

INSIGHT REPORT:
A co-production project to
develop evidence-based
autism resources for health
visitors to support the families
they work alongside



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INTRODUCTION

The Institute of Health Visiting (iHV) was successful in securing a grant from the Burdett Trust for Nursing aimed at supporting health visitors by developing an easily accessible toolkit which consolidates evidence and best practice guidance in supporting families where autism is suspected. The toolkit produced will be the first national resource designed exclusively to meet the needs and context of health visiting practice to help support early recognition of signs of autism. Improving health visitors' knowledge and skills in this way aims to support earlier referral for diagnosis, adapted support approaches and better signposting.

This report provides an overview of the insights gathered during this first step in the project, which aimed to scope the current needs of both parents / carers and health visitors to inform the development of resources. The findings from all aspects of the insight's phase of the project have been triangulated into key themes and recommendations to inform the development of resources and the toolkit.

AIM AND BACKGROUND

The Royal College of General Practitioners (2016) identified that there is an urgent need to improve healthcare of people with autism, to reduce inequalities and associated poor outcomes throughout the life course (NHS, 2019). Research shows that people with autism are more likely to die, on average, 16 years earlier than the general population and this inequality gap increases if they also have learning disabilities. Identifying difficulties early in childhood and supporting uptake of evidence-based early intervention has the potential to deliver significant social and economic benefits. Yet children with autism continue to be missed or fall through gaps between services.




Autism remains the most common primary type of need for pupils with a statement or Education Health and Care (EHC) plan, with a prevalence of 28.2% of pupils with a statement or EHC plan in January 2018. Health visitors provide leadership for delivery of the Healthy Child Programme 0-5 and work with partners to deliver a comprehensive programme of support. "The Early Years High Impact Area 6: Health, wellbeing and development of the child aged two" sets out the central role of health visitors in child development. Health visitors work with every family to identify risks and variations from the norm, with the intention of reducing any negative impact. As such, they are ideally placed to identify the signs of autism early and ensure parents receive prompt support and appropriate assessment and early intervention for their child. However, training in autism is not a part of health visitors' core training and there are few resources available for health visitors to help them to work in partnership with families.

CO-PRODUCTION APPROACH

To support the development of the resources for health visitors, it was essential to work in partnership with parents and key stakeholders - therefore, a model of co-production was adopted from the inception of the project. We were able to work with parents, Learning Disability Nurses (LDNs), the National Autistic Society, ICAN, Health visitors (HVs), Speech and Language Therapists (SALTs) and Occupational Therapists (OTs) to gather insights to shape the final resources and training.

The project was led by a Steering Group comprising parents of children with autism, nurses (LDNs, HVs), academics and representatives from national bodies.

Engagement with these stakeholders was achieved using a Patient and Public Involvement (PPI) approach which included the following activities:

-  Baseline survey of healthcare professionals' knowledge and confidence in providing autism advice and guidance
-  Joint national survey with KIDS Charity to gather parents' views on the current support and guidance they receive and what their experience of living with autism is
-  Insights from focus groups with: (a) parents of children with suspected or diagnosed autism, (b) health visitors and

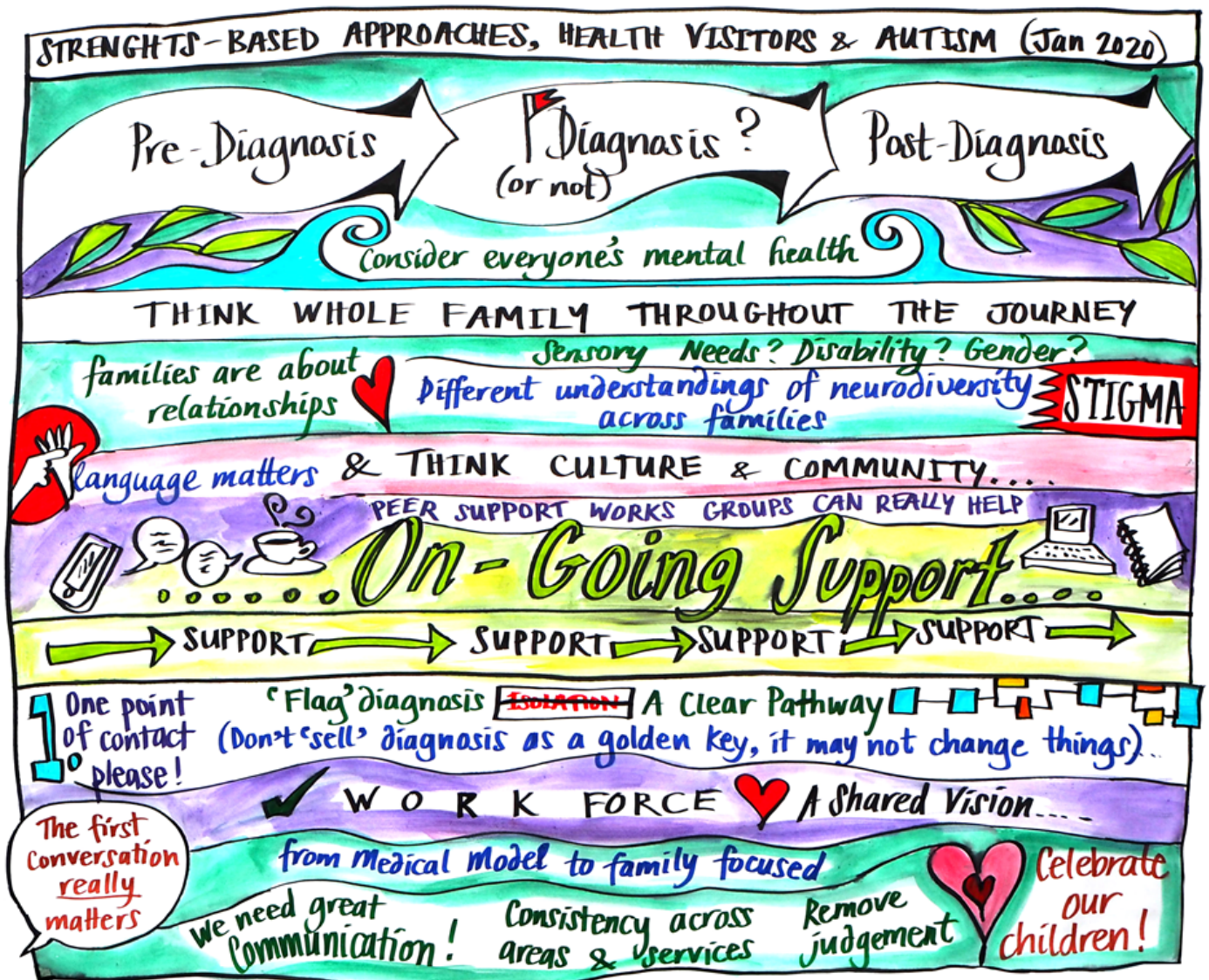
health visitor team members including community nursery nurses and community staff nurses.

🌈 An “Experience-Based Co-Design” group to gather experiences from parents, HVs, LDNs, experts in Autism, SALTs and OTs. Identify key themes during the period from parents’ first concerns about their child’s development to transition to school

The insights gathered from each of these approaches aimed to guide the development of the digital toolkit and 4 national events.

A summary of each of these approaches and the key findings is presented below.

Picture 1 - Graphics from the first co-production meeting



Autism Institute of Health Visiting Burdett Project, January 2020. Graphic facilitation by www.penmendonca.com @MendoncaPen

1. HEALTH VISITOR SURVEY

This study involved a survey design with a purposive sample of respondents aimed at gaining a greater understanding of health visiting teams' work with families with children with autism. The iHV has significant reach through its survey function and this was determined as a robust method to gather insight from practitioners with current health visiting practice experience.

The questions were formulated and then agreed by the expert steering group before being transferred to an electronic survey using Survey Monkey. This was then disseminated for completion through the iHV network, e-mailing members and associates, thereby ensuring the widest reach of HVs working with families was achieved.

N.B. See Appendix 1 for a copy of the survey questions.

1.1 Background of those who answered


A **total of 288** professionals completed the survey and of these 99 practitioners completed an expression of interest in being further involved in the project. Those involved were asked to provide their details (see Map 1 showing geographical spread of engagement/interest).


Map 1: Location of health visitors interested in being part of the project



Table 1: Break down of respondents by professional group

RESPONDENT ROLE	PERCENTAGE	NUMBER	COMMENTS
Health Visitors Specialist Community Public Health Nurses (SCPHNs)	74%	213	1. Of which 45% (n=120) were from an adult nursing background 2. Of which 31% (n=84) were from a Paediatric Nursing background 3. Of which 14%(n=37) were from a midwifery background 4. Of which 2.5 % (n=7) were from an LD background
Family Nurse Practitioners	2%	6	
HV Managers	6%	18	
CSN	1%	4	
NN	5%	13	
Student HVs	0.7%	2	
A selection of professionals working with children with learning difficulties	6%	15	

 The respondents were drawn from England, Wales and Scotland. Despite efforts to represent all 4 UK nations, the study did not achieve any representation from Northern Ireland.

 The study also achieved a small sample from outside the UK including those who work in the military overseas.

Note: For this report, the term HVs will be used to describe all professionals who responded to the survey as this was the majority.

1.2 Prevalence of families who are known, or suspected, to have autism that health visitors work with

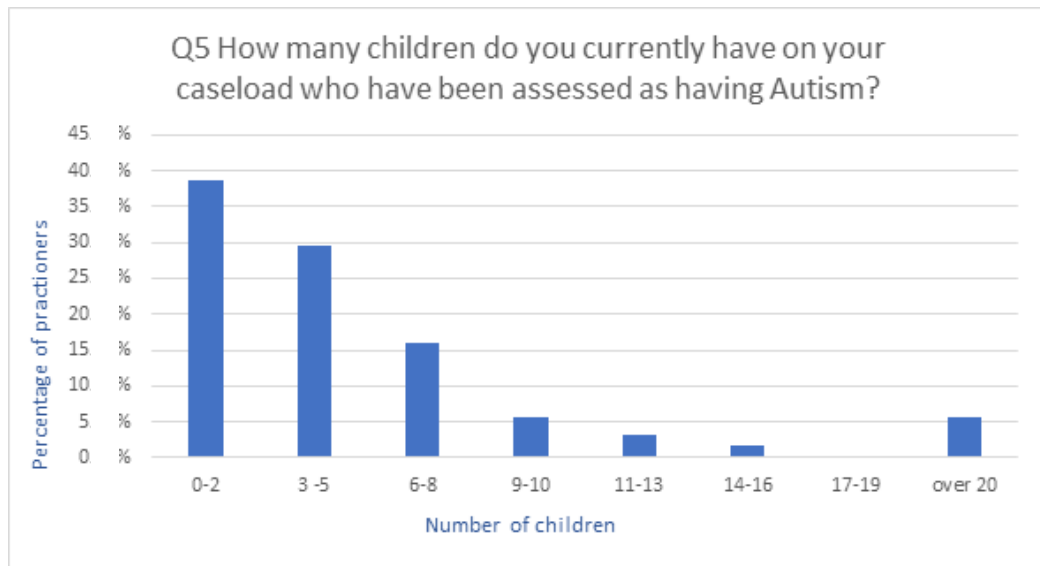
The questions focused on gaining an understanding of the number of children and families that HVs are currently working with - this was important to understand the potential scope for the training and the best methods of delivery.

The majority of respondents, 89% (n=254), stated that they had less than 5 children on their caseload with autism, and less than 2% (n= 4) said that they had 14 or more children on their caseload with autism. A similar number 93% (n=265) stated that they had less than 5 children on their caseload with suspected autism and again less than 2% (n=4) have more than 14 children with suspected autism. Graphs 1&2 show these results.

Graph 1 – Survey Question 4

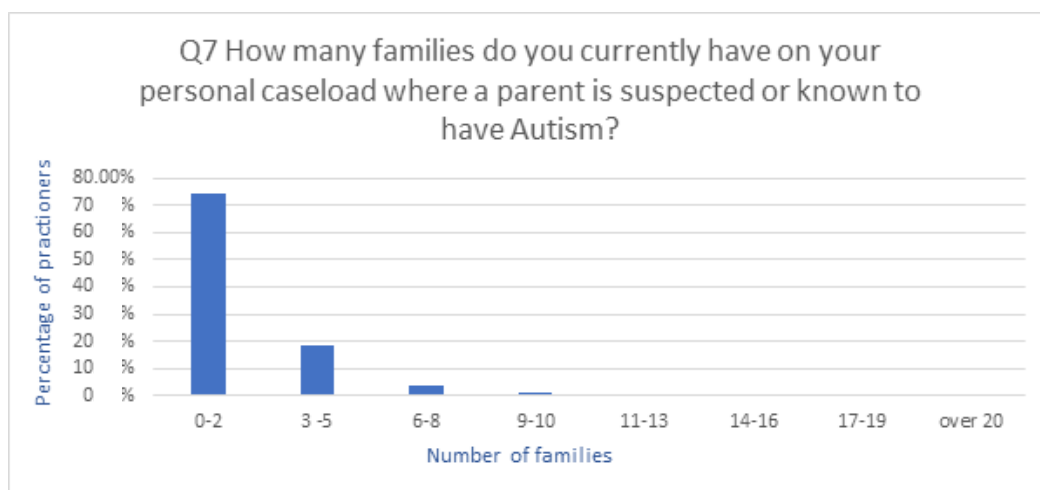


Graph 2 – Survey Question 5



The survey asked about the number of parents that HVs were working with who were suspected/diagnosed with autism. The results of this were similar to the number of children on the HVs' caseloads, 93% (n=265) have 5 or less parents on their caseload with suspected or diagnosed autism and less than 2% (n=4) had more than 14 parents on their caseload with suspected or diagnosed autism, see graph 3.

Graph 3 – Survey Question 7



Discussion

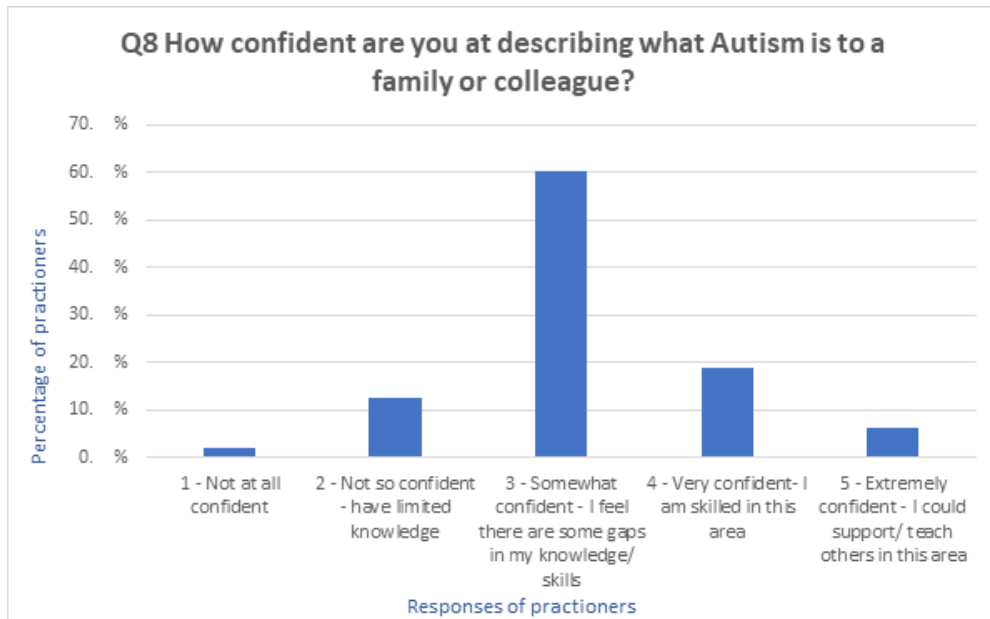
From this, it can be concluded that all HVs will be working with families with autism to a greater or lesser degree. The majority of HVs have at least 1 child or parent on their caseload with autism or suspected autism, although some had considerably more. This is important and validates the need for HVs to be supported to work with these families.

1.3 Knowledge and confidence in working with families

HVs were asked a series of questions on their self-reported knowledge and confidence in working with families with autism based on their current practice.

Graphs 4 and 5 show that the majority of HVs who responded reported a neutral score of “feeling somewhat confident” with few health visitors stating that they were very confident or extremely confident. Most practitioners had some confidence in describing autism to families and working with these families but recognise that they have gaps in their knowledge.

Graph 4 – Survey Question 8



Graph 5 – Survey Question 9



It is important to address the gaps in HVs’ knowledge to ensure that families receive the support that they need. 10 different topics for support were identified from the literature and feedback through the steering group.

These included support to manage: sleep; toileting; eating/diet; meltdowns/tantrums; sensory issues; behavioural development; communication; socialising; and transition to preschool offers (childcare, nursery settings).

In all these areas, over half of HVs stated that they were not at all confident, or had some gaps in their knowledge of working with families who are suspected or known to have Autism, see Table 2.


Table 2 – Confidence in offering support to parents by topic


TOPIC	% Answered that were not at all confident to some gaps in their knowledge	Number who answered
Sleep	80%	321
Toileting	81%	223
Eating/Diet	79%	218
Meltdowns/Tantrums	79%	209
Sensory issues	83%	230
Behavioural development	50%	223
Communication	78%	215
Socialising	81%	222
Transition to preschool offers (childcare, nursery settings)	79%	219


1.4 Assessment process


The survey then explored the current assessment processes employed by HVs.


The majority of HVs, 87% (n=232), reported that they were confident in identifying autism, and 84% (n=233) stated that they were confident in discussing this with parents in the assessment process.

 60% (n=162) were assessing children using a development tool, but there is no standardised tool used and less than half 49% (n=130) of HVs have had training on the tools they are using

 63.5% (n=169) of HVs state that they have limited confidence in using these tools to inform their interaction with children and families


 74% (n=198) of the HVs stated that they had a local referral pathway for autism

 79% (n=209) were confident in using this pathway in advising and supporting families when there is a concern that a child has autism

 However, 86% (n=464) HVs felt they had some to no confidence in supporting children with autism transitioning to school.

1.5 Supporting families post diagnosis

The survey explored the reported confidence of HVs working with families following an autism diagnosis.

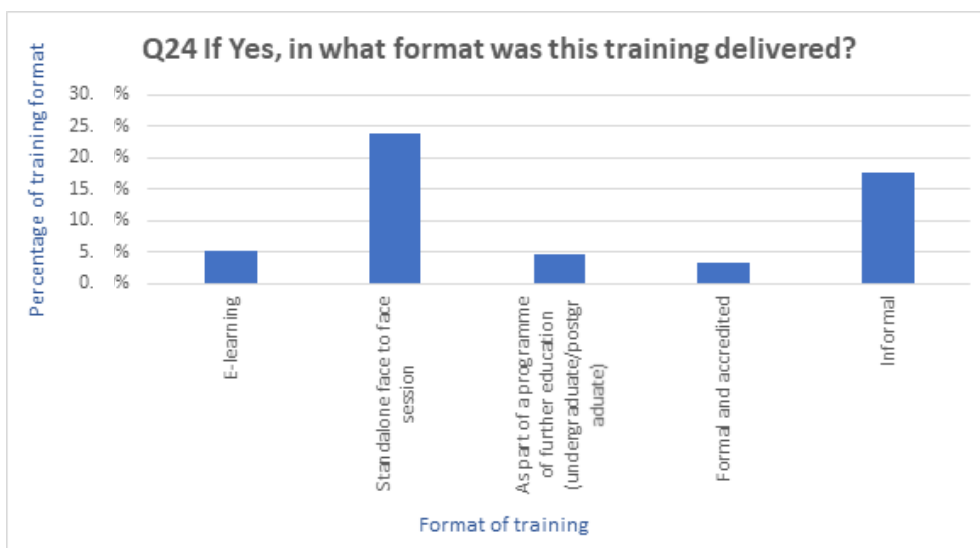
 76% (n=201) of HVs stated that they felt confident in having a strengths-based conversation with parents following their child being diagnosed with autism.

This question relates to skills in “how” information and support is provided using strengths-based conversations. This increased level of confidence in supporting families in this way is in contrast to the reported lack of confidence in “what” was provided in terms of advice on interventions to support the families.

1.6 Training

Only half of HVs reported that they have had some training on autism, the majority of which was about 2-3 years ago; the training was from a variety of sources. See Graph 6.

Graph 6 – Survey Question 24



Interestingly, although throughout the survey HVs stated that they were confident in supporting children and families in some areas of behaviour and autism, half reported having limited training to support families and children with autism. Alongside this:

🌈 99% (n=207) stated that they wanted more training on working with families of children with autism.

The survey asked HVs what specifically they wanted further information and resources on, see table 3 for responses.

Table 3 – Breakdown of responses to Question 27

If Yes, please indicate the subjects that you would find helpful to have further information and/or resources on.

SUBJECT	PERCENTAGE	NUMBER
Risk factors and when to wait/when to watch and when to refer	63.16%	132
Role of the health visitor	46.41%	97
Support to have strengths-based conversations with families about Autism	64.11%	134
Using a behavioural change model to support children with Autism	87.08%	182
How to encourage age-appropriate development for children with Autism	82.30%	172
Evidence-based resources to support advice for children with Autism	89.00%	186
Supporting children with Autism	77.03%	161
Supporting parents on the Autism	82.30%	172
Current research, information, and resources available online for families with children with Autism	81.34%	170
Local Neurodevelopmental Pathways and support for Autism	66.99%	140
Tools and routes to escalation including Care Education Treatment Reviews and Dynamic Risk Registers	67.94%	142
Alternative options other than medication to support sleep	77.99%	163
Other (please specify)	11.48%	21

The respondents also offered text feedback asking for training in the following areas:

- 🌈 supporting the family holistically
- 🌈 parental relationship
- 🌈 how to support with other aspects such as housing and benefits
- 🌈 guidance to multi-agency working

The mode of delivery of the training was important to explore to inform the development of the toolkit and resource.

- 🌈 80% (n=169) stated that the resources/training would have to be evidenced based
- 🌈 72% (n=151) stated that having the training locally would be a priority
- 🌈 50% stated that having managerial support was important

1.7 Summary of the health visitor survey

The survey highlighted the following key factors that need to be considered in the development of resources:

- 🌈 Recognition that all health visitors are working with both parents and children with, or suspected of having, autism and therefore need the knowledge and skills to effectively support children and families in this area of their work. 98% of health visitors requested more training
- 🌈 Health visitors had variable levels of confidence to support the needs of these families, with some specific gaps in knowledge including transition to school and supporting specific behaviours
- 🌈 Health visitors specifically requested:
 - » training in autism
 - » need for evidence-based resources
 - » training on strategies to support families
 - » training on behavioural change approaches and strengths-based conversations
 - » accessible training, provided locally

2. PARENTS' SURVEY - Provided with thanks by Melissa MacKell, KIDS

The iHV has committed to work more closely with the people who use its products by embedding co-production methods at every stage of our projects and within our core business. Working in partnership with families with lived experience of autism was central to the aims of this project.

The purpose of the survey was to help identify parents' experiences to support the development of a toolkit for health visitors working with parents.



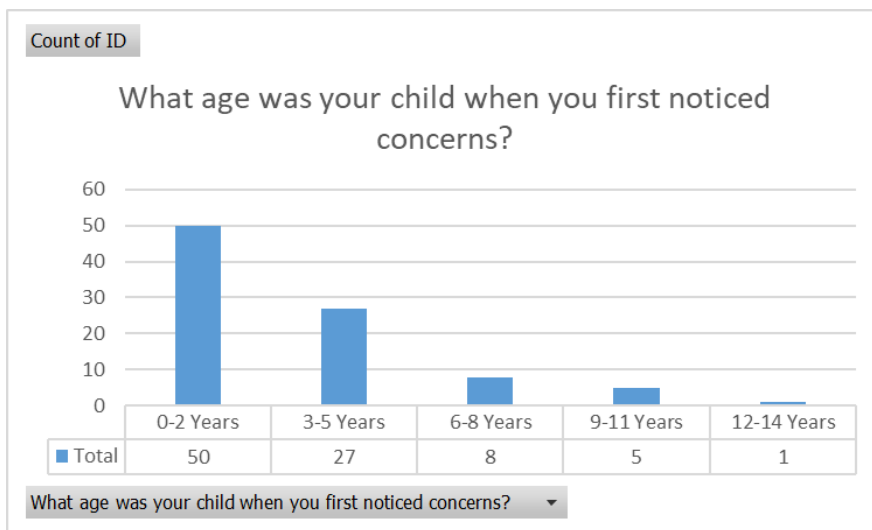
KIDS asked parents to complete an electronic questionnaire, using a standard survey format. The questions were formulated by KIDS and then agreed by the expert steering group before being transferred to an electronic survey platform. This was then disseminated for completion through the KIDS network, iHV network, e-mailing members and associates and released to social media, thus ensuring the widest reach with families was achieved.

2.1 The responses

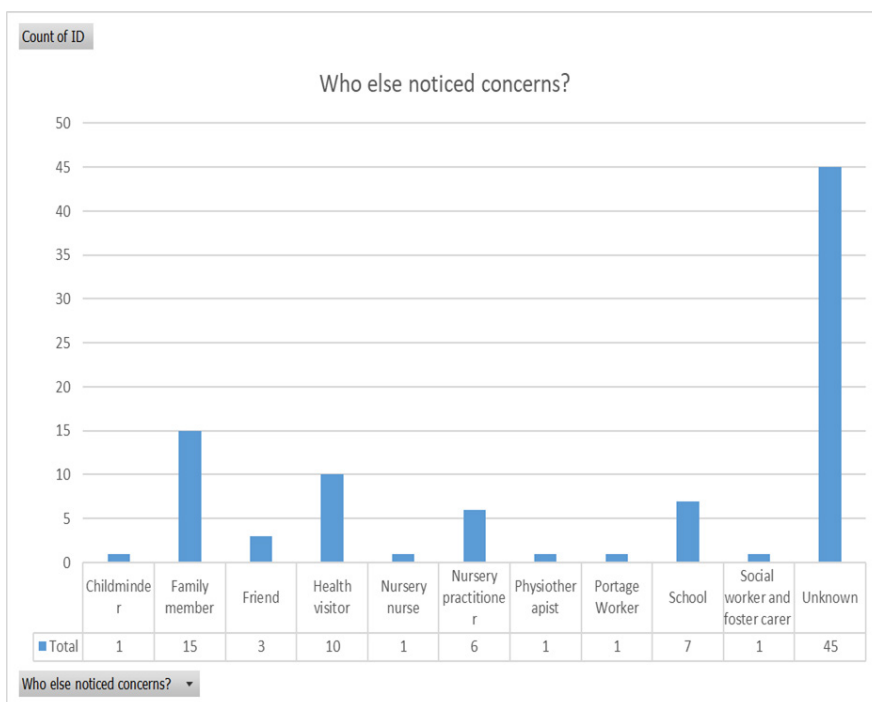
A total of 91 responses were received. The survey was open for completion for four weeks and closed on the 10th April 2020. KIDS thanked parents and carers for taking the time to complete this questionnaire.

2.2 Initial concerns

Of the 91 families that responded, 55% (n=50) noticed concerns when their child was aged 0-2 years and 30% (n=27) families noticed concerns between the ages of 3-5 years.



Families reported the following people noticed concerns:



3.5 Summary of parent survey

The survey highlighted the following key factors that need to be considered in the development of resources.

All respondents:

- 🌈 The importance of early support - over half of the parents had recognised early signs of autism and were first concerned when their child was between 0 -2 years.
- 🌈 Behaviour and speech were the most reported concerns prior to diagnosis, sleep was also highlighted.
- 🌈 Parents wanted support with 40% of parents seeking support from health visitors and 28% contacting their GP.
- 🌈 Worryingly, a large number of parents reported they were offered no support and over half of parents felt unsupported.
- 🌈 Feelings following diagnosis were mixed and included some relief following support from professionals. However, a significant number of parents highlighted that they felt unheard, disregarded, belittled and frustrated by contact with professionals.
- 🌈 The time of diagnosis was a particular trigger point, with parents reporting that they experienced a range of feelings from being relieved to devastated. Support for their own mental health and adjustment to the diagnosis was highlighted.



- 🌈 A key message from the survey was that parents want to be listened to, heard, understood and helped.
- 🌈 The importance of not being passed between professionals, in a “refer-on” culture, was clear – parents valued continuity of practitioner.
- 🌈 Post-diagnosis support was inconsistent for most parents, and for some respondents, none was offered.
- 🌈 For those without a diagnosis, the picture was similar with a lack of support expressed.

4. CO-DESIGN INITIAL WORKSHOP

Co-design was a key principle that we aimed to embed from the start of the project. An initial co-design workshop was held at the inception of the project to steer and guide the development of resources that would meet the needs of both families and practitioners.

A wide range of stakeholders were identified and invited to a full day event in January 2020.

A total of 14 attended:

Name	Job Title	Organisation
Alex Kelly	Managing Director	Speaking Space
Alicia Goulding	Parent	
Alison Worsley	Director of External Affairs	Ambitious about Autism
Amy Loxley	Speech and Language Therapist	iCAN
Cath Burton	Regional Manager	KIDS
Charlotte Carr	Learning Disability Workforce Specialist	Health Education England North
Gwen Moulster	Learning Disabilities Nurse	Independent
Ian Sutton	Right from the Start Programme Manager	Ambitious about Autism
Jenny Osborne	Specialist health visitor	North
Kath Bromfield	Parent	
Marina Rus	Learning Disabilities Nurse and parent	
Mellissa Mackell	Parent KIDS representative	KIDS
Oriana Morrison	Trainer Consultant -Training, Consultancy and Conferencing Consultant Specialist for Health and Local Authorities	National Autistic Society
Siobhan Gorry	Senior Manager Children & Young People, Yorkshire & Humber, Learning Disability and Autism Program	NHS England & NHS Improvement: North

4.1 Structure of the workshop

The workshop was facilitated using a world café approach. The participants were asked to rotate round the room to tables, where each group explored a range of questions focusing on the family's journey; from initial concerns through to post-assessment or diagnosis. This approach draws on experience-based co-design which involves gathering experiences through in-depth group discussions, identifying key touch points (emotionally significant points) and assigning positive or negative feelings. During the session, participants were also asked to co-produce solutions, including highlighting resources and strategies that they believed would be helpful for the families.

A graphic facilitator captured the conversations from the session and provided a graphic summary of the key messages. Please see appendix 3.

4.1.1 Key themes from the workshop

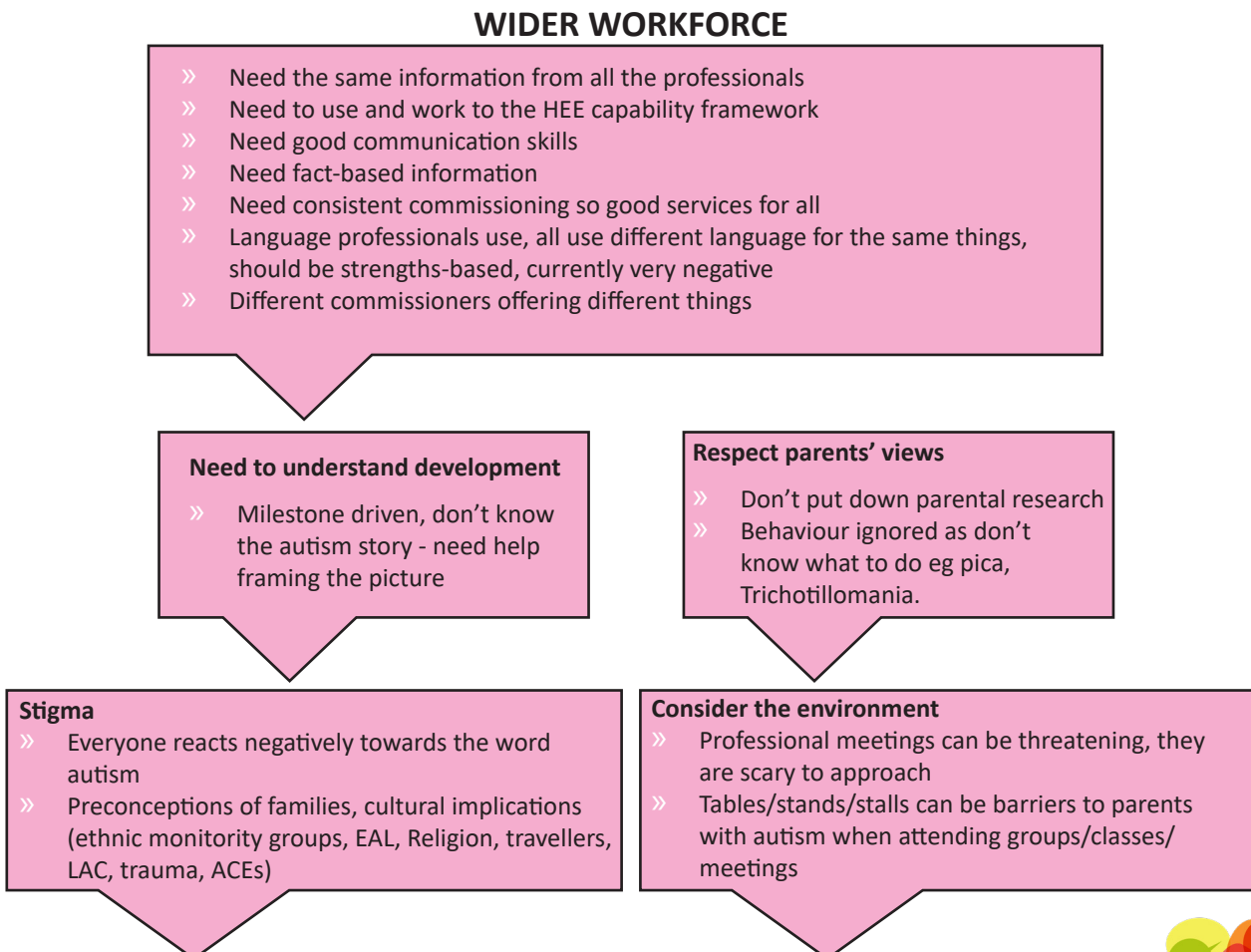
Feedback from the session was collated.

Several areas of need were highlighted, and these are depicted in Figure 1. These themes were considered in the schedules developed for the focus groups to gain a deeper understanding of the views of both families and health visitors to inform the development of the toolkit.

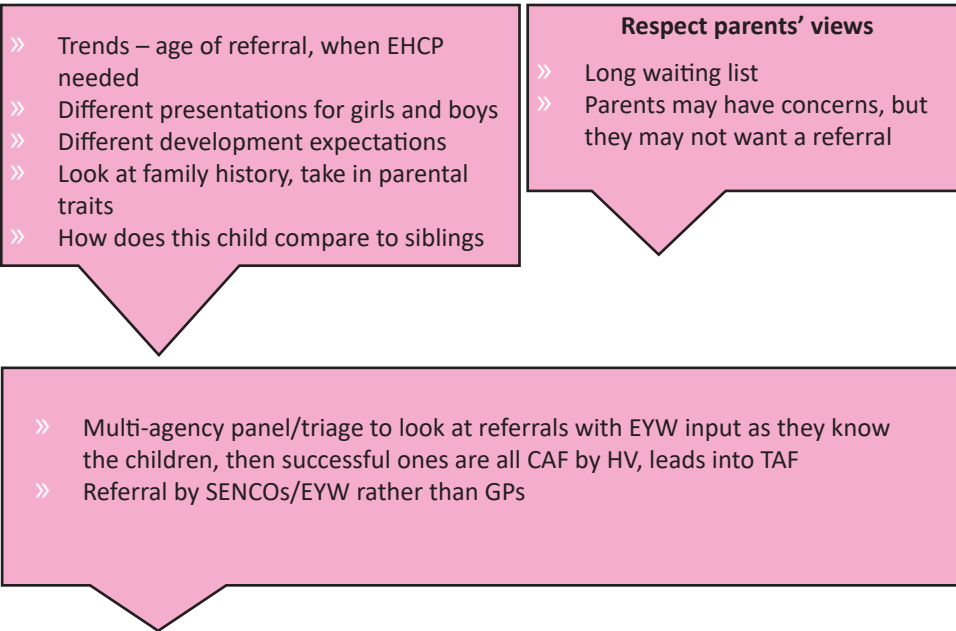
Figure 1 : Key themes from the co-design workshop



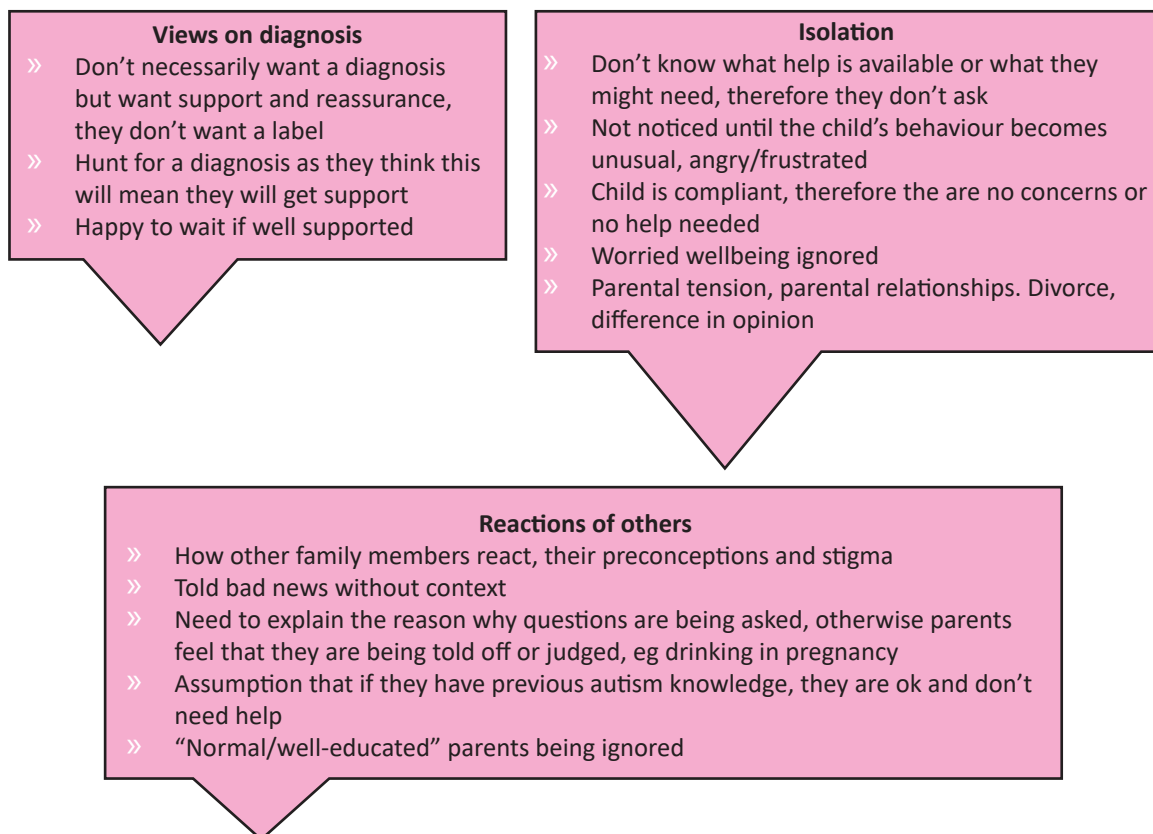
Figure 2: Pre-diagnosis identified from the co-design workshop



REFERRAL



PARENTAL EXPERIENCES



PARENTAL EXPERIENCES

What would help?

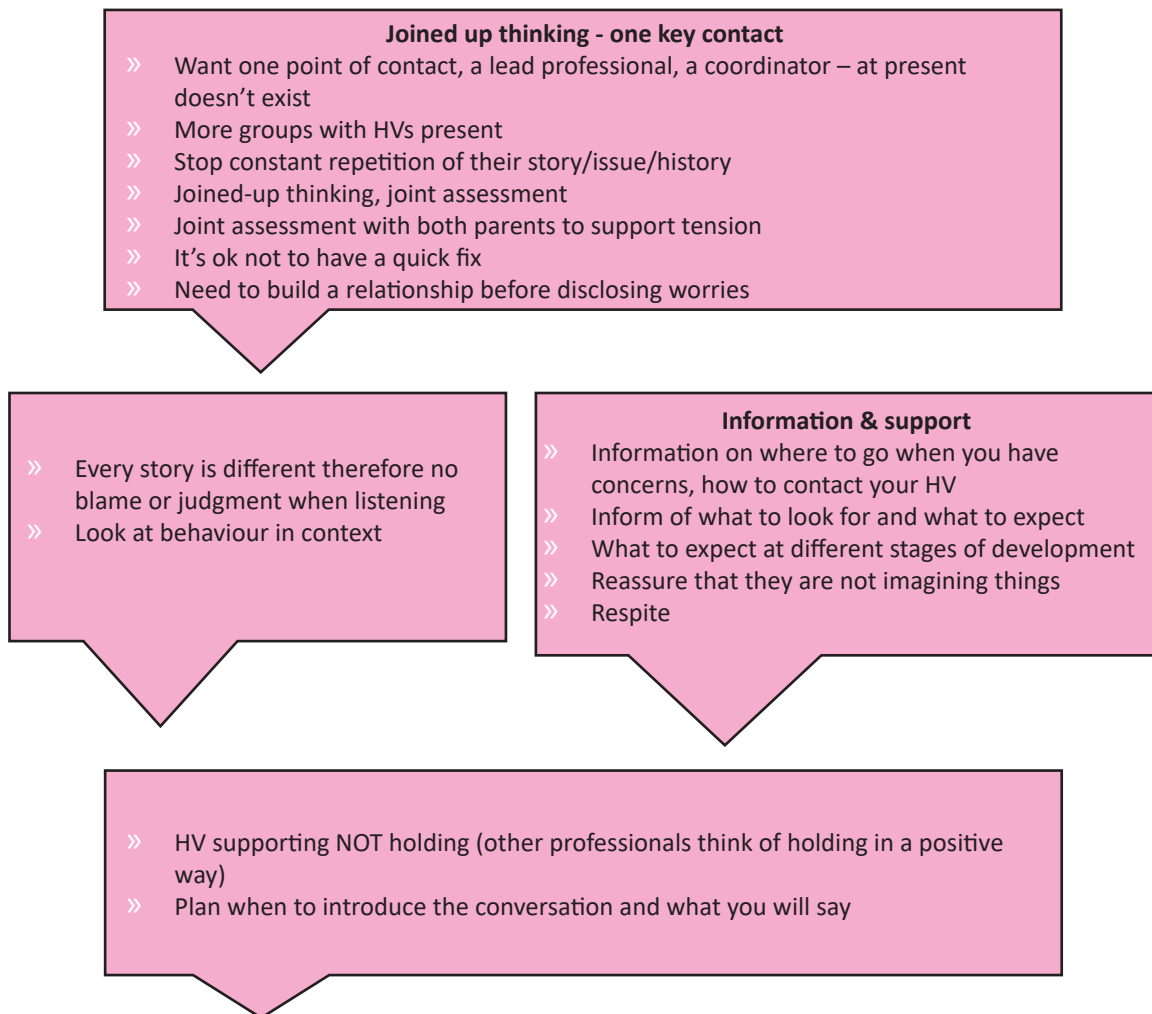
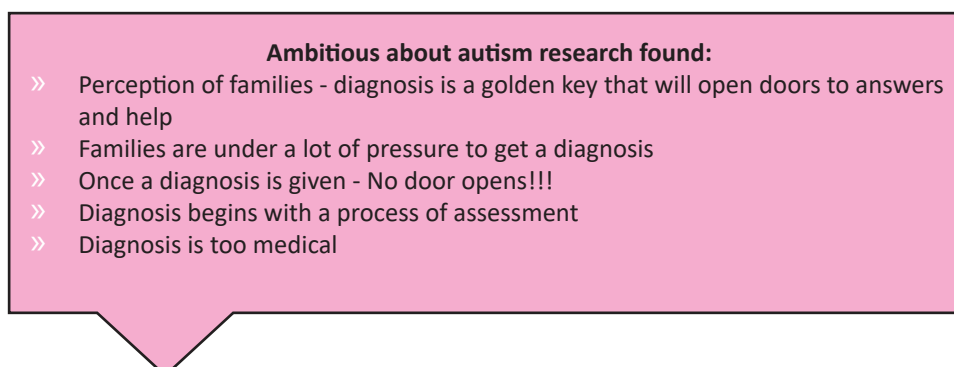


Figure 3: Diagnosis identified from the co-design workshop



Appointments for a diagnostic assessment

- » People wait a long time, often longer than 2 years
- » Why doesn't diagnosis have a follow up?
- » We lose dads at this point. They take time off for the initial appointment, but then any further appointments or work is usually just with the mum.
- » Receiving a diagnosis **can be traumatic**

- » Need a one stop shop for support

- » All money seems to be put into diagnosis instead of help
- » The pressure is to reduce waiting lists and use quantitative measures to identify success
- » No qualitative measures

- » Less likely to get a diagnosis unless the ASC causes a deficit

- » There can be an impact of loss – cycle of grief and loss

- » Paediatrician-suggested assessment of the whole family would be a better approach, as often other family members are also on the autism spectrum

Medical Training

- » Male-dominated medical model – influences time and approach. These doctors are often the least trained and skilled in other things e.g. person-centred approaches
- » Medics don't attend enough relevant training

- » Cultural blocks – not enough assessors have knowledge and personal experience of ethnic minority group communities and their needs
- » Huge workforce issues, not enough doctors
- » The family system becomes autistic, then on diagnosis this becomes formalised
- » Some families can be more upset on diagnosis of a second child, especially if their needs are different and they display fewer autistic signs. Others find second diagnosis easier.

HEALTH VISITORS' KNOWLEDGE AND SKILLS

- » Health visitors can't identify autism
- » Health visitors don't know what happens during diagnosis
 - There are so many different diagnostic pathways and tools
 - In some areas, health visitors may know but parent forums often know more

» When a health visitor comes from a mental health or learning disability background, they are more likely to pick up neurodiversity early and be more aware of the diagnostic pathway

» The health visitor may give a family a leaflet or a phone number, but not be aware of where the number takes the person, or what the service can offer.

- » Decisions are made about what pathway to refer a person to are made before diagnosis
- » Diagnosis pathway is fixed
- » Many children have more than one diagnosis or need

- » Wait and see approach is often adopted prior to diagnosis
- » The family is often well informed by the point of diagnosis, but professionals treat all families as if they know nothing
- » Professional expectations don't match family experience

ISSUES

» There's a big separation between preschool and once at school access to diagnosis – ages vary in different areas. There is an age cut-off for access to diagnosis which changes from the paediatrician to CAMHs and this affects the waiting time.

- » Resources are dependent on commissioning
- » Depends on local offer

» No One Stop Shop

- » Reasonable adjustments may need to be made in organising assessments – the environment, time etc
- » Consider the environment - Husband fell asleep in room because of the stuffy environment and long-term sleep deprivation

» No resources available

» Not eligible for many services

BEST PRACTICE

- » In some areas, local CCG and local authority jointly commission services available to all (including before diagnosis)
- » Wakefield provides a key worker service, this model may be adopted by other areas too
- » Develop autism hub model

- » Providing a one stop shop where people can ask questions, get advice and practical help, training etc
- » Autism Hub

- » Develop a family diagnostic pathway

- » Service that is not just about initial diagnosis, but that kick-starts follow up and ensures adequate information is made available to families

- » Add a 'flag' to a person health and social care record at diagnosis so everyone working with them knows they may need to make reasonable adjustments

- » Ensure resources include culturally-sensitive information e.g. pictures, translation, audio and video material in different languages, especially for those where culturally Mums are recognised to be less likely to be able to read

- » Develop minimum standards for health visitors
 - Ensure health visitor is informed following diagnosis
 - Health visitor can then set up follow up visits to support the family, undertake a needs assessment and provide advice

GAPS

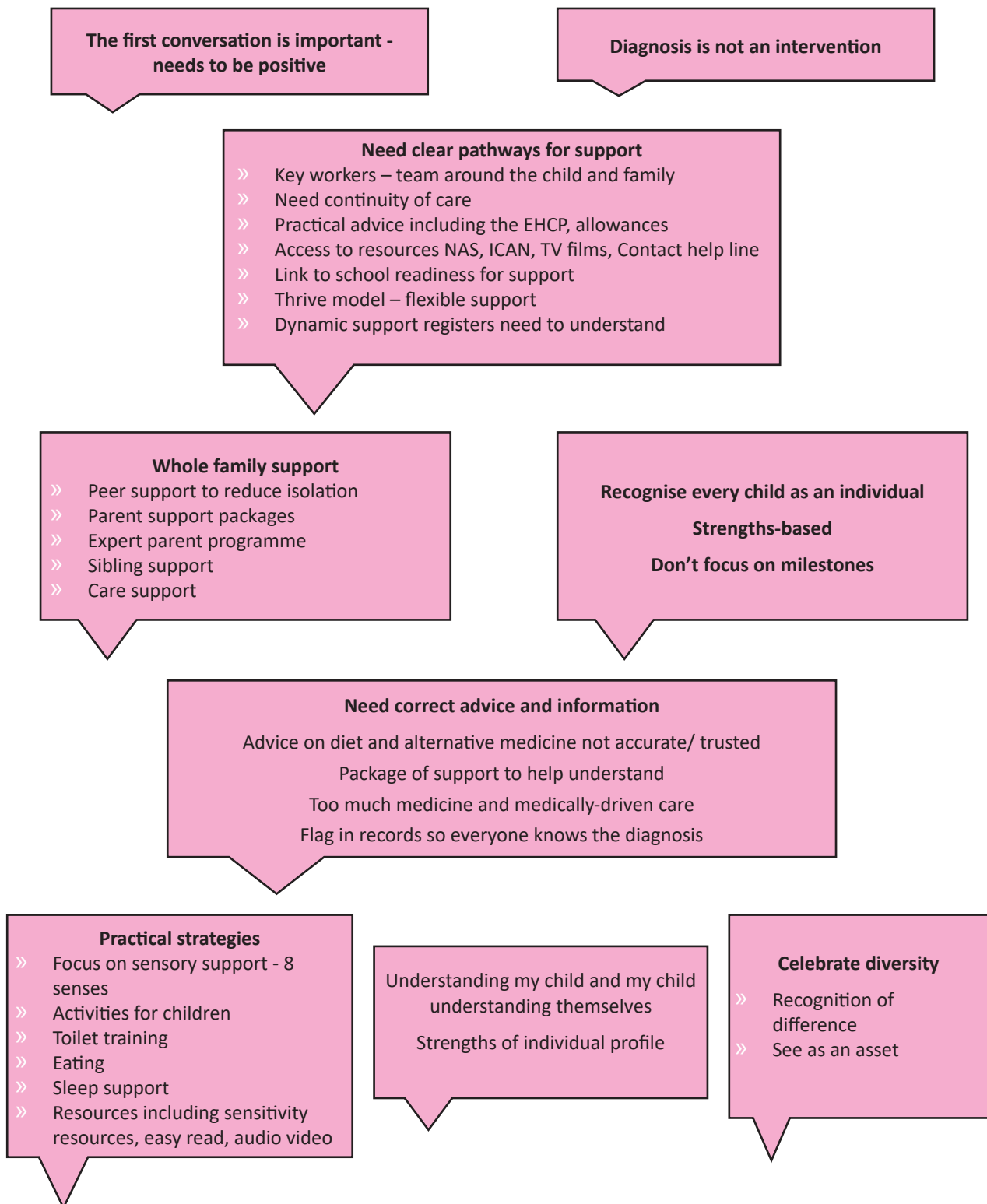
- » No sustainable training offer
- » Some areas no longer have an autism partnership board
- » Approaches to supporting families is often not strategic and can be splintered

- » Girls/women are often diagnosed late (average age for girls is 14)
- » Pattern of girls going through mental health services
- » Mental health doesn't have knowledge and skills
- » Need to develop approaches that enable earlier diagnosis and support

- » The updated autism strategy needs to be used to kick-start revised approaches

- » Families are not diagnosed

Figure 4: Post-diagnosis identified from the co-design workshop



GENERAL COMMENTS

Health visitors
need a set of
standards, eg
follow up visits
after diagnosis

Can we access
survey data?

Expectations
shared with
families - what can
you do?

Don't need to
know more, need
to feel confident in
interpersonal skills

Safeguarding –
it's a barrier

DIAGNOSIS
Pathways/workforce
strategies
Finding a diagnosis versus
support
Diagnosis with no follow up
Deficit-based tools

Has to help
with Culture
Change

This child is
still normal,
it's ok

Framework!

- Delivering
Different news
- Sath project

5. FOCUS GROUPS

Three separate focus groups were conducted, two in Newcastle and one in London. One further event was planned for parents in London however, due to the lockdown restrictions of COVID-19, this was cancelled. The areas were selected based on the co-design members' local connections. The aim of the focus groups was to gain insights to inform the development of resources and explore insights gathered from both the professional and parent surveys. The recruitment of parents was supported by local health visitors sending information out on an information sheet to parent support groups.

In accordance with PPI guidance, information sheets and consent forms were provided to participants (see Appendix 2).

A small incentive in the form of a £15 shopping voucher was offered to the parents who participated, as a thank you for their time and contribution; travel expenses were provided for the HVs who attended.

The focus groups were arranged locally and held at times and venues agreed as mutually convenient. Representatives from the iHV and the co-design group facilitated each session. Where all participants agreed, focus group discussions were recorded and/or notes taken to capture participants' views.

5.1 Attendance

Area	Number attended	Participants
London Health Visitors team	6	Black, Asian and Minority Ethnic groups, Mixed ages, all female
Newcastle Health Visitor team	11	All White, Mixed ages, all female
Newcastle Parents	9	Other White, White, Asian, Black, Afro Caribbean, Bangladeshi. 1 Male, 8 Female

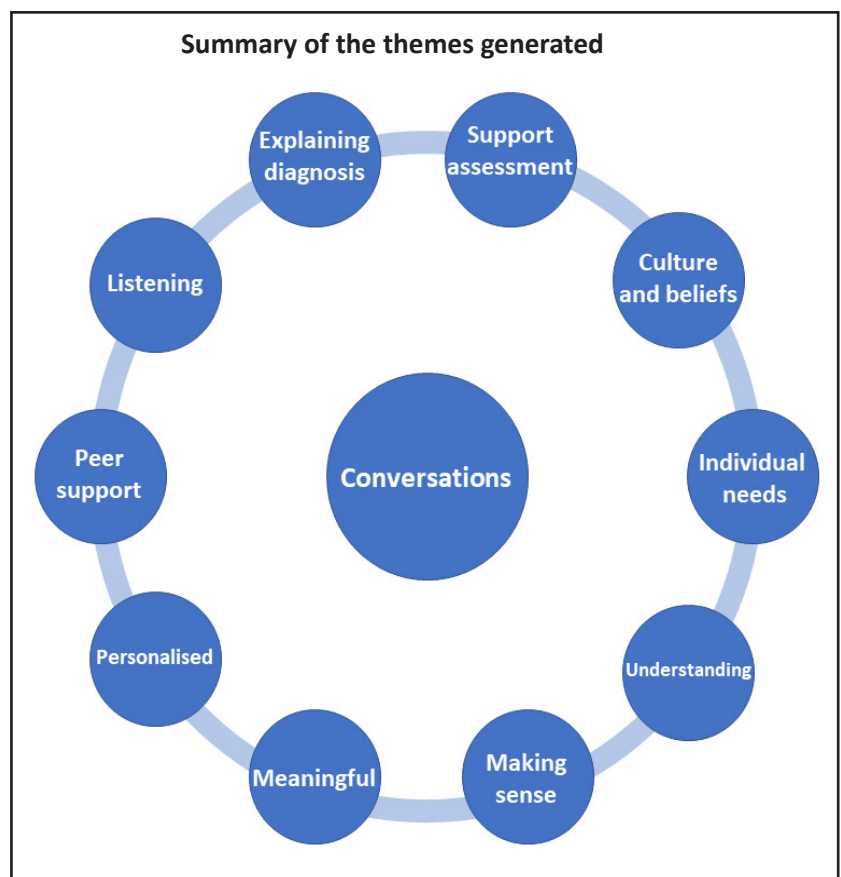
5.2 Analysis

5.2.1 Parents and carers

The focus group schedule focused on eliciting the experiences and views of the parents on their journey with their child(ren) from pre-diagnosis to post-diagnosis (if applicable). There was a specific focus on the role of the health visitor within this.

All the parents had preschool children who were either diagnosed with, or in the process of being diagnosed with, autism.

A high-level analysis of the data was conducted and resulted in a number of key themes being identified to inform the development of the resources for health visitors.



Reviewing the data from both the health visitor and parent focus groups, the term “**sense-making**” emerged:

Sense-making is the ability or attempt to make sense of an ambiguous situation. More exactly, sense-making is the process of creating situational awareness and understanding in situations of high complexity or uncertainty in order to make decisions. It is “a motivated, continuous effort to understand connections (which can be among people, places, and events) in order to anticipate their trajectories and act effectively”.

<https://cognitive-edge.com/blog/what-is-sense-making/>

In both the feedback from the parents and professionals, they expressed how they both struggled to make sense of the situation. To support this, health visitors expressed the need for knowledge, time and capacity to work with families. The need for clearer processes and pathways was expressed to avoid parents having to be left waiting for support. The health visitors in the groups expressed they would value training, highlighting a number of specific areas.

For parents, the importance of having “**meaningful/personalised conversations**” with the health visitors that validated their concerns, acknowledged their views and their individual needs was a key theme. These conversations would then support the parents to make sense of their situation and support them to move forward positively rather than feeling stuck and feeling alone.

Discussion of the feedback

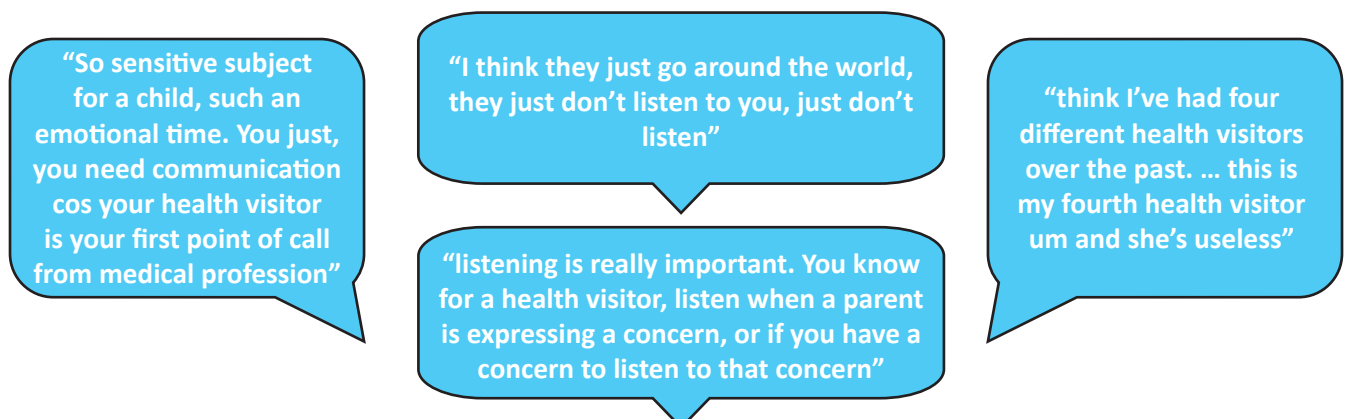
In the focus groups, we explored the journey that both the health visitor and parents went through considering at each stage feelings and experiences. These are summarised below, for ease of reading quotes from health visitors are coloured in green and parents in blue.

Pre-diagnosis

The health visitors fed back the challenges at this time and the **importance of listening** and showing **understanding to make sense** of the parents’ concerns:



Parents expressed the need for a sensitive approach, validating their concerns, listening to their needs, supported by continuity of health visitor at this time:



Supporting the emotional needs of families was seen as really important:

“when you’re working with family, you’re not only dealing with their child because you’re also dealing with the parents’ mental health ...”

“a lot of the time, even though you’re there to help the child, you’re there to help their family”

Parents also expressed their own need for personal support, expressing at times a view that it was all focused on the child:

“..... it is about the children but it’s about the parents and a while ago I said where, there’s all this help for the children, ... we’re everything to them, where’s our help?”

“And you feel you’re going mad,... If you’ve got somebody in the family who is in denial, your wider family’s in denial... or is uneducated, you don’t know. People do it in the street to you ...you have no idea; you have no idea my children”

“Communication I think, phone call would just, be nice. Just a follow up call. You could even say do you want a follow up call, say yes or no if you need it and it’s just are you alright? Can I do anything? Have you thought of this that would just, at the time 2 years ago been better goals, yeah”

“because you become very isolated, you don’t want to go out.... Behaviour, if you’re worried about behaviour in a normal children’s group. You do become a little bit, you come away from family, you come away from friends, well I did anyway.”

“..mine was at least maybe was that when I was at my lowest and when I was on waiting list. By the time he was diagnosed, there’s nothing he could have told us that I didn’t know”

“Listening to what you are saying, their understanding that can then support you on your journey.”

The health visitors recognised the need to personalise their approach to the individual needs of the child:

“I think it still comes back to every child being so different..... individual.”

Similarly, health visitors also acknowledged that the experiences of parents were also unique and required a personalised approach, based on a shared understanding of the individual journey, needs and preferences of each parent:

“They’re kind of grieving for the fact that their child is not as they expected their child to be..”

“...Some people say Don’t worry about the future, well I do, ...There’s no sense of danger I mean it’s really only going to get bigger, stronger, ...I’m only knowing now what to do from a waiting list, helpful but if a health visitor has got info, I’d have grabbed it a long long time ago.”

In the parent group, the need to understand culture and beliefs was highlighted as it had been in the codesign group.

“because I’m from another country and I didn’t tell anything about this diagnosis in India, ... I’m telling them she has got learning problems ... Autism is different meaning in the UK”

“Sometimes it’s easier to stay in than go out..”

When and how to explore diagnosis was a recurring topic and health visitors expressed concerns about what they perceived they could say, or not say, to parents which created a barrier at times:

“I think for me as well there’s something about being comfortable with what kind of conversation you can have with families as well NHS Long Term plan and prevention green paper”

“ I think that’s really difficult ... I’ve had experiences in the past where, as a health visitor I’ve not used the A word with a family because it’s not my place”

“..But then when they’ve got to the paediatrician, paediatrician’s told the family. They’ve been really cross with me because they felt that I should have, you know, told the family ... and then on the other hand you ... one of the parents this morning made a comment about nobody mentioned the word, but I knew..”

“We’re not a specialist in diagnosis, but you can see and then the parents obviously can see, they know .. but it’s how you have an open and honest discussion with the parents ..”

These quotes highlight the tension for health visitors in being seen to be not making a diagnosis, which is clearly outside of their professional scope of practice whilst, on the other hand, holding and validating a parent's concerns in a sensitive way.

Parents in the focus group expressed frustration that health visitors didn't feel able to talk about the possibility of autism with them or offer support, with some reporting seemingly arbitrary age-related cut-offs when children presented with signs at a young age:

"Everybody knew that my children had it, no one could speak of it or say it, I was the only one that used to say it, but it's like until you get that tick and that go ahead you can't go any further"

"... I'll never forget the day of the two-year check. I was dreading it anyway all the anxieties about going. She said "We don't label children Mrs" I remember her saying that and I thought that's patronising because, I just remember her saying we don't label ... Could it be? Cos I wanted an answer!"

"really long queue and its really upset you and you are worried about all the time"

"She says this every time I rang her I can't do Annoying, I can't do anything until she's two, I can't do anything until she's two"

Several health visitors commented on the **process for assessment** expressing their concerns:

"The waiting lists are absolutely ridiculous. So, what we're supposed to be doing in the meantime? and I feel, I feel so sorry for parents and when parents are crying again you think, like, what can you do..."

"all these children were just left. It was awful because the parents like, when you just want to help the parents because they're trying to deal with all this. And there's nobody there to support."

"I felt families were left high and dry."

" I think what we heard from both professionals and parents almost that people are waiting and not doing anything because they're waiting for the diagnosis so it becomes, So, from the parents' perspective, they're just told they're referred to Speech Language, referred to them people and then nobody is supporting them."

In the parent focus groups, the feedback mirrored the views of the health visitors, with parents reporting feeling left with no support, however they expected that the health visitors should be able to offer support in this early stage:

“I think the waiting list is absolutely ridiculous. ... why can't the health visitor have some kind of knowledge or interventions or something to bring to your house when they come and see you rather than see somebody for 5 weeks speech and language that you're not going to see again”

“My health visitor, but it took three months to come see us”

The need to be confident to offer something was highlighted with health visitors clearly struggling to not be able to support some of these families:

“want someone to be with them, in that time when things that their child is doing, they're finding difficult, and they need support actually, there are things you can be doing to help their child's progress, regardless of what the end diagnosis might be.”

“how they can be involved rather than feeling they've got to wait for somebody to figure out how they can take it, how they can help that child to cope with life and nursery and all the other things that might be an issue practical things.”

The parents talked about the need to have some advice to help them, with many resorting to seeking this for themselves:

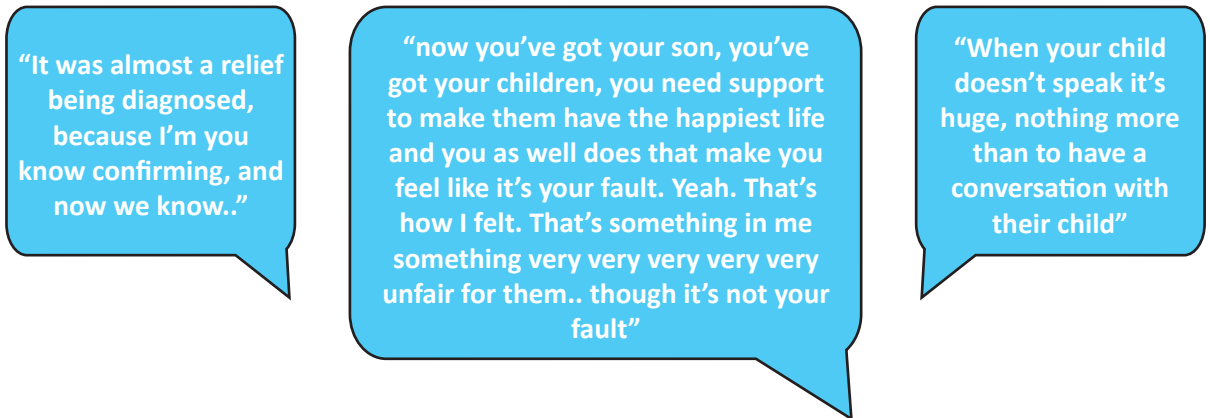
“I read, and I read and I watch and I go on YouTube and I read everything and I honestly knowledge is power... refused to wait on a waiting list for occupational therapy so we do things at home like”

The impact on the wider family was really important and families wanted the health visitor to understand and support them to make sense of what was going on for them as a family:

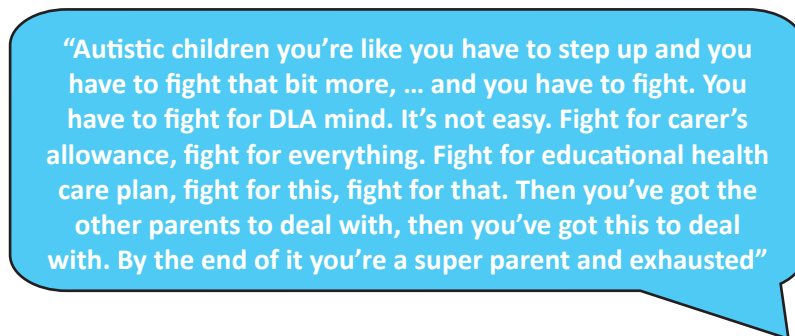
“not only just looking at them the child's needs and have a better understanding how that child is learning, choosing to learn ... but also the rest of the family there's a massive role there for the health visitor..”

“it does impact on the rest of the family, it's not just about a child's disability. It's about everything else..”

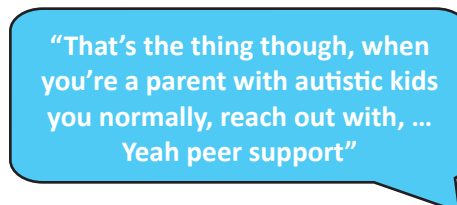
Parents were asked about their feelings **during and following diagnosis**; as with the parent survey they gave mixed views of this time:



The parents expressed the difficulties they had in getting help, which they frequently described as a “fight”; again these views replicated those collated through the survey of parents:



The importance of peer support to make sense was highlighted in the parent group:



Health visitor resources for sense-making

Key themes were highlighted from the insights from health visitors, the importance of balancing the capacity with demand was clear.



The health visitors and parents were asked about what would be meaningful for them in a resource to support working with families. The level of confidence in health visitors' knowledge was reflective of the survey findings with some clear gaps in both knowledge and confidence as demonstrated in the following quotes:

"and it's just, and there's only so much we can do, it then, it's out of our depth I think, it's certainly been out of my depth at times....."

"it's almost like specialist kind of behaviour support we need because we will just do general ... I just feel like sometimes you're going in and ah I think you (parent) know more than me, then you kind of think oh, they're not going to want you back .."

"people being able to have conversations knowing they're not going to say the wrong thing"

A number of **specific topics** were highlighted as gaps in the health visitors' knowledge:

"I think we do definitely need more in-depth sensory knowledge"

"But the challenging behaviour will be as a result of something sensory ... having that full understanding of what it is, what is causing that issue."

This highlighted the need for health visitors to have an understanding of **sensory and communication difficulties**.

Health visitors summarised what they would want in a resource that supported them to work with the family during the process of assessment:

"when someone says to you I'm worried. They get a response which is supportive and signposts and sometimes the right people.."

"if there was like a pack or something like you know this is kind of what we're going to work through till you kind of get that diagnosis.."

"So I think in that toolkit, we really need to have something that has got behaviour, support behaviour strategies that families can take away and use.."

"I think from a universal kind of level, we should be offering something to all the children"

The health visitors made some suggestions which included checklists, guides for parents, things they can support parents to do before the specialists are involved including understanding sensory and communication. The need to have factual and evidence-based information to draw upon was seen as important.

We also asked the parents on the need for training for health visitors. Parents clearly wanted support from a health visitor with knowledge and skills in autism:

“I was shocked when you said they had no autism training and it’s so high”

“There shouldn’t be autism awareness there should be autism understanding. ... People are aware, people know that it’s there but they haven’t got any understanding of it.”

“one day’s basic training I think that would be beneficial as part, to become a health visitor you know a little bit about autism. “

The need for joint working was also highlighted as important for health visitors to support families:

“that multi-agency approach because I think it’s difficult as an individual practitioner”

“I think, I really do believe it’s not just around sort of the family health visitor it’s having that support and also the professional staff who’ve got that specialist assessment”

It will be important to ensure the importance of joint working is threaded through the resource we develop.

Constraints of current service delivery models on the quality of support that health visitors are able to provide: The findings from this study highlight the frustrations that health visitors experienced from **the level of service** they are able to offer due to restrictive visiting, inflexible and limited HV service delivery models and challenges in meeting meeting other prioritised key performance indicators.

“What’s manageable within the constraints of practice... just haven’t got any time or capacity“

“my worry is that the additional support visits which is very very much valued by families would take second place as they’re not measured are they? And because you will be penalised if you didn’t meet the mandated contract”

“it’s a real challenge in that the contracts with the local authority will be based on the mandated contacts.”

SUMMARY AND NEXT STEPS

The co-production activities described in this report enabled the project team to co-produce with parents the topics and types of resources to support health visitors in their role with families of children with autism.

The views of parents, from both the parent survey and the focus group, offer a powerful message to all those that work with them and the need to really listen to parents, treat them with respect, validate their concerns, acknowledge their experiences and feelings in order to personalise support.

The need to change conversations, using positive language about autism, and have an approach that is responsive and receptive to the needs and preferences of parents were powerful emerging themes.

For the health visitors, a lack of structured training was evident, and this, compounded by the limitations of some HV delivery models, has resulted in variation in the quality and amount of support provided to families; many parents expressed dissatisfaction in the level of support that they received throughout the process from their first concerns to post-diagnosis. Whilst in many ways this is inevitable, given the lack of training that health visitors had received, it reinforces the need for the development of resources to support health visitors to work effectively with these families.

The initial aim of the insights gathered through this process was to inform recommendations to support the next steps in developing the products as follows:

1. There is a need to support health visitors to have meaningful and different types of conversations with families focused on a strengths-based approach.
2. The resources should focus on reducing stigma and promote inclusivity.
3. Need to increase health visitors' awareness of the importance of the individual family's journey, including their feelings and needs for support during this time.
4. Need to focus on building confidence in health visitors' knowledge of specific touch points, or times where parents may find things particularly hard and need additional support.
5. The need to ensure resources are evidence based and accessible to the families and health visitors.
6. The need for training for health visitors is welcomed by the practitioners.
7. The health visiting service provides an important part of a whole system approach to support families who are known, or suspected to have autism. However, to achieve this will require strengthening the HV service to make sure that it has both the capacity and capability to ensure families receive the support that they need.

We will be taking the learning from this report forward to support and inform the development of resources in the toolkit and in the creation of the awareness sessions for health visitors.

ACKNOWLEDGEMENTS

We would like to thank the wide variety of stakeholder partners who contributed to this report by promoting the health visitor and parent surveys, supporting the organisation and hosting of focus groups with parents of children with autism; and health visitors who work with children and families living with autism. Thanks also go to the co-design group for the project, who provided valuable insights throughout the project.

Specifically, we would like to thank Gwen Moulster and Jenny Osbourne for their support in organising the focus groups with health visitors and parents in London and Newcastle, respectively. Special thanks are also owed to the project steering group comprising representatives from the Institute of Health Visiting, the National Autistic Society, National Parent Forum, Autistica and parents.

Finally, we would like to thank the survey respondents, focus group and co-design participants for sharing their experiences, insights, and resources with us to support the development of a digital tool kit.

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APPENDIX 1**Health Visitor Survey Questions**

1. What is your current role?
2. If you are a qualified SCPHN what was your primary field of nursing?
3. Which region of England do you work in?
4. How many children do you currently have on your caseload where you are concerned that they may have Autism Spectrum Disorder?
5. How many children do you currently have on your caseload who have been assessed as having Autism Spectrum Disorder?
6. How many families do you currently have on your personal caseload where more than one child in the same family is suspected or known to have Autism Spectrum Disorder?
7. How many families do you currently have on your personal caseload where a parent is suspected or known to have Autism Spectrum Disorder?
8. How confident are you at describing what Autism Spectrum Disorder is to a family or colleague?
9. How confident are you in working with parents who are suspected or known to have Autism Spectrum Disorder?
10. How confident are you in supporting families with young children with or suspected to have Autism Spectrum Disorder in the following areas?
11. How confident are you at identifying Autism Spectrum Disorder needs/risks that may require review or early referral?
12. How confident do you feel in having strengths-based conversations with families to identify when you are concerned that the child may have behavioural or communication difficulties that may indicate Autism Spectrum Disorder?
13. Are you regularly using tools/assessments to support your work with families to identify children with suspected Autism Spectrum Disorders?
14. If yes, please name the tools/assessments you are using and if possible, provide a link to the tool/assessment
15. Have you had training on the tool/s?
16. How confident are you in using these tools /assessments in your current practice to inform your interaction with the child and family?
17. Are you aware of your local children's Autism Spectrum Disorder referral pathway?
18. How confident are you in using local referral pathways to inform your current advice and support to families when there are concerns that their child may have Autism Spectrum Disorder?
19. How confident do your feel in having strengths-based conversations with a parent after their child has been given a diagnosis of Autism Spectrum Disorder?
20. Please give three examples about the advice you give to families about managing behaviour with children who have or are suspected of having Autism Spectrum Disorder.
21. How confident are you in supporting children with Autism Spectrum Disorder in transitioning to school?
22. Have you attended any training about supporting children with Autism Spectrum Disorder in the early years and their families?

23. If Yes, when was this?
24. If Yes, in what format was this training delivered?
25. What difference did the training make to your practice i.e how did it impact on individual children and families?
26. If more training were available on working with families with children with actual or suspected Autism Spectrum Disorder would you be interested in accessing this?
27. If Yes, please indicate the subjects that you would find it helpful to have further information/resources on
28. Are there any specific areas relating to health visiting practice with families with children with Autism Spectrum Disorder that you would like us to cover with a Good Practice Point(s)?
29. What would support you to access training on Autism Spectrum Disorder and what else would support you in the future in order to improve outcomes for children?
30. In 2020 we will be developing a toolkit of resources using co - production methods with families with lived experience of Autism Spectrum Disorder and front-line health visitors to support and improve practice. If you have resources to share or are interested in being part of our Expert Advisory Group, please provide your details below so we can get in touch. Thank you for completing the survey the results of which will be used to support practice and inform the resources we develop.

APPENDIX 2

Focus Group - Information for Professionals working with early years children who have autism or are being assessed for autism?

Background information

The Burdett Trust Fund for Nursing has provided the Institute of Health Visiting (A National Charity) with some funds to develop a toolkit of resources to support health visitors working with families of early years children, both before and after a diagnosis of Autism.

So far, we have established a National group to help develop the resources and invited health visitors to complete a survey. We are also working with the National Parent Forum to complete a parent/ carer survey.

We are now keen to find out more about the experiences and views of professionals.

Interested in being involved?

We are holding a short-focused session, 1-2 hours to help us understand the views of health visitors on what knowledge and resources you feel you need, to best support families and young children.

The session will be on **date time and venue**

What to expect?

You will be invited to attend the session on the date and time above where we will be talking with you and other colleagues.

At this meeting we will explore with you your experience of working with children and families with autism or potential autism and how we can best support health visitors to work with families in the future.

We may use an audio recorder during the session to help us to capture the messages you provide us with. Any direct quotes that may be used in a report or other writing will not be attributed or traceable to any named individual. The audio recordings are stored as digital files on a secure server at the iHV which is password protected.

What are we looking for and what can you expect from us?

You do not need any previous experience, just a willingness to attend the group and to give your perspective and views.

If you are able to attend or are interested in supporting the work in the future, please email Victoria Jackson: victoria.jackson@ihv.org.uk to book your place.

We have attached a form for you to complete, confirming your consent to participate in the session. We would be grateful if you could bring it with you to the meeting.

We fully appreciate that travel costs may be incurred in relation to your attendance at this session and we will cover the costs of travel in relation to your attendance at this event as long as it is within a 50 mile radius of the group. As a charity we are unable to cover any further costs to support your attendance.

If you would like further information or to talk about this work further, please contact Vicky Gilroy, Project Lead: vicky.gilroy@ihv.org.uk or 07941822134

Focus Group Information for Parents and Carers

- *We are looking for parents or carers to help inform the development of training and a toolkit for health visitors. This will support their work with children who have autism or who are in the process of being assessed for autism.*
- *Do you have an early years child who has autism or who is being assessed for autism?*
- *Do you want to influence how health visitors provide support to early years children and their families?*
- *Interested? Please read on:*

Background information

The Burdett Trust Fund for Nursing has provided the Institute of Health Visiting (A National Charity) with some funds to developing a toolkit of resources to support health visitors working with families of early years children, both before and after a diagnosis of Autism.

So far, we have established a national group to help develop the resources and invited health visitors to complete a survey. We are also working with the National Parent Forum to complete a parent/ carer survey.

We are now keen to find out more about the experiences and views of parents and carers.

Interested in being involved?

We are holding a short-focused session to help us understand the views of parents/ carers on what knowledge and resources you feel Health Visitors need, to best support families and young children.

The session will be on **date time and venue**

What to expect?

You will be invited to attend the session on the date and time above where we will be talking with you and other families.

At this meeting we will explore with you your experience of having a child with autism or potential autism, and how we can support health visitors to work with families in the future.

We may use an audio recorder during the session to help us to capture the messages you provide us with. Any direct quotes that may be used in a report or other writing will not be attributed or traceable to any named individual. The audio recordings are stored as digital files on a secure server at the iHV which is password protected.

What are we looking for and what can you expect from us?

You do not need any previous experience, just a willingness to attend the group and to give your perspective and views.

We fully appreciate that travel costs may be incurred in relation to your attendance at this session.

- We will cover the costs of travel in relation to your attendance at this event.
- As a parent/carer you will receive general high street shopping voucher for taking part in this focus group to the value of £15.

If you are able to attend or are interested in supporting the work in the future, please email Victoria Jackson: victoria.jackson@ihv.org.uk to book your place.

We have attached a form for you to complete, confirming your consent to participate in the session. We would be grateful if you could bring it with you to the meeting.

If you would like further information or to talk about this work further, please contact Vicky Gilroy, Project Lead: vicky.gilroy@ihv.org.uk or 07941822134

Focus Group Consent Form

Please indicate whether you consent to take part in the focus group by placing your initials in the box to the right of each statement. If you do not consent to an aspect of the research leave the box blank.

	Place initials in this box to indicate consent
I have read and understood the information provided about the project	
I agree to take part in the focus group	
I have had the opportunity to ask questions	
I understand I can withdraw my consent at any time	
I understand that my confidentiality will be maintained	
I agree that I can be audio recorded and my anonymised comments retained on a secure server at the Institute of Health Visiting as appropriate until the end of the project (December 2020)	

Signature: _____

NAME: _____

(Please use block capitals)

Date: _____

Thank you. Please return this sheet to the project lead when attending the meeting.



APPENDIX 3

Graphis captured by Pen Mendonca, a graphic facilitator at the co-design group meeting to capture the conversations.

IAV Institute of Health Visiting
Excellence in Practice
Burdett Trust for Nursing

SURVEY 2020
 ✓ 250+ responses
 ✓ Mostly Health Visitors
 ✓ Across U.K.
 ★ Most working with high numbers of families where children have 'suspected' neurodiversity as well as those with diagnosis
 ★ Many who responded said they had little or no confidence/knowledge for supporting families in this area
 Autism? [WE NEED A CLARIFY CONDITION?/EXPLAINING TERMS Neurodiversity?] & CONCEPTS

OUR NEW TOOL:
 Co-designed
 To include the voice of families as well as Health Visitors
 Easy & accessible for professionals & families
 Not adding to the stress of already stretched professionals
 To offer strategies Strengths-based

ASK families too

Do you have any concerns about him?
 Why is it always so negative? My son is fantastic & unique.

I CANNOT BE HONEST ABOUT VIOLENCE AS COMMUNICATION. Don't take her away!
 How are things going?
 Fine. Everything is great.

I need to tell you that she was hitting children again. We are not coming again. It is too hard...
 Risk of ISOLATION...

There's nothing wrong with him, you're worrying for nothing!
 Oh come on! You can't be serious!

It might be 'evidence-based', but it won't work for my child!

You already have a child with autism so you will be fine...
 Don't make assumptions

How can the Health Visitor really see what I mean when they only see her for 5 minutes?
 I don't know the medical term but I know something is not right...

Neurodiversity?! I don't have the training for this!
 A toolkit? I'm already overwhelmed. There's not enough time

A parenting course? I need to get back to work!

She is gorgeous! I don't have all the answers, but we can work through this together.
 Thank you!

We want commissioning to be done with families & Health Visitors

Try to understand the complexity of sibling relationships
 THINK FAMILY! DON'T JUDGE!

The Health Visitor made sure we felt supported.....
 ...but also gave us information & strategies that helped

Information / machumad

Those first conversations are crucial! We need a culture of open, non-judgemental & informed discussion
 Culture Change Now

Autism Institute of Health Visiting Burdett Project, January 2020. Graphic facilitation by www.pennendonca.com @MendoncaPen

STRENGTHS-BASED APPROACHES, HEALTH VISITORS & AUTISM (Jan 2020)

Pre-Diagnosis | Diagnosis? (or not) | Post-Diagnosis

Consider everyone's mental health

THINK WHOLE FAMILY THROUGHOUT THE JOURNEY
 families are about relationships
 Sensory Needs? Disability? Gender?
 Different understandings of neurodiversity across families
 STIGMA

Language matters & THINK CULTURE & COMMUNITY...
 PEER SUPPORT WORKS GROUPS CAN REALLY HELP

On-Going Support
 SUPPORT → SUPPORT → SUPPORT → SUPPORT

One point of contact please!
 'Flag' diagnosis [ISOLATION] A Clear Pathway
 (Don't 'sell' diagnosis as a golden key, it may not change things)

W O R K F O R C E A Shared Vision
 from medical model to family focused
 We need great Communication! Consistency across areas & services Remove judgement Celebrate our children!

Autism Institute of Health Visiting Burdett Project, January 2020. Graphic facilitation by www.pennendonca.com @MendoncaPen





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