

Advice and Information on ASD ADHD pathway letters



The Essex Alliance

*Working together to represent the parents and
carers of Southend, Essex and Thurrock*

Southend Essex and Thurrock



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- Mid and South Essex (MSE) ICB covers Southend Essex and Thurrock (SET Essex).
- This information was gathered as part of Essex Family Forums work in Essex only, under the Essex Neurodevelopmental Strategic Partnership Group in Essex SEND.
- We included the views of parents and carers of Southend and Thurrock with a view to support wider system improvements across the MSE ICB Footprint, not just Essex.
- The Outcomes and effectiveness measures for ASD and ADHD diagnostic and support pathways, as mentioned overleaf are part of the Essex SEND Improvement work **only** and **do not** cover Southend and Thurrock. However, it should be noted that it is our ambition that any changes made as a result of this feedback would be implemented across SET Essex, where possible.

What is an Integrated Care Boards (ICB)?

Integrated care boards (ICBs) replaced clinical commissioning groups (CCGs) in the NHS in England from 1 July 2022. They are responsible for deciding how the NHS budget for a specific area is spent.

Outcomes and effectiveness measures for ASD and ADHD diagnostic and support pathways*



Following engagement with Parents In Essex Outcomes and effectiveness measures for ASD and ADHD diagnostic and support pathways measures were agreed and are supported by the Neurodevelopmental Strategic Partnership Group whose overall purpose is developing, overseeing, and advising the delivery of Neurodevelopmental Diagnostic and Early Support Pathway improvements across Essex.

These measures will be used to support the outcomes work. Membership of the Neurodevelopmental Strategic Partnership Group includes Essex County Council, Hertfordshire & West Essex ICB, Mid & South Essex ICB, Suffolk & North East Essex ICB, Multi-Schools Council and provider representation.

You can read more and access the document [here](#).

*Essex Families only

What district do you live in?

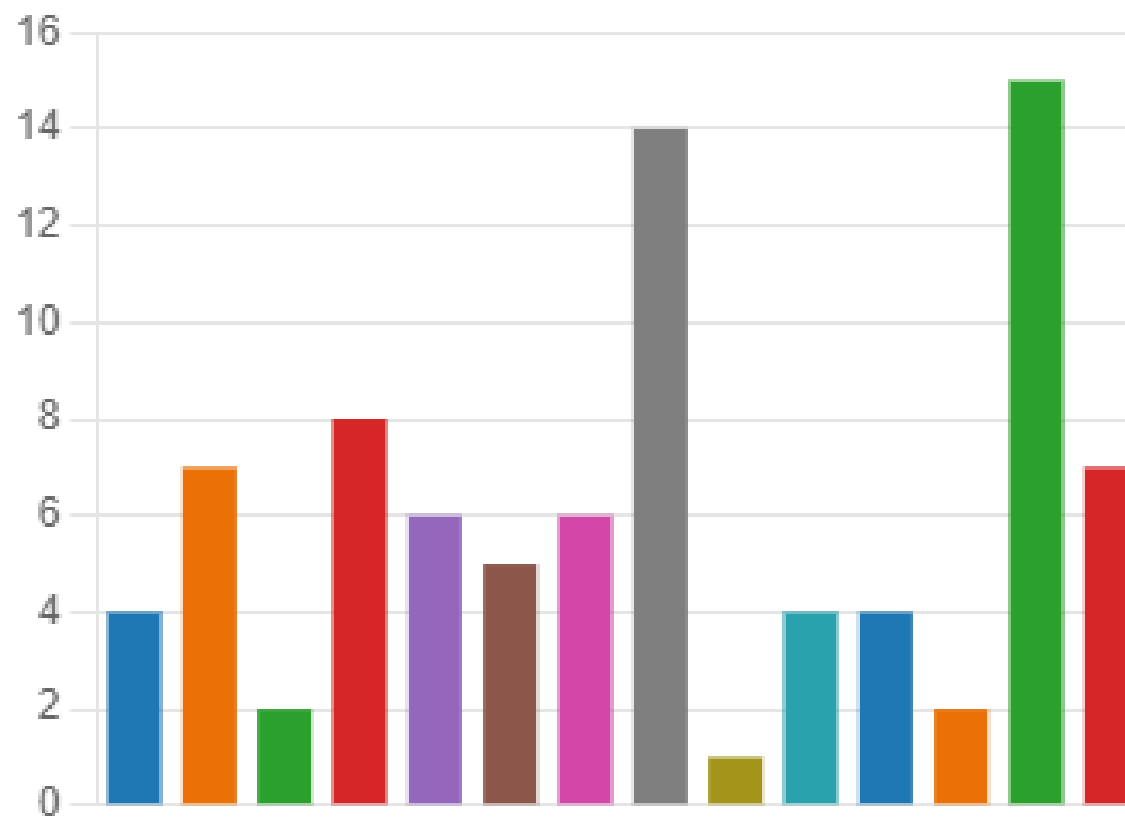


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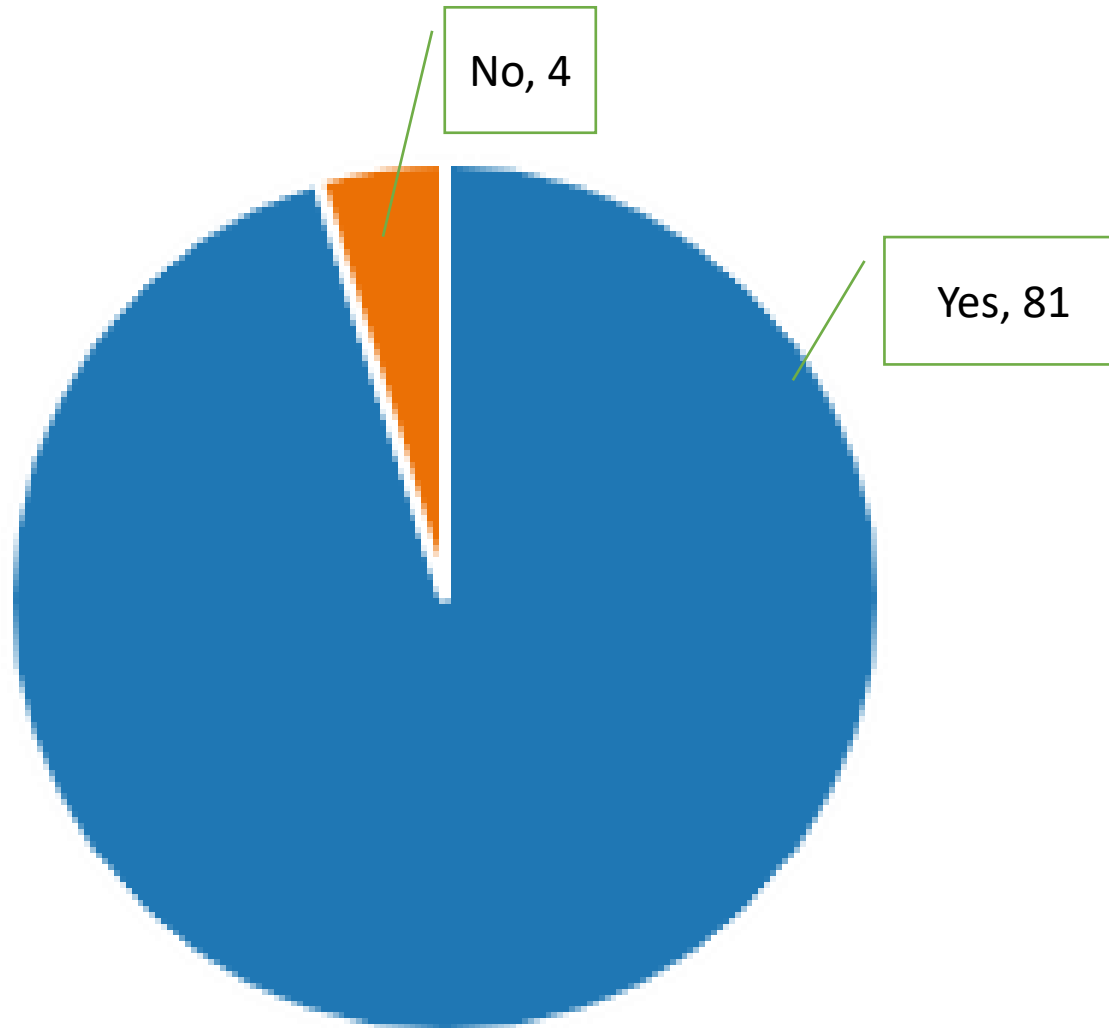
[More Details](#)

● Braintree District Council	4
● Chelmsford City Council	7
● Maldon District Council	2
● Tendring District Council	8
● Colchester Borough Council	6
● Rochford District Council	5
● Castle Point Borough Council	6
● Baidon Borough Council	14
● Brentwood Borough Council	1
● Uttlesford District Council	4
● Harlow Council	4
● Epping Forest District Council	2
● Southend on Sea City Council	15
● Thurrock Council	7

Total: 85

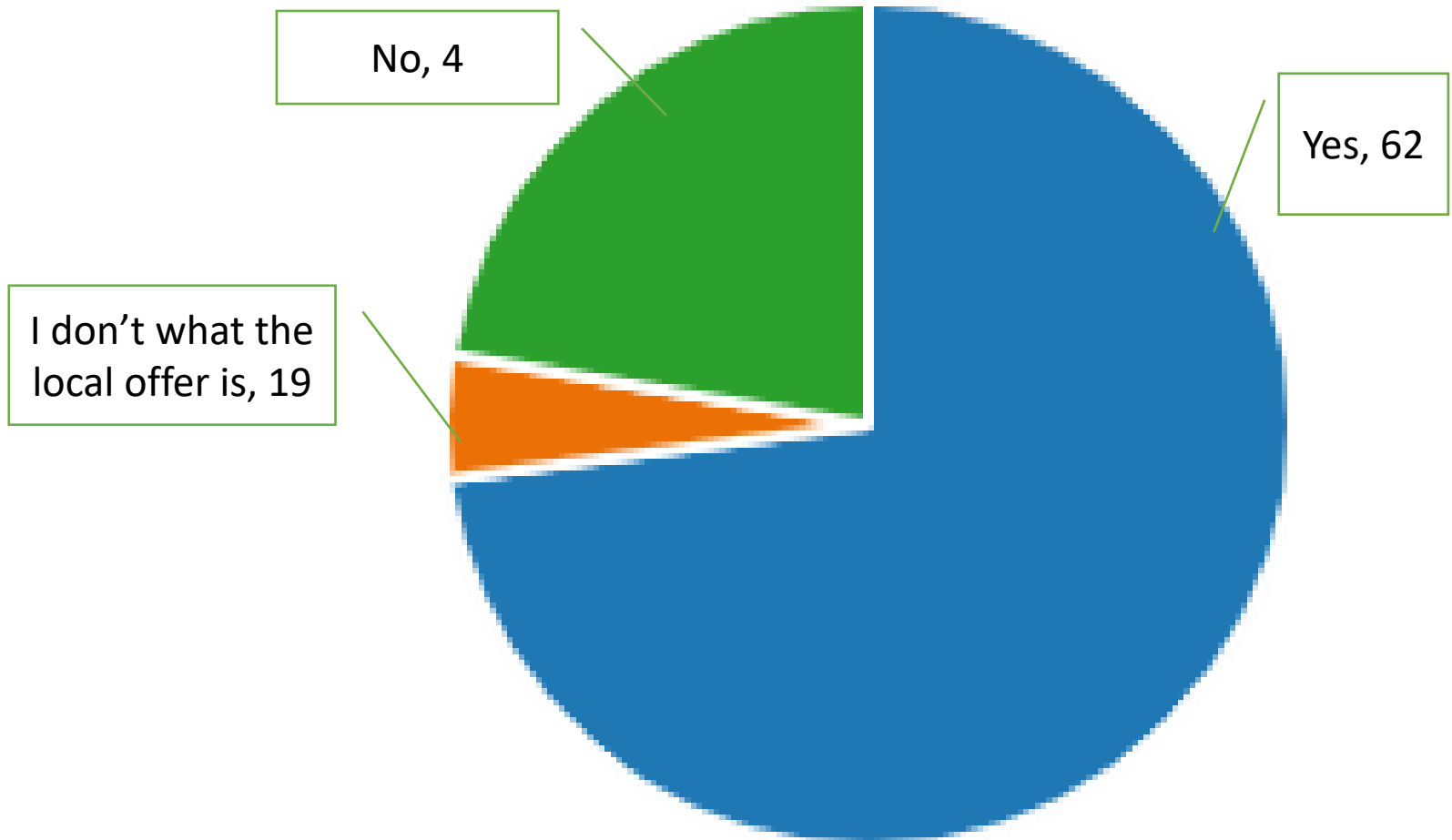


Do you want letters to provide information on helpful resources and/or services that provide advice and support?

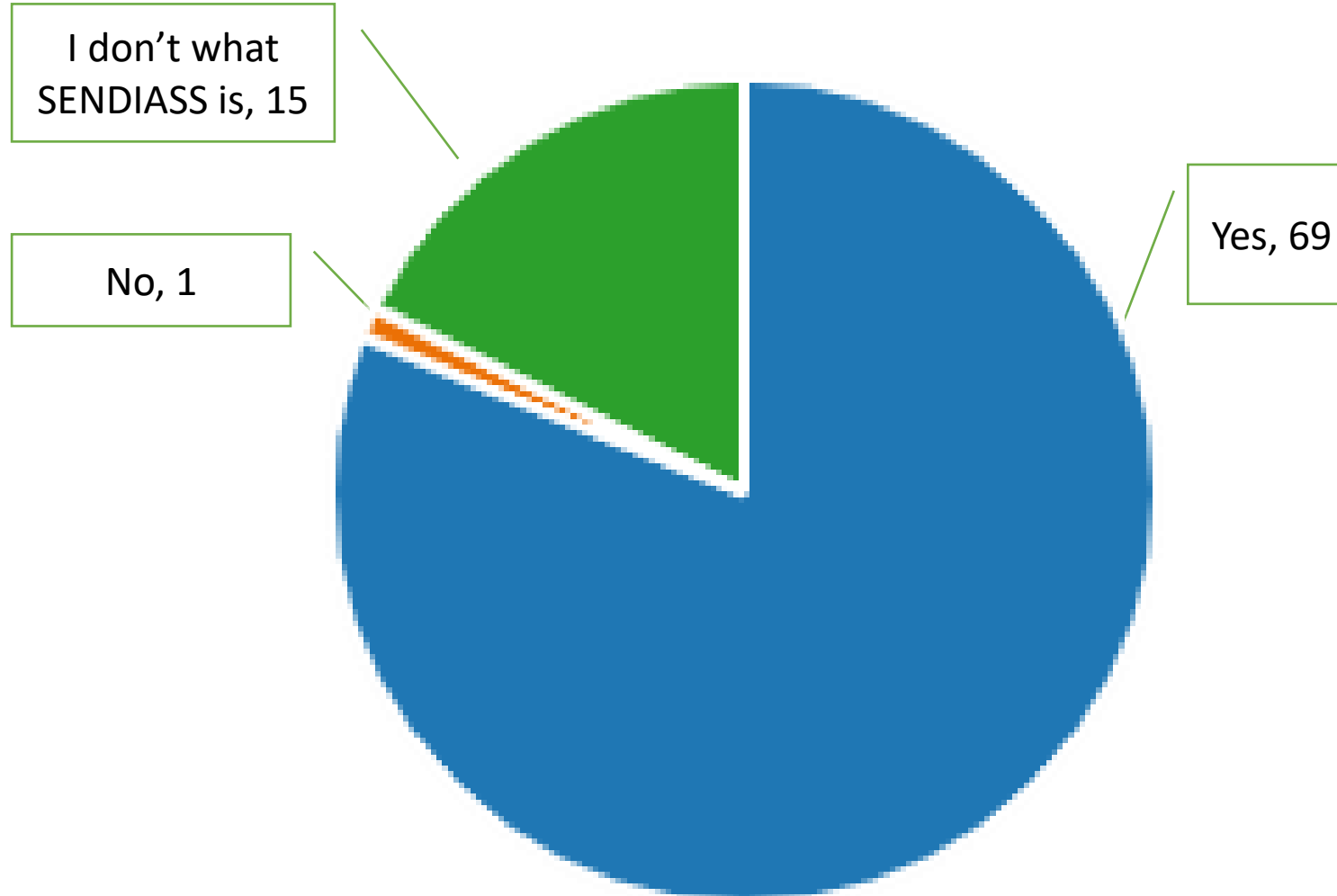


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Do you think the letters should signpost families to the appropriate Local Offer (Southend, Essex or Thurrock)



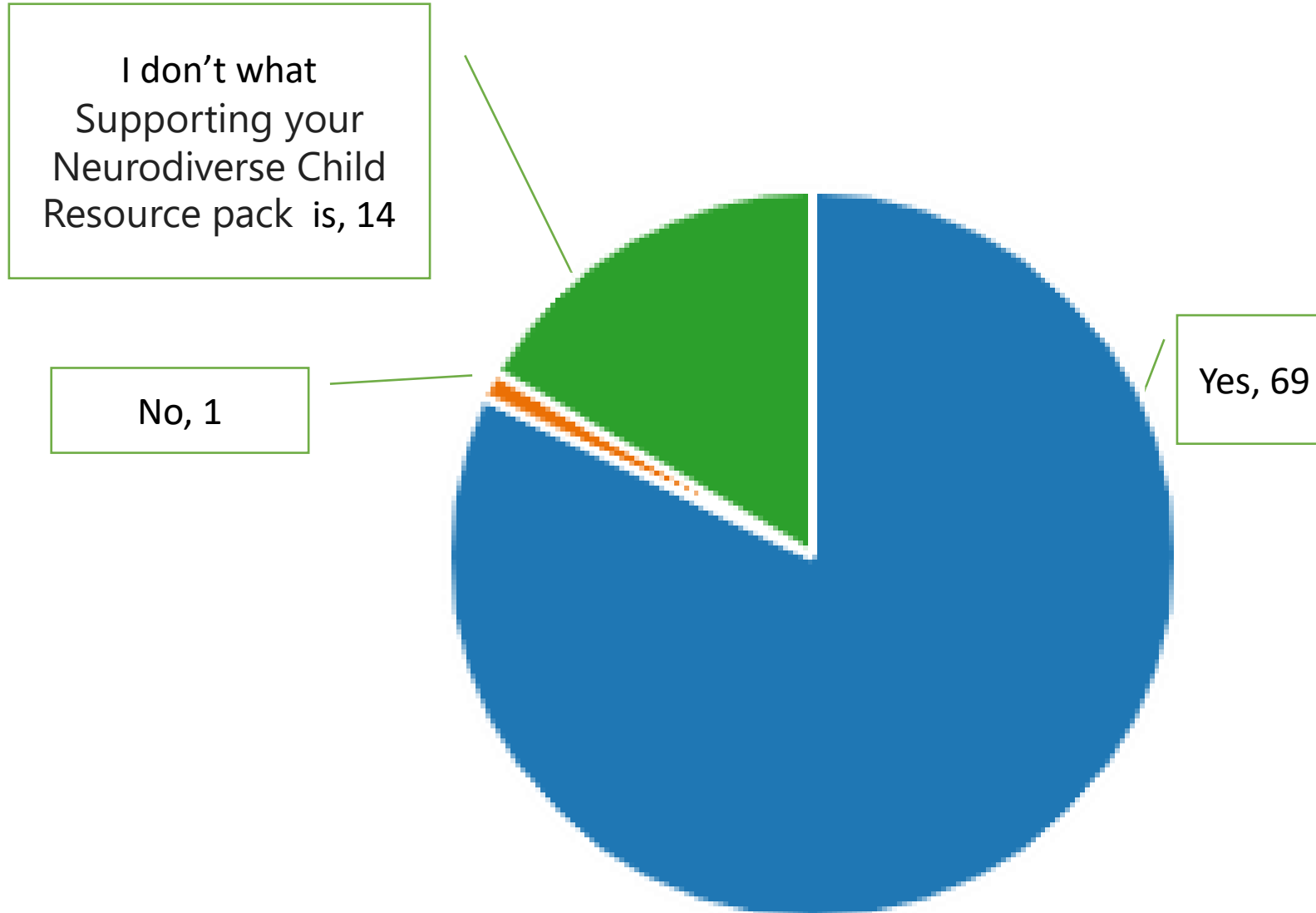
Do you think the letters should signpost families to the appropriate Special Educational Needs and Disabilities Information Advice and Support Services (**SENDIASS**) (Southend, Essex or Thurrock)



Do you think the letters should include a link to the Supporting your Neurodiverse Child Resource pack



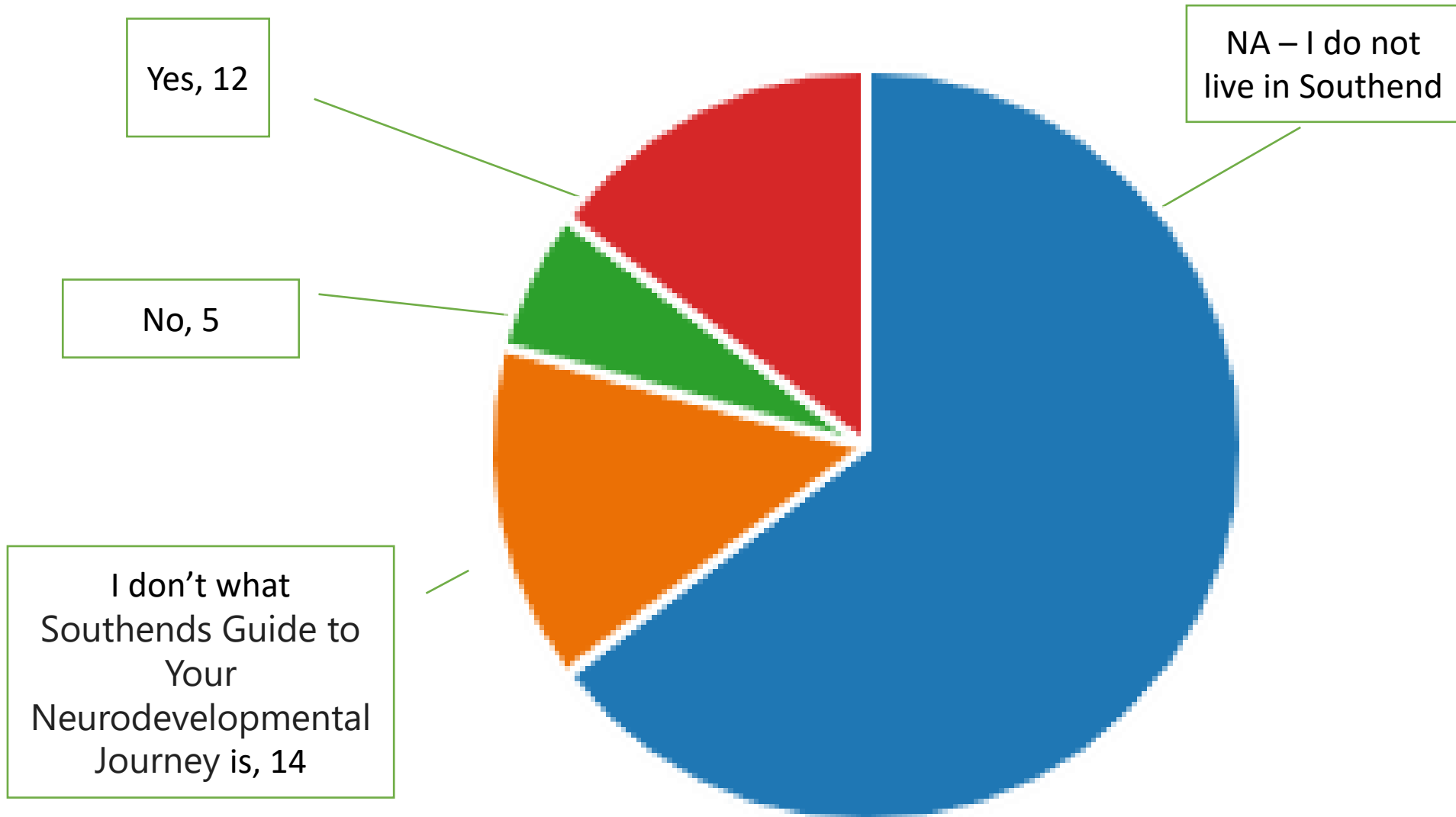
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Do you think the letters should include a link to the Southends Guide to Your Neurodevelopmental Journey (Southend Families only)



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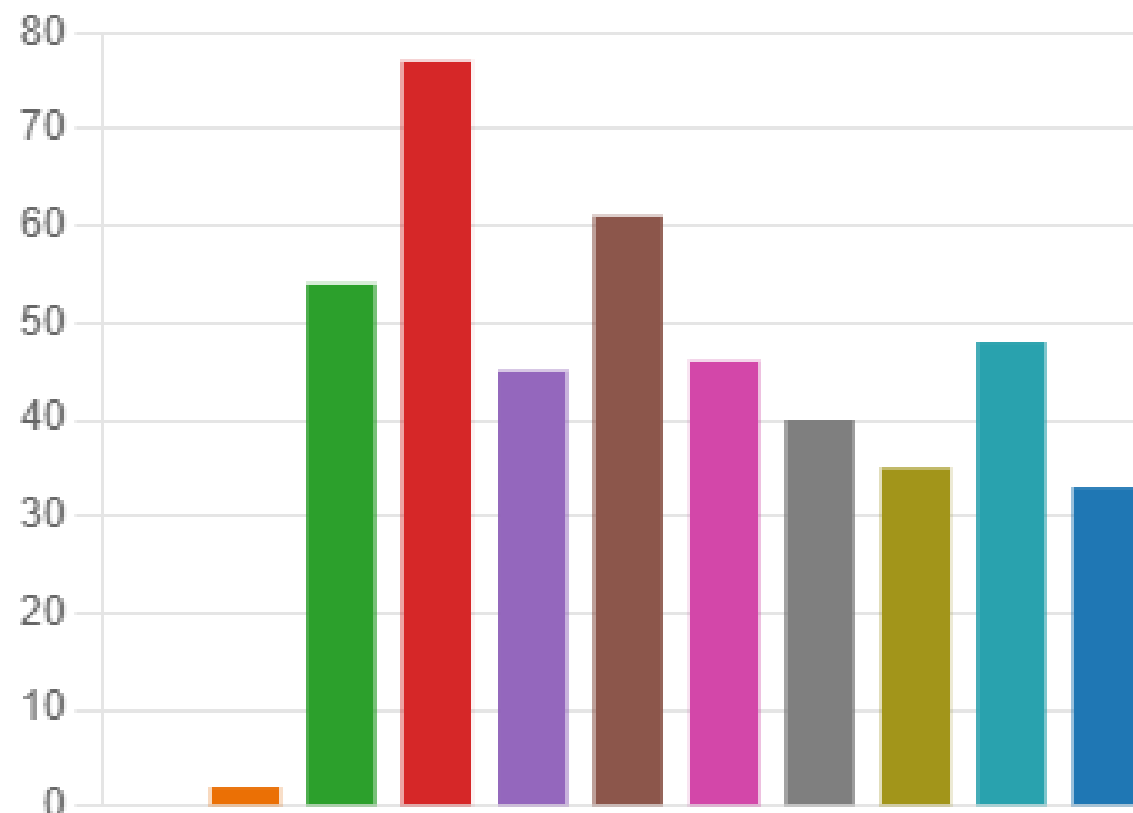


What other information regarding helpful resources and/or services that provide advice and support would you like to see? (tick all that apply)



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- None at all, 0
- Basic information only. I am happy to do my own research, 2
- Local early help provision and services (such as Family Hubs and Parenting Programs), 54
- Local support groups, charities and organisations, 77
- National support groups, charities and organisations, 45
- Information on who to contact at education settings regarding your child and young persons needs, 61
- Links to websites, 46
- Links to resources such as social stories, 40
- Books, 35
- Resources for child and young people to access themselves, 48
- Links to You Tube pages and videos, 33

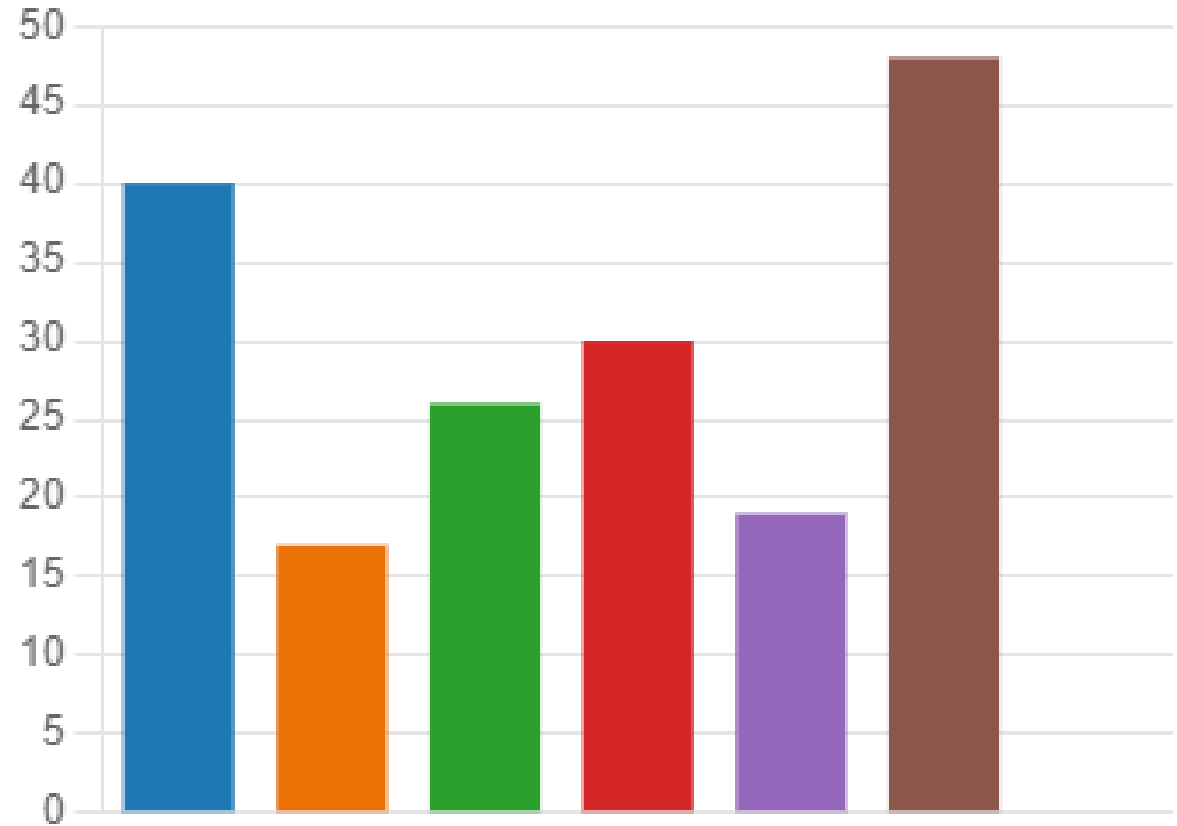


When would you like to receive information on advice and support? (tick all that apply)



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-  Acknowledgment of referral Letter, 40
-  Appointment Letter, 17
-  Appointment outcome letter, 26
-  Outcome of assessment Letter, 30
-  Discharge Letter, 19
-  All letters and communication, 48
-  None, 0

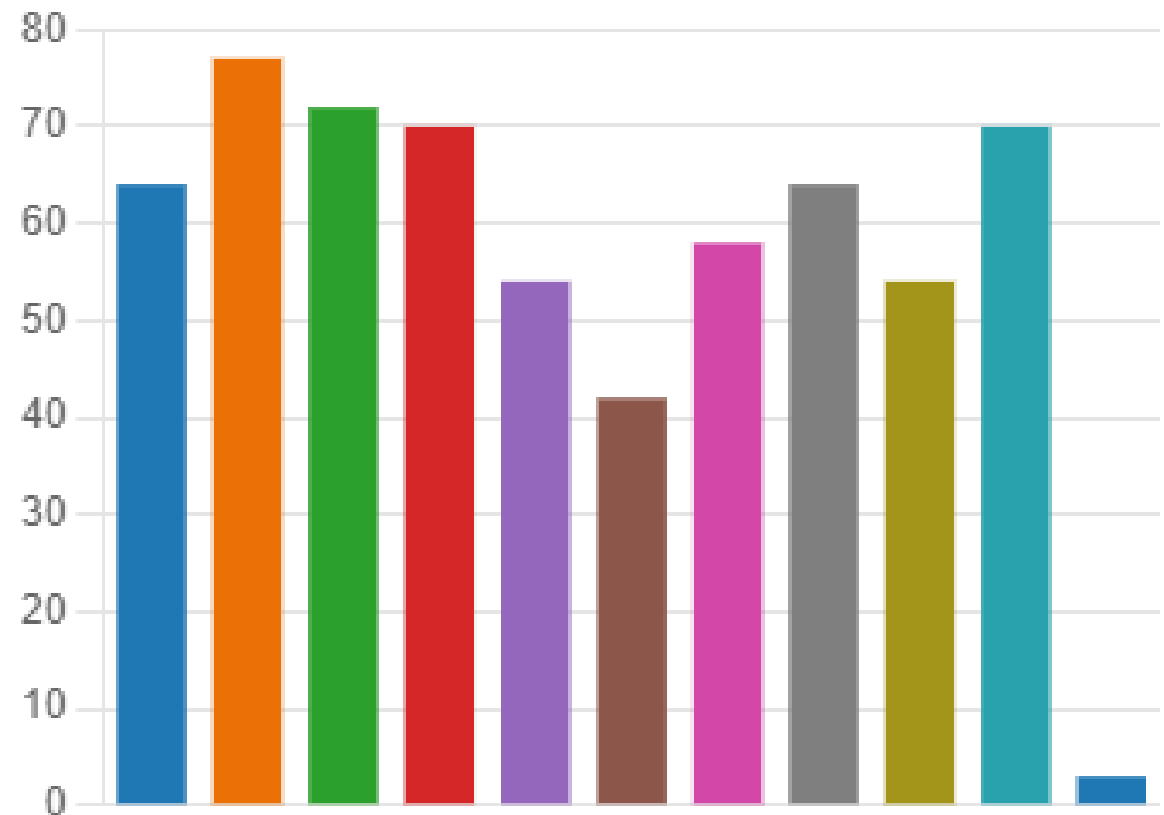




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Would you like to see the following information on community pediatrician websites? (with links provided in communication to you) Please tick all that apply

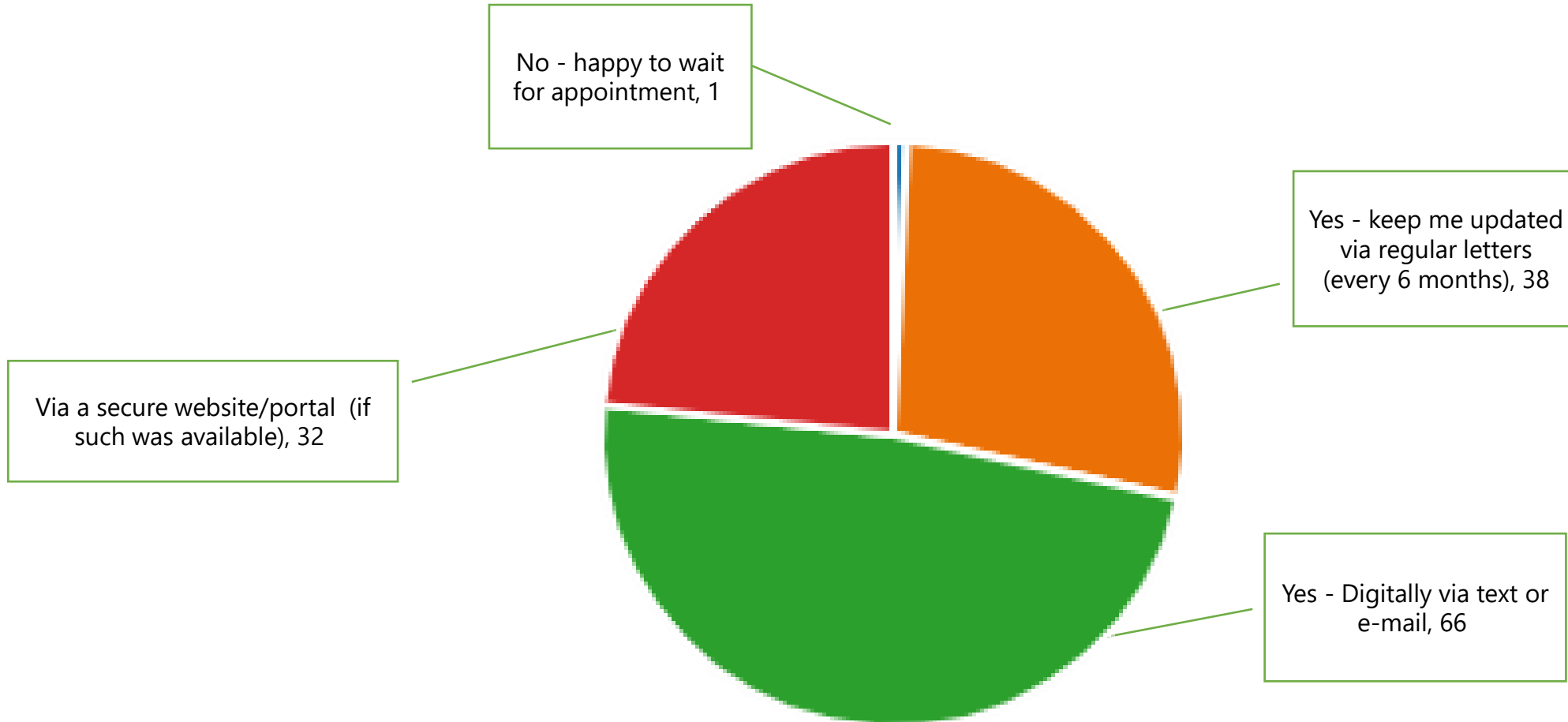
- Who can refer your child or young people to the service, 64
- What the steps of the journey may look like (the Pathway), 77
- What types of assessments may be undertaken, 72
- What the assessments look like for you and your child or young person, 70
- Social Stories to support children and young people to attend, 54
- Videos of clinics' areas to support attendance, 42
- Pictures or information on who you might meet (ie: Speech and language therapist, ADHD Nurse, Pediatrician), 58
- Advice on what to do, or who to contact, if your child's needs change whilst waiting for an appointment, 64
- NICE guidance on wait times, 54
- Estimated wait times, 70
- None of the above, 3



Whilst you are waiting, is it important to be able to "check - in" and know what current wait times are? (tick all that apply)



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Is there any other information you would like to receive?

Connections to local support services. When my son was diagnosed with ADHD we were pointed to SNAP in Brentwood, but we are Southend based so I can't drop in on coffee mornings etc. I eventually found STRM via social media after 2 years searching for resources online alone.

A clear indication on wait times and resources that families can use in the mean time

Information of what each appointment is and what to expect eg my first appointment was a development assessment and I would have liked to know what to expect as was on ASD referral

May the access to the same information on the website so if I lose the handout I can easily find it again

What to do if school doesn't back you up for referral

Supporting you neurodiverse child the strm book would be amazing

Alternative help available if you're child isn't diagnosed but has behaviour issues presenting as ASD/ADHD or similar

what to do or who to go to if you don't feel the school is being as supportive with your child's needs. What a one plan is and what a ECHP is and who gets one.

Pathway and options and whether patient choices if more than 18wks time frame is exceeded

Estimated wait times is gaslighting. Nice guidelines is 18weeks for ASD.GP still telling parents to get a supporting letter from schools.Parenting Programs that are suitable for neuro divergent families not Triple P or NVR courses. Titration information and reguakr medical reviews when you should be seen etc. This is a massive gap. The Southend ND book has unlawful information on it as well like transport and NEU pathway in southend is confusing and unlawful.

Information on each of the letters should be tailored to the stage of the process and age of child (no early years info for older children). Maybe also info regarding some of the medication and process to get it changed if not working for the child (such as ADHD meds).

advise on the whole thing for the parents and for child

Some councils on diagnosis offer parental training and guidance on parenting a child with adhd or autism. This would be helpful to highlight content as well as connect with other parents so you don't feel as alone.

list of schools with sen unit

I think every parent should be given a book called supporting your neurodiverse child at first port of call GP if there is a need for a referral to see a paediatrician

Is there any other information you would like to receive?



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Diagnosis is sought because there is a need either at home or school and also often questions about related diagnosis needs. Next steps to achieve support in these areas is critical

I would really just like them to follow guidelines and make sure my son is seen within 18 weeks. They seem to think they can get away with failing my child if they provide a few links. They can't.

Truthful next steps - that there is no treatment, no help available and a simple best of luck message

Positive stories about neurodiversity as I felt all the information provided was focussed on the negatives / struggles. So many positives to neurodiversity

Services commissioned by local CCG, for eg PDA not permissible for ASD diagnosing paediatrician to confirm - so who can?

Need ongoing support - eg a keyworker to offer assistance for ASD kids that struggle in mainstream school.

Disclaimer

The information and comments presented in this report are the views of the survey respondents and in no way, express or implied, should be construed to represent the views of The Essex Alliance, and the three parent carer forums of Southend, Essex and Thurrock.

As a Parent Carer Forum, our purpose is established under the legal requirements of the Children and Families Act 2014. We therefore have a duty to faithfully relay the views and experiences of parents and carers of children and young people with SEND aged 0 – 25 years with regard to the services they use.

Parent Carer Forums aims to work co-productively with services to improve the users' experiences and to recognise good practices. We accept no legal liability for the personal accounts, views, or opinions that survey respondents shared.



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