% of our Learning Disabled respondents and 45.71% of our Autistic respondents identified themselves as carers. While the training aims to ensure the needs of Autistic and Learning Disabled patients are met, it is crucial that it is clear that parent/carers are highly likely to share their child(ren)'s Neurodivergence, and that their needs are also considered.

We asked carers to inform us of who they care for, and the following table provides a breakdown of those responses. It is important to note that support needs do not equal arbitrary "functioning labels" and/or neurotypical ideas of cognition. It should also be noted that people's support needs often vary, however the limitations of a static survey do not allow for these variations.

We would advise that any professionals reading this report note that outward appearance is not a good indicator of support needs. It is essential that needs are established on a person-to-person basis, and are regularly reviewed to account for natural variation.

Answer Choices	
Autistic Child - High Support Needs	25.58%
Autistic Child - Moderate Support Needs	32.56%
Autistic Child - Low Support Needs	6.98%
Non-Autistic Child - High Support Needs	2.33%
Non-Autistic Child - Moderate Support Needs	9.30%
Non-Autistic Child - Low Support Needs	2.33%
Autistic Partner/Spouse	11.63%

Non-Autistic Partner/Spouse	11.63%
Parent	16.28%
Other Family Member	23.26%

Awareness of the Oliver McGowan Mandatory Learning Disability and Autism training for all health and social care staff

We asked all respondents whether or not they were aware of the proposed implementation of the Oliver McGowan Mandatory Learning Disability and Autism training for all health and social care staff prior to the contract announcements in August. Only 37.8 % of all respondents were aware, dropping to 25% of Learning Disabled respondents. 39.13 % of Autistic respondents were aware, however Paula McGowan posted petitions in many of the Autistic-led social media groups.

We asked for further information regarding the ‘yes’ responses, and were informed that:

Responses
I submitted a response to the consultation and campaigned for the petition to be signed
Aware training to be planned
Many groups that I am part of discussed this
Paula McGowan
The organisation registered an interest in the training at the procurement stage.
Follow Paula McGowan on Twitter
Very disappointed with some of the choices of groups to implement the training who have a very bad track record in regards to autism
Have followed Paula's campaign for some time
My organisation provides training and works with a training consortium looking at delivering autism training
Social media
As per national announcements
Heard via news media
I was on social media and the news the work his mother was doing.
I have seen information about it from Paula McGowan on Facebook
I follow Paula on twitter
Via Twitter. I clicked links to read details of the training and tender plans and even downloaded the application documents but found them inaccessible
I've seen information about it in Facebook groups aimed at autistic adults
Saw articles shared on Twitter
I follow the updates on Twitter
I had heard about it not long before the announcement was made through autistic community channels, but I didn't know much about it.
Heard about it from social media announcements
I have been following the campaign
Been aware of the McCann proposals through media.

Through social media announcements and campaigns to introduce training
followed the story in the news and on social media
Twitter autistic community
When the tender process was announced to the NHSE engagement groups
I was aware of the petitions, but not aware of any bid, tender, or consultations.

This demonstrates that while many people were aware through social media campaigns, very few people were aware of bids, tenders, or consultations. This echoes the reports being received through social media channels in which Autistic people state that they were unaware that they could provide information via consultations. Though official reports state that there was a consultation period during which Autistic and Learning Disabled people could express their views and concerns, it is clear that invitations to do so were not well publicised, and that fair representation from our communities was not sought.

We continued by asking our respondents whether or not they were aware of the companies who have won the training bids. The following table sets out the awareness of all respondents:

	Yes	No	I work/have worked for this organisation	I, or my family, are/were service users
BILD	25.00%	75.00%	0.00%	0.00%
Gloucestershire Health and Care NHS Foundation Trust	31.25%	67.50%	0.00%	1.25%
Royal Mencap Society	72.50%	23.75%	1.25%	2.50%
National Autistic Society	90.12%	3.70%	2.47%	3.70%
Pathways Associates CIC	8.75%	91.25%	0.00%	0.00%
National Development Team for inclusion	12.35%	86.42%	1.23%	0.00%

Percentages are similar when filtered for Autistic respondents, whereas a slightly higher percentage of Learning Disabled respondents were aware of Mencap, but none of those respondents were aware of Pathways Associates CIC or the National Development Team for inclusion.

We followed this question up with asking respondents to rate each organisation based on their knowledge and experience. The following table contains all of the responses:

	Very Good	Good	Neither Good nor Bad	Bad	Very Bad	No Opinion
BILD	2.44%	2.44%	17.07%	4.88%	7.32%	65.85%

Gloucestershire Health and Care NHS Foundation Trust	0.00%	1.25%	20.00%	5.00%	1.25%	72.50%
Royal Mencap Society	1.22%	15.85%	20.73%	12.20%	9.76%	40.24%
National Autistic Society	10.98%	23.17%	18.29%	23.17%	18.29%	6.10%
Pathways Associates CIC	1.23%	1.23%	12.35%	1.23%	0.00%	83.95%
National Development Team for inclusion	1.23%	4.94%	9.88%	1.23%	0.00%	82.72%

When filtered by Learning Disabled respondents, BILD was either rated 'Bad' or the respondent had no opinion, and the National Autistic Society was rated 'Neither good nor bad' by 25% and 'Bad' by 75% of respondents. No company received a rating of 'Very good' or 'good'.

When filtered by Autistic respondents, BILD was mainly rated 'Neither good nor bad' or the respondent didn't have an opinion (85.51%). However, 11.6% of Autistic respondents rated BILD as 'Bad' or 'Very bad' and only 2.9% (two people total) rated them 'Very good' or 'Good', one is a carer for a high support needs Autistic person. 40.58% of Autistic respondents rated the National Autistic Society as 'Bad' or 'Very bad', compared with 30.43% who rated them 'Very good' or 'Good'.

For both cohorts, 'Very good' or 'Good' ratings were not often awarded, which is reflected in the figures in the above table with the exception of the National Autistic Society. When looking at those respondents who awarded positive ratings (28 respondents), the vast majority were parent/carers and/or professionals, with one professional being a current or former employee. They were also more likely to rate the other companies similarly.

Some respondents expanded on their experiences of the organisations, which are listed in the table below:

Responses
I feel that the organisations that are most representative of, and who advocate for autistic equality/equity are not included e.g. any organisation that was set up and is run by autistic people for autistic people
Not much help from NAS for women on the spectrum with 'low' support needs
The Nas have been using autistics for too long and scandal seems to follow them around-they are not fit for purpose- mencap is also in trouble due to poor management fraud and abuse
I personally feel that the NAS do not meaningfully included autistic adults in their work.
NAS good at national level but local politics and personal preferences can affect how local NAS operates
I believe that training on autism should be delivered by autistic people and focus on autism, not co-occurring learning disabilities or mental health issues
National autistic society have provided poor service in the past by failing to listen to requests for advice
The National Autistic Society FREQUENTLY bully autistic adults. They threatened me, and when I put a screen shot of their threats on their Facebook page review feature, they disabled reviews.
They are guilty.
They are bad.

I don't want them anywhere near anything to do with autistics.

It's about time neurotypicals stop being given the right to do things about us, without us.

Just stop talking, NTs.

Autistic persons make guidelines for autistic persons .

NAS - didn't want to tick 'neither good nor* bad', as generally I think they do very good work. However I sometimes worry that some of their views are a little out-dated (eg via NAS website, magazine) compared with other sites/research I read.

*comparatives: either/or, neither/nor :)

The NAS has repeatedly failed the autistic people in its care, eg Mendip House. They also use ABA, which is horrendous.

The local groups can be very good, but the central organisation itself leaves a lot to be desired.

The National Autistic If society is actively harmful to the autistic community.

They continue to fail to ensure up to date information about autistic people is available.

The actively support the use of ABA and advertise for ABA trained staff for their schools.

When they were alerted to the use of MMS on vulnerable Autistics a protest had to be organised for them to agree to give a shit (excuse my language but I think it is appropriate in this context) the irony being they agreed all very last minute but the protest went ahead anyway because of what happened at Mendip became public around this time.

The settlement of a measly 6,000 paid to the CQC And no review of how this happened is disturbing not least considering their annual expenditure is more then 90 million this highlights the lack of ability to adequately deal with issues of Ongoing abuse in their own facilities and raises huge concern that the have an input into this training which is meant to prevent a repeat of what happened to Oliver and every other Autistic Learning Disabled person currently failed by society who gets their training and information from the National Autistic Society

They have a clear contempt for Autistic people and tokenise those of us who try to join their org in an attempt to influence change for the better.

They monopolise the care for autistics in this country yet we continue to be abused and to die far too often at facilities accredited by or sometimes even owned and run by them.

NAS are irrelevant to autistic adults. They don't seem to do anything other than acquire funds for themselves, over charge autistic people and social services for 'support' and run the odd low-profile unhelpful campaign here or there.

Bild = PBS = ABA = abusive conversion therapy

NAS = NT organisation with token autistic rep

Mencap was one of the charities that got into bed with the coalition government and legitimised its oppression of disabled people. They've also often been in the news because of their staff doing dodgy things like sharing racist stuff on social media and mistreating people in care homes.

The National Autistic Society is a complex one. Full disclosure: I'm a member, because I decided I wanted to influence it for the better from the inside, but I constantly go back and forth over whether that's been the right choice. I fill out the surveys they send me about what direction they'll take and hope it's enough. When you look at the Mendip House scandal, and the fact they've recently closed a school for autistic people, it seems like they don't always know what they're doing.

Maybe they're trying to do too many different things - I think they can be very useful as. central hub for information and support of various kinds, and their lobbying government is valuable, but I do have concerns.

I would like to see them speak out firmly against ABA, and I worry about the fact they're in bed with the PDA industry at a time when we don't even have recognised diagnostic criteria for PDA. People with that profile deserve more clarity, and people on the spectrum in general deserve not to have our autonomy undermined.

None of these organisations are actually led by people with lived experience. As such they are outdated and ill equipped.

Past problems with the big charities are well documented

Nas, the website can be a good source of information as can the members forum, but the services and treatment of people in their care is abhorrent

Failings by these orgs in facilities they run, little pragmatic help or accountability to those they represent

NAS is a hate group and is responsible for all the negative stereotypes and has abused autistic people also responsible for the lack of resources for autistic people. Just a fund raising machine

Mencap & NAS both have a poor track record in terms of providing care in institutional settings.

Any organisation or 'charity' that uses ABA methodology or practices is working immorally.

I now know of BILD and think they're awful.

Autistic and Learning Disabled people's Representation

Many of the responses we received regarding the concerns raised in our [statement](#) advise that Autistic and Learning Disabled people were consulted at each stage of the procurement process. However, the community we serve are repeatedly stating that they either didn't know this was possible, or that their input and/or bids were rejected.

Therefore, we wanted to officially ascertain how confident our respondents are that Autistic and Learning Disabled people's views have been fairly represented to this point. The table below contains details regarding all respondents:

Answer Choices	
Extremely confident	0.00%
Very confident	3.03%
Somewhat confident	18.18%
Not so confident	24.24%
Not at all confident	54.55%

As you can see, the vast majority of respondents are not confident that the views of those to whom the training pertains have been represented in the outcome of the tendering process.

When filtered for Learning Disabled respondents, the views were split 50/50 between ‘Somewhat confident’ and ‘Not at all confident’. Whereas 56.36 % of Autistic respondents were ‘Not at all confident’ that their views have been represented, compared to 16.36% who were ‘Somewhat confident’ and 25.45% ‘Not so confident’. 1.82% (1 respondent) was ‘Very confident’ that Autistic and Learning Disabled people’s views have been fairly represented to this point.

We then asked our respondents whether or not they were confident that Autistic and Learning Disabled people’s views will be adequately represented in the design of the training as it happens. The table below demonstrates that the respondents in general are somewhat optimistic, with the percentage who answered ‘Very confident’ or ‘Somewhat confident’ being higher than the previous question. However, you can see that the majority still feel unconfident that this will be the case:

Answer Choices	
Extremely confident	0.00%
Very confident	3.03%
Somewhat confident	30.30%
Not so confident	30.30%
Not at all confident	36.36%

This sentiment is echoed by Autistic respondents, 69.09% of whom are ‘Not so confident’ or ‘Not at all confident’ that Autistic and Learning Disabled people’s views will be adequately represented in the design of the training as it happens, whereas the Learning Disabled people’s views were, again, split 50/50 between ‘Somewhat confident’ and ‘Not at all confident’.

It is clear that, regardless of intent, the very people who the proposed training is designed to help feel that their views are not being represented. It is critical that a wide range of Autistic and Learning Disabled people’s views are used in the development of the training, and not just a select few who have been chosen by the aforementioned companies.

Training Design

Most importantly, we asked our respondents a series of questions relating to the design of the training. These questions were separated into ‘Autism training’ and ‘Learning Disability training’. It needs to be made extremely clear that ‘Autistic’ and ‘Learning Disabled’ are not synonymous, and should not be treated as such. While each person should be treated as an individual and their own needs established as part of patient-centred care, we understand that general training is not able to be that nuanced. However, the amalgamation of Autism and Learning Disabilities – whether intentional or not – will undo decades of work and lobbying undertaken by Autistic and Learning Disabled adults.

We first asked who the respondents thought should be involved in the design of the Autism training. The below table highlights the results from all respondents:

Answer Choices	
Independent Autistic People	98.48%
Independent Learning Disabled People	56.06%
Residential Service Users - Autistic	84.85%
Residential Service Users - Learning Disabled	50.00%

Autistic and/or Learning Disabled People's Organisations (DPO)	59.09%
Independent Autistic Advocates	77.27%
Independent Learning Disabled Advocates	42.42%
Families of Autistic People	54.55%
Families of Learning Disabled People	27.27%
Carers of Autistic People	45.45%
Carers of Learning Disabled People	24.24%
Professionals working with Autistic people	43.94%
Professionals working with Learning Disabled people	19.70%
Academics specialising in Autism	31.82%
Academics specialising in Learning Disability	15.15%
Commissioning NHS Staff	13.64%
Government Officials	6.06%
Charities - Autism Related	34.85%
Charities - Learning Disability Related	16.67%
Other (please specify)	10.61%

We then asked who the respondents thought should be involved in the design of the learning disability training. The below table highlights the results from all respondents:

Answer Choices	
Independent Autistic People	57.58%
Independent Learning Disabled People	92.42%
Residential Service Users - Autistic	46.97%
Residential Service Users - Learning Disabled	78.79%
Autistic and/or Learning Disabled People's Organisations (DPO)	59.09%
Independent Autistic Advocates	40.91%
Independent Learning Disabled Advocates	72.73%
Families of Autistic People	28.79%
Families of Learning Disabled People	46.97%
Carers of Autistic People	27.27%
Carers of Learning Disabled People	40.91%
Professionals working with Autistic people	16.67%
Professionals working with Learning Disabled people	40.91%
Academics specialising in Autism	18.18%
Academics specialising in Learning Disability	30.30%
Commissioning NHS Staff	15.15%
Government Officials	7.58%
Charities - Autism Related	15.15%
Charities - Learning Disability Related	28.79%
Other (please specify)	4.55%

As you can see, in both examples the respondents overwhelmingly state that the training should involve the people it represents – 98.48% of respondents think that independent Autistics should be involved in the design of the

autism training, and 92.42% of respondents think that independent Learning Disabled people should be involved in the design of the learning disability training.

In both examples, charities, commissioning NHS staff, academics, and government officials have been selected far fewer times, with similar percentages being reflected when filtering for Autistic respondents. This divide is stark when filtering for Learning Disabled respondents, none of whom think that the aforementioned parties should be involved.

This demonstrates that the companies selected in the tendering process are not reflective of who the communities would like to see design the training. However, those who do meet the preferred criteria of our respondents – independent Autistic and/or Learning Disabled people, Autistic and/or Learning Disabled advocates, residential service users, and Autistic and/or Learning Disabled People’s Organisations – were all unsuccessful in their pitches, or were unable to apply due to unreasonably short timescales and/or inaccessible processes.

The community are intensely repeating ‘Nothing About Us Without Us,’ yet it seems that this has not been reflected in the process.

While decisions have already been made regarding who is designing and delivering the training, we have been informed that Autistic and Learning Disabled people will have opportunities to provide their input at each step of the process. However, the opinions being expressed on social media are that the communities are not confident that this will be open to all, but rather a select few chosen by the organisations who have won the work.

Therefore, we asked our respondents how confident they are that Autistic and Learning Disabled people will be involved in this process, outside those who are service users and/or representatives of the appointed organisations.

The following table highlights all responses:

Answer Choices	
Extremely confident	0.00%
Very confident	4.55%
Somewhat confident	15.15%
Not so confident	37.88%
Not at all confident	42.42%

As you can see, most are not confident that there will be meaningful involvement of Autistic or Learning Disabled people outside of the organisations. Confidence drops when filtered for Autistic respondents, with a total of 83.63% being either ‘Not so confident’ or ‘Not at all confident’. There was a further 50/50 split among Learning Disabled respondents who replied either ‘Somewhat confident’ or ‘Not at all confident’.

We went on to ask our respondents how confident they are that the views of the entire Autistic and/or Learning Disabled communities will be heard.

Answer Choices	
Extremely confident	0.00%
Very confident	4.55%

Somewhat confident	12.12%
Not so confident	22.73%
Not at all confident	59.09%
Other (please specify)	1.52%

Percentages are similar to the previous question, however more respondents are ‘Not at all confident’ that the views of the entire communities will be heard. When filtered by those who identify as Learning Disabled, respondents were either ‘Not at all confident’ or had no opinion. Within the Autistic responses, only one person is ‘Very confident’ the communities will be heard, and 85.45% of Autistic respondents are either ‘Not so confident’ or ‘Not at all confident’.

Our final question regarding the confidence of our respondents related to whether or not the training will be co-produced. This is defined as Autistic and Learning Disabled people being equal partners in consultation and content design. Below is the table containing figures from all respondents:

Answer Choices	
Extremely confident	0.00%
Very confident	1.52%
Somewhat confident	22.73%
Not so confident	34.85%
Not at all confident	40.91%

Confidence across the board has dropped when considering co-production. This demonstrates that even those who were confident that Autistic and Learning Disabled people’s views would be represented think that that input would not be deemed of equal value by those charged with designing and implementing the training.

This confidence is lower again when filtered by Autistic respondents, 45.45% of whom are ‘Not at all confident’ training will be co-produced, with a further 36.36% being ‘Not so confident’. Learning Disabled participants responded with either ‘Somewhat confident’ or ‘Not at all confident’, again with a 50/50 split.

Training Content

Our final group of questions related to what respondents thought should be included in the training. Again, we separated the Autism and Learning Disability training as these should be produced separately.

Autism specific training

We asked our respondents whether or not they thought certain elements should feature in the Autism specific training. This table contains the data for all respondents:

	Yes	No	Don't Know
Differences between Autism and Learning Disability	98.48%	0.00%	1.52%
Autism Specific Needs	100.00%	0.00%	0.00%

Learning Disability Specific Needs	79.37%	14.29%	6.35%
What is Autism?	98.48%	0.00%	1.52%
What is a Learning Disability?	84.13%	12.70%	3.17%
PBS and/or ABA	9.23%	76.92%	13.85%
Other behavioural management techniques and therapies	30.30%	53.03%	16.67%
Sensory Needs - Internal	98.48%	0.00%	1.52%
Sensory Needs - External	100.00%	0.00%	0.00%
Communication Needs	100.00%	0.00%	0.00%
Alternative Forms of Communication	98.48%	1.52%	0.00%
Meeting social needs (Including online communities and Social Media)	92.42%	1.52%	6.06%
Duties under law (Autism Act , Health and Social Care Act, Adult/Child Safeguarding etc.)	92.42%	0.00%	7.58%
Individual's Rights under Law (Autism Act, Human Rights Act, Adult/Child Safeguarding etc.)	96.97%	0.00%	3.03%
Restraint and seclusion	24.62%	60.00%	15.38%
Neurodiversity	95.45%	1.52%	3.03%
Autistic specific Mental Health care and prevention	93.94%	1.52%	4.55%
Learning Disabled specific Mental Health care and prevention	69.23%	20.00%	10.77%

We also provided an opportunity for respondents to advise of other elements they thought should be added to the training:

Anything Else (please specify)
The low-arousal approach, as best-practice.
The options that I have ticked NO to, if they are to be included, it should be in terms of avoidance and the (negative) consequences of their uses
Behavioural management ABA and any other measures that only serve the neurotypical carers and organisations should be banned- so should the use of controlling and derogatory terms
Different brain physiology of neurodivergent people - the very different ways we can react to medication or express pain or not feel pain. Our different ways of thinking and expressing ourselves - we are misunderstood and dismissed because of this.
The questions are ambiguous.
Do I think ABA and PBS should be taught? I've said no, on the assumption that it means taught to them to abuse us with?
It's very ambiguous.
The inclusion of PDA (Pathological Demand Avoidance) as part of autism.
Some form of testing/confirmation to indicate a minimum level of understanding has been reached by the person receiving training; training update annually, with full retraining every 5-10 years (as appropriate for the user role)
Emphasis on how one ascertains that the autistic or Learning Disabled person's communication has been correctly received/interpreted. Vitally important as a life skill for everyone (autistic/Learning Disabled/neurotypical alike) but often missed. Am especially aware of the need for this among autistic individuals who mask (esp with Asperger's Syndrome / AS Level 1).

It is more important how these topics are covered and that they are representative of the experiences and preferences of people who are autistic and/or have a learning disability. It also needs to be relevant to the context the recipient works in.

It needs to be clear that not all autistic people have a learning disability, but also that functioning labels etc are generally seen as unhelpful or misleading by people who are actually autistic.

Self advocacy and representation should feature heavily

Where I've said no to ABA/PBS and restraint/exclusion I mean they should not be recommended. I do though think the problems with them need to be covered.

I have said don't know for restraint because my concern is that restraint should only ever be a very last resort and for as limited a time as possible if absolutely avoidable but teaching it can lead to overuse.

They need to teach that if you are using restraint you have failed that person because what's important is not exposing that level of distress onto a human that they end up requiring restraint

Similar for behaviour management techniques and therapies? What ones exactly because some are good but some are bad so I don't know

ABA is abuse

Differences between Autism & Learning Disability, and Neurotypicality

The things I said no to I don't want the training teaching people to use these...but I would want the training to teach NOT to use them. I wasn't sure how to interpret the question.

I'd like our rights to also be discussed within the context of the CRPD (the UN Convention on the Rights of Persons with Disabilities), with reference to the CRPD Teaching Guide. I would also like the training org to have signed a statement in support of the CRPD.

Training should focus on RESPECTING individuals and realising that difference is not less than. Respect everyone and LISTEN to each individual because every individual is unique and if you listen to a person and respect what they say they need then you will learn how to provide them with what they need to thrive.

If only service providers would listen to individuals and their designated representatives/partners/parents and comply with their lived experience and knowledge then life would be so much easier and safer for the individuals and for the service providers.

Learning rules and treating people according to tick boxes is not good enough and never will be.

It should be made extremely clear that autism does not include any learning or cognitive or intellectual disability. Autistic people may also have learning or cognitive or intellectual disabilities, as may neurotypical people; but these are co-occurring conditions and not intrinsic to autism. This is very important indeed.

Only time ABA/PBS should be raised is to explain how detrimental it is

Information about ABA shouldn't be included as it has been shown to create PTSD responses in autistic adults.

Language used around Autism should be addressed too. It's not a condition or a disorder, also Autism first language should be used. Not person with autism

I don't want any of this covered if it's not from autistic/ Learning Disabled individuals. We've been burned by outsiders waaaaay too many times. This is ridiculous.

Therapies, for things like dyspraxia

The only way ABA/PBS/Restraint should be on the training is to say why it's horrific and shouldn't be used.

We note the comments from respondents regarding the ambiguity of the questions and first of all apologise. We wanted to ensure that we weren't asking leading questions (for the data to in turn be rejected), but accept that it made some questions difficult to answer, particularly regarding ABA/PBS.

However, those responses also demonstrate that ABA/PBS is overwhelmingly rejected by respondents, with only 9.23% of respondents thinking they should be included in the training. Furthermore, if ABA/PBS is to be included, it should only be in order to highlight that it is abusive.

Learning Disability specific training

We asked our respondents whether or not they thought certain elements should feature in the Learning Disability specific training. This table contains the data for all respondents:

	Yes	No	Don't Know
Differences between Autism and Learning Disability	95.38%	1.54%	3.08%
Autism Specific Needs	63.33%	28.33%	8.33%
Learning Disability Specific Needs	98.48%	0.00%	1.52%
What is Autism?	65.52%	29.31%	5.17%
What is a Learning Disability?	95.45%	3.03%	1.52%
PBS (Positive Behavioural Support) and /or ABA (Applied Behavioural Analysis)	15.63%	75.00%	9.38%
Other behavioural management techniques and therapies	35.94%	45.31%	18.75%
Sensory Needs - Internal	92.42%	1.52%	6.06%
Sensory Needs - External	90.91%	1.52%	7.58%
Communication Needs	98.48%	0.00%	1.52%
Alternative Forms of Communication	96.97%	1.52%	1.52%
Meeting social needs (Including online communities and Social Media)	89.23%	1.54%	9.23%
Duties under law (Autism Act , Health and Social Care Act, Adult/Child Safeguarding) etc.)	95.38%	0.00%	4.62%
Individual's Rights under Law (Autism Act, Human Rights Act, Adult/Child Safeguarding etc.)	96.92%	0.00%	3.08%
Restraint and seclusion	19.05%	61.90%	19.05%
Neurodiversity	90.77%	6.15%	3.08%
Autistic specific Mental Health care and prevention	54.84%	37.10%	8.06%
Learning Disabled specific Mental Health care and prevention	93.94%	3.03%	3.03%

We also provided an opportunity for respondents to advise of other elements they thought should be added to the training:

Anything Else (please specify)
As before - low-arousal approach, as best-practice.
The different physiology of neurodivergent brains - unusual reactions to medication. Different ways we think, express ourselves and show pain - we are misunderstood and dismissed because of this.
Not sure what is being asked. ABA should only be mentioned in terms of the damage caused at the expense of 'normalisation'
As previous question.

See above
The importance of assuming capacity and not infantilising individuals
Where I've said no to ABA/PBS and restraint/exclusion I mean they should not be recommended. I do though think the problems with them need to be covered.
Don't know for seclusion and restraint as per my previous answer
ABA is abuse
As previous answer
The things I said no to I don't want the training teaching people to use these...but I would want the training to teach NOT to use them. I wasn't sure how to interpret the question.
As per my earlier answer, the content about legal rights needs to be delivered in the context of the CRPD.
It worries me that people should find it necessary to categorise individuals. Differences between being autistic and learning disability are not important - what is important is - who is the individual and what does the individual need to be safe and treated so they can benefit from medical treatment or the service provided? Many individuals have complex mixtures of all sorts of needs and frankly categorising them is not important if there is a culture of respecting every person and listening to each person without preconceived notions of what they 'should' present in terms of behaviour or needs. especially since such things change depending on stress levels or health conditions at the time or simply whether they have had enough sleep. Respect for people and listening to them and discussing with them what they need and working to fit in with what they need is the way forward. Do that properly and there should never be any need for restraint and making them fit into neurotypical standards of behaviour.
I don't mean "don't even mention autism" as some learning-disabled people will also be autistic. But concentrate on the matter in hand, which in this case is learning disability.
I ticked no for restraint and seclusion, I do think it should be covered but only to highlight its misuse and dangerous practices etc
The role of National Autistic society in promoting hate ,abuse and exploration of autistic people
The only way ABA/PBS/Restraint should be on the training is to say why it's horrific and shouldn't be used.

As with the Autism training, respondents are strongly indicating that they don't think ABA/PBS should be included in the Learning Disability training, unless it's to highlight the harm they cause.

In the responses to both training programmes, 100% of Learning Disabled and over 77% of Autistic respondents don't think ABA/PBS should be included. Therefore, it is concerning that BILD have one of the contracts to devise and implement the training. Despite reassurances that the training will not contain ABA/PBS, BILD quickly released a job advertisement for a project lead heading a dual venture of the Oliver McGowan Mandatory Autism and Learning Disability training and PBS. This advertisement was rapidly removed from social media when it was highlighted by the Autistic community, however as BILD are staunch proponents of PBS/ABA, it is unclear how the two streams will be kept separate.

Summary

To conclude, our respondents are overwhelmingly unconfident that the views, needs, and beliefs of the communities the Oliver McGowan Mandatory Autism and Learning Disability training for Health and Social Care staff will be taken into account. Our respondents do not have much confidence in the companies selected to devise and implement the training, and this confidence is reduced further when we isolated the responses from Autistic and Learning Disabled respondents.

We asked all respondents if there was anything else they would like to say on this matter. The table below contains their responses:

Responses
VERY much against PBS/ABA being promoted as an effective method or treatment for autistic people or people with a learning disability (or both). There's strong evidence that PBS/ABA is ineffective (meta analysis) and results in PTSD. Autistic advocates are very against these purely behavioural approaches. Instead, services should be working towards pre-empting the issues caused, by using a low-arousal approach. Rather than relying on sticking-plaster solutions that focus on the distressed person changing their behaviour.
I have concerns about who will be designing this program and their intentions and whether autistic people/people with learning disabilities will be genuinely included in the design
The church is one organisation everyone misses out. They say they are inclusive but when it comes to actually dealing with autism they are untrained and useless and uninformed.
The need for autism specific training designed, produced and delivered by autistic people is huge. We need this training to make a difference. At the moment it feels like an opportunity lost. It also feels like the Autism Act not really worth the paper that it is written on.
I am not happy that it takes a neurotypical to make neurotypicals feign an interest in us.
I do not believe anything good will come from this. I hope it does, but I just see further pushing of the martyr rhetoric.
Really glad to see such training has got approval to go ahead. The very best of luck with it. I can't remember now who you said would receive training, but I really hope it includes schools, CAMHS and GPs. My experience over the past 10-15 years with my daughter have shown that, as a generalisation, there is a massive need for further training about autism and other neurodiverse conditions.
Oh - what else to include? How to listen - really listen - to the parents of those still seeking diagnosis for their children. I suspect many parents have 'Fabricated or induced illness' (formerly Munchausen by proxy) written in their child's notes. Parents know their children best, and should be believed until proven otherwise, not the other way round. This is particularly pertinent for parents of girls/young women with undiagnosed autism; the way we are sometimes treated by schools and clinicians is unforgivable. Thank you.
My child has been failed by education dept
Not be in school for over a year
Autistic people to be involved in all stages of this process, as do Learning Disabled people. Their views need to be heard and used to ensure that this training is person-centred, rather than being based on stereotypes and misinformation
It is important that the views and experiences of autistics who do not identify as part of the 'autistic community' are represented.
I did notice the recent job vacancy related to this, said that Oliver's training will be delivered "alongside" PBA training. So Oliver's training won't need to cover that then!
Thanks for doing this; I'm glad you are helping the community to engage on this issue.
I'm very concerned that power is concentrated in hands of few high profile campaigners who are not representative of autistics. It is very concerning that the big charities involved promote ABA/PBS.
Please run every part of the training past people who are actually autistic and encourage them to tell you if they believe something is inaccurate or does not, in fact, reflect the autistic experience. Because the point is the autistic experience; not what it looks like from outside to the neurotypical. Where neurotypicals see "behaviours" autistic people have "experiences". The behaviours tell you nothing unless you understand the experiences.
The role of foreign charities in UK autism specifically Autism Speaks
I don't trust the companies being used. They don't speak for Autistics.

We also received some information via email which we have been allowed to include in our report:

We have multiple concerns about the lead organisations that the training has been awarded to and the process taken to select those organisations. I will briefly set them out below;

1. The training is as a result of inequalities people with learning disabilities and autistic people face in health care, the large numbers of preventable deaths in this group and the age at which people die which is significantly younger than the rest of the population. The training is to educate health and social care staff on learning disability and autism, change attitudes and help them understand the reasonable adjustments needed. It was made clear in the consultation that this training should be led by autistic people and people with learning disabilities but disabled led groups are noticeably few in the successful organisations. There is also a requirement to take account of equality law in public procurement and we do not believe that reasonable adjustments were made to ensure that disabled led organisations were able to meaningfully lead on the training that is about us. https://www.equalityhumanrights.com/sites/default/files/buying_better_outcomes_final.pdf

2. The person who is unofficially leading the training has a debatable understanding of autism, has made public accusations of hacking email/website against autistic people who questioned the organisations appointed and has overall behaved unprofessionally. This is not a slur on this person who has done much work to get the petition for training supported by the government, but they should not be in the position of leading the training.

3. The contracts were awarded to two national charities, NAS and Mencap, who both have failing services which is evidenced in CQC and Ofsted results and serious case reviews. They are not able to train their own staff adequately and have a poor reputation in the field because of numerous scandals that include staff torturing service users, having to close schools because of poor teaching/abuse and avoiding accountability for deaths in their care. We believe that Health Education England failed to adhere to procurement law that explicitly states that due diligence must be taken to look at past failed public sector contracts. There is a requirement in public procurement to check past contractual performance in section 9 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/417211/PPN_04-15_Supplier_Past_Performance_.pdf If this had taken place, it would be hard to imagine these organisations being appointed.

4. We are concerned that the organisations appointed are not fit to deliver training and will reinforce the beliefs in the medical profession that autistic and Learning Disabled people are worth less than everyone else. Even if they were able to employ good trainers, their past performance will undermine the credibility of the training.

5. The whole process to appoint organisations was unprofessional and disorganised. There were people with a conflict of interest on the panel who did not step down about making decisions about organisations they were close to. Several organisations that applied were not informed about the outcome until after it was publicly announced. Those that got through to the final 5 said it was a shambolic process with an enormous amount of work and poor communication.

Autistic UK CIC offers training and support for professional and family groups and promotes independence and self-advocacy for all autistics.

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8. Autistic people and organisations that are upset about this have been blocked from discussing it and made to feel that the questions they have are unreasonable. The very attitudes that we are trying to change have been in evidence from people and organisations leading the training.

We also received comments from one respondent which, while disappointing to receive on one of our surveys as we are an Autistic owned and led organisation, highlight two things:

1. It is assumed that all official surveys and work is undertaken by organisations run by Neurotypicals, because that is normally accurate.
2. Autistic people and Learning Disabled people are fed up of being ignored, are tired of being asked questions when it is too late for their answers to affect real change, and are rightly demanding that our communities are listened to and are the leaders in training, support design, and information.

“Functioning labels are nonsense. My child is autistic and that is all you need to know. All those options and I couldn't just pick "autistic child" ffs. Have you consulted a single autistic person about this prior to this survey?”

“I think you're not listening to the Learning Disabled/ autistic community AT ALL, judging by these questions. There is literally no such thing as universal autism specific needs. We're all individuals just like non autistics. Y'all don't have a set of needs that apply to everyone in your neurotype either.”

“I think you should've consulted Learning Disabled and autistic individuals long before this survey. If you had you might not even need this survey. The ableism is pretty easy to read between the lines, to the point that I'm not confident that you're not going to automatically toss the answers from anyone who states they're autistic or Learning Disabled and only take parents and caregivers opinions into account. This was highly offensive to me as an autistic adult.”

We agree with the final statement that often, when giving feedback to organisations run by Neurotypicals, views expressed by Neurodivergent people which do not echo what the organisation wants to hear are “automatically toss[ed].” Autistic UK endeavours to be transparent in all our work, and while we do not have any Neurotypical directors or staff, we acknowledge and empathise with the frustration that our questions raised.

We also acknowledge that some respondents found a few of our questions too vague. As previously stated, we wrote them as such so that we could not be accused of writing leading questions, however the wording became too ambiguous. We will ensure that any follow up surveys are clearer.

Thank you to all who took the time to provide such detailed responses.

Finally, to the organisations involved in designing and implementing the training, we hope that this information which has been generated at great cognitive expense by the communities the Oliver McGowan Mandatory Autism and Learning Disability training will be considered before any training is finalised and/or delivered.