NHS
Midlands and Lancashire
Commissioning Support Unit

Policy for Sensory Integration Therapy

Public Engagement Report of Findings

September 2021

Your NHS partner for **improving health** and **integrating care**

Introduction

A public engagement exercise was undertaken to seek views of patients and the general public on the proposed policy for sensory integration therapy.

This policy has been developed by all the Clinical Commissioning Groups in Lancashire and South Cumbria and it identifies that the CCGs will not routinely fund this treatment. This is a new policy for all the CCGs across the area.

This is one of a suite of policies which the Lancashire and South Cumbria CCGs are developing or seeking to review, update and harmonise to ensure equitable, uniform and up to date clinical policies are being applied across the area.

Sensory integration therapy is a direct, one-to-one clinic-based therapy for children and adults who have been assessed to have a level of sensory interference or dysfunction. The therapy is usually delivered by an Occupational Therapist (OT) with the intention of reducing the impact of the person's sensory dysfunction/disorder. However, there is no common approach or agreement on how to define sensory integration and in practice, sensory integration therapy tends to be offered to children who have ADHD or Autistic Spectrum Disorder.

An online survey was created to capture the views of patients, members of the public and other stakeholders. The survey ran from Friday 28th May until Friday 9th July 2021 and was disseminated via CCG networks and social media. In addition, a presentation to the Children and Maternity Commissioning Network was undertaken during the engagement exercise, and through them SENDIASS and parent/carer groups for children with special educational needs were contacted to inform them of the survey and seek their feedback.

Respondents were given the opportunity to read the new draft policy and complete the survey accordingly. Respondents, as individuals or groups, were able to request a virtual meeting or discussion if they wished to be involved in a more personal or direct involvement in the engagement process. There was very little uptake of this opportunity.

Two Occupational Therapists took the opportunity to provide a significant level of feedback during the patient engagement exercise. The content of this feedback was more closely aligned to the clinical engagement process and has therefore, been forwarded on to be added to the clinical engagement feedback that has already been received prior to the public engagement process taking place. However, reference to this feedback has been made where appropriate.

Overall, 32 responses were received to this survey and an additional 4 comments sent by email or by 'phone (including the responses from the Occupational Therapists). This is a reasonable level of response, and the feedback has been summarised in this report of findings.

Report of Findings

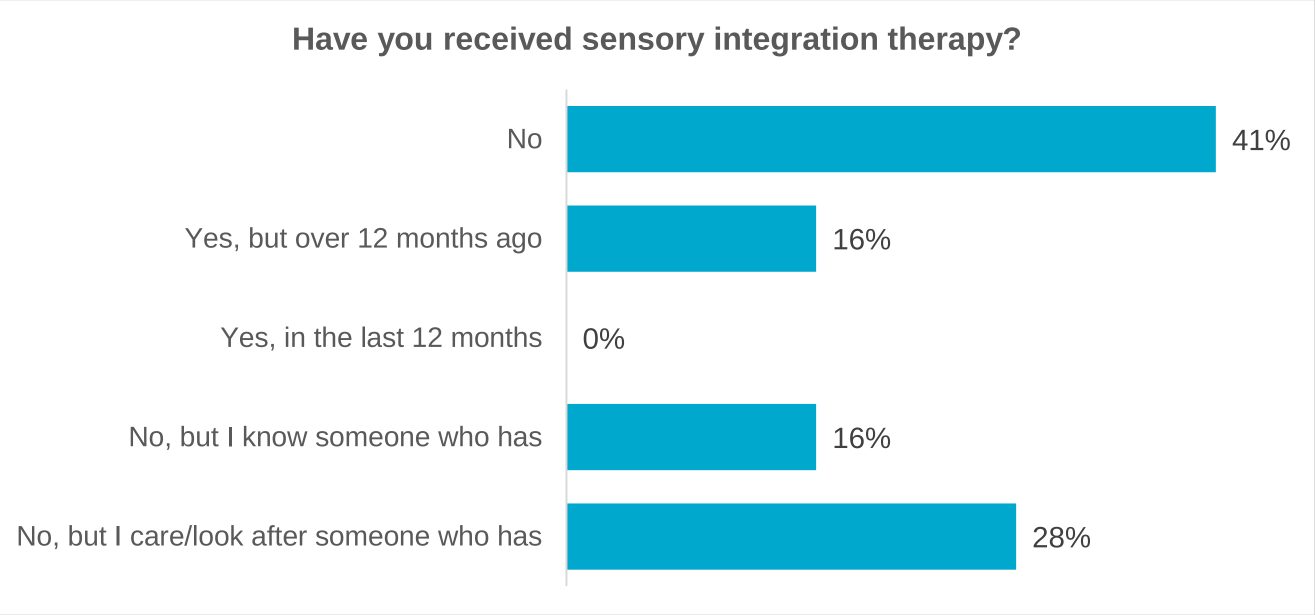
Survey Responses

In total there were 32 responses to the survey. The table below summarises which CCG these respondents fall under.

CCG	**Number of Patients**
NHS Fylde & Wyre CCG	5
NHS Blackpool CCG	2
NHS Chorley and South Ribble CCG	1
NHS Greater Preston CCG	1
NHS West Lancashire CCG	0
NHS Blackburn with Darwen CCG	2
NHS East Lancashire CCG	2
NHS Morecambe Bay CCG	19
Total No. Respondents	32

This indicates that the majority of responses (59%) came from residents of one CCG, Morecambe Bay.

Engagement Feedback

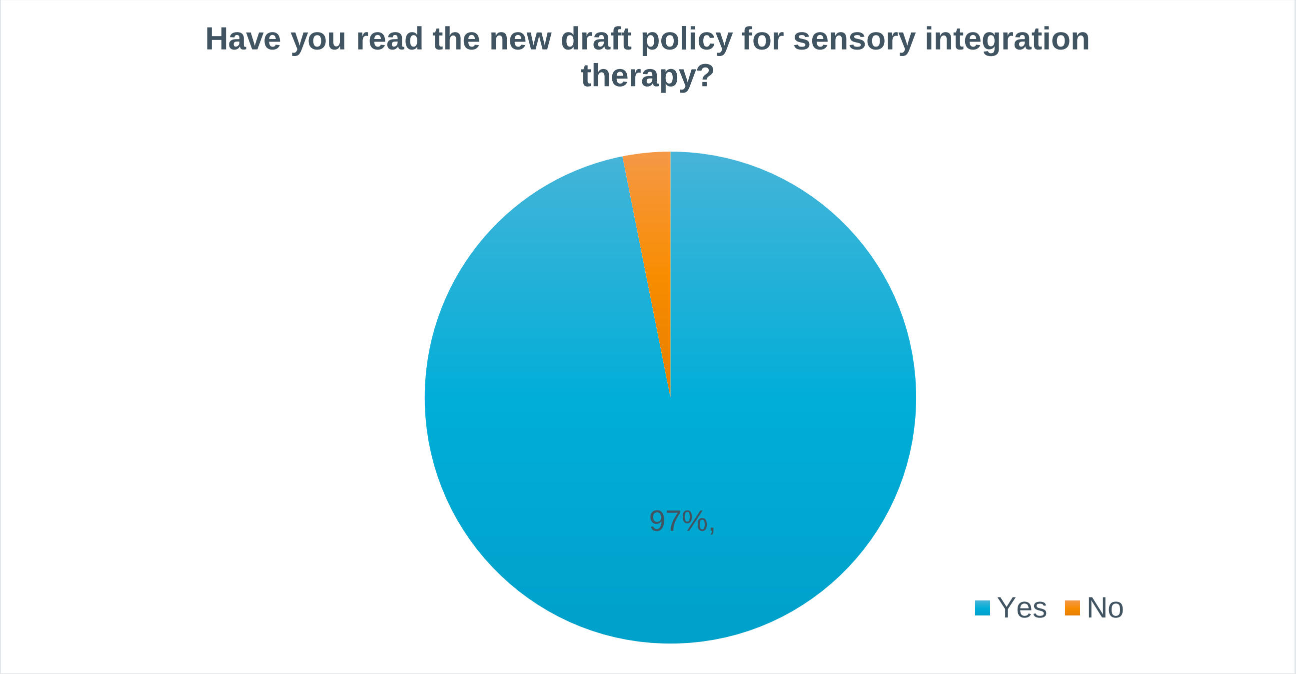


Base: 32 (Closed responses)

Over a third (41%) of respondents to the survey confirmed that they have not received sensory integration therapy. However, a little under a third (28%) of respondents cared for or looked after someone who had received sensory integration therapy, while a further 16% of respondents had received the treatment over 12 months ago. 44% of respondents therefore, had either received sensory integration therapy or cared for someone who had received it. In addition, a further 16% knew someone who had received it. Overall, most respondents (60% - figures are rounded up) had experience of or were familiar with sensory integration therapy.

Although no respondents indicated they had received sensory integration therapy in the last 12 months, this could be a little deceptive in this instance, as the comments made (see below) indicate that most, if not all respondents, were adults responding on behalf of their children and more likely to choose option 3 (no, but I care/look after someone who has), rather than option 1 (yes, I received sensory integration therapy in the last 12 months).

97% of respondents had read the new draft policy for sensory integration therapy, as only 1 respondent had not done so:

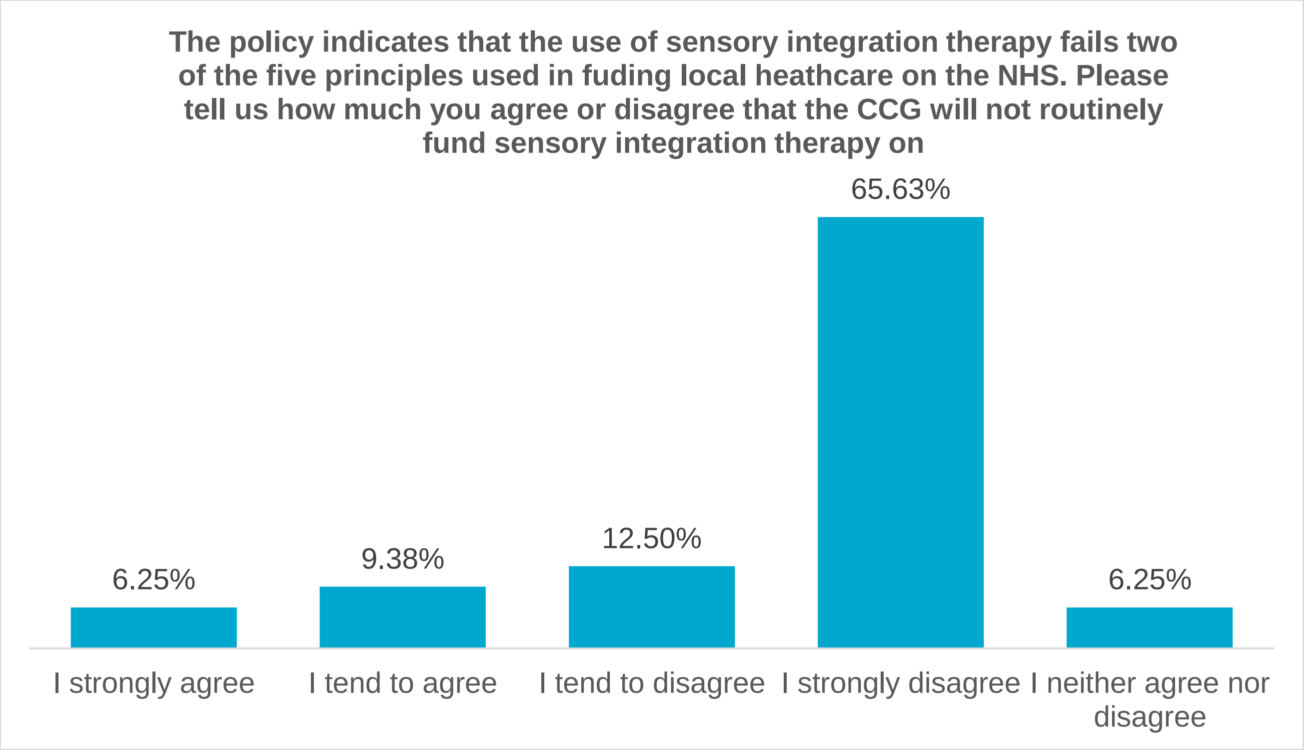


Base: 32 (closed responses)

The draft policy for sensory integration therapy indicates that the use of sensory integration therapy fails two of the five principles used to determine the funding of local healthcare on the NHS, and would therefore, not be routinely funded. These principles (appropriateness, effectiveness, cost-effectiveness, ethics and affordability) apply to all clinical policies and procedures.

Agreeing or disagreeing with the sensory integration therapy not being routinely funded:

Respondents were asked how much they agreed or disagreed with sensory integration therapy not being routinely funded. Almost two-thirds of respondents (65.63%) strongly disagreed, with a further 12.50% tending to disagree. Overall, just over 78% of respondents did not agree with the policy in this respect, with only 15.61% agreeing that the procedure should not be routinely funded. Respondents who strongly disagreed came from most CCG areas and were not confined to one locality.



Base: 32 (closed responses)

Twenty-three (72%) of the survey respondents provided feedback on why they disagreed.

A significant number of these respondents have had direct experience of sensory integration therapy (referred to on occasion as sensory integration diet), as they have funded the therapy for their children themselves. All respondents who had done this were very positive about the benefits of sensory integration therapy:

“Sensory integration therapy provides an essential therapy for my grandson, without this he would not be able to function.”

“I privately funded sensory integration for my son with Autism. The OT was the first person to understand my son and his needs and was able to offer strategies, techniques and understanding which I strongly believed influenced his abilities as he has progressed. It also assisted me to get the correct support.”

A high proportion of respondents found it ‘appalling’ that sensory integration therapy would not be funded and/or that it was not available through the NHS or via other education or social service channels. Respondents indicated that Lancashire was behind other counties in this respect, “I know people living in other parts of the country that have access to this and autistic people can really thrive when the root cause of their difficulties is addressed”, and that the research used to justify the policy was out of date, “recent research from many countries that is newer than that used to decide the policy shows that the therapy is valued”.

Respondents generally felt that the lack of support and services for children with ASD or ADHD was a grave concern for parents and there was a firm belief that sensory integration therapy, for those able to access it, provided a greater understanding of sensory difficulties and how this supported their children’s educational and personal development. “It is invaluable for people with sensory integration difficulties and their caregivers to have an assessment/sensory profile from an SI practitioner so that everyone has an understanding of the person’s needs. Sensory diets are life changing as is viewing behaviours/ difficulties through the correct lens. We had to pay private for this as it isn't available in the Lancaster area, we also bought in training for school staff and again this has been life changing.”

This view was supported by a telephone respondent who responded separately and by a teacher who feels that “Sensory Integration therapy has such a positive and important impact upon the ASC children I teach and care for. I think the CCG should fund this in all settings for all who have sensory issues or ASC.”

Respondents also expressed the view that the use of sensory integration therapy would reduce the need for other treatments, including mental health and medication, in the long term. “With improved understanding of the person with ASD many behaviour issues can be avoided or reduced which in the long term would be a huge saving on the support needed further down the line if such behaviours get out of control. Early intervention and proactive therapy by far outweigh the reactive issues that will arise further down the road for that child/adult. You should be thinking long term for these children.”

Some respondents felt these benefits were a turning point for their children. “From a personal point of view and that of many of other friends of mine who also care for children/young people with SEN there is no doubt in my mind that Sensory Integration therapy was a turning point for our children. The dangers associated with agreed antipsychotic medicine treatment far outweighs any that can occur from using SI therapy. Most OT's use it in some form anyway and it would be nice if they could use their skills to do this to provide early help for those that are struggling.”

There was an overwhelming impression that respondents already felt let down by a lack of appropriate services for people/children with autism and ADHD and that a potential, and for some a very real, area of support was being withdrawn or withheld from those who needed it most. There appears, on occasion, to be some confusion, or at least a correlation, between not funding sensory integration therapy and not funding sensory integration assessments. This may well be, in part, to the fact that the latter may not be taking place or difficult to access in a number of areas.

The respondents’ feedback on why they disagreed with sensory integration therapy not being routinely funded is shown in full below:

“That is such a lack of therapies in this area for individuals to access; these therapies help persons develop and integrate in society. They are an alternative to medication in some cases if they work.”

“Many people are failed because their needs are not being met. The cuts to funding is unacceptable and these services should be offered to all people who are suffering and need sensory therapy.”

“Access to services that can support children who are on the autistic spectrum are already very severely lacking within Lancashire. The LCC has repeatedly failed to provide an adequate ''ASC/neurodevelopmental' pathway for assessment, diagnosis and support services and this has been recognised and reported by repeated OFSTED inspections.

“Many of us who are parent/carers for children who are autistic already do not get any useful or practical services offered to us to help support our children engage fully in mainstream education or find it incredibly difficult to access those that are there (long waiting lists and limited provision across a very large county boundary, poor Local Offer and poor standard of Sendiass provision). To further withdraw a service that is currently one of the very few things that IS provided within Lancashire is a backward and retrograde step that will badly and in some cases critically impact an already over-burdened and over-whelmed group of parent/carers.

“To be blunt it is frankly cruel to withdraw this potential service. Sensory integration approaches are at the 'cutting edge' research wise of what autistic children need if we adopt a truly social model of disability - i.e. to change the environment for those who are ASC rather than expect the child to modify/adapt/change or be medicated instead, in order to cope. Sensory integration approaches are crucial for ASC children to survive in mainstream education for instance - if you withdraw this service you will have even more parents having to remove their children from school environments as they cannot cope.”

“My daughter is diagnosed autistic with speech delay and learning differences and she has huge sensory processing challenges. I think it is appalling that no help with her sensory problems is offered as this is fundamental to her other problems. How can she access learning/education if she is distressed by hearing problems or problems relating to proprioceptive?

“I believe in the future we will look back on this and be shocked about the lack of provision in Lancashire for people with sensory processing disorder. It’s like Lancashire doesn’t understand the fundamental importance of it and how it dictates an autistic’s child entire day. It’s like you’re writing off a generation of autistic kids by failing to see the importance of spd and the amazing things that can be achieved by helping children with it. It will be a bit like how decades ago people didn’t understand mental health problems and looking back now we can’t believe how little provision was given to helping people with mental health problems. Please Lancashire, speak to other counties who actually off sensory OT support etc. I know people living in other parts of the country that have access to this and autistic people can really thrive when the root cause of their difficulties is addressed. I even wonder if it is legal in this day and age not to offer help.”

“Sensory Integration therapy has such a positive and important impact upon the ASC children I teach and care for. I think the CCG should fund this in all settings for all who have sensory issues or ASC.”

“Sensory integration therapy is vital for a lot of people with sensory processing disorders either as a primary diagnosis or as a secondary diagnosis caused by neurodiverse conditions such as autism and ADHD. It could really help people manage their sensory processing disorders, minimising the mental health conditions that can be caused or exacerbated by untreated sensory processing disorders. This in turn would surely save the CCG money as the sensory integration therapy will treat the sensory processing disorder, improving mental health and reducing pressure on the already grossly stretched mental health services.”

“There is a definitive gap between CAMHS and ASC pathway through Paediatrics which has regularly been discussed in MDT meetings and professional liaisons. This gap identifies Young People (YP) who show signs of sensory need, however CAMHS are not able to support this, and it is identified as an unmet need due to lack of training / commissioning. Paediatrics will acknowledge the YP has further sensory needs, however they may feel the YP doesn't meet criteria for a diagnosis / further paeds input. Leading families who are in the service of CAMHS for mental health with unmet sensory needs that contribute to mental health needs. Having sensory integrated therapy in the trust will help families with this matter.”

“Sensory integration therapy provides an essential therapy for my grandson, without this he would not be able to function.”

“Having a sensory input will support to learn new skills, pay attention, socialise and build self-awareness and will stop some degree of struggling.

It will also support and help overstimulated or sluggish and help to learn to achieve a calm within themselves.”

“Doing nothing should not be an option once again.”

“The role this could have for some children should not be underestimated.”

“I privately funded sensory integration for my son with Autism. The OT was the first person to understand my son and his needs and was able to offer strategies, techniques and understanding which I strongly believed influenced his abilities as he has progressed. It also assisted me to get the correct support.

“The sensory issues relating to Autism Spectrum Disorder can be supported and treated to help the child function. While there is no cure for ASD understanding the sensory needs of the person goes a long way to improve understanding of them and improve their quality of life. With improved understanding of the person with ASD many behaviour issues can be avoided or reduced which in the long term would be a huge saving on the support needed further down the line if such behaviours get out of control.

“Early intervention and proactive therapy by far outweigh the reactive issues that will arise further down the road for that child/adult. You should be thinking long term for these children.”

“It is invaluable for people with sensory integration difficulties and their caregivers to have an assessment/sensory profile from an SI practitioner so that everyone has an understanding of the persons needs. Sensory diets are life changing as is viewing behaviours/ difficulties through the correct lens. We had to pay private for this as it isn't available in Lancaster area, we also bought in training for school staff and again this has been life changing. It is a huge backward step at a time when our understanding of autism and other conditions with a sensory base is increasing.”

“My daughter is 18 and got disability and we try our best look after her and got sensory problems.”

“Healthcare and health needs should not be assessed on profitability for shareholders but rather its value to the patients in need of the therapy.”

“Why would you deny help to children who desperately need this therapy and whom this therapy will help?”

“Recent research from many countries that is newer than that used to decide the policy shows that the therapy is valued. The information used to decide this policy is therefore out of date.”

“From a personal point of view and that of many of other friends of mine who also care for children/young people with SEN there is no doubt in my mind that Sensory Integration therapy was a turning point for our children. The dangers associated with agreed antipsychotic medicine treatment far outweighs any that can occur from using SI therapy. Most OT's use it in some form anyway and it would be nice if they could use their skills to do this to provide early help for those that are struggling.”

“If the CCG recognises that a patient may have certain features, such as

having sensory disorder/dysfunction,

wishing to have a service provided for their sensory disorder/dysfunction,

being advised that they are clinically suitable for sensory integration therapy, and

be distressed by their sensory disorder/dysfunction, THEN IT SHOULD PROVIDE THE SERVICE!!”

“My child attended several NHS appointment but no success. We spent well over £500 with [redacted] and got a positive outcome.”

“The sensory therapy that my child had (which I paid for in full) solved her problem which normal NHS clinical services had failed to do.”

“It is accepted and most practical and understandable practice for helping people with sensory difficulties. It is pan disability and implementation is transferable in real life settings.”

“Whilst the CCG will not routinely fund sensory integration therapy on the NHS, lots of children with disabilities or additional needs are missing out on the sensory input that they so desperately need, whilst they are not accessing it they maybe having to access other services for instance CAHMS because of meltdowns caused by sensory overload. If the children were to have a sensory assessment then sensory input and where the parent is involved and then can use a sensory diet it would take the pressure off other services.”

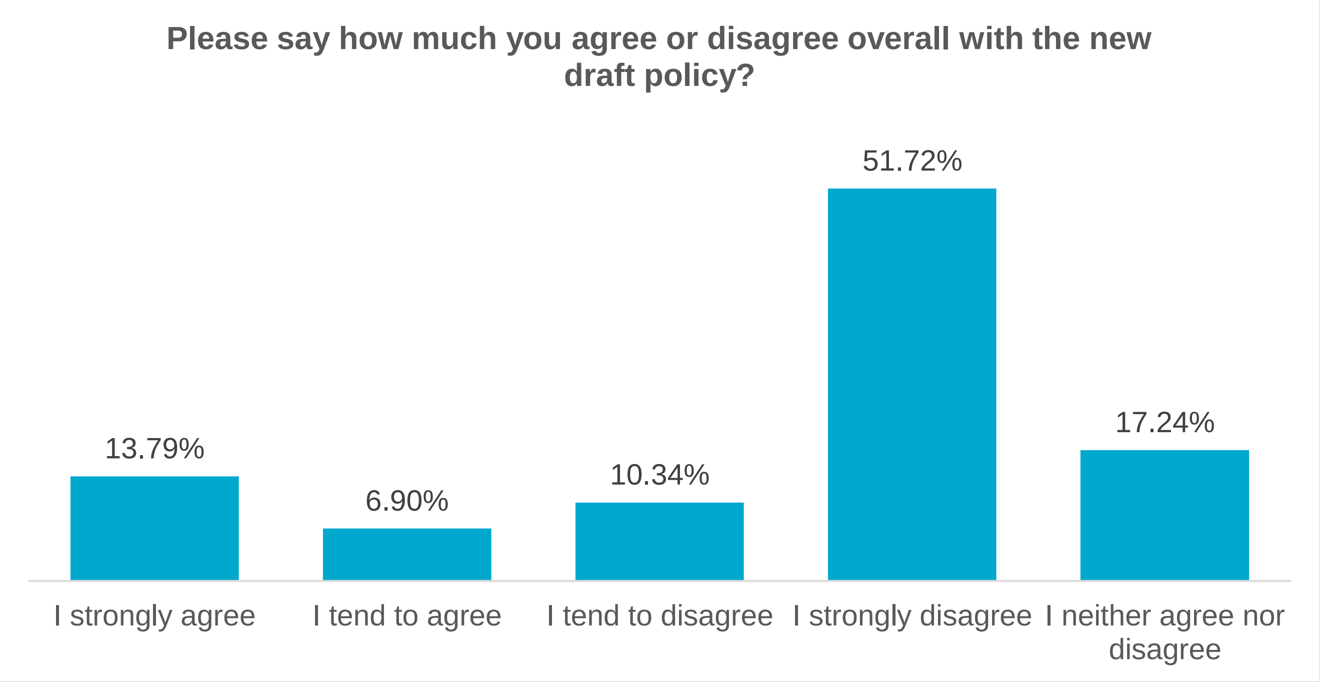
“Many people are unable to function until their sensory needs are met. They need support and strategies to allow them a quality of life. Without it the needs cause heightened anxiety and a cycle of mental health and wellbeing issues that affect all aspects of their lives.”

“Everyone should have access to these therapies if needed, with the relevant specialists.”

“Firstly, I am a parent who has had to pay for SI for my child as there is no service available on the NHS. He ended up being out of school (unable to attend) as the school could not or would not make the necessary reasonable adjustments. (Possibly because it wasn't through the NHS).”

Agreeing or disagreeing with the policy overall:

When considering the policy overall, a similar pattern of responses was received, with a larger proportion of respondents agreeing with the overall policy (20.7%) and a lower proportion of respondents strongly disagreeing, although this still amounted to over half the respondents (51.72%). Quite why 13% of respondents should strongly disagree with not routinely funding sensory integration therapy but not strongly disagree with the policy overall is not clear.



Base: 29 (closed responses)

Survey respondents were asked whether they wished to make any further comments about the sensory integration therapy policy or to explain their answers further. Over half of the respondents (53%) took the opportunity to make some further comments. In some cases this repeated what was written in response to the previous question or simply indicated that they felt the therapy should be funded, especially as little or nothing else was for this cohort of patients. Some of the comments expanding upon points raised or added additional points:

- Several respondents provided additional detail on their own experiences of the benefits of sensory integration therapy, either as a parent funding this themselves for their child or as a professional (teacher, CAMHS or OT), using this therapy or witnessing it being used to support children with ASD or ADHD. “My son who has ADHD Autism and learning difficulties benefited from the course of SI therapy he received. As a Scientist, a teacher and a mother I saw the effects with my own eyes. I ran voluntary sessions in my local school and have many colleagues in the medical profession who agree that this therapy works with many children although it is not always successful with genetic disorders (depending on the disorder).”
- Some respondents felt a nuanced approach to sensory integration issues was required, with a policy that allowed a stepped care model for children and families. “Sensory processing issues are so important to most if not all autistic children and if you have very complex/involved cases you cannot have a "one size fits all" approach - you need the individualised /nuanced/detailed assessment that can be given within a sensory integration approach, in order to assist children to be supported to learn.”
- There were also some additional comments regarding the evidence used to determine the policy and about how NICE guidelines may not be up to date. “Can I suggest that the reason sensory is not in the NICE guidance is because it has only recently been incorporated into the DSM V and is still filtering through into our policies & procedures in the UK? It was not in the triad of impairments originally, but it is now at the centre of the "triangle" as it does affect other parts of it, and also it increases anxiety (anxiety is also increased by sensory issues). So Sensory is a key part of ASD and affects behaviours and ability to learn.” Further comment is also made about other counties/CCGs within the UK supporting the use of sensory integration therapy.
- The evidence base and research supporting the use of Sensory Integration Therapy and the importance this has for children and adults with ASD, ADHD, Learning Difficulties and other conditions was explored in some detail by the Occupational Therapists from Lancashire and South Cumbria Foundation Trust, who responded separately as part of the engagement process. This was, in essence, a clinical engagement response but, as it was submitted during the public engagement process, is added in full in **Appendix 1**. The information submitted by the Occupational Therapists, supported by comments from parents, challenges the lack of evidence around the clinical effectiveness of Sensory Integration Therapy and champions the vital role that understanding and supporting sensory difficulties in the learning and development of children and adults with ASD and other conditions.
- The Occupational Therapist responses, together with a few other respondents, also highlights the confusion around the use of language or terminology in relation to sensory integration therapy, sensory diets and other terms, in both professional and lay circles, and this should be addressed.
- Comment is also made about the inequality the current environment creates, as those who can afford to pay privately can get SI support for their children while those who cannot afford this have no alternative. “It would have been nice to have been able to access this treatment free through the NHS as I was unable to pay for it because I had to

give up my career in order to care for my son and as such was unable to afford to complete the treatment.” “I am a parent of a 12-year child who had to leave education as we couldn't access the proper support that would enable her to continue to learn within the school environment. The only real help and support I have ever received in the last 4 years has been that which I have paid for myself and accessed privately - so I would say - what about all of those parent/carers/children/families who cannot afford to do this?”

- There was also an additional comment concerning the difficulty in reading the policy and completing the survey as it was not ‘phone friendly, and that it was not in easy read format, which would exclude some parents from being able to participate.

The comments received are shown in full below:

“There is no support for the effects sensory processing disorder has on our children and how as a parent it is best to support them. We keep being told early intervention is most important then we are left to work it out ourselves”

“I am a parent of a 12 year child who had to leave education as we couldn't access the proper support that would enable her to continue to learn within the school environment. The only real help and support I have ever received in the last 4 years has been that which I have paid for myself and accessed privately - so I would say - what about all of those parent/carers/children/families who cannot afford to do this? Clearly they are just left without support. Sensory processing issues are so important to most if not all autistic children and if you have very complex/involved cases you cannot have a "one size fits all" approach - you need the individualised /nuanced/detailed assessment that can be given within a sensory integration approach, in order to assist children to be supported to learn.”

“There should be more funding, research and best practice shared of sensory integration therapies across Lancashire (& across UK)
Parents and children (or persons affected) should have education on how sensory integration helps them and of the different practices/ resources which could be used to help the individual- plus funding for resources to use at home (if applicable).
More therapists and resources needed in schools and care facilities”

“I would like to see a policy which allows a stepped care model for sensory integration work with children and families. For many, there is a need for general advice and guidance across home and school (e.g. movement breaks, adaptations to the environment). Other people will need a more personal and tailored plan, which should be readily available (and which in my own CAMHS work over 20 years I have seen to be one of the most helpful, practical and effective ways to make a difference - trouble is it is rarely available). For others yes they may need individual sensory integration therapy. Increased OT or other appropriate professional time and roles could allow all of the above to be available to those who need it, as part of ASD pathways and outside of them.”

“For a young individual to reach their outcomes an accurate sensory assessment is vital so that they can remain regulated, calmer, concentrate, feel part of the community as more able to integrate with others.”

“This should be fully commissioned by NHS, as in Lancashire occupational therapist assessment doesn't do sensory integration. This is done through paediatric learning disabilities team which is very overstretched I feel.”

“The policy to difficult really for me to understand as written.
All I would like is to support is that there is a requirement for better understanding and support for sensory integration therapy

There is nothing available so support and I don’t wish for this to continue support is needed”

“Support for children with ASD is woefully underfunded and not easily available. Anything which can support child development should be offered.”

“More important things to spend money on. There are other services constantly being cut despite evidence showing how much they benefit they provide and to a wider cohort.”

“If central government can provide over £96 billion to fund private healthcare, it can most certainly fund NHS treatment. Local councils need to hold the government to account and fight for its communities.”

“Sensory therapy helped my son immensely when he was small. It was the difference between being able to focus and concentrate and do well at school. To stop funding vital therapy is disgusting.”

“My son who has ADHD Autism and learning difficulties benefited from the course of SI therapy he received. As a Scientist, a teacher and a mother I saw the effects with my own eyes. I ran voluntary sessions in my local school and have many colleagues in the medical profession who agree that this therapy works with many children although it is not always successful with genetic disorders (depending on the disorder). The therapy is not a cure but helped with many developmental issues that my son had and as such he turned into a child that would have had to go to special to one capable of attending mainstream. It would have been nice to have been able to access this treatment free through the NHS as I was unable to pay for it because I had to give up my career in order to care for my son and as such was unable to afford to complete the treatment. It should either be available through the OT's or via educational establishments.”

“As the policy is written on the basis of lack of evidence for effectiveness I suggest that more recent research that supports effectiveness should be considered and not just that within the NICE guidelines.”

“Other counties and CCG's see the value of SI as a form of therapy that can help the parent/carers as well as the child young person and form part of a preventative programme of help that will reduce the health costs to the NHS in the long run.”

“Not every child is the same.”

“It puts no account of individual need.”

“No alternative provision suggested. There's already a huge gap in provision, please don't make it wider!”

“I think a service should be available and schools/setting with several people with sensory needs be available. Signposting for individuals and families is key to this.”

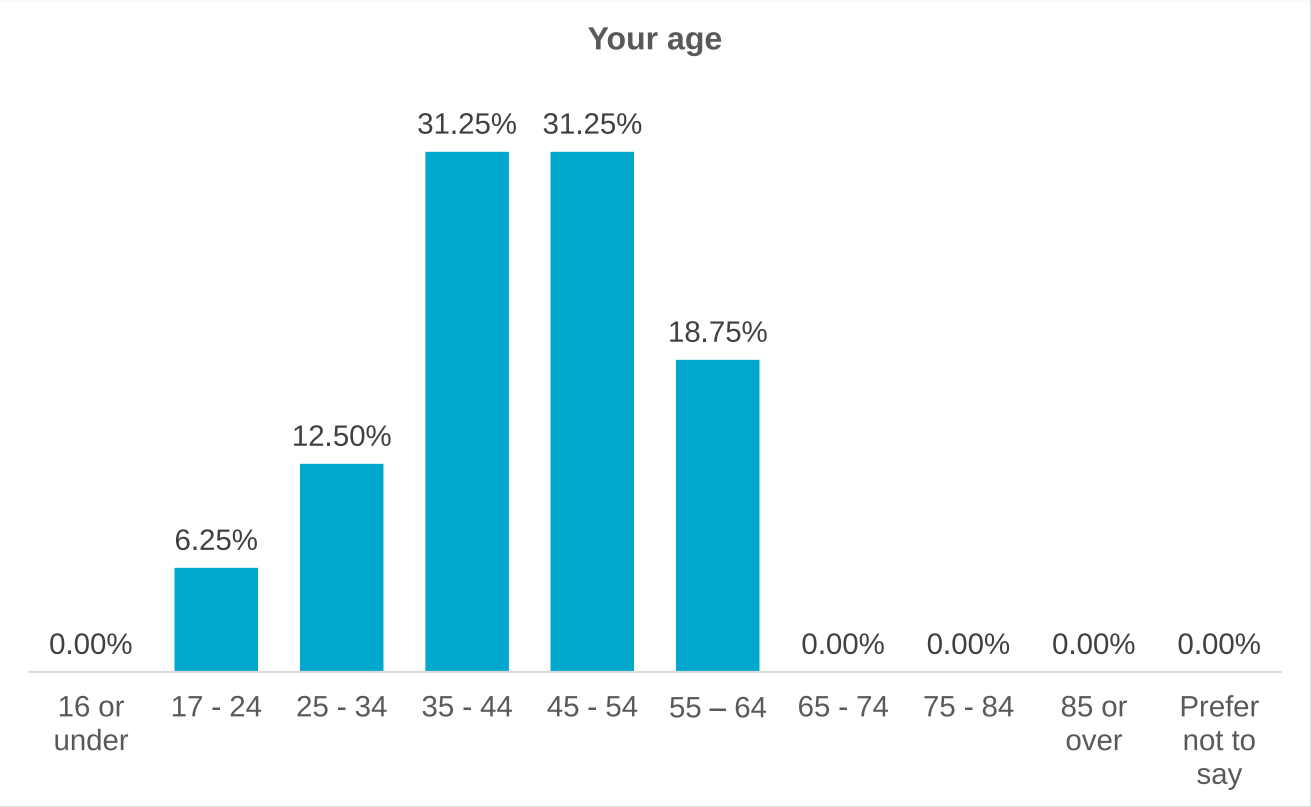
“I am putting that I disagree but to be honest, I completing this on my phone and the policy is not phone friendly. Part of it is cut off my screen and I cannot alter that. Also it is not in an easy read format, which would exclude some parents from being able to participate.”

“Can I suggest that the reason sensory is not in the NICE guidance is because it has only recently been incorporated into the DSM V and is still filtering through into our policies & procedures in the UK? It was not in the triad of impairments originally but it is now at the centre of the "triangle" as it does affect other parts of it, and also it increases anxiety (anxiety is also increased by sensory issues). So Sensory is a key part of ASD and affects behaviours and ability to learn."

Demographics

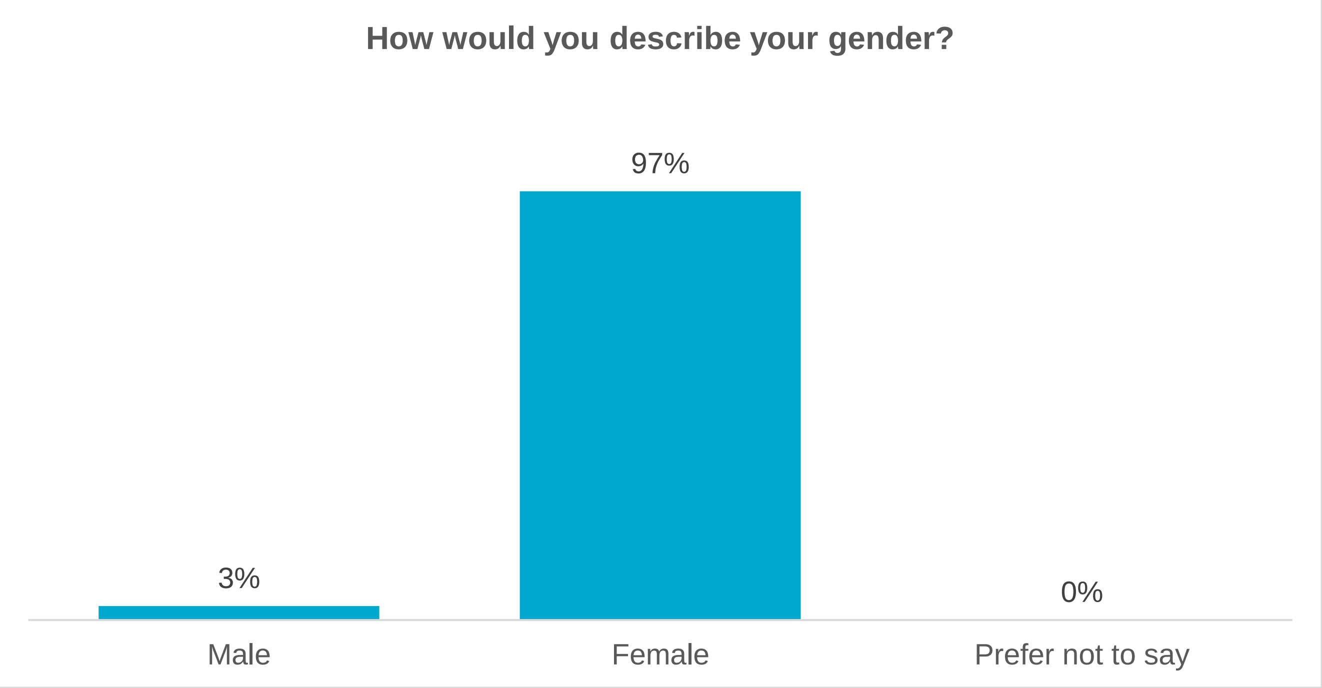
It is important to ascertain the demography of those providing their responses in order to determine which sections of the communities the NHS serves have or have not contributed to the feedback received.

Almost two thirds of survey respondents (62.5%) were aged between 35 and 54, with a further 12.5% between the age of 25 and 34. This tends to reflect the pre-dominance of parents responding. All respondents were of working age, with no-one above the age of 64 responding and no-one below the age of 17.



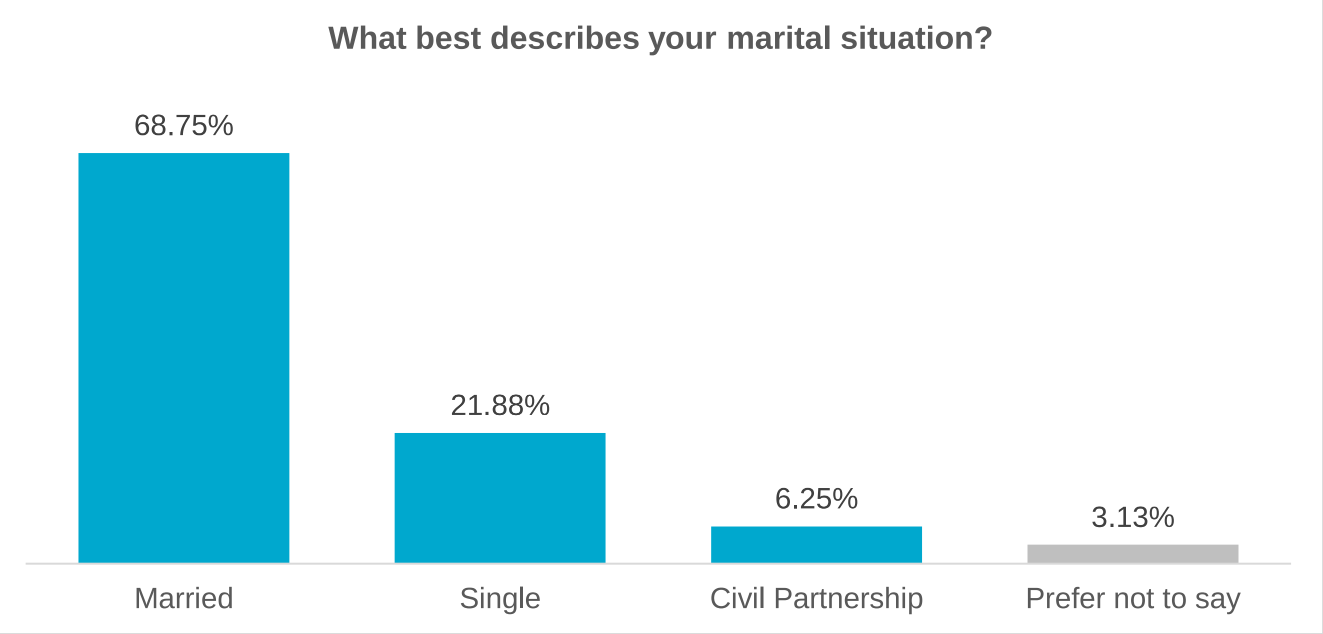
Base: 32 (closed responses)

Most survey respondents were female (97%) with only one respondent describing their gender as male (3%). Although this is a major imbalance, as they were mainly responding as parents, it cannot be determined that this has any material impact in the responses received, although it is possible. All respondents indicated this was the same gender that they were given at birth.



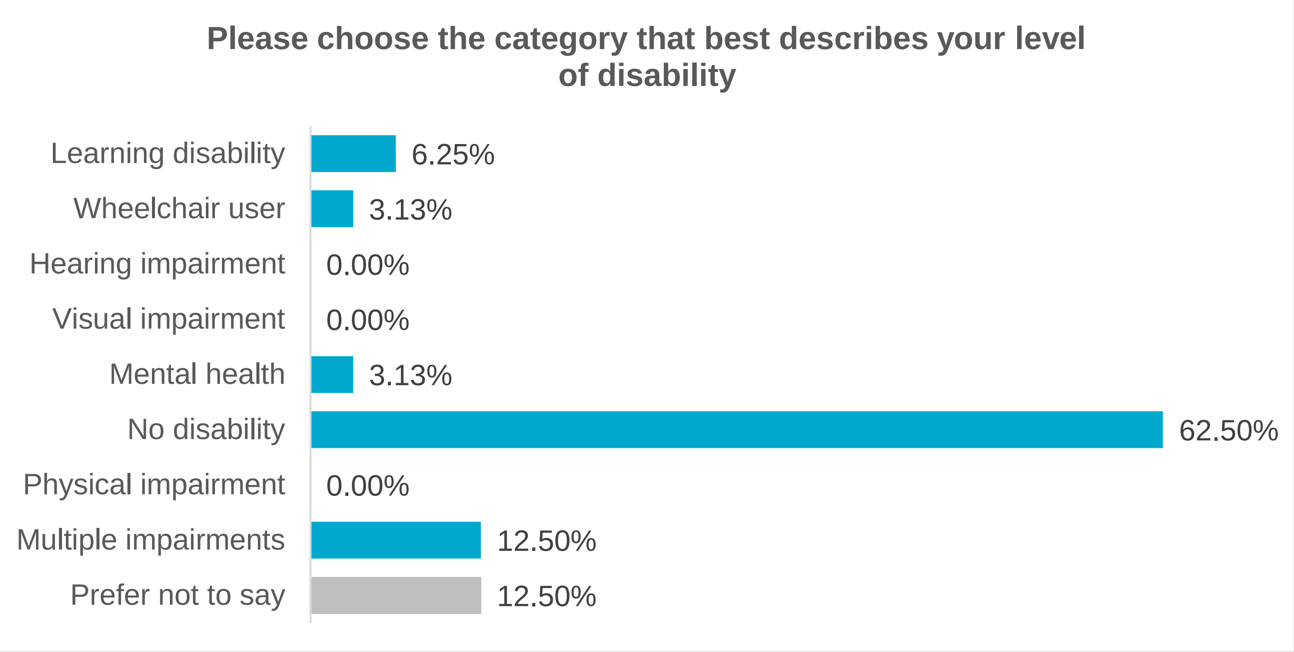
Base: 32 (closed responses)

Over two thirds (69%) of survey respondents indicated they were married with just over a fifth confirming they were single (22%). A few respondents indicated they were in a civil partnership and only one respondent preferred not to say.



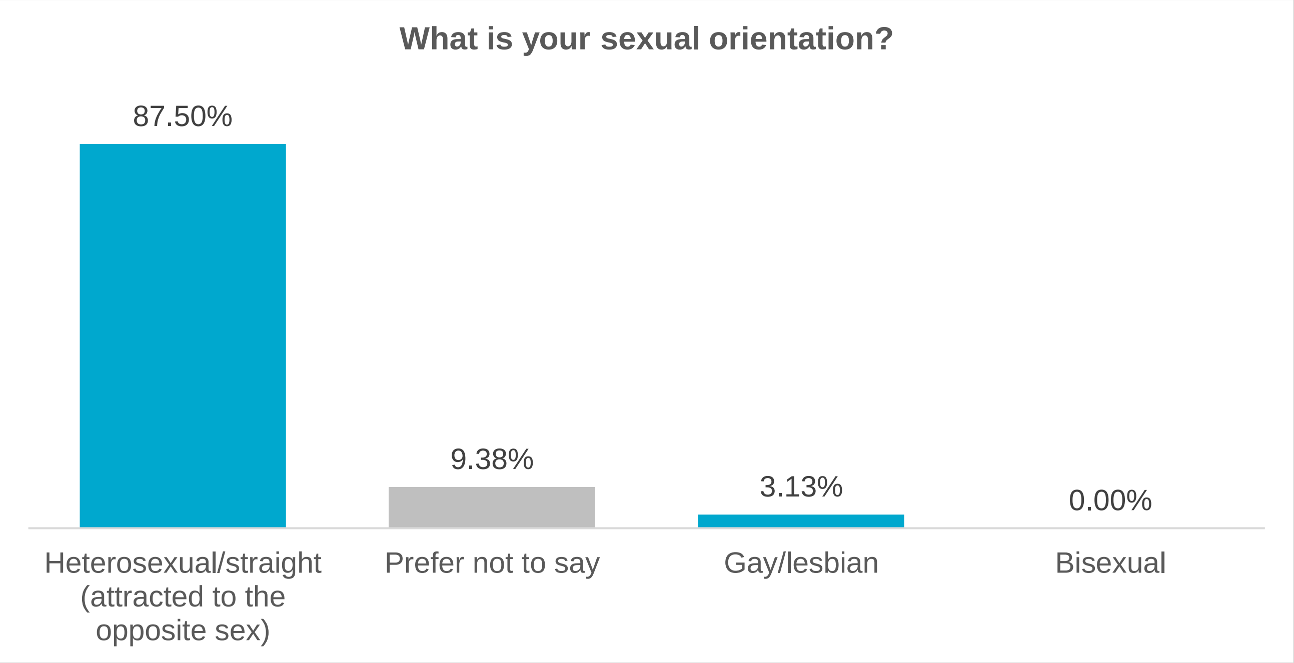
Base: 32 (closed responses)

Approximately six in ten (62.5%) respondents did not consider themselves to have a disability. A quarter of respondents (25%) indicated they have a disability, with the majority of these having multiple impairments. This is a significant proportion of respondents with disabilities, and higher than the national average. A further 12.5% preferred not to say.



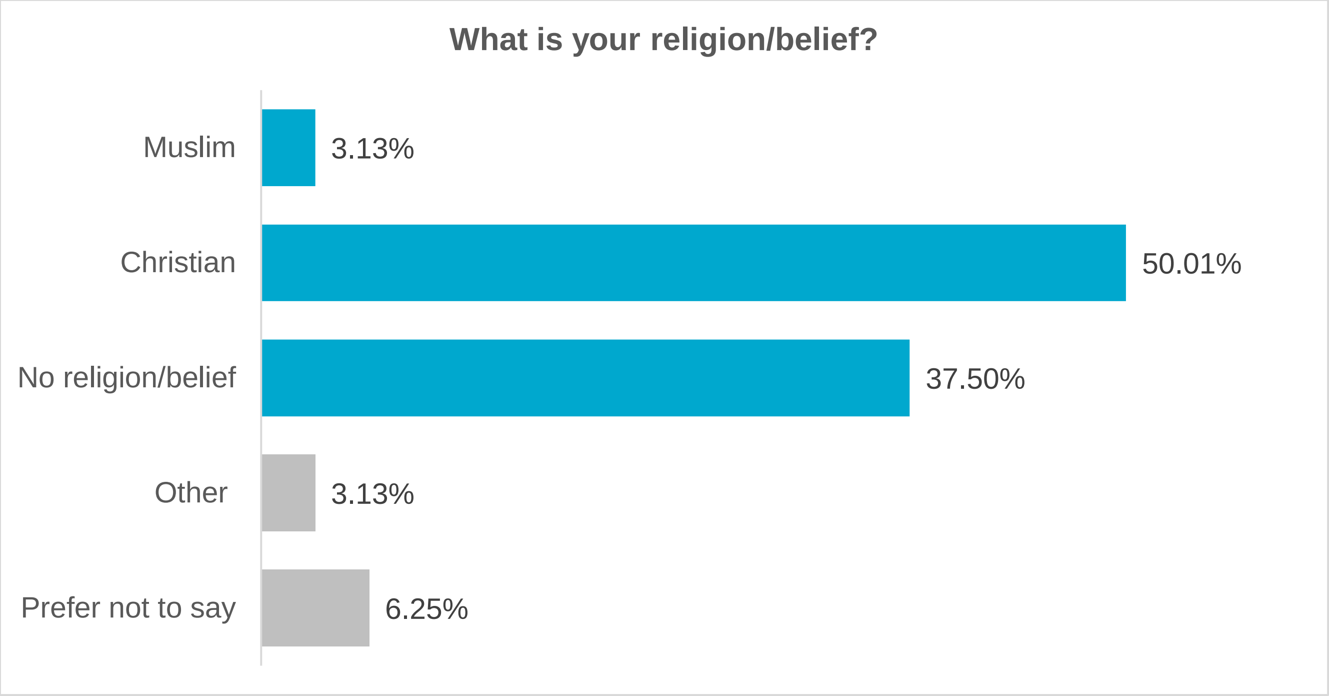
Base: 32 (closed responses)

Over four-fifths of the survey respondents were heterosexual (87.5%), with 3.13% gay/lesbian and 9.38% who preferred not to say.



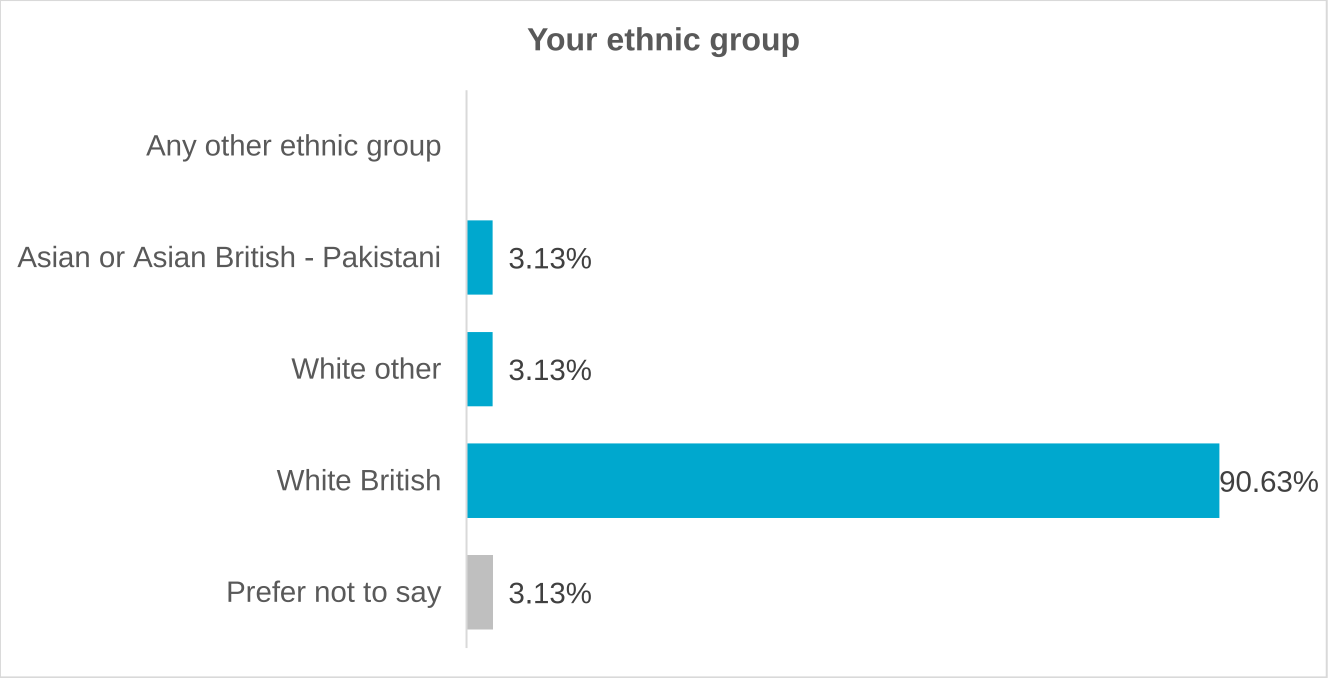
Base: 32 (closed responses)

Just over half of survey respondents (50.1%) were Christian whilst over a third (37.5%) of respondents had no religion or belief. 6.25% of respondents preferred not to say and a further 3.13% were Muslim..



Base: 32 (closed responses)

Nine tenths of all the survey respondents were White British (90.6%) with only 6% of respondents from other ethnic backgrounds. 3.13% of respondents preferred not to say. Other ethnic groups were therefore, underrepresented in these responses.



Base: 32 (closed responses)

Conclusion

The level of response to this survey was statistically low and the sample size gives a wider margin of error and a confidence level in the results below the industry standard, but this should be viewed with caution, as sensory integration therapy has a relatively small cohort of the population that will have any real awareness of it. Although it was not fully representative, some protected groups, especially disabilities, were well represented. Age groups were also reasonably well represented, given the usual demographic of the treatment concerned.

All survey respondents had read the policy, and more than 60% of survey respondents disagreed with the policy criteria and the policy overall, most of whom strongly disagreed. This correlates with more that 60% of respondents indicating they had experience of sensory integration therapy. Overall, this was a reasonable, although low, level of response but one that may reflect a relatively low level of awareness and experience of this treatment within the general population.

The level of strident opposition to the policy from respondents should be acknowledged, together with the despair expressed by some respondents on accessing support of any kind for children with ASD and other conditions. There are, therefore, a few points raised by respondents that need some consideration within the policy or in a wider perspective. These are as follows:

- Whether the evidence base on which the policy relies needs further examination and liaison with Occupational Therapists within localities included in any further research
- Whether by implementing the policy as it stands the inequalities identified by respondents will be exacerbated, intentionally or unintentionally, and if so, what action, if any, may be needed
- Whether the nature of the evidence provided, and questions around what constitutes evidence, should lead to a change in the intentions of the policy or its withdrawal
- Whether the purely clinical orientation of this and other policies is restricting patient and public understanding, participation and feedback on clinical commissioning policies

The CPDIG are asked to consider these points and note the other points made. CPDIG is also asked to note that overall, responses were reasonably low and may represent a risk of challenge. It should also be noted some respondents provided contact details and will require feedback on decisions/progress made.

Appendix 1

Occupational Therapist Feedback

Written by: [redacted], Professional Lead for Occupational Therapy- LSCFT

08 July 2021

This paper is a response to the CCG Draft Policy for Sensory Integration Therapy:

This response is based on the following:

- The authors clinical experience and knowledge gained from Post Grad Certificate in Sensory Integration, gained in 2017
- Review of recent guidance and research literature.
- Interviews and workshops with Specialist Occupational Therapists within LSCFT who have specialist training and accreditation in ASI

The response focuses on the following areas:

1. Evidence base for Sensory Integration Therapy
2. Terminology
3. Principles of appropriateness, principles of effectiveness and cost effectiveness
4. Exceptions to the policy
5. Suggested model of care

1. Evidence base for Sensory Integration Therapy

Within the draft policy for Sensory Integration Therapy it is stated that:

> *"The CCG will not routinely commission sensory integration therapy, as it considers that the intervention does not accord with the Principles of Effectiveness and Cost-Effectiveness"*
>
> SIGN 145 is referenced for this statement.

NICE CG170, CG128 and SIGN 145 highlight that:

- Hyper- or hypo reactivity to sensory input or interest in sensory aspects of the environment are listed in the DSM-5 criteria for Autistic Spectrum Disorder (ASD)
- People with ASD vary considerably in their strengths and difficulties. As such a more detailed assessment, which includes motor and sensory skills may be helpful
- When reviewing motor and sensory skills SIGN 145 states that there is insufficient evidence to make recommendations about OT or Physio assessment; however sensory behaviours being taken into account when profiling the needs of individuals with ASD is strongly advocated and it is suggested that OT and physio assessment should be considered "where relevant".
- It is suggested that adapting the communicative, social and physical environments of children and young people with ASD may be beneficial, including minimising sensory irritations
- Within SIGN 145 a "good practice point" suggests that children and young people may benefit from occupational therapy, advice and support in adapting environments, activities and routines in daily life. When defining occupational therapy it is recognised that therapists may draw on an understanding of sensory processing and intervention could include reducing the impact of sensory sensitivities.

- NICE CG170 and CG128 recommend a referral to a regional or national autism service if there is a lack of local skills and competencies to provide interventions and care for a child or young person with a complex coexisting condition, such as a severe sensory or motor impairment.
- SIGN 145 made the following research recommendations in relation to sensory integration:
    - controlled trials with large sample sizes to evaluate the efficacy of sensory integration and sensory-based interventions
    - a study into the neurophysiological mechanisms by which sensory regulation influences psychological state and behaviour in ASD

The above highlights that sensory challenges should be considered a key focus of assessment and provision for children and young people with ASD. It also highlights that occupational therapist, with relevant clinical competencies are able to contribute to this. It is acknowledged in SIGN 145 that further research is required to confirm the efficacy of such approaches. A randomised control trial comparing “sensory integration therapy” with “usual treatment” is currently on the way; this study is aiming to have 216 participant, 108 per group which is a very large sample size (Randell et al 2019)

There is a wealth of scientific literature spanning 5 decades concentrating on "sensory techniques", "environmental modification", "sensory based approaches" and "sensory integration therapy"- this is a very broad, sometimes contradictory collection of intervention tools (Bundy and Lane 2020). The literature is further compounded by differing dosages of therapy being included in studies i.e. variance in the frequency of therapy sessions (1 -3 times a week) and the duration of treatment (anything up to 40 weeks) (Schoen et al 2019).

The literature also covers a wide range of conditions including but not limited to: ASD, DCD, ADHD and Learning difficulties; each of which contains a spectrum of difficulties and/or sub classifications (Bundy and Lane 2020). Alongside this, sample characteristics are often poorly defined and there is often an omission to complete an adequate sensory assessment; this makes the samples in the literature very heterogeneous with no certainty that children included in the studies have an underlying sensory integration difficulty which is impacting on function (Schoen et al 2019).

Up to 2016, the inclusion criteria of relevant systematic reviews, such as those referenced in the SIGN 145 guidelines have significant flaws in their search and selection criteria for example:

- They combined studies using "sensory based approaches" and studies using "sensory integration therapy" into the same review.
- They did not rigorously review studies purporting to be using "sensory integration therapy" against the sensory integration fidelity measure. In some studies it is not possible to tell what invention was actually provided, in others it is clear that the intervention used does not meet the criteria for sensory integration therapy.
- There is significant variation in the sample characteristics across studies included in systematic reviews and at times there is a lack of clarity of sample characteristics. This results in a lack of homogeneity and therefore difficulties with ascertaining meaningful findings.
- Within individual studies participants were not given a comprehensive assessment of sensory integration to confirm that they were appropriate candidates for intervention i.e. children experiencing difficulties processing and integrating sensation and this is impacting behaviour and functional skills

This significantly reduces the confidence in any conclusions drawn from such systematic reviews (Schoen et al 2019).

Schoen et al (2019) completed a systematic review of Ayres sensory integration intervention (ASI) for children with autism. This systematic review ensured:

- Only studies that meet the ASI fidelity measure were included, ensuring confidence that the same intervention is under investigation in all included studies
- Only studies that used a group comparison design (with or without random assignment) or a multiple baseline, changing criterion, or alternating treatment single case experimental design were included.
- Sample characteristics were narrow and clearly defined: diagnosis of autism or pervasive developmental disorder, age 0-18, with an IQ above 65
- Inclusion of research papers from 2006-2017

Three research papers were included in this systematic review, 2 of which were randomised control trials. Using Council for Exceptional Children (CEC) standards for Evidence-based Practices, it was concluded that ASI is an evidenced based approach with a strong effect size (effect size takes into account the meaningfulness of the outcomes for the population being studied).

The above research and national guidance support the need to comprehensively assess the sensory challenges for children with ASD and support the need of occupational therapy, ASI and sensory based interventions. A more extensive review of the literature would provide a more robust understanding of the same for children, young people and adults with:

- Other neurodevelopment disabilities including: developmental coordination disorder (DCD), attention deficit hyperactivity disorder (ADHD) and specific learning difficulties
- Learning difficulties
- Mental health difficulties

2. Terminology

Within the draft policy for the commissioning of healthcare it is stated that:

> *"In current practice there is no single agreed definition of what constitutes Sensory Integration Therapy. The various schools use different theories and approaches and involve markedly different procedures. The Ayres Sensory Integration® is an attempt at standardisation, but even within that school there is no single specific intervention described. For the purpose of this policy the CCG defines sensory integration therapy as stand-alone, one-to-one clinic based therapy for children or adults who have been assessed to have a degree of sensory dysfunction."*

It is noted that there is inconsistency with professional language used in the literature leading to misunderstandings and misinterpretations of research results. However a definition for what constitutes Ayres Sensory Integration (ASI) is clear and non-negotiable. There is a fidelity measure that must be adhered to in order for an intervention to be deemed ASI. A more accurate CCG definition of sensory integration therapy would be:

> *One-to-one clinic based therapy which adheres to the ASI fidelity measure and is provided for children or adults who have been assessed to have a degree of sensory dysfunction*

It is noted that the policy is focused on sensory integration therapy. It is not clear from the document what the commissioning intentions are to support an appropriate assessment and provision for children with potential sensory challenges. The OT process covers assessment, plan of intervention, implementation and evaluation. The evidence and guidance discussed above advocates sensory challenges to be considered at each step of this process. It is important to recognise that ASI is one intervention tool that can be implemented by appropriately trained therapist. It does not cover the whole OT process, nor does it represent the sole focus of the sensory integration and sensory processing literature.

3. Principles of appropriateness, principles of effectiveness and cost effectiveness

Principles of appropriateness and principles of effectiveness are discussed in the draft policy for sensory integration. It is understood that the draft policy acknowledges the purpose of ASI to be appropriate but reasons there to be insufficient evidence to demonstrate its effectiveness in supporting or improving a patient's adaptive responses to sensory experiences.

In the 2019 systemic review completed by Schoen et al, ASI is shown to be an evidenced based approach for children with ASD. This is based on the findings of 3 group comparison studies including 2 randomised control trials completed by 2 separate research team. A further 3 group studies were reviewed but ultimately not included as they did not meet the strict criteria of the systematic review but it was noted that within each of these studies positive results were shown for participants receiving ASI. It is also highlighted that a further randomised control trial (Kashefimehr, Kayihan, & Huri, 2018) was published but not included in the results as it fell outside the date range of the systematic review. Though this study was not included it was reviewed by the research team who found it to be of robust methodology with positive impacts on individuals' participation in daily activities being demonstrated following ASI.

It is noted that the evidence used to inform the view of effectiveness and cost effective in the CCG draft position paper has been taken from SIGN 145 (2016). Schoen et al systematic review was published in 2019 and Kashefimehr et al randomised control trial was published in 2018. Both of these key research papers were not available for consideration when SIGN 145 was written. These more recent research papers are demonstrating clinically relevant effectiveness of ASI. Further publications of randomised control trials are expected in the near future; in particular Rendell et al (2019) have published a study protocol outlining their plans for a randomised control of sensory integration therapy verses usual care for sensory processing difficulties in autism spectrum disorder in children. Proposals include a large sample of 216 children, 108 per group.

Cost effectiveness is an interesting consideration. It is noted that in the more recent research papers demonstrating ASI effectiveness there is variance in dosage; even at the lower end this is an intensive block of therapy in terms of frequency and duration compared to other interventions typically offered within NHS therapy services. That being said a fair review of cost effectiveness should consider the other fiscal cost that ASI provision could potentially reduce e.g. level of 1:1 support needed in school, level of social care support needed at home, optimisation of engagement in universal services such as school, optimisation of engagement of other health care services i.e. CAMHS, LD support, Children's therapy services.

4. Exceptions to the policy

The draft policy states that:

> *"The current NICE guidance for Autism Spectrum Disorders does not make any mention of sensory integration therapy"*

While NICE CG170 doesn’t mention sensory integration therapy specifically it does recommend the following:

> *"Refer autistic children and young people to a regional or national autism service if there is a lack of:*
> - *local skills and competencies needed to provide interventions and care for a child or young person with a complex coexisting condition, <u>such as a severe sensory or motor impairment</u> or mental health problem, or*
> - *response to the therapeutic interventions provided by the local autism team."*

While it would be more helpful to have a definition of a "sever sensory or motor impairment" it can be inferred that the above recommendation includes:

- consideration of a thorough assessment of sensory challenges and how this impacts function
- Interventions focusing on reducing the impact of these challenges which would include sensory based strategies and/or ASI therapy

5. <u>Suggested model of care</u>

The draft policy does not indicate what should be commissioned in terms of assessment and intervention for children and young people with potential sensory challenges. Nor does it define the client group to which this service should be considered. The following is recommended as a holistic model of service provision. ASI provision is only one part of this and is highlighted in red.

Principles of the model

- Tiered outcomes based approached spanning: universal provision, targeted provision, specialist provision and highly specialist provision.
- Provision would be available to all those with potential sensory challenges impacting on engagement with activities of daily living. This includes:
    - Children and young people with ASD, ADHD, DCD, specific learning difficulties
    - Children, young people and adults with learning disabilities
    - Children, young people and adults with mental health difficulties
- Clear rationale would be needed re: moving up the tiers of provision with evidence that goals cannot be effectively met by a lower level of provision.
- Provision under this model should be integrated into current existing care pathways such as those in children’s therapy services, learning disabilities services, community CAMHS and Tier 4 CAMHS.

Clinical content of the model

- **Universal provision** would focus on education and awareness to support early identification of need, self-management and appropriate and timely referrals. Provision would include:
    - Web-based platforms to provide education and signposting
    - Tutorial/training sessions to the universal workforce (schools, charities, health visitors, school nurses)
    - Referrer training and guidance
- **Targeted provision** would focus on empowering children and parents/support network to achieve self-management. Provision would include:

    - Combination of group based workshops and 1:1 support. Focus on skilling up the child and/or their family to recognise their sensory challenges and reduce the impact of these by minor adaptations to the environment and/or activities
- **Specialist provision** would focus on providing an enhanced assessment and support plan. Provision would include:
    - 1:1 Specialist OT assessment reviewing the following as appropriate:
        - Sensory reactivity
        - Sensory discrimination
        - Praxis
        - Fine motor skills
        - Engagement with self-help activities, school activities and leisure activities
        - Environmental supports and barriers
    - Assessment tools would include one or more of the following:
        - Sensory integration and praxis standardised assessment- SIPT, EASI
        - Sensory reactivity standardised questionnaires – SPM, Sensory Profile
        - Visual perception standardised assessment- DVPT3, TVPS3, Beery VMI
        - Movement and coordination standardised assessment- BOT2, MABC2
        - Handwriting standardised assessment– DASH
        - Sensory clinical observations
        - General observations of performance in real life setting
        - Non-standardised activity based assessments- observation of ability to complete fine motor skills (scissor skills, writing), self-help skills (dressing, cutlery skills) and life skills (cooking, domestic tasks)
        - MOHOST
        - Departmental environmental risk assessments
    - Outcome measures would include one or more of the following:
        - Risk assessments which demonstrate the impact of a recommended control measure on risk
        - Goal attainment scale
        - Re-administer standardised assessment post intervention
        - Proximal and distal SMART goals
    - Intervention would include one or more of the following:
        - Bespoke advice and strategies re removing sensory triggers
        - Handover of tools that the child or young person can use to communicate their level of sensory challenge i.e. sensory ladder
        - Advice on sensory supports/activities and how these should be integrated throughout the day to support the just right challenge
        - Recommendations for equipment
        - Recommendations for environment adaptation
        - Provision of 1:1 therapy block aimed at supporting skill progression with self-help skills, life skills and/or fine motor skills
- **Highly specialist provision** would focus on providing enhanced therapeutic intervention. This would be based on assessment findings from specialist provision and would include one or more of the following:
    - Further assessment to collect any outlying baseline data
    - Provision of ASI
    - Provision of sensory based approaches
    - Provision of highly bespoke advice re development of a “calming environment” i.e. to prevent escalation of distress and to support de-escalation of any distress

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Response from [redacted], Specialist Occupational Therapist and Advanced Sensory Integration Practitioner, Children's Learning Disability Service, Lancashire Care and South Cumbria Foundation Trust

- (1:1) in policy - I have emailed [redacted] quite a substantial amount of research papers that evidences the effectiveness of sensory integration, as I was concerned the proposal is saying there is not enough evidence I was wondering what is considered enough evidence? I do have quite a few additional documents including a couple of case studies. I have a case study using ASI and a case study using sensory attachment intervention (SAI) – not my case studies but happy to share if needed.
- I was concerned about the wording around the training, (2.2) in policy - there is definitely agreed standardisation of Ayres sensory integration training - which the policy does not state. – I have completed both training pathways and the same principles are followed – it's just course content that is delivered differently – both follow ASI theory, use a data driven process and manulaization and fidelity protocols.

- I'm unsure what the policy is defining as one to one sensory integration therapy and what this therapy looks like? I think language is getting used interchangeably and it would be really helpful for language and terminology to be defined. I think this is also what parents find confusing, as I have many parents saying sensory diet, sensory assessment, sensory integration therapy but they are talking about the same thing (or different).
-
- I was also wondering how many families have actually accessed sensory integration therapy in Lancashire and what this therapy consisted of ? I think the numbers may be fairly low. Families may have accessed an assessment, and a "sensory diet" of

recommendations. There are some videos by CLASI that show case studies using sensory integration therapy. I’m happy to share the links if needed.

-
  - I do know a parent who is not a Lancashire parent, she’s from Liverpool. She has Ayres sensory integration therapy written in her son’s EHCP and would be happy to talk to you about how ASI has supported her son. If you would like me to put you in contact with her please let me know.
-

Lastly, I would be happy to volunteer for a planning group if you still need any more OT’s.

[redacted]

Communications and Engagement Specialist

05 February 2019

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