

Bristol, North Somerset & South Glos  
Parent Carer Forums



Working together  
for SEND families



Bristol, North Somerset  
and South Gloucestershire  
Integrated Care Board

# Neurodiversity Transformation Discovery Conference

Outputs from 23<sup>rd</sup> November 2023

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**Thank you to everyone who took part in  
this Neurodiversity Transformation  
Discovery Conference.**

**We conducted and captured several brief  
interviews with delegates during the  
event. You can watch these by clicking  
[‘here’](#)**

# Conference objectives & activities

## Session One

Understanding early Identification of needs

Table activity to answer the following

1. What ages are we first seeing needs
2. How do early needs present
3. Do we know the impact of unmet need
4. What's the impact on CYP / families when needs are across multiple conditions/ pathways

## Session Two

Understanding the increase of referrals

Online Menti activity to answer the following

1. What do you think is the root cause of the increase in referrals?
2. What are the benefits of a diagnosis?
3. What are barriers CYP/families face when navigating the referral pathway?

## Session Three

Understanding the experience post assessment

Table activity to answer the following

1. Are needs being met after assessments, if not which ones and why?
2. How is support accessed
3. What works well and what doesn't work well
4. What needs to change to make the most impact

## Session Four

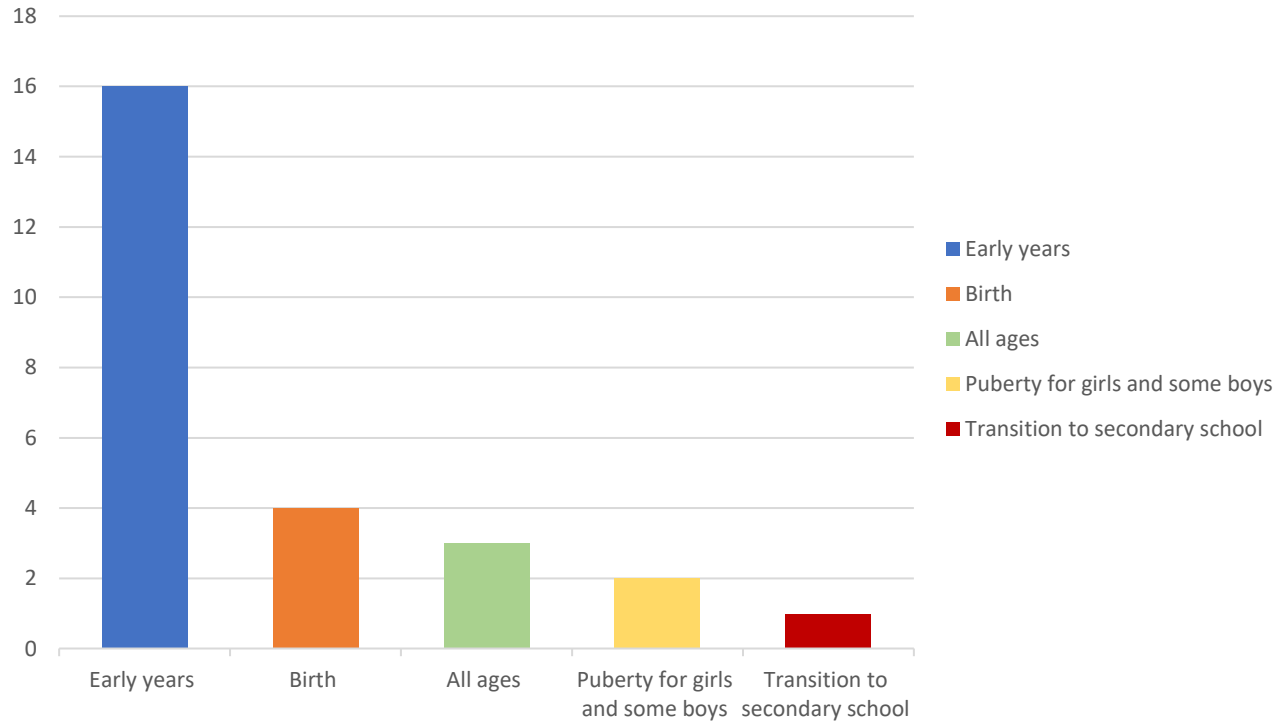
What else do we need to consider/ know to respond to the problem statement?

Carpark activity from throughout the conference.

Prioritising identified further insights and engagement required to respond to the Problem statement

# Session One - Understanding early Identification of needs

## Question 1. What ages are we first seeing needs

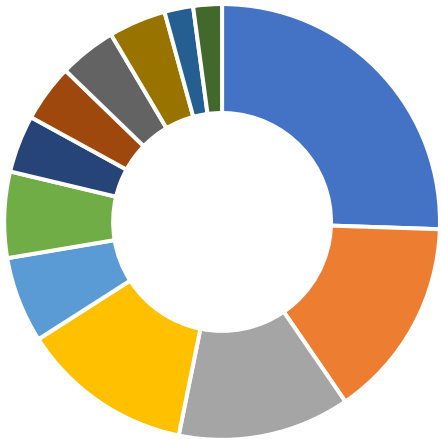


What ages are we first seeing needs	Percentage
Early years	62%
Birth	15%
All ages	12%
Puberty for girls and some boys	8%
Transition to secondary school	4%

# Session One - Understanding early Identification of needs

## Question 2. How do early needs present?

### Behaviours & coping methods



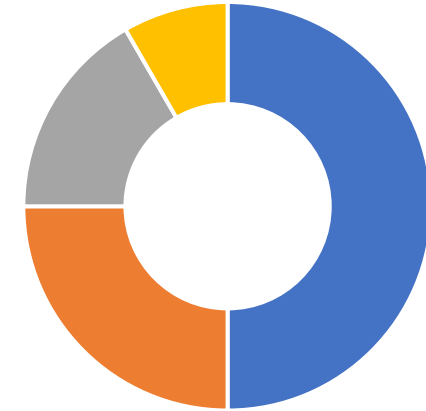
- Challenging behaviours/ rule breaking
- Restricted diet
- Masking & coke bottle effect
- School refusal/ Non-attendance
- Poor sleep
- Unusual behaviours and quirksiness
- Biting and throwing
- Compliant behaviour
- Rigid thinking
- Toilet issues and smearing
- Attention levels
- Girls + autism – eating disorders (anorexia)

### Communication



- Social interaction differences and difficulties
- Echolalia
- Expressiveness
- Difficulties with concentration
- Hearing difficulties
- Inability to communicate own needs
- Struggling to show/share emotions

### Relationships



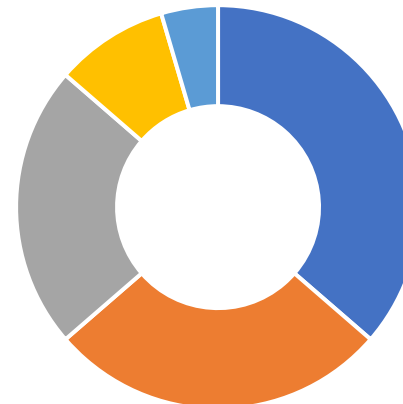
- Withdrawal and lack of interaction and engagement (with peers, family and at school)
- Attachment needs and separation anxiety
- Difficulties with relationships (including peers)
- Difficulty turn taking

### Emotional



- Emotional distress
- Anxiety
- Emotional dysregulation
- Crying (and difficulty settling in EY)
- Frustration
- Meltdowns
- Vulnerability

### Development



- Delayed speech/ speech difficulties
- Delayed development/ milestones and resisting against milestones
- Playing differently
- Lack of awareness of danger
- Motor skills

# Session One - Understanding early Identification of needs

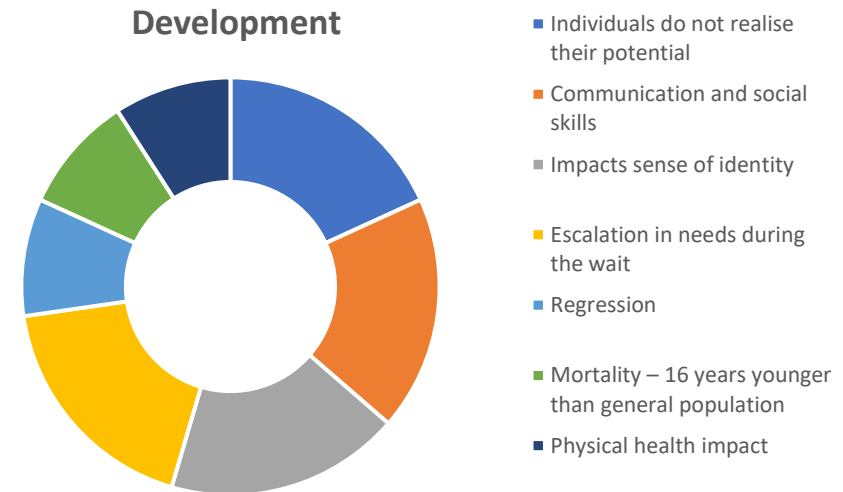
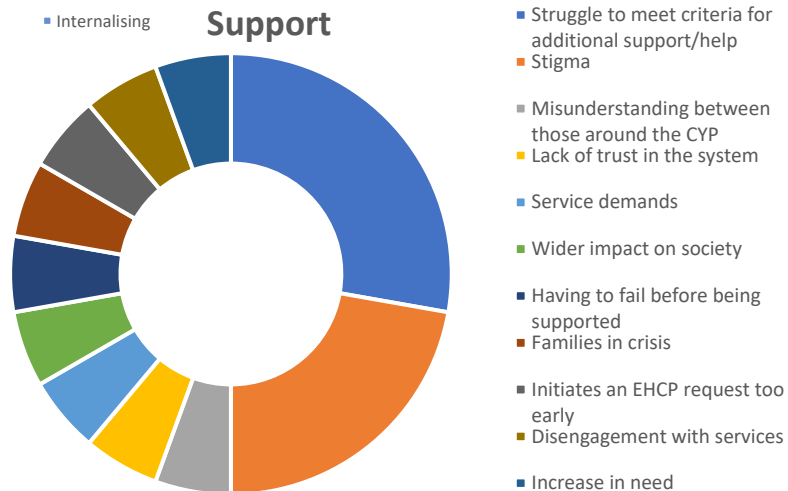
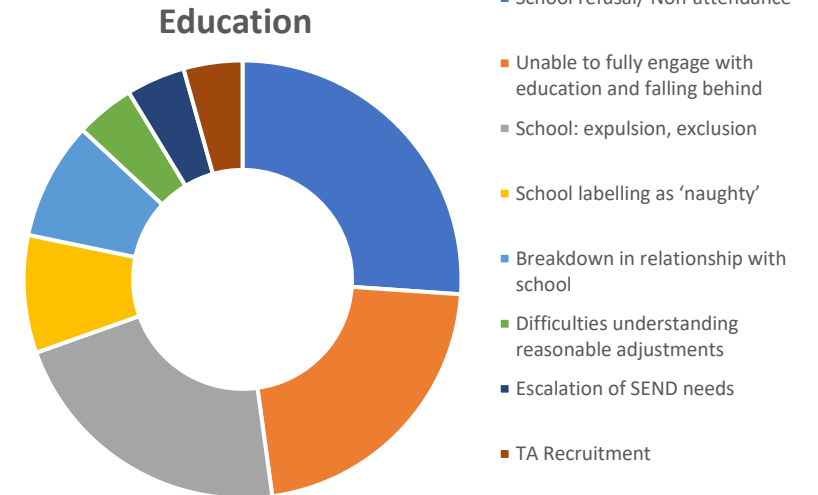
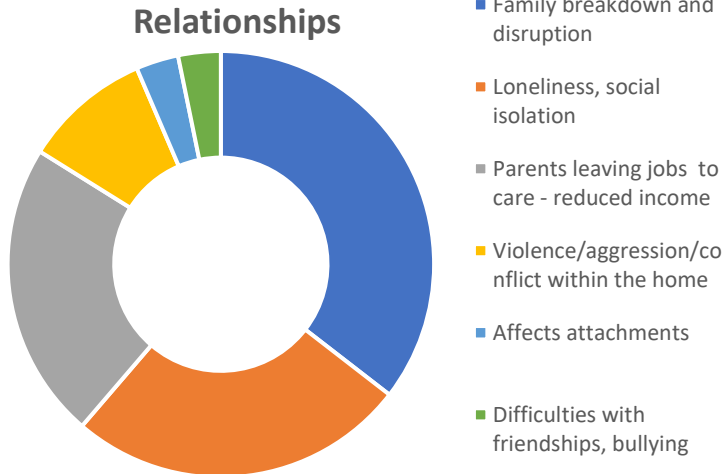
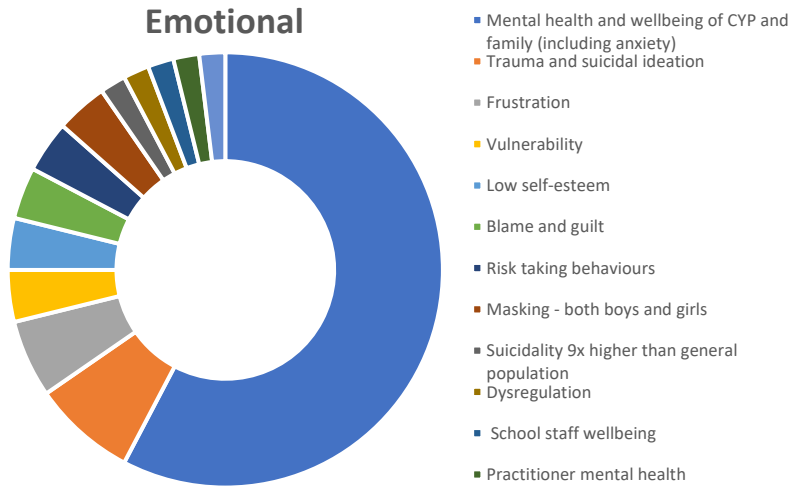
## 2. How do early needs present

Behaviours & coping methods	Percentage
Challenging behaviours/ rule breaking	26%
Restricted diet	15%
Masking & coke bottle effect	13%
School refusal/ Non-attendance	13%
Poor sleep	6%
Unusual behaviours and quirkiness	6%
Biting and throwing	4%
Compliant behaviour	4%
Rigid thinking	4%
Toilet issues and smearing	4%
Attention levels	2%
Girls + autism – eating disorders (anorexia)	2%
Emotional	Percentage
Emotional distress	29%
Anxiety	24%
Emotional dysregulation	18%
Crying (and difficulty settling in EY)	12%
Frustration	6%
Meltdowns	6%
Vulnerability	6%

Communication	Percentage
Social interaction differences and difficulties	50%
Echolalia	8%
Expressiveness	8%
Difficulties with concentration	8%
Hearing difficulties	8%
Inability to communicate own needs	8%
Struggling to show/share emotions	8%
Development	Percentage
Delayed speech/ speech difficulties	36%
Delayed development/ milestones and resisting against milestones	27%
Playing differently	23%
Lack of awareness of danger	9%
Motor skills	5%
Relationships	Percentage
Withdrawal and lack of interaction and engagement (with peers, family and at school)	50%
Attachment needs and separation anxiety	25%
Difficulties with relationships (including peers)	17%
Difficulty turn taking	8%

# Session One - Understanding early Identification of needs

## 3. Do we know the impact of unmet need



# Session One - Understanding early Identification of needs

## 3. Do we know the impact of unmet need

Development:	Percentage
Individuals do not realise their potential	18%
Communication and social skills	18%
Impacts sense of identity	18%
Escalation in needs during the wait	18%
Regression	9%
Mortality – 16 years younger than general population	9%
Physical health impact	9%
Education:	Percentage
School refusal/ Non-attendance	26%
Unable to fully engage with education and falling behind	22%
School: expulsion, exclusion	22%
School labelling as 'naughty'	9%
Breakdown in relationship with school	9%
Difficulties understanding reasonable adjustments	4%
Escalation of SEND needs	4%
TA Recruitment	4%
Relationships:	Percentage
Family breakdown and disruption	35%
Loneliness, social isolation	26%
Parents leaving jobs to care - reduced income	23%
Violence/aggression/conflict within the home	10%
Affects attachments	3%
Difficulties with friendships, bullying	3%

Emotional:	Percentage
Mental health and wellbeing of CYP and family (including anxiety)	58%
Trauma and suicidal ideation	8%
Frustration	6%
Vulnerability	4%
Low self-esteem	4%
Blame and guilt	4%
Risk taking behaviours	4%
Masking - both boys and girls	4%
Suicidality 9x higher than general population	2%
Dysregulation	2%
School staff wellbeing	2%
Practitioner mental health	2%
Internalising	2%
Support:	Percentage
Struggle to meet criteria for additional support/help	28%
Stigma	22%
Misunderstanding between those around the CYP	6%
Lack of trust in the system	6%
Service demands	6%
Wider impact on society	6%
Having to fail before being supported	6%
Families in crisis	6%
Initiates an EHCP request too early	6%
Disengagement with services	6%
Increase in need	6%



# Session One - Understanding early Identification of needs

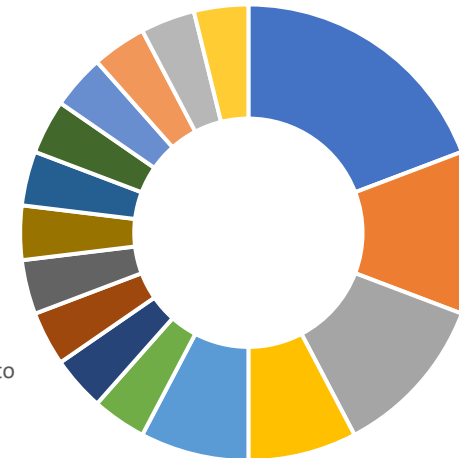
## 4. What's the impact on CYP / families when needs are across multiple conditions/ pathways

### Emotional and relationships



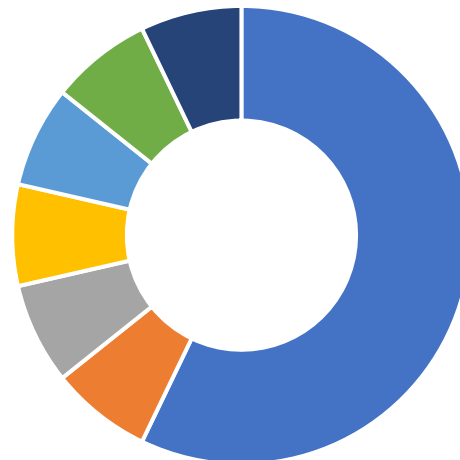
- Impact on family life
- Multiple assessments could affect their self-worth
- Effect on careers for parents
- Stress
- Frustration
- Increased anxiety

### Support



- Barriers between services
- Disconnect between services and families
- Families instantly have to fight to get heard, and disengage from the process
- Families go from service to service without any support or diagnosis
- Lack of confidence in the system
- Families feel they are not listened to
- Uncertainty around who is taking responsibility for the child
- Lack of early intervention
- Health only offers an assessment service, not help or intervention
- System not proactive
- Families having to retell their stories
- Lack of formulation guiding intervention
- Lack of keyworkers to navigate services
- Not person centred
- Can lead to no support as don't fit into one diagnosis 'box'
- Misinformation

### Referral process and threshold



- Confusing and complex to navigate
- Lack of consistency
- Too much admin/ paperwork, disruption/ stress
- Having to restart process over again
- Long waiting times
- Diagnostic overshadowing if more than one condition
- Having to choose between pathways e.g. EY SLT/ ASD

# Session One - Understanding early Identification of needs

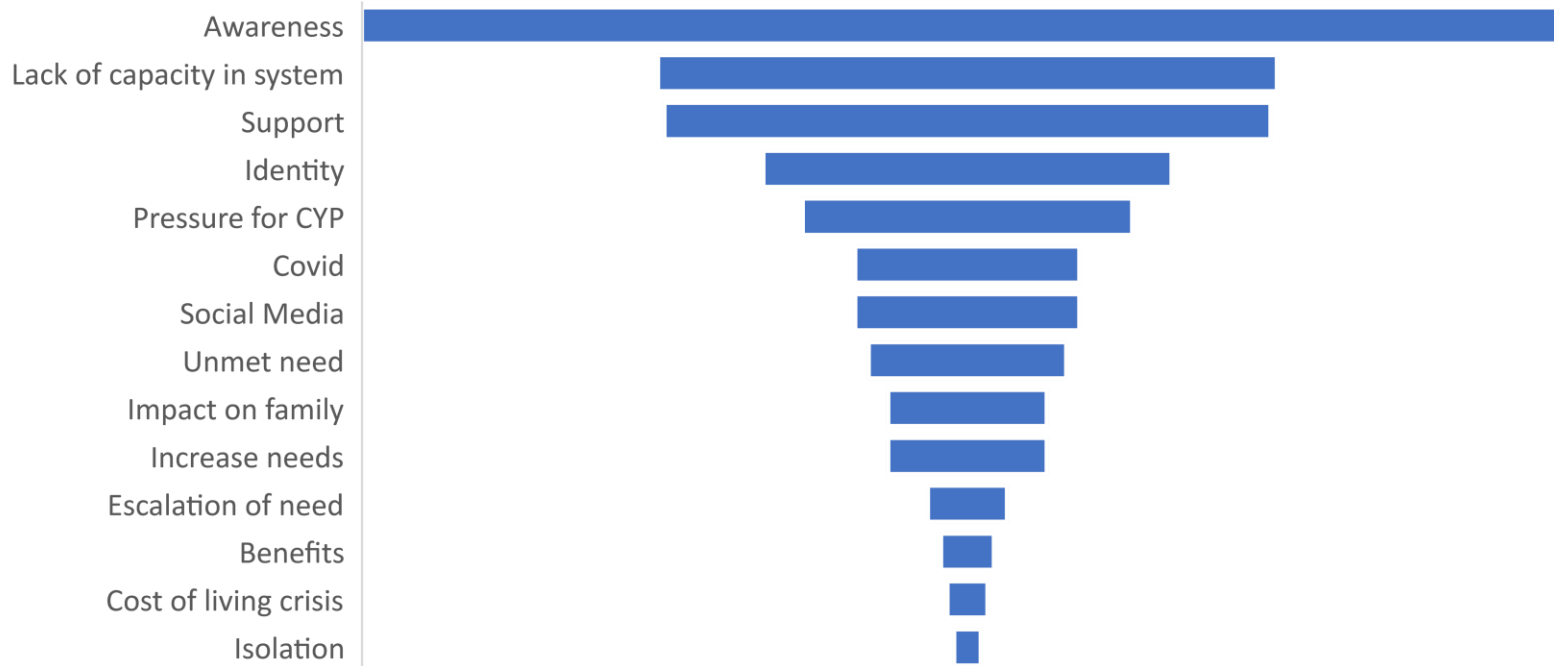
## 4. What's the impact on CYP / families when needs are across multiple conditions/ pathways

Emotional and relationships:	Percentage
Impact on family life	29%
Multiple assessments could affect their self-worth	14%
Effect on careers for parents	14%
Stress	14%
Frustration	14%
Increased anxiety	14%
Referral process and threshold	Percentage
Confusing and complex to navigate	57%
Lack of consistency	7%
Too much admin/ paperwork, disruption/ stress	7%
Having to restart process over again	7%
Long waiting times	7%
Diagnostic overshadowing if more than one condition	7%
Having to choose between pathways e.g. EY SLT/ ASD	7%

Support:	Percentage
Barriers between services	19%
Disconnect between services and families	12%
Families instantly have to fight to get heard, and disengage from the process	12%
Families go from service to service without any support or diagnosis	8%
Lack of confidence in the system	8%
Families feel they are not listened to	4%
Uncertainty around who is taking responsibility for the child	4%
Lack of early intervention	4%
Health only offers an assessment service, not help or intervention	4%
System not proactive	4%
Families having to retell their stories	4%
Lack of formulation guiding intervention	4%
Lack of keyworkers to navigate services	4%
Not person centred	4%
Can lead to no support as don't fit into one diagnosis 'box'	4%
Misinformation	4%

# Session Two - Understanding the increase in referrals

## 1. What do you think is the root cause of the increase in referrals?



■ Number of mentions

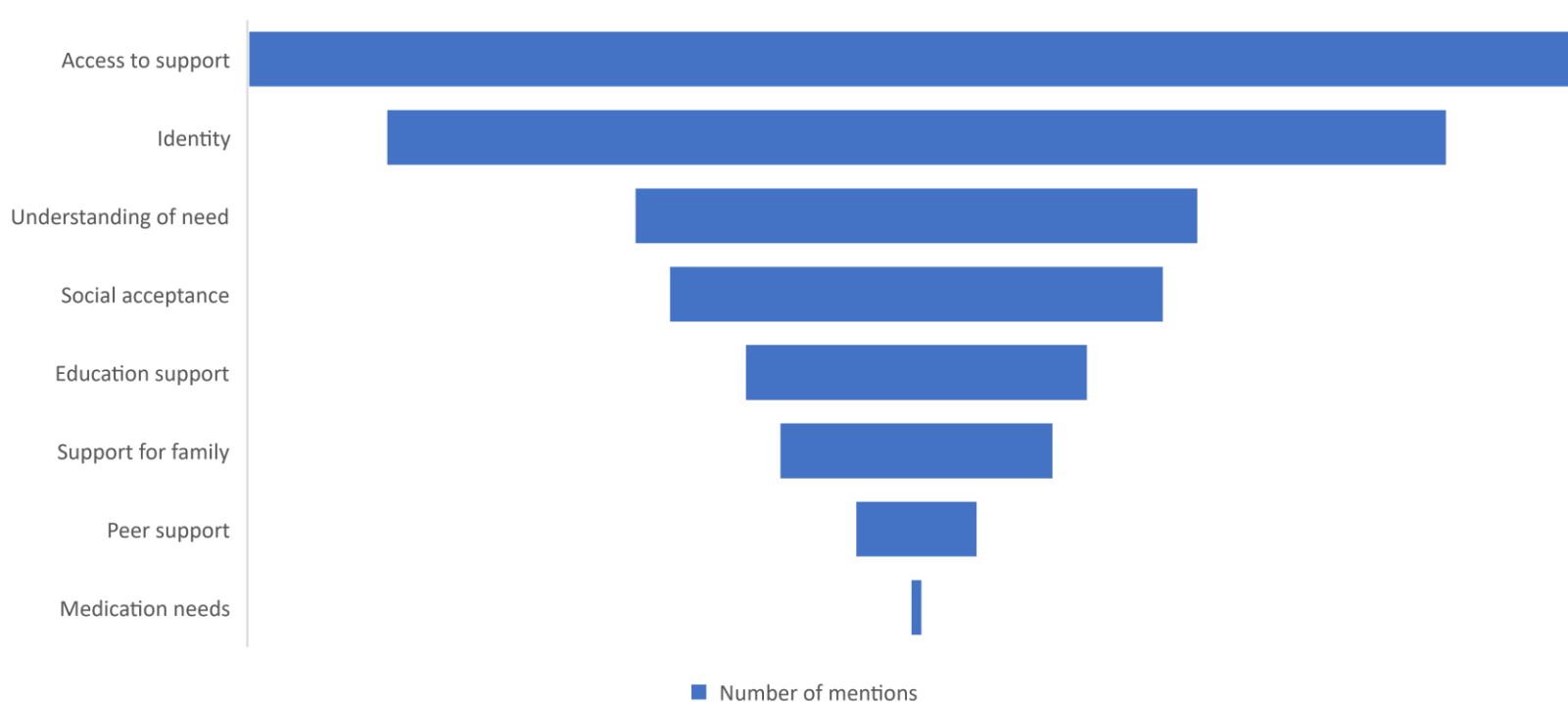
Theme	Number of mentions	Percentage
Awareness	92	28%
Lack of capacity in system	47	14%
Support	46	14%
Identity	31	9%
Pressure for CYP	25	8%
Covid	17	5%
Social Media	17	5%
Unmet need	15	5%
Impact on family	12	4%
Increase needs	12	4%
Escalation of need	6	2%
Benefits	4	1%
Cost of living crisis	3	1%
Isolation	2	1%
Total	329	

# What do you think is the root cause of the increase in referrals?



# Session Two - Understanding the increase in referrals

## 2. What are the benefits of a diagnosis?



Theme	Number of mentions	Percentage
Access to support	97	32%
Identity	77	25%
Understanding of need	41	13%
Social acceptance	36	12%
Education support	25	8%
Support for family	20	7%
Peer support	9	3%
Medication needs	1	0%
Total	306	

# What are the benefits of a diagnosis?

education support

medication needs

identity

peer support

access to support

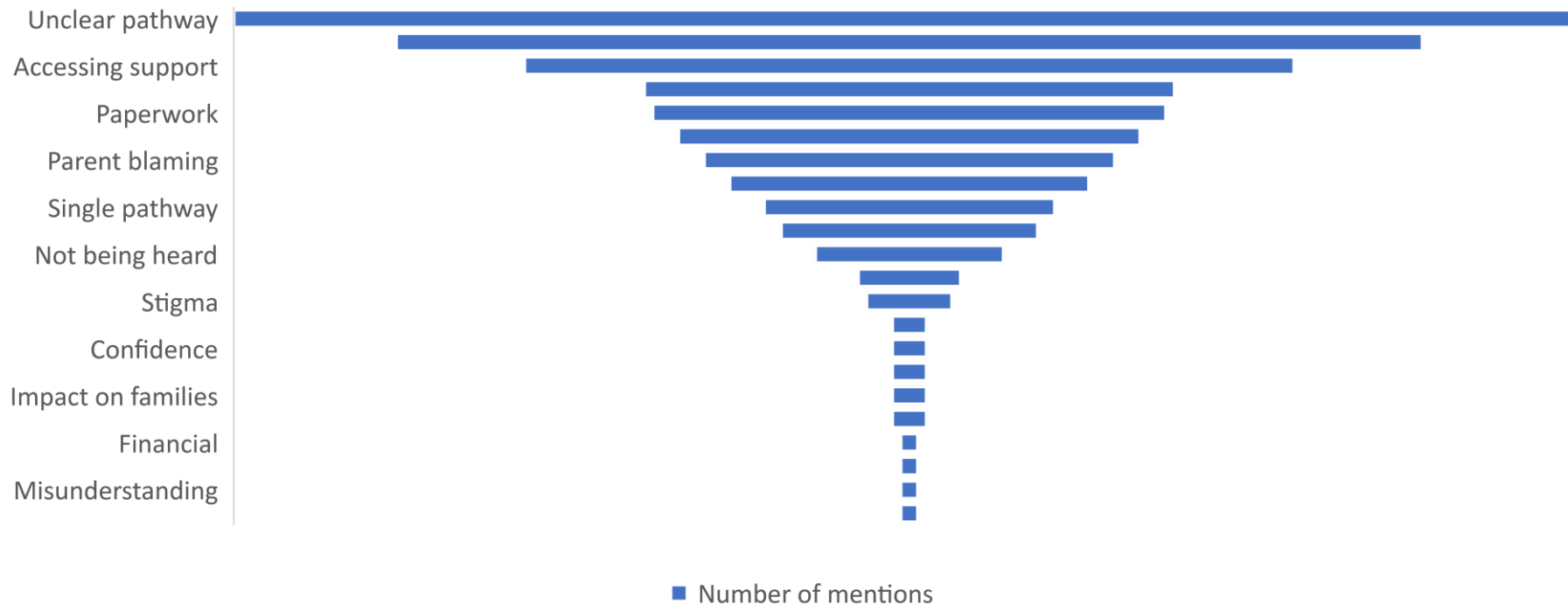
understanding of need

social acceptance

support for family

# Session Two - Understanding the increase in referrals

## 3. What are barriers CYP/families face when navigating the referral pathway?



Theme	Number of mentions	Percentage
Unclear pathway	79	21%
Waiting time	60	16%
Accessing support	45	12%
Needs not recognised	31	8%
Paperwork	30	8%
Capacity for parents	27	7%
Parent blaming	24	6%
Cultural differences	21	5%
Single pathway	17	4%
Trust	15	4%
Not being heard	11	3%
Digital access	6	2%
Stigma	5	1%
Child masking	2	1%
Confidence	2	1%
Fear of labels	2	1%
Impact on families	2	1%
Repeating stories	2	1%
Financial	1	0%
Holistic is not the default	1	0%
Misunderstanding	1	0%
Travel & Cost	1	0%
<b>Total</b>	<b>385</b>	



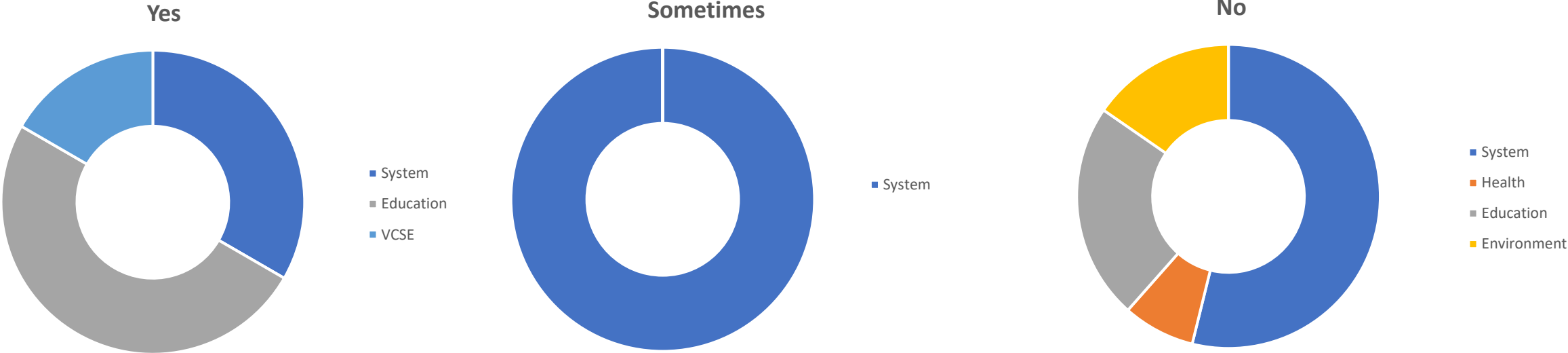
# What are barriers CYP/families face when navigating the referral pathway?





# Session Three - Understanding the experience post assessment

1. Are needs being met after assessments, if not which ones and why?

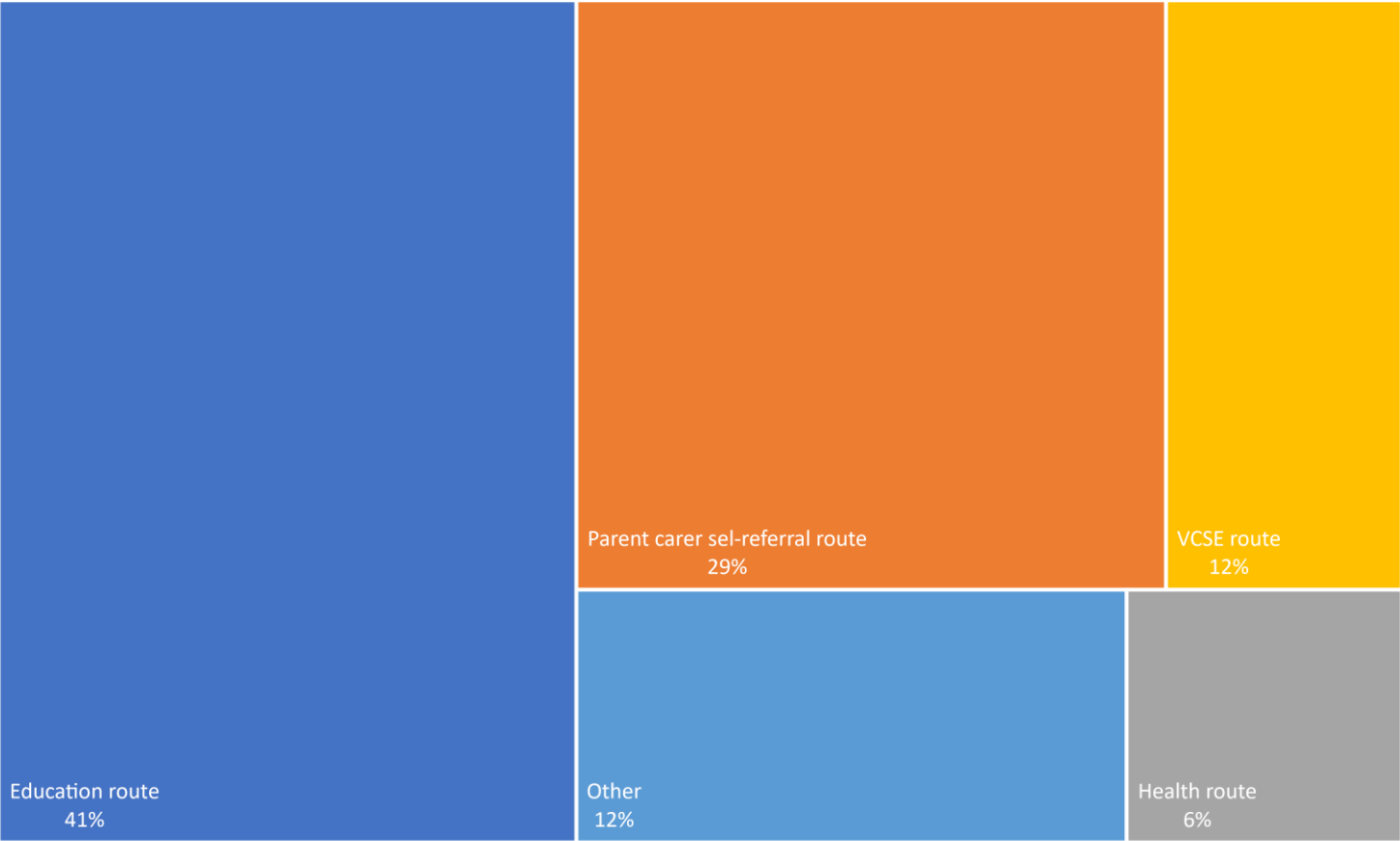


	System	Health	Education	Environment	VCSE
Yes	2	0	3	0	1
No	7	1	3	2	0
Sometimes	3	0	0	0	0

# Session Three - Understanding early Identification of needs

## Question 2. How is support accessed?

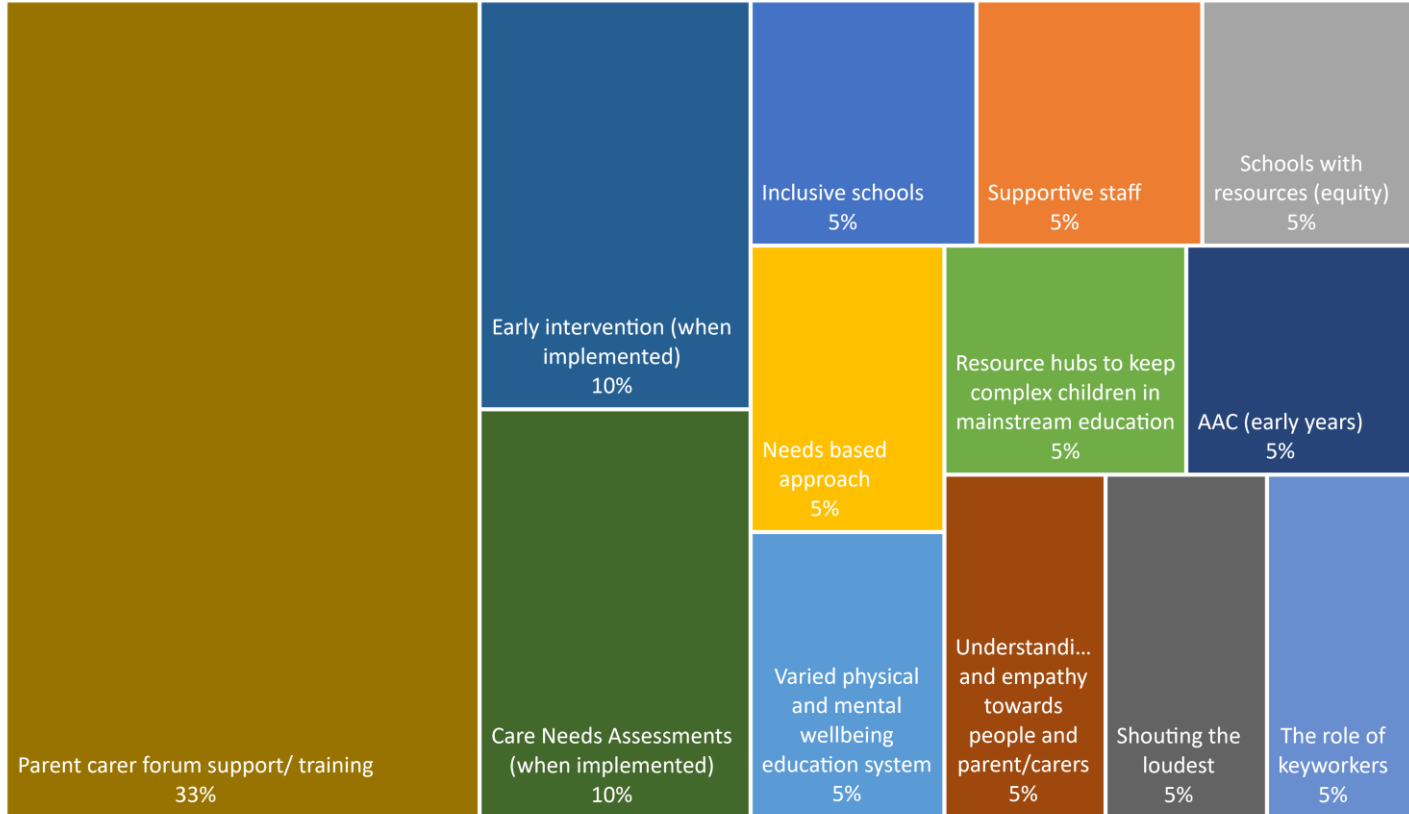
■ Education route ■ Parent carer sel-referral route ■ Health route ■ VCSE route ■ Other



How is support accessed?	Percentage
Education route	41%
Parent carer self-referral route	29%
Health route	6%
VCSE route	12%
Other	12%

# Session Three - Understanding early Identification of needs

## Question 3. What works well?

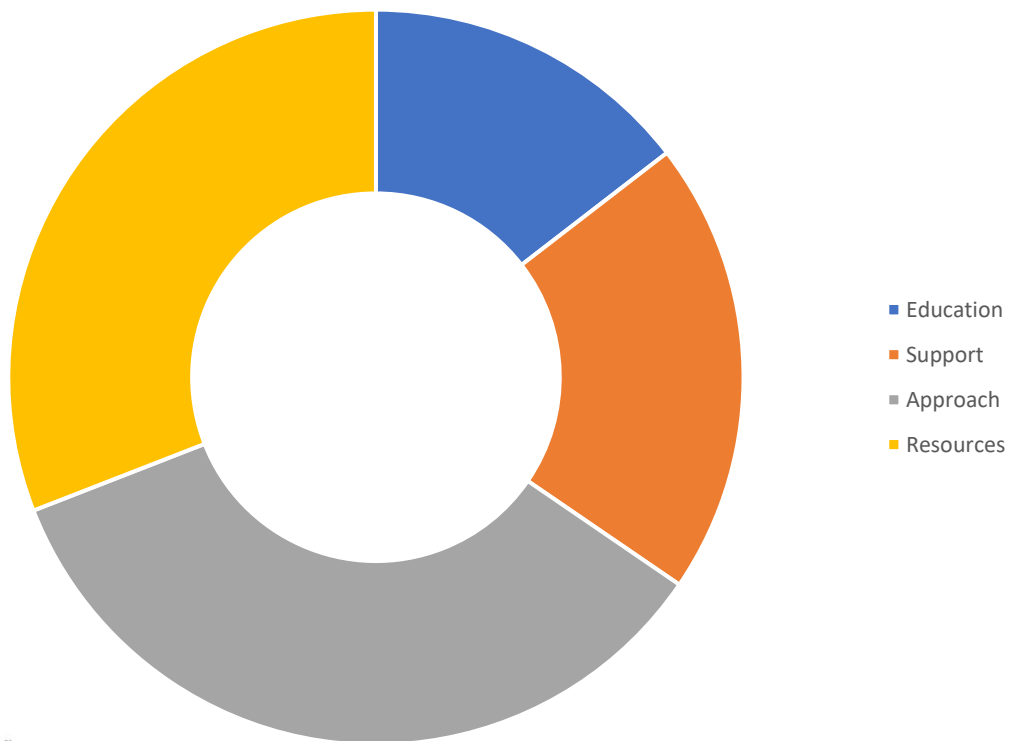


What works well		Percentage
Education	Inclusive schools	5%
	Supportive staff	5%
	Schools with resources (equity)	5%
	Varied physical and mental wellbeing education system	5%
	Resource hubs to keep complex children in mainstream education	5%
	AAC (early years)	5%
Approach	Understanding and empathy towards people and parent/carers	5%
	Shouting the loudest	5%
	Needs based approach	5%
Support	Parent carer forum support/ training	33%
	Early intervention (when implemented)	10%
	Care Needs Assessments (when implemented)	10%
	The role of keyworkers	5%

# Session Three – Understanding the experience of post assessment

## 4. What needs to change to make the most impact?

Area of change needed



Area of change needed	Percentage
Education	15%
Support	20%
Approach	35%
Resources	31%

# Session Three – Understanding the experience of post assessment

## 4. What needs to change to make the most impact?



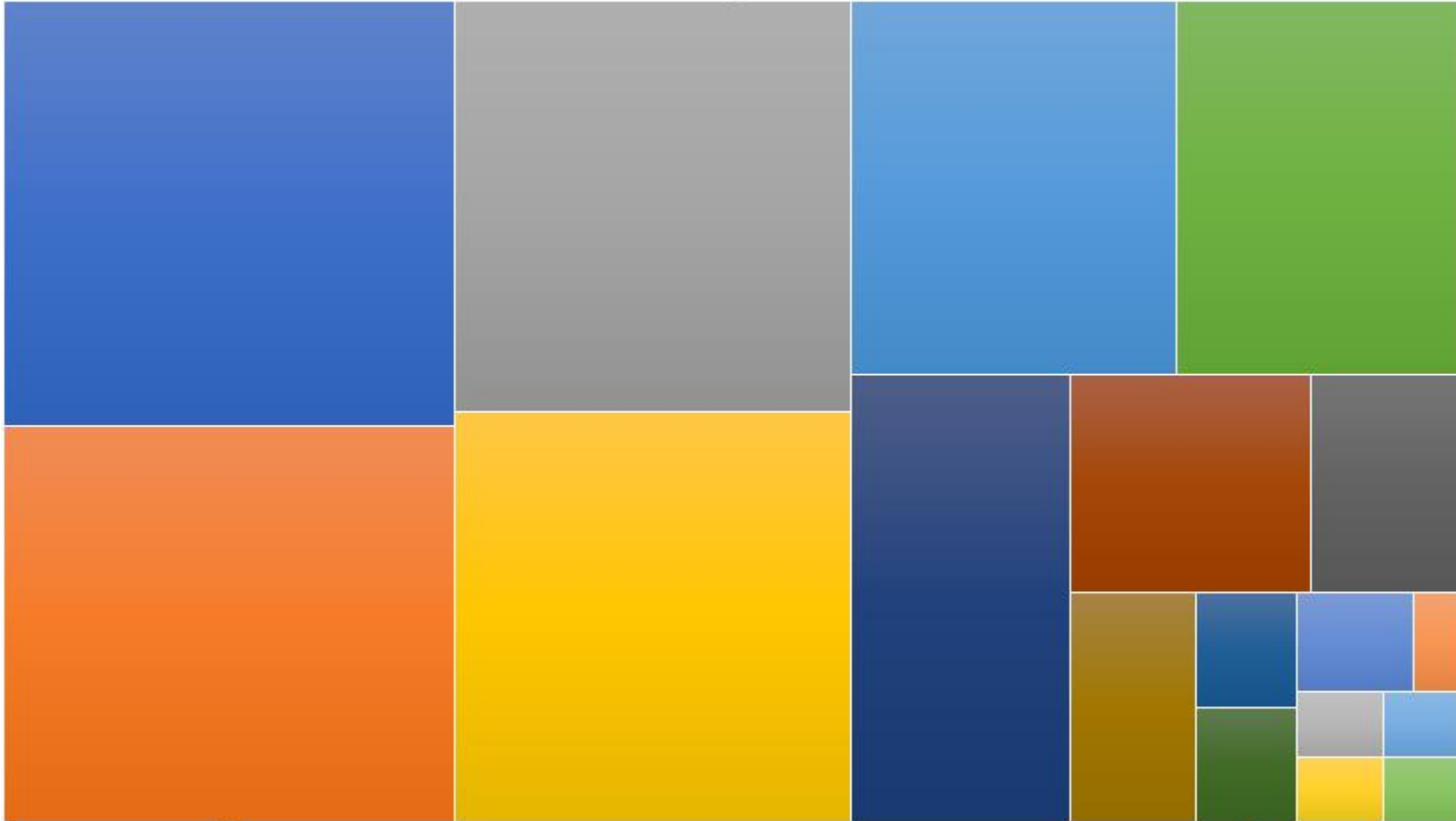
# Session Three – Understanding the experience of post assessment

## 4. What needs to change to make the most impact?

Education	Percentage
More inclusive teaching system	4%
Overhaul of SEN system process - proper inclusion	4%
More flexibility and creativity in teaching	2%
Increase specialist and personalised approaches in every school	5%
Approach	Percentage
Remove language barriers	2%
Understanding need through sensory processing assessment and SALT assessment	2%
Diagnosis should include needs assessment	2%
Joined up and creative thinking from services	7%
Clear pre and post assessment pathways with clear ownership	7%
Whole family approach	4%
Proactive, needs-led services	4%
Better communication and expectation management	4%
Realisation that assessment is only part of the journey	2%
Less parent blaming	2%

Support	Percentage
More availability of support	9%
Improve parenting courses	2%
Signposting when you get an assessment	2%
Community Paeds (ADHD) to have ability to offer package	2%
Access to therapies	2%
Meeting needs of all CYP - not all needs require professional support	2%
Support of staff	2%
Resources	Percentage
Staff training/ retention	7%
Funding	13%
Equity across geographical areas	5%
OT for sensory needs	2%
Resource - not just money - for universal services	2%
Developing LSA's as areas of specialism	2%

# Session Four - What else do we need to consider/ know to respond to the problem statement?



- Early engagement with health visitors (2-4 year old settings) and early years awareness training
- Engagement with teacher training providers so neurodiversity is a focus on the curriculum
- Engagement with mental health services
- Pre-emptive inclusivity
- Such disparity in schools about their ability to support children. Quality of SENCo's vary so much
- Voice of the young person
- What societal factors affect engagement in services? How are we meeting this need?
- What is the baseline for SENCo's in schools in BNSSG? Is there variation in resource/time
- What support is offered for young offenders or those in the prison system?
- Are adult services aware enough of the impact of a child's needs on the whole family?
- Engagement with teacher/training providers
- Engagement with central government OFSTED
- Evidence
- Can clinical support be better targeted for sibilings when a child is diagnosed
- What is the actual impact on children accessing education/ ESBA in schools in BNSSG?
- Engagement with nursery schools for training/ teaching purposes
- ND: What does it mean? We have spoken mainly about Autism.
- During school assessment there is not enough time given to what a person can do
- Diagnosis do it right: NICE, DISC, ADOS, ADER 3D

# Session Four - What else do we need to consider/ know to respond to the problem statement?

Further information areas identified	No. of votes
Early engagement with health visitors (2-4 year old settings) and early years awareness training	33
Engagement with teacher training providers so neurodiversity is a focus on the curriculum	31
Engagement with mental health services	28
Pre-emptive inclusivity	28
Such disparity in schools about their ability to support children. Quality of SENCo's vary so much	21
Voice of the young person	19
What societal factors affect engagement in services? How are we meeting this need?	17
What is the baseline for SENCo's in schools in BNSSG? Is there variation in resource/time	9
What support is offered for young offenders or those in the prison system?	6
Are adult services aware enough of the impact of a child's needs on the whole family?	5
Engagement with teacher/training providers	2
Engagement with central government OFSTED including:	
- OFSTED Framework	
- National Curriculum	2
- SEND Green and White paper	
- Teacher training	
Evidence	2
Can clinical support be better targeted for siblings when a child is diagnosed	1
What is the actual impact on children accessing education/ ESBA in schools in BNSSG?	1
Engagement with nursery schools for training/ teaching purposes	1
ND: What does it mean? We have spoken mainly about Autism.	1
During school assessment there is not enough time given to what a person can do	1
Diagnosis do it right: NICE, DISC, ADOS, ADER 3D	0