



Parent & Carer Ballot Summary Report July 2019

Background

In October 2018 the newly launched SEND partnership board agreed priorities areas for the board to focus on in the new Terms of Reference.

The SEND Partnership board is taken over by young people with SEND on an annual basis. The takeover meeting is facilitated by the Voice Influence and Change Team and enables young people with SEND to share the top issues young people voted for in the Annual Make Your Mark Ballot and request support / make asks to the partnership to help them address the priorities.

Parent representatives (EPIC Leeds) are members of the SEND partnership board and after reviewing the terms of reference it was identified that parents and carers of children and young people with SEND should also have the opportunity to identify a priority for the board to focus on over the next 12-18 months. The Voice Influence and Change Team offered to work in partnership with EPIC Leeds to develop an approach to identifying a key issue from parents and carers.

Planning meetings with VIC Team and EPIC Leeds led to the ballot being based around the 12 child friendly wishes which underpin our vision to be a child friendly city. Parents and carers of children and young people with SEND will have the opportunity to vote for which wish they want the SEND partnership board to address and asked why this is and ideas / suggestions for actions the board could take to address issues raised.

Objectives

- To actively involve a wide range of parent and carer support groups in surveying parents / carers of children and young people with SEND to identify the top issue/ priority they want the board to address.
- Share the top issue/ priority for parents and carers back with the SEND Partnership board.
- Board members work with EPIC Leeds and parents/ carers to further understand and explore the priority issue and develop and oversee actions to address the issue raised.

Outcomes

Parents and carers of children and young people with SEND will have identified a priority for the SEND partnership board and will be involved in identifying and agreeing actions to address the issues raised.

Communication

Online ballot form developed and circulated to list of parent groups and services/ organisations to circulate. Paper ballots printed and available for parent groups to use.

Timescales

Approval of draft ballot and additional information	March 13 th
Online ballot live and paper ballots available from (Online ballot hosted on Family Information Service Website).	15 th April to 14 th June
Communication / promotion from SEND Partnership Board members and circulated to VIC network for staff working with parents, carers and families.	WC 15 th April

Results collated
 Results shared with SEND Partnership Board
 Feedback results and share next steps via Parent groups and VIC Network.

WC 17th June
 15th July
 WC 22nd July



Key Roles

VIC Team:

- Develop a draft of the ballot form in partnership with EPIC Leeds
- Coordinate the ballot and provide a summary of results for the Board.
- Provide advice and guidance to EPIC Leeds and board members in development and implementation of an action plan.

EPIC Leeds:

- Help develop ballot
- Encourage parents/ carers to complete the ballot.
- Promote the ballot
- Feedback ballot results to parents/carers
- Facilitate a wider groups of parents/ carers to meet with board members to identify how to address the top issue identified in the ballot.
- Work with the relevant board members to develop and implement the actions agreed
- Update the board on progress.

Parent / Carer Support Groups:

- Promote and encourage parents/carers to complete the ballot.
- Feedback ballot results to parents/carers

SEND Partnership Board

- Approve the draft ballot, additional information and list of parent/carers groups.
- Work in partnership with EPIC Leeds and parents/carers to explore how to address the top issue voted for in the ballot.
- Develop an action plan and monitor progress.

Results of the Ballot

- 229 ballots were returned.
- 2 by email.
- 52 paper ballot
- 175 online ballot

Where did parents/ carers find out about the ballot?

No. Votes	How did you hear about the ballot?
96	School
38	EPIC Leeds
14	No answer
13	Facebook
11	Zig Zag
8	Email from LCC
5	Jigsaw
5	Little Hiccups
5	Sunshine and Smiles
4	Fostering



3	SENDIASS
2	DEAL Leeds
2	Nursery
2	SNAPS
2	Weekenders
2	Boston Spa twin group
1	ABC Leeds
1	CAMHS
1	CANN
1	Complex Needs Team Email
1	DAHIT
1	Family placement
1	Work
1	Leeds area parents of T1 diabetics
1	Leeds Asperger's /ASD parent conversation group
1	Leeds Carers
1	Leeds Mencap
1	PDA Yorkshire
1	Post
1	Adams Court
1	Social Worker
1	The Market Place
1	Twitter

Ongoing Engagement and Communication

Parents and Carers were asked to provide their contact details if they would like to be kept up to date on the outcome of the ballot and be invited to work towards addressing the top issue identified by this ballot.

- 75% of parent/ carers who completed the ballot want to be kept up to date on the outcome and be invited to work towards addressing the top issue with the SEND partnership Board.
- 173 parents and carers provided their contact details (173 email addresses and 4 postal addresses)
- 52 parents and carers did not provide their contact details.

Findings of the Ballot

- 35% of the parents/carers who responded chose “learning places identifying and addressing barriers that prevent children and young people from engaging and enjoying in learning”.
- The second and third top wishes voted for relate to children and young people having places and spaces to play and things to do and being treated fairly and feeling respected.

Number of Votes	Wish
80	All our learning places identify and address the barriers that prevent children and young people from engaging in and enjoying learning
31	There are places and space to play and things to do, in all areas and open to all
30	All children and young people have their basic rights met
21	Children and young people are treated fairly and feel respected
12	Children and young people find the city centre welcoming and safe, with friendly places to go, have fun and play
11	There are greater number of better quality jobs, work experience opportunities and good quality careers advice for all

11	Children and young people express their views, feel heard and are actively involved in decisions that affect their lives
10	Children and young people can make safe journeys and easily travel around the city
8	Places and spaces where children and young people spend time and play, are free of litter and dog fouling
5	Children and young people can easily find out what they want to know, when they want it and how they want it
5	Children, young people and adults have a good understanding of children's rights, according to the United National Convention of the Rights of the Child
3	Void: Picked several wishes
2	Children and young people have the support and information they need to make healthy lifestyle choices

What do Leeds do well?

221 parents/ carers responded to this question.

29 parents/carers completing the ballot did not respond to this question

31 parent/ carers left negative feedback

What do Leeds do well?	Number of responses	Example of feedback
Support, provision and staff (SENCOs and teaching Assistants) in School / SILCs	31	<i>"A great choice of schools that offer great support for children with special educational needs." The school my son attends is outstanding , the staff are well trained and the kids love the school. There is family support too which is vital."</i>
Max Card/ Leeds Extra Card	8	<i>"The Leeds card extra means that I can afford swimming lessons for my children and afford days out and places such as Lotherton Hall and Temple Newsham" "Leeds have venues that are including max card users to access places free or at a discounted price which means a lot to those with children with sen as you may only manage 5 minutes before having to go home and paying high costs for 5 minutes is always a worry."</i>
STARS	7	<i>"STARS Autism team have transformed the understanding of our son's needs and how these can be met, both in school and at home. They have provided Cygnet parenting training and Autism Education Trust training for school staff; they have worked in school observing our son and making recommendations; they have supported our family on an ad-hoc basis through participation in the monthly drop-in at Leeds Central Library."</i>
Inclusive events and activities on offer (e.g. Breeze, disability gymnastics, Leeds Young Film Festival)	7	<i>"There is always an event somewhere going on in Leeds. There is always something to do."</i>
Health Services (e.g. hospital services, physio, paediatric care, medical practice)	7	<i>"Paediatric care, the NHS does a good pathway. The amount of hospital services that are open to us, as and if needed."</i>

SENDIASS	6	<i>"SENDIASS have been brilliant supporting my family through the EHCP process."</i>
Museums and Galleries e.g. City Museum, Templenewsam, Lotherton Hall	5	<i>"Leeds is very family focussed. There are often events on which interest children, be it in museums, parks, libraries and outdoor spaces. More publicity of such events would be useful as often they are quite hard to find."</i>
Community/ Voluntary sector support groups and activities	5	<i>"Excellent community groups and opportunities within our local area and city centre." "Scouting is flourishing in Leeds we have found groups that allow her to fit in and grow."</i>
EPIC Leeds (e.g. support and sessions they run)	5	<i>"Support groups, like EPIC, have helped me lots. Just being with other people in the same situation to chat about things."</i>
Transport provided to and from school / escort	5	<i>"Leeds council provide a mini bus to school the staff are amazing so supportive and friendly." "Transport to school. Without which I would be unable to work."</i>
Social care staff (social worker, supervising social worker, RES worker)	4	<i>"Good, supportive supervising social workers who care about both the carers and the children" "I have a RES worker, who is fantastic." "She really supports me with school and tells me I'm doing all that I can when I'm falling to pieces."</i>
ZigZag	4	<i>"The only real support that has been easy to get has come from a parent led support group called Zig zag autism group."</i>
Short Breaks offer/ provision (e.g. Rainbow House and Weekenders)	4	<i>"Very good short breaks offer" "Rainbow House helps us as a family"</i>
Leeds MENCAP (also mention Hawthorn MENCAP)	4	<i>"Hawthorn Mencap. It is the most amazing supportive place. My child loved the sensory focussed nursery and the support and friendships made with other parents in the family room has been so useful. The family support worker is so knowledgeable and skilled. She has helped me and my child in so many ways. They also organised for me to attend the E-pats course which I believe every parent with a child with needs should attend. I cannot praise them enough."</i>
Inclusive events and activities on offer (e.g Breeze, disability gymnastics, Leeds Young Film Festival,	7	<i>"Putting on events which include SEND events such as the Leeds Young Film Festival" "Activities that are organised for younger children could have a relax hour or two like you do for breeze. Which I have seen become extremely popular over the years."</i>
SENSAP (service and staff)	4	<i>"Our caseworker is incredibly helpful and open but probably overstretched too "</i>
Parks and play areas	3	<i>"Nice outdoor green spaces"</i>
Childrens Centres	3	<i>"Horsforth Children's Services have provided great support for our family through courses and counselling. Children's centres have been amazing, the staff have always been very helpful, access to services and workshops, courses and support."</i>

SNAPS	3	<i>"There are some incredibly supportive small charities who deserve more recognition than they get whose support we aren't sure where we would be without. For example SNAPS and Leeds Mencap. They deserve support."</i>
Direct Payments	3	<i>"Provides a small amount of Direct Payments so we can manage consistence for our family."</i>
EHCP support	3	<i>"My son has an EHCP which has been invaluable in enabling him to get the support he needs."</i>
CAMHs	3	<i>"West Leeds CAMHs have been brilliant for us"</i>
Personal Transport Budget	2	
SCOPE and PAs	2	<i>"For me having a PA has really been good to our family. My child enjoys going for activities and it has built up his confidence."</i>
Carers Leeds	2	<i>"We have carers Leeds as a good way to voice concerns. They also provide activities for special needs families."</i>
Negative comments/ feedback		<i>"Unfortunately none of our young person's needs have been met or fulfilled and we've had to fight for anything "</i>

Other team/ services parents and carers mentioned include SENIT, Visually impaired team, Cluster contacts and post adoption supports service, support applying for a DFG (Disabled facilities grant).

"I have to say the support when apply for a DFG was outstanding. Neighbouring councils I know do not offer this level of assistance to help parents and kids stay in their homes"

Parents/ carers also mentioned changing places toilets, leisure centre, green spaces, parks, access to information and *"how Leeds seeks views and listens"*.

The 31 parents/carers who left negative feedback mainly focused on lack of funding, lack staff, waiting for support/ diagnosis, EHCPs, having to fight for everything and rights not being met.

Top priority for SEND Partnership Board (voted for by 35% parents and carers completing the ballot)

"All our learning places identify and address the barriers that prevent children and young people from engaging in and enjoying learning"

Summary of key issues

Issue 1 Training to increase awareness and understanding of staff **(Raised by 14 parents/carers)**

Why is this a priority?

- Schools are not meeting child's individual learning requirements due to lack of training
- CYP disengaging as learning styles not being met
- Lack of understanding of need from professionals
- Staff not always aware of impact of trauma and poor attachment on children
- Staff should have training on FASD (Foetal Alcohol Spectrum Disorder)

“Identification and understanding of specific conditions are not always known or understood by teaching staff which in itself creates an extra barrier to learning.”

“More training in schools for teachers to understand different children's needs and to address them appropriately before things escalate.”

Ideas and Suggestions for the Board

- Earlier assessments was mentioned by 7 parents/carers)
- Train staff on SEND
- Train staff on trauma and attachment

“Educate, educate and educate staff who work directly with children”.

“Better trained and relevantly qualified staff in school. Better ratio of staff to children with needs.”

“Good quality training for all school staff in trauma and attachment. It would be wonderful for every school in Leeds to be able to adequately support children whose barriers to learning are caused by past or present trauma.”

Issue 2 Current provision not meeting children’s needs **(Raised by 14 parents/carers)**

Why is this a priority?

- Quality of provision – different standards across city
- Lack of school places
- Child had to go to residential school out of area
- More support in classroom needed
- Lack of funding for schools means reduced staffing and resources
- Teaching Assistant jobs have been cut
- Schools not able to fulfil recommendations in EHCP due to lack of funding and resources.

“Due to government funding cuts many SEND children are still not having even their basic needs/rights met, which should be just a given, rather than a fight for their families.”

“Cuts to school funding has the most impact on SEN children especially when TA jobs are cut.”

“Because most schools and learning places are not meeting the needs of send pupils adequately due to a lack of training and lack of money.”

“Understaffed and under resourced.”

“Many of the barriers are due to schools not having sufficient resources to meet the learning needs of children”

“Schools not implementing EHCP / guidance”

Ideas and Suggestions for the Board

- Challenge spending cuts and campaign to the government (with parents/carers)



- Provide more specialist school places

“Campaign for more assistants in classrooms to assist children with disabilities with all aspects of school life”

“Value schools on how they treat most vulnerable, as well as SATs”

“Create more specialist school places for kids with a range of learning needs”

“More provision, more support, more inclusion and activities, more awareness, more investment”

Issue 3 Better information and communication with families **(raised by 12 parents/carers)**

Why is this a priority?

- Lack of awareness of SEND partnership board and role
- Families need support to understand their rights
- Need to improve communication and enable parents to work more closely with SENCO
- More support and better communication between schools/parents/carers.
- Responses are too slow and so deadlines aren't being met for EHCP
- Process too complicated
- Lack of staff training can mean they provide inaccurate information

“Make access to information easier to find.”

“Reply to emails and phone calls in a timely manner.”

“SEND schools to have more contact with parents and offer more family support”

“We have had a good service this is only because we are aware of the rights of our children and know how to access the support and push for what they need.”

Ideas and Suggestions for the Board

- Work more with parents – have conferences where parents can have their say.
- Think tank with parents
- Advise SENCO has termly review with parents/ carers.
- It should be mandatory for SENCO to meet with new parents of children with additional needs.
- Provide a support pack for all parents before starting the EHCP process
- Simplify procedure and meet deadlines
- Make sure that FFI teams and SEN teams are providing correct advice to schools and parents.
- Involve the monitoring officer at the council to ensure EHC plans are lawful.

“Think tank with parents”

“Provide relevant information and training to schools, remind schools of their duties under the Equality Act 2010 and the Children and Families Act.”

“All still too much working in professional lanes and not joining up working or information. “



“Ensure that NHS provides quick support and intervention and that there is some partnership working - why am I as parent the person who has to share info between different agencies?”

“Ensuring parents have more information on the support and approaches to learning that could be implemented and looking to establish standard guidelines across the different learning establishments.”

Issue 4: Provision and support for CYP with Autism

(raised by 10 parents/carers)

Why is this a priority?

- Lack of provision that meets child’s needs
- Poor interagency working
- Lack appropriate resources
- Long waits diagnosis
- Lack reasonable adjustments
- Need for more accurate assessments
- Rigid education policies mean damaging environment for CYP
- Leading to CYP missing school
- Withdrawal of the SENDIASS service from accompanying parents to meetings further exacerbates the difficulties parents have in accessing the correct support for their children

Feedback

“Too many SEND children, especially those with 'high functioning' autism and associated mental health difficulties, cannot access specialist education, yet mainstream provision is woefully inadequate and rarely understands or meets a child's needs, despite EHCP's.”

“My son has lost 2 years of education so far. He is only 9 years old.”

“SILC buildings and partnership primary schools in Leeds are no longer fit for purpose and create environmental barriers for autistic children to learn.”

“A proper workforce development overhaul is required in all schools and services to work effectively and inclusively with ASC children and young people. The board would do well to re-launch with schools the notion that inclusion means doing things in a way that everyone can access and not just doing something a bit different for that SEND child. So promote real inclusion.”

“I know that a lot of autistic children are finding it difficult to access school due to a lack of reasonable adjustments... being excluded from school or having anxiety levels so high when at school to the extent learning becomes impossible is damaging for the rest of life”

“Recognise dyslexic and less typical autism presentations and less typical add/ adhd too. Encourage educators to focus on building strong collaborative relationships as opposed to controlling punitive based regimes(‘positive discipline ‘is sanction based)”

“There is a massive gap for educating 'high functioning' autistic and/or anxious children who for whatever reason cannot cope in mainstream but don't want to be segregated in a 'special' unit. SEMH schools are not appropriate for autistic children.”

Ideas and Suggestions for the Board



- Develop the autism offer for CYP with CYP and Parent/carers.
- Allow the STARS team and CAMHS team to work with families in the family home where the ASC child has significant difficulties engaging in school life.
- Earlier identification - individual multi agency support plans with person centred strategies
- Increase funding for STARS service as provide such valuable support but long waiting list
- More STARS sessions- not just in city centre
- Mandatory training about autism and reasonable adjustments provision for all school staff.
- Provide more funding for SENDIASS to support parents at meetings
- Share best practice amongst schools
- Create more schools and autism units
- Insist academies cant off roll children

“a proper workforce development overhaul is required in all schools and services to work effectively and inclusively with ASC children and young people. The board would do well to re-launch with schools the notion that inclusion means doing things in a way that everyone can access and not just doing something a bit different for that SEND child. So promote real inclusion.”

“We are fortunate that the school has made reasonable adjustments to meet his needs; the support he receives enables him to be included and enjoy learning. Schools in Leeds could learn from each other to promote a 'can-do' approach to including children and young people with SEND, to remove the variation that currently exists.”

“Create more schools and autism units that fully & genuinely understand 'high functioning' autistic children. (use schools like Limpsfield Grange, Breckenborough and Ackworth as ideal models)”

“More "STARS" employees to make regular visits to all educational settings and regular accessible help/groups/advice sessions for parents and carers. (more than once a month in the city centre)”

Issue 5 School Priorities, Policies and Procedures **(Raised by 8 parents/carers)**

Why is this a priority?

- Children are missing school as cannot cope with behaviour policies/ uniform policies
- Overuse of exclusions and isolations booths for CYP with SEND
- Schools off rolling

“My son is year 7, high functioning asd. He cannot deal with the structure and behaviour policies of mainstream school and has been mentally unable to attend for the last couple of months. He was on target for top grades in most lessons but his grades are sliding due to the amount of time he has spent in isolation and absence.”

“From personal experience and constant barrage of exclusions for my kids because of lack of knowledge and understanding from schools.”



“There is huge variation in how well schools in Leeds accommodate special needs, and many schools follow uniform and discipline policies that actively discourage parents of disabled children from sending their children there. This needs to be urgently addressed, to make schools a more nurturing environment for all.”

Ideas and Suggestions for the Board

- School make reasonable adjustments to policy and procedure
- Training for staff
- Advise schools to review behaviour policy in consultation with CYP with SEND and their families.
- Advise against using isolation booth and exclusions for CYP with SEND
- Share best practice

“More help with strategies for schools, especially Academies who seem to throw SEN children into isolation as much as they can (first-hand experience)”

“Ensure children aren’t excluded due to special needs; ensure all schools think about the impact of their behavioural policies on children with special needs (some of the popular new behavioural policies are too rigid in my opinion)”

“Examine uniform and discipline policies in schools across Leeds, identify the best and worst practices and engage with schools to make the changes to while school policies that help disabled children fit in without excessive adjustments needing to be made.”

“Isolation booths for low level behaviour for children such be made illegal”

“Encourage educators to focus on building strong collaborative relationships as opposed to controlling punitive based regimes (‘positive discipline ‘is sanction based)”

INSIST academies cannot off-roll our children and that they learn how to support our children properly

Other issues raised by a smaller number of parents and cares included need for improved support for children with dyslexia (2) and reduced access to social clubs and activities after school due to transport.

Second priority for SEND Partnership Board (voted for by 14% parents and carers completing the ballot)

“There are places and space to play and things to do, in all areas and open to all”

Why is this a priority?

- Families feeling isolated as lack of accessible places to go nearby
- Lack of awareness about accessible places to play – outdoor and indoor
- Better communication /information about what’s available
- Sometimes play areas with accessible play equipment have steps so make them inaccessible
- Need for more changing places facilities.
- Quiet areas / zones helpful for CYP with SEND
- More soft opening times for CYP with additional needs
- Need for more groups /activities for teenagers



“Easy for families with SEND children to become isolated”

“It’s very difficult to entertain my particular special needs child as so many places are not accessible and or appropriate. Changing places are essential as are quiet spaces but in amongst mainstream entertainment as he has siblings without special needs”

“Trying to consider all disabilities together when designing neighbourhood parks, every child should not only be able to access the playground but also have something to do once they are there.”

Ideas and Suggestions for the Board

- Provide Max card for families
- Better communication and promotion of what’s available
- More involvement of families in development of outdoor play provision
- Encourage more organisations and services to provide quiet spaces and soft opening times for CYP with additional needs
- Encourage more places to have changing places facilities
- Learn from other cities

“Better communication of what is available for families”

*“Consult with children and families with send more frequently and commit to inclusive practices.”
Improve accessibility in mainstream activities by sharing good practice across the city. Work with external partners to make real differences at grass roots level. Raising awareness of young people with SEND in local communities will help them be safe and involved and the wider community will feel ownership of the inclusion.”*

“Quiet sessions at appropriate times not at times of the day that prevent them from joining in.”

*“Learn from others ... Kids Playground - Parc de Montere, Park in Luxembourg City, Luxembourg
[https://www.trier-info.de/petrispark-info.](https://www.trier-info.de/petrispark-info)”*

Third priority for SEND Partnership Board (voted for by 13% parents and carers completing the ballot)

“All children and young people have their basic rights met”

Why is this a priority?

- Right to an education that meets their needs
- Right to play
- Right to healthcare
- Right to have a say

*“If children and young people don't have their basic rights met, the other outcomes can't be achieved.
Hierarchy of needs.”*

“Quite often having a child with a disability you find that their needs are not met in some way or another. For example it is a basic need to be able to use a toilet however for my son who has cerebral

palsy, in many places this need is not met because of a massive lack of changing spaces available or being able to enter a shop without worrying about whether they will get up a step in a wheelchair.”



Ideas and Suggestions for the Board

- Inform and communicate rights to children and families
- Training of staff on rights of children with SEND, where information and support is available
- Encourage change of attitude – focus on inclusion and increase understanding of challenges families facing.
- Make council run events, activities and buildings more accessible and inclusive.

“Just let us know what our rights are, plus make schools aware we know our rights”

“Encourage inclusion and help parents and carers to understand and focus on what their children can do, not what they can't”

“Understand how difficult our lives can be, what we are dealing with and help us cope. “

“I guess more funding would make sure their basic rights are met but I understand that it is out of your hands. The most important thing is to have capable and competent SEN staff.”

“Start with the right to education, which many children with send are denied due to a lack of understanding and support. More accessible leisure opportunities. More support to families and parents, particularly respite, so they don't reach crisis point.”

“Encourage places, not just council places but everywhere to have disabled people as a first thought rather than an afterthought. Encourage people to think about how they would feel if their basic needs such as toileting and free movement were not catered for. Even some 'accessible' events are not well thought out and feel like they are run because they have to be.

“Make sure that every school/college/gp practice has a family support worker or a person who can guide people to the appropriate schemes/available help.”

“All children have a basic right to be in a safe environment. SEN children especially should be able to access all the same activities/spaces that all their peers access. Travel especially in LEEDS is not offered in a way accessible to Sen children many are unable to access public transport and so are reliant on private cars yet the ability to obtain a disabled badge to easy access is impossible; the people overseeing the scheme have no experience with Sen children specifically autism . Refusing access to a badge means these children do not access the wide world or have exposure to the things there peers do.”

Next Steps and Actions

- The findings provide quality feedback for the Children and Families Leadership Team which will be incorporated into the refresh of the SEND strategy and self-evaluation framework
- The Head of Learning Inclusion confirmed that key themes will be incorporated into service action plans
- Parents who gave contact details and raised concerns that haven't already been followed up will be contacted directly by the SENSAP team.

- The findings will be shared and discussed with the SEND partnership board on 22nd July to agree next steps and how they will address the priorities and issues raised by parents and carers.
- This summary report and information about next steps, will be shared with all parents/carers who provided contact details when completing the survey and made available on the local offer website.

