

Ambassadors for Changing Conversations: End of project report



Authors

Vicky Gilroy MSc, RGN, RSCN, RHV, Head of
Projects and Evaluation, Victoria Jackson RCN,
SCPHN-HV, Project Coordinator, and Dr Sarah Brown,
Research Associate, Institute of Health Visiting

Institute of Health Visiting
c/o Royal Society for Public Health,
John Snow House, 59 Mansell Street,
London E1 8AN
Tel: +44 (0) 207 265 7352
Registered Charity Number: 1149745

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ABOUT THE iHV

The Institute of Health Visiting is a UK Centre of Excellence for health visiting, supporting the development of universally high-quality health visiting practice. Launched in 2012, our aim is supporting excellence and consistency in practice, to improve health outcomes for all children, families and communities. As part of our portfolio, we offer a range of contemporary, acclaimed training programmes, developed in collaboration with some of the country's leading subject experts. We have earned a reputation for the high quality of our programmes, which have proved hugely popular as evidenced in our delegate evaluation and feedback.

ACKNOWLEDGEMENTS

The iHV is grateful for the support, advice and input of the many individuals who worked collaboratively with us throughout all stages of this project, including The Burdett Trust for Nursing for the funding, parents and practitioners for their valuable insights, the individual contribution of steering group members, and the hard work of the dedicated iHV team including our wonderful admin team. We would also like to thank the digital toolkit designers Onclick and our graphic designer Alan Lowbridge, and Sightline for the filming and editing of the filmed resources. And finally, for the sustainability of the project and its ongoing success, we would like to thank the health visitor Ambassadors who attended the awareness events for their important contribution and commitment to then roll out the awareness session to their colleagues.

EXECUTIVE SUMMARY

This project aimed to raise awareness and understanding of the needs of families who may have an autistic child or a child who is pre diagnosis. This was achieved through the co-production of resources and training for health visitors who are in the unique position to universally support families of pre-school children.

This end of project report will provide a summary of each stage of the project from inception through to the evaluation of the final products.

We have been inspired and motivated by the contribution of parents, practitioners and partners in supporting the development, and wish to extend our gratitude to all involved.

The project set out with a number of core deliverables - Table 1 provides an overview of achievements against these. It should be acknowledged that this was not without challenge due to the restrictions in place during the national pandemic.

TABLE 1:

Project deliverables	Achievement
Development and dissemination of a National Survey to health visitors to determine current knowledge, confidence and training needs in autism, to inform baseline and training development	<ul style="list-style-type: none"> ✔ 288 health visitors responded ✔ Full Insight report produced ✔ Confirmed the need for training and key topic areas to be addressed
Development and dissemination of a National Survey to understand families' experiences of health visitor support for autism	<ul style="list-style-type: none"> ✔ Purposive sample - 91 parents/ carers responded ✔ Full Insight report produced ✔ Key themes informed the development of the resources and training

Project deliverables	Achievement
Co-produce the resource with involvement of field experts and parents	<ul style="list-style-type: none"> ✔ X 1 Co-production group London ✔ X 2 Co-production online meetings ✔ X 6 Steering group meetings to inform resources ✔ Resources reviewed by parents and practitioners
Scoping of current evidence base for autism	<ul style="list-style-type: none"> ✔ Literature review completed ✔ A-Z of resources produced
Design a toolkit of resources	<ul style="list-style-type: none"> ✔ An online toolkit designed and developed through co-production, accessible to health visitors via the iHV website
Resources to support practice included in the toolkit	<ul style="list-style-type: none"> ✔ Literature review ✔ A-Z library ✔ Films of parent journeys ✔ X 4 Good Practice Points ✔ X 3 Top Tips for Parents ✔ Poems from a young autistic boy ✔ Parent stories/voices ✔ Health visitor case studies ✔ Cascade resources for health visitor Ambassadors to share with teams
Develop and deliver the awareness sessions to health visitors	<ul style="list-style-type: none"> ✔ 4 virtual awareness events held - 116 health visitors trained as Changing Conversations Ambassadors ✔ These Ambassadors have trained 512 members of their teams who can access the toolkit ✔ 1 stakeholder event - 27 attended
Evaluation and impact	<ul style="list-style-type: none"> ✔ 97% of participants completed the pre-evaluation questionnaire ✔ 96.5% of participants completed the post-evaluation questionnaire ✔ 77.5% of participants completed the toolkit evaluation ✔ 100% of health visitors reported that they would recommend the training to a colleague ✔ There was an overall increase in health visitors' knowledge, confidence, understanding and skills to support children with autism and their families ✔ The area with the greatest shift was confidence and skills in having strengths-based conversations with a parent after their child has been given a diagnosis of autism ✔ The key themes of the feedback highlighted the importance of how we communicate with families, that we discuss autism in a positive way, and offer appropriate support. A personalised response was particularly important, ensuring that support is focused on what the family are asking for and listening to their concerns without judgment or being dismissive

Future Recommendations

The project findings highlighted the need for further training and resources in this topic area, including:

- Regular updating of the training resources to maintain the relevance and quality assurance
- Raising awareness in different audiences, including: awareness sessions for early years workforce, multi-agency training, and school nursing
- Further develop the resources to provide more in-depth and practical resources with a focus on:
 - » More practical support for sleep, eating, behaviour, toilet training, communication, sensory needs and anxiety
 - » Consideration of co-morbidities

- » Supporting the wider needs of the family, including parents with autism
- Further work to consider the specific needs of minoritised ethnic groups and those with English as an additional language
- Increasing the reach of the training to a greater number of health visitors, with support from external funding

1. Introduction and background

The Royal College of General Practitioners¹ identified that there is an urgent need to improve healthcare for people with autism, to reduce inequalities and associated poor outcomes throughout the life course². Research shows that people with autism are, on average, more likely to die 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 January³. Health visitors provide leadership for the delivery of the Healthy Child Programme 0-19⁴ and work with partners to deliver a comprehensive programme of support. “Early years high impact area 6: Ready to learn and narrowing the word gap⁵” 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 that 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.

To help address this gap, the Institute of Health Visiting (iHV) was successful in the tendering process and was offered a grant by the Burdett Trust for Nursing to develop resources for health visitors to support them in working with families whose children may have autism, and deliver four awareness sessions to health visitors nationally.

This report will provide a summary of the stages of the project delivery, from scoping through to development of the resources, delivery and dissemination, highlighting key findings from the evaluation and making recommendations for future sustainability.

2. Summary of scoping to inform the development of resources

2.1 Approach and method

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, KIDS Charity, health visitors, Speech and Language Therapists (SALTs) and Occupational Therapists (OTs) and a range of other national charities to gather insights to shape the final resources and training.

The project was led by a Steering Group comprising of parents of children with autism, autistic adults, nurses (LDNs, health visitors), 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 288 health visitors’ knowledge and confidence in providing autism advice and guidance
- Joint national survey with KIDS Charity to gather views of 91 parents/carers and support the development of resources
- Insights from focus groups with: (a) parents of children (n=9) with suspected or diagnosed autism, (b) health visitors, and health visitor team members including community nursery nurses and community staff nurses (n=17)
- An “Experience-Based Co-Design” group to gather experiences from parents, health visitors, LDNs, experts in Autism, SALTs and OTs. Identify key themes during the period from parents/carers’ 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 four national events

2.2 Key findings from the Insights and scoping

As discussed in the full Insight report, the combined analysis of the Insights from parents and practitioners provided the project team with the themes and direction needed to inform the development of the resources. 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 themes. The views of parents, from both the parent survey and the focus group, offer a key message to all those that work with them and the need to really listen to parents, treat all with respect, validate their concerns, and acknowledge their experiences and feelings in order to personalise support.

For the health visitors, a lack of structured training was evident and this, compounded by the limitations of some health visitor 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 an inevitable consequence of the lack of training that health visitors had received and current capacity issues within the workforce, it reinforced the need to address these capability gaps through the development of resources to support health visitors to work effectively with these families.

The Insights gathered are summarised below:

- a. There was a need to support health visitors to have meaningful and different types of conversations with families focused on a strengths-based approach
- b. The resources should focus on reducing stigma, and valuing inclusion and diversity
- c. 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
- d. 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
- e. The need to ensure resources are evidence based and accessible to the families and health visitors
- f. The need for training for health visitors is welcomed by the practitioners
- g. 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 health visitor service to make sure that it has both the capacity and capability to ensure families receive the support that they need

These Insights were then considered in the development of the resources and structure of the awareness events.

3. Resource development

3.1 Imagery

The imagery for the project was important to ensure that it reflected the Insights gathered and the need for positive conversations. During the co-production work the phrase “Changing Conversations” was suggested by a parent and agreed that this should be an aim of the training and resources, to change the conversations about autism from negative and frightening, to positive and inclusive. This led to the development of the imagery for the project; see Image 3. The heart represents that conversations about autism should be positive and the love families have for each other. The heart is made up of a spectrum of coloured speech bubbles again reflecting conversations and that autism is a spectrum condition and therefore every child and family are unique individuals with different support needs.

IMAGE 3:



3.2 Toolkit

The original funding bid stated that the resources created would be housed in a digital toolkit for health visitors. Through discussions with the Steering Group, Co-design Group and Focus Groups, it was suggested that the toolkit could represent a village, building on the African Proverb “It takes a village to grow strong children.” This also symbolises how autism affects every aspect of a child/family’s life, and all areas need to be considered when working with families. See Image 4 for image of the toolkit.



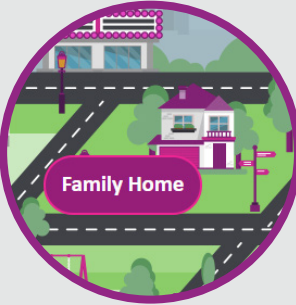
IMAGE 4:


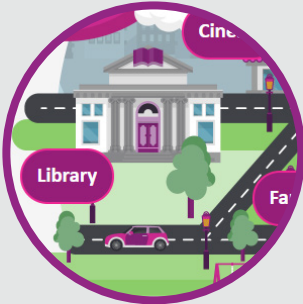




The toolkit is divided into 6 buildings, each reflecting different aspects of support and information that families and health visitors may find helpful. These are detailed in Table 2 on page 9.



TABLE 2:

<p>Login page</p>	<ul style="list-style-type: none"> Autism Toolkit – Sitemap
	<p>In this section, you will find a number of filmed resources which have been specifically developed for health visitors to support practice. They aim to give an insight in to what it is like for children with autism and their families.</p> <ul style="list-style-type: none"> Health visitor and parent Q&A The start of our journey Our concerns in the early years The Health Visitor’s role and support Moving forward iHV training day video - 28/10/2020 Reading of a Poem by Logan, 10 years old
	<p>In this section, you will find documents to support you in your Ambassador role of sharing and cascading your learning with your colleagues.</p> <ul style="list-style-type: none"> Changing Conversations Ambassador – FAQs List of resources available in the iHV Training Hub for cascading 1-hour awareness session Literature and policy review Insight report: A co-production project to develop evidence-based autism resources for health visitors to support the families they work alongside Health Visiting and Autism Image by Pen Mendonca Co-design summary Image by Pen Mendonca Ambassador for Changing Conversations: End of project report
	<p>In this section, you will find documents you can share with families to support them at different stages of their child’s development and their family life.</p> <ul style="list-style-type: none"> Top Tips for Parents <ul style="list-style-type: none"> Supporting your child’s speech, language and communication development Accessing health visiting support for you and your family Using positive statements to guide our children Messages from parents: A collection of stories and experiences of parents with autistic children A Poem by Logan - Different me A Poem by Logan - Autism Agony - COVID-19 Ambitious About Autism: Right from the start toolkit Right from the start: School open day checklist Right from the start: SENCO meeting checklist A-Z of Useful resources and organisations (PDF of the resource found in the library)

 <p>Health Visitor Office</p>	<p>In this section, you will find documents to support effective practice and improved understanding of how health visitors can support children with autism and their families.</p> <ul style="list-style-type: none"> • Good Practice Points <ul style="list-style-type: none"> » GPP – Supporting families with pre-school children to promote their SLC development when there are signs of autism or learning difficulties » GPP – Supporting children on the autism spectrum and their families » GPP – Transition to School for Children with Complex Health Needs/Special Educations Needs and Disabilities (SEND) • Case Studies from health visitors and professionals – Ambassadors for Changing Conversations
 <p>Library Cinema Family Home</p>	<p>In this section, you will find an interactive A-Z of useful resources and organisations that you can share with families, you will find a PDF version in the family home.</p>
 <p>Nursery / School</p>	<p>In this section, you will find documents that will support families in the school and nursery environments and your knowledge and understanding of these environments.</p> <ul style="list-style-type: none"> • Good Practice Points <ul style="list-style-type: none"> » GPP – Supporting families with pre-school children to promote their SLC development when there are signs of autism or learning difficulties » GPP – Supporting children on the autism spectrum and their families » GPP – Transition to School for Children with Complex Health Needs/Special Educations Needs and Disabilities (SEND) • DfE Local offer guidance – Guidance for local authorities • Ambitious About Autism: Right from the start toolkit • Ambitious About Autism: School open day checklist • Ambitious About Autism: SENCO meeting checklist
	<p>MAIN MENU (top right on all pages)</p> <ul style="list-style-type: none"> • Autism Toolkit – Disclaimer • Autism Toolkit – Acknowledgements

Each resource was co-produced based on the themes elicited from our PPI strategy; they were co-authored with subject experts, and peer reviewed by health visitors and parents to ensure they met the requirements of their intended audience. All the external links and resources that are signposted to have been through a robust quality assurance process, with each resource being reviewed by the iHV, at least one subject expert, a health visitor and parent, see appendix 1. This ensured that the resources align with national guidance/policies, and are evidence-driven, so that health visitors and families can access them with peace of mind that the resources are safe and trustworthy.

3.2 Awareness sessions

We aimed to deliver four national training events to raise awareness and introduce the resources including the toolkit. A cascade model was used to maximise reach through the creation of the Changing Conversations Ambassador Programme. The programme was structured to support the maximum use of the resources to inform practice. Ambassadors would then become local advocates, engaging colleagues and key partners from their area in the resources and learning. A resource pack was created alongside a 1-hour cascade session for the Ambassadors to deliver in their area, this would in turn give those they trained access to the toolkit. Collectively they would enable the voice of the child and family to be heard, ensuring that the changing conversation message was widely disseminated to as many professionals working with the family as possible, and to support health visitors' work with families pre, during and post diagnosis.

The role of an ambassador is to be a voice and advocate for families by:

- Cascading training and learning to team members
- Ensuring students and new team members are updated with the training when they start
- Working with local services to influence local pathways of support for families
- Ensuring all families know how to contact the health visitor and the role of the health visitor, including the healthy child programme and any local variance
- Being an advocate for families, especially in difficult situations and when lines of communication become challenging

The following cascade resources were developed for the Changing Conversations Ambassadors and held in the iHV Training Resources Hub.

- Raising awareness of the needs of families with autistic children - PowerPoint slide set
- Lesson plan for the 1-hour awareness session
- Trainer PowerPoint notes
- Participant PowerPoint handout
- Training guidance on how to deliver training in the face-to-face or virtual environment
- Cascade planning tool to help plan the cascade of the awareness session
- Guidance for ambassadors to send to participants on how to access and prepare for virtual training
- Local Networking document to make note of local services which support children with autism and their families
- Post-awareness session evaluations to give participants
- Register of attendees
- Attendance certificate to give to participants on completion of the session

4. Raising awareness

4.1 Health visitor awareness Ambassador sessions

Health visitors who undertook the training were selected through an open application process using an electronic form. The awareness events were advertised through iHV communications which included direct e-mails to members and ex-members, and advertising in the iHV monthly newsletter and social media. The events filled quickly, and a waiting list was created. The events were only open to qualified health visitors as they have the leadership skills and understanding of the health visitor role to enable successful cascade to wider members of the health visitor teams.

- A total of **116** health visitors attended the awareness sessions, with attendance from England, Scotland and Wales, although none from Northern Ireland; see Map 1.
- The events were co delivered by Vicky Gilroy (iHV), Victoria Jackson(iHV), Alison Morton (iHV), Professor Dame Sarah Cowley (iHV), Gwen Moulster (Learning Disabilities Nurse), Oriana Morrison-Clarke (National Autistic Society (NAS), Deborah Gardener (NAS), Nikki Daniels (NAS), Tina Bang-Anderson (Specialist Lead Occupational Therapist and Sensory Integration Practitioner), Charlotte Wilson (Empowering Parents Empowering Communities (EPEC)), Dominic Ray (EPEC and a parent) and Melissa Mackell (KIDS and a parent).
- All attendees were sent information on the training and expectations of a virtual training event. They were also sent a pre-session evaluation form to complete.

MAP 1: Work location of the health visitors who attended the awareness sessions



- Attendees were provided with background information on autism; the families' experiences and the importance of positive conversations with families about autism. At the end of the event, attendees were provided with information on the digital toolkit and resources for the 1-hour cascade session they were asked to deliver.
- 512** health visitors have attended an awareness session delivered by an Ambassador at the time of publication.

See Appendix 2 for lesson plan of the awareness events

4.2 Stakeholder event

Following the awareness events, it was recognised by the Steering Group that the project findings contained considerable wider system benefit. It was agreed that the Insights and learning needed to be shared with wider organisations and stakeholders involved in supporting families with autistic children in the Early Years. To increase the reach of the findings, a stakeholder event was held via Zoom in February 2021 - the attendees included members of the co-production group and representatives from the following organisations:



The 1½ hour virtual event provided an overview of the Changing Conversations Ambassador events and the Ambassador role. Insights from the project were shared, including the importance of health visitors and their teams being upskilled to support children with autism/suspected autism in the Early Years and their families. The attendees also participated in group work which allowed them to consider the key messages and think collectively about these specific questions:

1. What can you do to support us to change the conversation and sustain this work in the early years and very young children including babies?
2. What can you do to support the transferability of this programme to a wider audience?

The event was received really positively with **96%** stating that the event had supported them to consider how in their area/service they could differently offer to support children in the Early Years and their families. Following the event, we have held several additional meetings and networking sessions to consider how the Changing Conversations Awareness can be developed and sustained, including translation of the learning for the wider Early Years workforce and for Learning Disability professionals.

5. Evaluation

Evaluation is key to consider “what went well” and “what we could improve” in the future.

5.1 Method

- The pre- and post-questionnaires formed the main part of the evaluation, alongside an evaluation of the toolkit
- Attendees were given access to the toolkit following completion of the post-evaluation. This supported full participation in the evaluation process

- The questionnaires focused on levels of confidence, knowledge, understanding and capability
- **97%** of participants completed the pre-evaluation questionnaire
- **96.5%** of participants completed the post-evaluation questionnaire, all participants were encouraged to complete the post-evaluations within 24hrs, they were then sent reminders to complete the post-evaluations
- Both pre- and post-questionnaires used the same 5 questions. Participants were requested to give a score of 1-4, using the values in Table 3. The post-evaluation also asked questions about the delivery of the events
- **77.5%** of participants completed the toolkit evaluation. The toolkit evaluation looked specifically at the ease of use, the relevance and usefulness of the resources within it

TABLE 3:

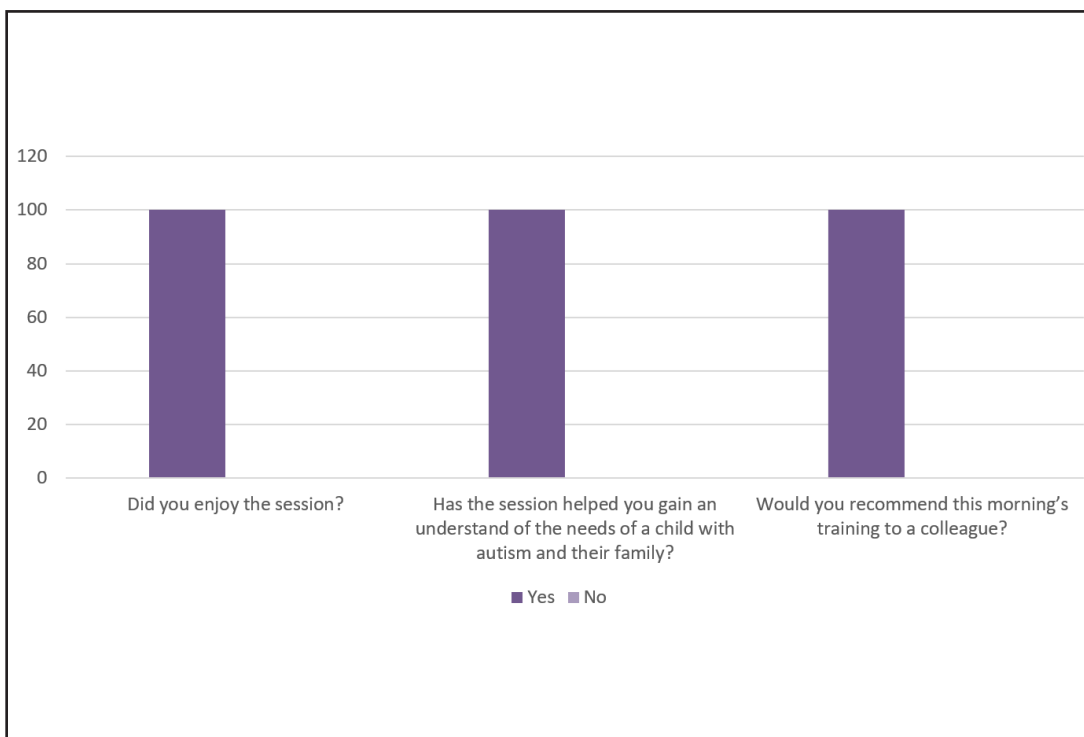
1	Not at all confident / No Knowledge
2	Not so confidence – have limited knowledge
3	Somewhat confident – I feel that there are some gaps in my knowledge/skills
4	Very confident / Very Knowledgeable - I am skilled in this area

5.2 Outcomes from delivery of training events

This next section provides an overview of the analysis from all pre- and post-training evaluation questionnaires from the combined training event.

At the end of each of the four events, a quick poll was completed to get immediate feedback from the session and the responses were anonymised to reduce bias and encourage attendees to share their honest opinions, both positive and negative. Graph 1 below shows the questions, and it can be seen 100% responded positively.

GRAPH 1:

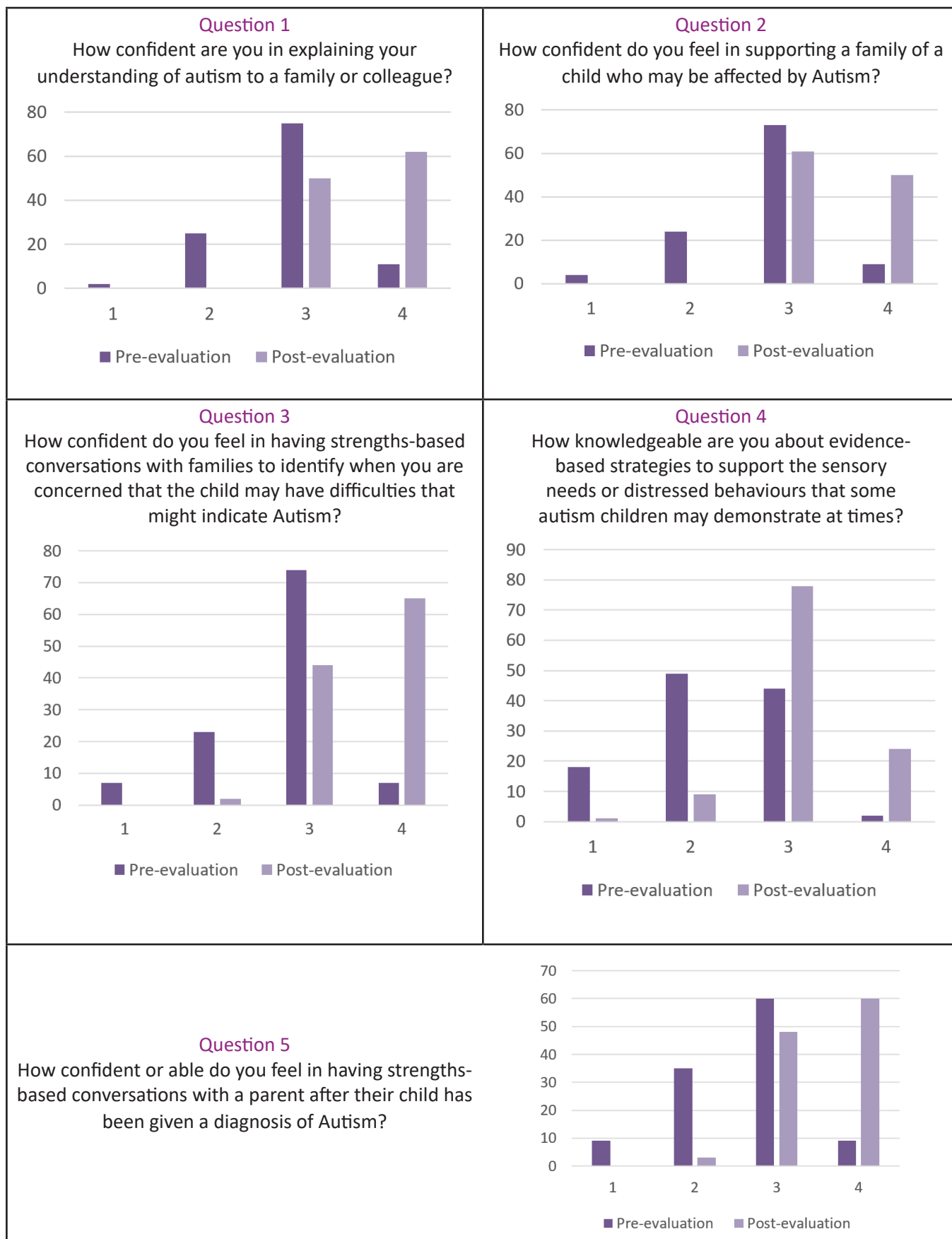


* N.B Individual analysis of the 4 training events has been undertaken but has not been reported here in order to maintain a concise reporting approach, please contact projects@ihv.org.uk if you would like more detailed analysis.



5.3 Quantitative feedback

The next graphs show the shift in understanding, knowledge and confidence pre- and post-attendance at the Ambassador training events.



The key messages:

- There was an overall significant increase in health visitors' knowledge, confidence, understanding and ability to support children with autism and their families from pre-attendance to post-attendance.
- The area with the greatest shift was in confidence and ability to have strengths-based conversations with a parent after their child has been given a diagnosis of autism. Before training, 31% of health visitors rated themselves as having limited knowledge and skills in this area. After training, 54% of health visitors rated themselves as highly confident in this area.

5.4 Qualitative feedback

This next section provides an overview of the qualitative feedback gathered from the participants. A thematic analysis generated several themes which are supported by examples of quotes from the health visitor respondents.

Question 6: What will you do differently in your practice?

Theme 1 - Importance of Communication	Theme 2 - Use of Language
<ul style="list-style-type: none"> • Listen carefully, keep reviewing and supporting the family • Realised the importance of listening to a family, even if you have no solutions • Open up communication with families; listen to families and their lived experiences as they are the expert on their child • Helping parents understand a meltdown isn't a temper tantrum, it's a way of showing distress • I will be listening better to parents when they share concerns and try to unpick with them more what they are experiencing with their child 	<ul style="list-style-type: none"> • Mindful of words used and negative connotations • Think about language such as challenging behaviour as "distress behaviour" • Support parents to take away the "don't" and "can't" in discussions with their children. For example, be specific with what you want your child to do, if you want them to not run, ask them to walk slowly instead • Careful consideration of language used. Role-modelling to consider the positives with parents
Theme 3 - Offer support	Theme 4 - Positivity
<ul style="list-style-type: none"> • I feel more confident to offer parents possible strategies to cope with their child's distressed behaviour • Share knowledge with parents to enable them to help their child with their needs. • I will listen to parents and offer them emotional support • Offer supportive phone call - ask how I can be helpful, LISTEN • Providing continuous support to families - signposting families to support 	<ul style="list-style-type: none"> • I will ensure I am delivering positive information and try to build on gaps whilst the family are awaiting specialist appointments • Be more confident to talk of the future - to explain that a diagnosis of autism does not have one gloomy outcome and there are many examples of people living positively with their diagnosis • Empowering parents to focus on the positives • Have more confidence in the positive conversations I have with parents
Theme 5 - Train others	
<ul style="list-style-type: none"> • I will cascade the toolkit to the health visitors and students. I will start having conversations with my colleagues to start changing conversations around Autism university wide • Use the tool kit ... to support/train my colleagues in working closely with family pre, during and post diagnosis • The online library is an extremely useful resource, I will definitely use this in practice and share will colleagues 	

Question 7 – If there was further training available on this topic what would you like to be included?

A general theme was that the participants wanted more training overall if it was offered
<p>The following topics were mentioned specifically:</p> <ul style="list-style-type: none"> • More on ASD from as early as possible • ASD links with ADHD and mental health and the additional co-morbidities to be able to prepare parents for school readiness • School readiness • More information on the specific difficulties autism can bring to a child and their family. Training in these areas such as sleep, communication, erratic behaviours, sensory issues etc. • Pathway for health visitors in identifying and supporting families • Working with minoritised ethnic communities who have an autistic child • Parenting skills and coping strategies • A package of support to bridge the gap between referral and being seen by SALT, OT.

Question 14 – Which part of the training event did you find most beneficial and why?

Theme 1 - Parents' contribution	Theme 2 - Networking
<ul style="list-style-type: none"> • The parent's views at the beginning were very powerful • Hearing from parents and autistic people • ...their perspectives at the early stages of their children's autism and what their experience of their health visitor was at the time • The views and feeling of those with autism were insightful and useful. After all, who better to tell us what a lived experience is like than those living it! 	<ul style="list-style-type: none"> • Learning about how the support for autism is delivered in other areas • Networking, breakout groups, shared learning • Discussion with other colleagues really useful • Sharing time in small groups was very beneficial connecting with HV across the country
Theme 3 - Practical guidance	Theme 4 - Resources and format
<ul style="list-style-type: none"> • Practical advice around sensory and communication needs • Strategies to implement in practice • I found the sensory needs section/ from OT (Proprioception and vestibular processing) a very useful refresher • An informal and positive approach, the opportunities to gain an up-to-date insight to autism and how to access resources to support and enhance my role 	<ul style="list-style-type: none"> • Interactive - use of videos, stories and professionals • The toolkit and the sharing of simple strategies • I found the whole session very informative and surprisingly interactive due to being on zoom wasn't expecting teamwork or opportunity to network very enjoyable session

Question 15 - Any other feedback?

A general theme was that the participants wanted more training overall if it was offered
<p>The following is an example of feedback given:</p> <ul style="list-style-type: none"> • I really think every Operational Lead in Health Visiting and their subsequent teams should do this training so that pathways are set up and the whole country is working to the same standard • The awareness raising and practical tips are fantastic • Whilst it's nice to see others face to face the training felt inclusive and enabled us to share our experiences. The event was well executed- thank you • It is such an exciting project to be involved with and it makes me hopeful that we are making progress in trying to bridge the huge gap in services for autism • I feel all health visiting and early years staff should attend this training. It can make a positive impact on practice

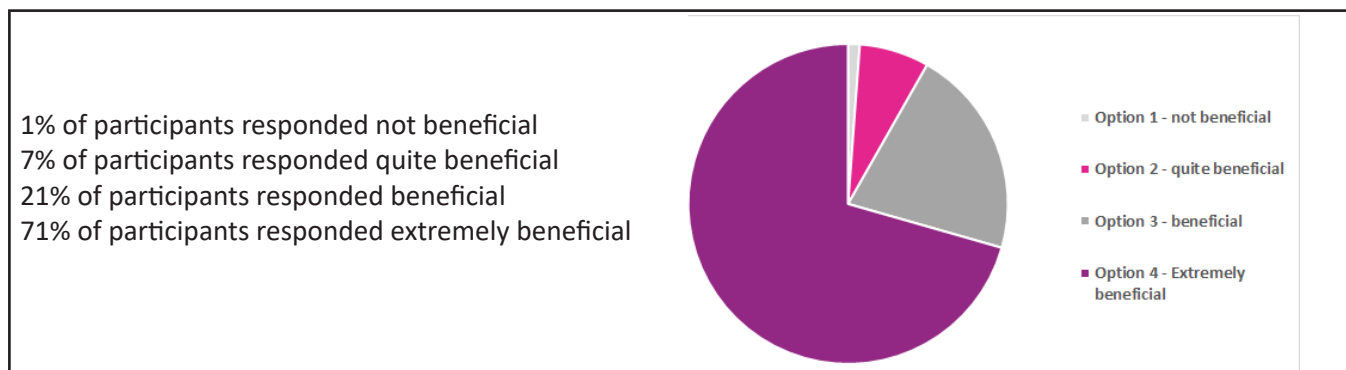
Summary of the evaluation feedback of the events

The responses to both the quantitative and qualitative questions indicate that there has been a positive shift in health visitors’ learning and understanding of autism in the Early Years and the specific support that families need pre-, during and post-diagnosis. The themes of the feedback reflect the different aspects that the awareness session focused on - how we communicate with families, that we discuss autism in a positive way, and offer appropriate support which is focused on the family’s needs, listening to their concerns without judgment or being dismissive.

5.5 Discussion - Toolkit

This next section provides a summary of the evaluation of the digital toolkit. It should be noted that this is optional and therefore more practitioners will have accessed the resources than recorded here.

Question 1 - Overall, will the resources benefit your practice with families?



Question 2 - Which resources did you find most useful and why? Please comment below:

Theme 1 - Resources for health visitors	Theme 2 - Resources for parents
<ul style="list-style-type: none"> I was blown away by all the information in this toolkit. It really is going to be beneficial for myself and my colleagues to use All is really useful and you have provided all the info and weblinks in the useful resources document and also in the library so making it really easy to find the info! The A-Z with links to resources - it is clearly structured and all in one place To have a dedicated site as an evidence-based resource toolkit is invaluable The resources for colleagues to take away with them - this enables training to be much more easily utilised and myself and colleagues will find these really useful to draw on as needed Very useful resources I was previously not aware of, which will help in supporting with eg. toilet issues, communication (now and then), sleep behaviours - diary, behaviour diary - understanding triggers and explaining why a child may have meltdowns, etc 	<ul style="list-style-type: none"> Really liked the links from the parent information guide (home section the first 5 years) particularly the sleep and food and dietary links I also really like the resources for parents such as the Right from the start toolkit and checklists for school The resources for families. We are definitely lacking in resources to share with our families and knowing that all this information is from a reliable source The guides to help and support parents - empowering them with information The family home section - really useful for families to read the experiences of others and know they are not alone in their journey. Also having the resources all in one area makes access and navigation very easy I specifically think the parent tips will be of good use

Theme 3 - Parent Perspectives

- Further information and helpful tips about what parents want and how a health professional can help them appropriately
- The parent’s stories - Was useful to hear things from their perspective in a non-medical way
- Having the service user perspective made me reflect on how I have conversations with parents, the importance of accepting and acknowledging their concerns came across strongly
- Parent’s feedback was especially poignant and insightful and has inspired me to be more proactive and support families by checking in regularly even after other support is put in place

Question 3 - Are there any gaps in the resources that you would like us to consider for future development? Please comment below:

48% of participants reported no gaps in the resources. The following are key themes of areas of future development derived from feedback given by participants:

More on the wider Multidisciplinary team

- Sensory processing info for parents, role of OH support in it and activities which can support parents with proprioception, vestibular sensory regulation
- Different Professionals involved and what their role is, i.e., what is an OT, SENCO

Support to wider family members

- It would be nice to see some more information regarding the siblings of children with autism and their views and also resources for the siblings to understand their brother/sister’s condition easier
- More child perspectives - voice of the child- teenager and how it feels to be autistic from point of view of an individual who has autism

Pathways

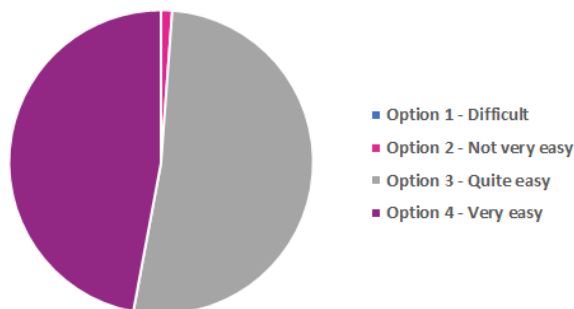
- More on supporting parents on the autism waiting list
- Flow chart for diagnosis - a quick summary.

Practical support

- Practical conversations about managing behaviour within toolkit rather than searching additional resources
- It would be good to maybe have information sheets available for different areas of need such as sleep, eating, sensory issues
- I would have liked to see resources for sensory activities if a child has these needs, and some tips about managing the child’s behaviour which is what I am asked about a lot

Question 4 - How easy overall was the toolkit to navigate?

0% of participants responded difficult
 1% of participants responded not very easy
 52% of participants responded quite easy
 47% of participants responded very easy



Any other comments or suggestions?

Positive comments on the toolkit	Accessibility of the toolkit
<ul style="list-style-type: none"> • Fantastic resource, easy to navigate and well evidenced • I feel this training and the resources will have a positive impact on practice as staff would feel more knowledgeable and confident with giving advice and support to families of children in the Early Years • Thank-you. The training was amazing. I wish I had more time to read through all of the resources • The information contained in this kit is very informative and has changed my practice, just what we need to support children with autism • Very comprehensive and excellent, but this is a lot of information for health visitors who are extremely short staffed (and were even prior to the Global Pandemic) to disseminate to other staff. It would be much more time efficient to email links to team members, then undertake a short summary (A Key points/ quick links section from iHV), to fellow staff • Abundance of easy to find information 	<ul style="list-style-type: none"> • Some of the information is quite wordy and it will be good to have an index which acts as an easy reference guide in navigating through the information • I really would have liked a sitemap to get a really good visual about what is available

Summary of feedback on the toolkit

The toolkit and resources were positively received and, together with the shift in confidence, knowledge, understanding and capability, provide evidence that the project has achieved its intended aim/impact on outcomes.

A site map to support easier navigation of resources within the site was recommended, and this has now been provided based on the feedback.

This has been a discovery project to explore and describe the wider and ongoing training needs of health visitors to improve their capability in working with families with autism. The findings from this study suggest that health visitors would benefit from further resources and information on autism, centred on sensory needs, parents with autism, minoritised ethnic groups, including families with English as an additional language, and training to other professionals such as schools and nurseries. These topics were also highlighted in the Insight work but were outside of the scope of the project and need to be considered in future developments.

5.6 Feedback from the steering group

A short questionnaire was sent to the steering group members to provide feedback on our engagement, co-production approach and role in the project.

- I learnt a huge amount - not least, what a wonderfully skilled team we have at iHV! (I knew that before, of course). Excellent project, really enjoyed being part of it.
- Just wanted to say it has been a pleasure to work with everyone on this project. I feel that this has been a genuinely co-produced piece of work and have thoroughly enjoyed being a part of the project.
- The iHV has from the start listened to all views and Changing Conversations is a brilliant piece of work. Thank you.
- I was only involved in the project for a short while. ... Based on my limited involvement, it has been a positive experience with a group of people who appeared very passionate about autism and supporting children and their families in the right way.

We are delighted that the engagement has been positive and it reinforced the importance of co-production as a central component of effective projects which we will build on in the future.

5.7 Challenges to the project overall

As with all projects there have been some challenges, specifically that the COVID-19 pandemic started during the project.

Table 4 below provides a summary of the challenges and mitigation that was taken.

TABLE 4:

Challenge	Mitigation	Outcome
Changing to virtual	<ul style="list-style-type: none"> » iHV used one online platform » Guidance sent to attendees on how to attend virtual training » Events held at various times and days » Mix teaching methods » Breaks 	<ul style="list-style-type: none"> ✔ iHV developed competency in digital solutions ✔ Supported attendees to understand expectations of attending virtual training and how to prepare ✔ Allowed flexibility for attendees to attend around work pressures ✔ Breakout rooms, pre-recorded and live presentations, poems and parent voices offset “Zoom fatigue” ✔ Regular breaks ensured a healthy approach to screen time was taken
Health visitor redeployment and recovery	<ul style="list-style-type: none"> » 1-day events changed to ½ day events » Cascade session 1-hour long » Continued professional development (CPD) 	<ul style="list-style-type: none"> ✔ To ensure a healthy approach to screen time was taken and allow flexibility for attendees to attend around work pressures ✔ Allowed for flexibility for attendees to cascade around work pressures ✔ Highlighted the importance of CPD during a national crisis to ensure families continue to receive the best possible care and health visitors have access to all the resources they require
Tech issues/ recording	<ul style="list-style-type: none"> » Pre-recorded sessions » Event specific tech support » Pre-event practice session and clear tech plan 	<ul style="list-style-type: none"> ✔ Ensure continuity throughout the events and if any presenters were unable to attend due to COVID or internet issues their presentation was not lost ✔ Ensured smooth running of the event and a point of contact for attendees if issues arose ✔ Allowed all members of the presentation team to understand all roles and detect any issues and resolve them before the event
Limitations of breath of project	<ul style="list-style-type: none"> » No scope to involve information on supporting parents with autism or the Early Years workforce » Little evidence and research on children of minoritised ethnic groups with autism and their families » The focus of the project on awareness 	<ul style="list-style-type: none"> ✔ This was understood at the start, but will be considered in any future bids ✔ Look at how families of minoritised ethnic groups are engaged with in Insight work to ensure their voice is heard ✔ The Insight showed that awareness of the needs of children and families was needed, however this meant that limited time could be given to practical support

Challenge	Mitigation	Outcome
Parent/child involvement	» Remote filming of parent voices	✔ A professional filming company was used to film the parent voice to ensure this was completed in a COVID safe way

6. Summary of the evaluation

The evaluations reinforced the findings from the initial scoping and Insight work that there are gaps in health visitors' knowledge, skills and confidence in supporting families with children who are autistic. The evaluations also highlight that the parents' voice was not well understood by health visitors. The increase in knowledge and understanding of the importance of having a positive, non-judgemental conversation with families and on-going support, pre-, during and post-diagnosis of autism. The findings also highlight that there is a need for autism-specific training and resources for health visitors, to ensure all families and children are given the best support possible to identify unmet needs and by early intervention to allow for children to meet their full potential. This is also reflected in the interest and attendance at the events, the size of the waiting list, and ongoing communication enquiring about more training.

7. Future recommendations

RECOMMENDATION	POSSIBLE SOLUTIONS
Attendees wanted more information on how to recognise autism and a pathway for support, review and assessment from birth to starting school, and how to support parents during this process	<ul style="list-style-type: none"> • This is difficult as each Trust and Local Authority will have a different process and pathway • The toolkit contains the Ambitious About Autism "Right from the Start Toolkit", which helps families navigate through different stages of their journey. There is also a Good Practice Point about transitioning to school • Development of further training and resources looking at possible early signs of autism and how to support families, highlighting what can be done without a diagnosis
Attendees wanted more conversations around children, who have autistic traits, but may have an overall language disorder, rather than reaching an autism diagnosis.	<ul style="list-style-type: none"> • Although the awareness session looked at how support is needed pre-, during and post-diagnosis the term autism was used a lot - possibly giving the impression that some information was specific to autism. Therefore, future work needs to reinforce that all skills and support discussed can be used at any stage and for children with or without autism
Attendees wanted information and resources specifically about meeting the needs of autistic children of minoritised ethnic groups and their families, and those with English as an additional language	<ul style="list-style-type: none"> • Due to limited research and information in this area, it is difficult to get a full understanding of the specific needs and challenges of these groups • Consider looking for funding opportunities to conduct health visitor research in this area • Consider how families of minoritised ethnic groups can be involved in future co-production work to ensure that their needs are heard and addressed

RECOMMENDATION	POSSIBLE SOLUTIONS
Attendees wanted more in-depth information about autism, specifically about genetic and research on impact of parental age and family history of learning difficulties on developing autism. As well as more information on the different types of autism	<ul style="list-style-type: none"> • Due to the length of the events, the focus had to be on ensuring all attendees have the same baseline information • More in-depth information and research is available in the toolkit within the literature review • Due to there being several national charities who specialise in autism, it was felt that signposting to these expert charities would be of more benefit than producing new health visitor resources which would not add value
Attendees wanted further information on co-morbidities of children with autism, including Attention deficit hyperactivity disorder (ADHD) and mental health and wellbeing, throughout the life course	<ul style="list-style-type: none"> • Further funding needs to look at what training or resources can be developed to specifically support, increased knowledge and understanding of supporting co-morbidities
Attendees wanted information on practical support for families about sleep, eating, behaviour, toilet training, communication, sensory needs and anxiety. And supporting parents with skills and coping strategies. They wanted these to be additional information sheets and resources within the toolkit rather than needing to go to additional websites	<ul style="list-style-type: none"> • Due to the scope of the project and the length of the awareness events it was not possible to cover these topics in-depth, hence signposting to quality-assured organisations and resources were felt to be of most use so that health visitors know where to get the information from • Future development of training on these specific areas of support needs to be considered and built on • Review of Good Practice Points, Top Tips for Parents, e-learning and filmed resources need to be undertaken to ensure the information is developed in the most useful way
Attendees wanted more information on the different professionals who may be involved in supporting a child with autism and their family. They wanted this to include what the support may look like, including the specific support and practical advice they can give about sensory processing issues	<ul style="list-style-type: none"> • This is difficult as each Trust and Local Authority will have a different process and may not have the same professionals available • An information sheet could be developed to add to the toolkit, giving a glossary of professionals and a summary of their role • Further funding needs to look at what training or resources can be developed to specifically support increased knowledge and understanding of supporting sensory needs
Attendees wanted more information about supporting the whole family in a holistic way. This would include siblings and parents who have, or may have, autism	<ul style="list-style-type: none"> • Due to the scope of the project and the length of the awareness events it was not possible to cover these topics in-depth. However, it was identified as a need within the Insight work, hence, signposting to quality-assured organisations and resources were felt to be of most use so that health visitors know where to get the information from • Further funding needs to be sort to develop resources to increased knowledge and understanding of supporting the wider needs of the family

RECOMMENDATION	POSSIBLE SOLUTIONS
Attendees wanted more of the child perspectives, including teenagers and how it feels to be autistic from the point of view of an individual who has autism	<ul style="list-style-type: none"> • Within the toolkit are poems from an 11-year-old boy about his life with autism and in the session was a talk from a young adult about growing up with autism • Consideration should be taken for future work on how to include a strong child voice throughout
Attendees wanted information on how to identify evidence-based interventions and navigating through untrustworthy, misleading and sometimes dangerous resources/websites etc	<ul style="list-style-type: none"> • Through the process of the project, all resources went through a quality assurance process which was reviewed by the members of the steering group. This meant all resources meet UK NHS, NICE, PHE, Unicef, Government and NMC guidance, so that health visitors can access and signpost to parent them without worry • Consideration should be given to a future Good Practice Point about how to review resources to ensure that they are evidence-based and reliable
Attendees wanted their colleagues in Early Years settings to have access to the training	<ul style="list-style-type: none"> • The attendees are encouraged to cascade the training to anyone within their teams that they feel would benefit from the training including Early Years settings • Future funding to be looked for to review the current ambassador awareness training and amend to meet the needs of all Early Years workers

8. Conclusion

This project has achieved its aim of raising awareness of the needs of families in the early years who have a child who is autistic or is considered to need assessment. The Ambassador cascade model of training has been a success with high numbers of staff trained and engaged in the future roll out of the resources.

The key impacts of this project are that it has: -

- Increased capability in the health visitor workforce to support families with autism or suspected autism
- Provided evidence-driven and quality-assured resources and a digital toolkit to support best practice
- Increased the confidence of health visitors to act as Ambassadors for Changing Conversations
- Raised the profile of the role of the health visitor in supporting this important agenda

The need to consider the sustainability of the toolkit and the Ambassador model is essential, we will continue to engage with key stakeholders to take this learning forward.

From the evaluation of the training and resources, the following recommendations are suggested:

- Regular updating of the training resources to maintain the relevance and quality assurance
- Raising the awareness in different audiences, including awareness sessions for Early Years workforce, multi-agency training, school nursing
- Consider expanding the resources to focus on:
 - » Practical support for sleep, eating, behaviour, toilet training, communication, sensory needs and anxiety
 - » Considering co-morbidities

- » Supporting the wider needs of the family, including parents with autism
- Further work to consider the specific needs of minoritised ethnic groups and those with English as an additional language

We thank all those involved in the success and collaborative approach that has been taken.



APPENDIX 1 - QUALITY ASSURANCE PROCESS

Quality Assurance Process Toolkit Resources

This guide provides the process for reviewing resources to form part of the training toolkits.

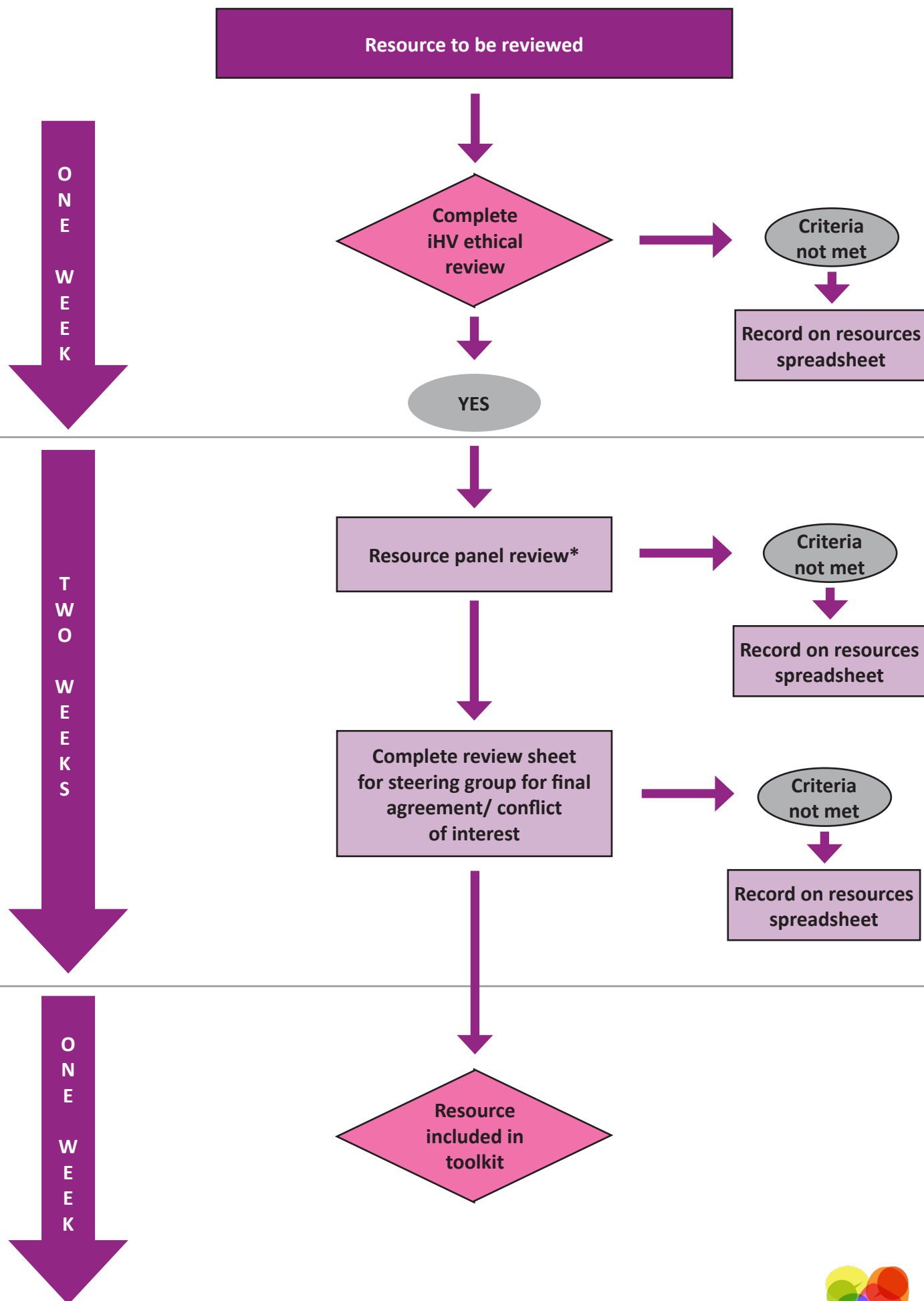
The resource to be reviewed will first go through the ethical review process completed by iHV project team, once the resources passes this stage it will then be reviewed by the resources review panel.

*Resources review panel

Panel members:

1. Parent from the co design process
2. Subject expert/Steering group member
3. Health Visitor

Review panel to each independently complete the review form available, via this link <https://bit.ly/35G1Oay>.



The Institute of Health Visiting Quality Assurance of Resources Form

This form is intended to guide you through the QA process for resources to support projects and be included in publicised resources pack and on the iHV website

Assessor and Resource Details			
Name of Assessor			
Job Title (if appropriate)			
Name of Organisation (if appropriate)			
Title of resource to be reviewed			
Audience of the resource	<input type="checkbox"/> Professional	<input type="checkbox"/> Family	
Resource review by	<input type="checkbox"/> Parent <input type="checkbox"/> Health Visitor	<input type="checkbox"/> iHV team <input type="checkbox"/> Subject expert	
Structure of the resource			
Is the resource clear and easy to follow?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Is the content clear and meaningful, in terms of the target audience?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Is there an appropriate mix of materials?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Does the resource use appropriate language that is non-discriminatory and inclusive?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Assessment			
Does it advertise products or services for commercial gain?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Does it provides advice and guidance	<input checked="" type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Do not know
• Based on up-to-date research and evidence?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Do not know
• Based on experience of children and/or families?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Do not know
• Do you think it is appropriate for parents/carers?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
• Do you think it is appropriate for professionals?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Is the resource suitable for those who are part of minority groups, e.g. BME, Gypsy, Roma and Traveller, Deaf and socially deprived communities?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Do not know
Is the resource suitable for all family members, e.g. the needs of fathers, same sex couples, parents with disabilities, children in care?	<input checked="" type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Do not know
Approval of resource			
Please expand on the answers as needed			
I confirm that I recommend this resource is included in the iHV toolkit	<input checked="" type="radio"/> Yes	<input type="radio"/> No	
Assessors E-signature:		Date:	

APPENDIX 2 - AWARENESS EVENT LESSON PLAN

Ambassadors for changing the conversation lesson plan			
Time	Activity	Resources and roles: Facilitator/Admin	Resources and roles: Delegate
08:45 - 09:10	Arrival, refreshments, networking	Check name badge on the zoom and register (and alter if needs). Meet and Greet Ask to write name, where from and hope write in chat in one post	Bring a cuppa
09:10	Welcome and introduction: inspire and energise! House keeping Overview of the day: Aims and learning outcomes	Slide 4 Facilitator -introductions of the core team Admin introduce role Slide 4 Facilitator welcome and state why here today Slide 4-5 Housekeeping Q & A and hopes for the day say hello to the group Slide 6-8 aims and learning outcomes & brief overview of the project	Slides and participants
09:25	Sharing insights	Slide 9 Show coproduction imagery –summary Slide 10 Show Parent insight - summary Slide 11 Show HV insight - summary	Slides
09:40	Introduction to talking about autism	Facilitator Introduce film – National Autistic Society (NAS) is here for Q&A Show pre-recorded session – (14 Minutes) Monitor chat for questions - Facilitate Q &A	Slides and short Q&A
10:00	Insights from parents - show film	Facilitators introduce KIDS and film Insights from parents - show film (18 Minutes)	Participants watch films
10:20	Group work	Introduce group activity Into break out groups x 5 random for 10 mins not facilitated Gather feedback one point from each group	Group work
10:40	Poem	Show reading from Logan play the film (3 Minutes)	Participants watch films
10:45	Break	All have a comfort break play music	
10:55	Sensory Integration – impact on development, behaviour and function in babies and toddlers	Facilitator Introduce video (Specialist Lead Occupational Therapist and Sensory Integration Practitioner) Play pre recorder session - (16 Minutes)	Participants watch films
11:10	Understanding stress and anxiety in autism, and the impact on behaviour	Facilitator Introduce video (NAS) Play pre recorder session – (11 Minutes)	Participants watch films
11:25	Working with the Autistic Child	Facilitator Introduce video (Empowering Parents Empowering Communities and Parent) Play pre recorder session (11.30 mins)	Participants watch films
11:40	Q&A	Facilitator Facilitate Q &A with awareness event panel	Q&A
11:50	The importance of listening	Poem message from Holland play the clip embedded	Participants watch films

Ambassadors for changing the conversation lesson plan			
11:55	The importance of changing conversations Group work	Facilitator Introduce KIDS session KIDS deliver session Slide 38 group work in same groups 10 mins KIDS complete session	Slides and participants Slides and participants Slides
12:20	My experiences	Key messages from lived experience (Autisitca) play film (4 Minutes)	Participants watch films
12:25	Next steps and your role as an ambassador Introducing the toolkit	Introduce the toolkit and resources talk through Discuss ambassador role and next steps	Slides
12:45	Group work	Explain group work Split into the same breakout rooms each agree key action to take forward from today nominate lead to write in the chat when return save chat	Slides and participants
13:05 - 13:15	Summary close and evaluation poll	Chairs closing messages Promote the poll and remind of evaluation survey	Slides and participants
13:15	Close		

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- 5 Public Health England (2021), Early years high impact area 6: Ready to learn and narrowing the word gap, available at: <https://bit.ly/3xOqSs6>



Institute of Health Visiting

A Registered Charity Number 1149745

c/o Royal Society for Public Health, John Snow House, 59 Mansell Street, London E1 8AN

Telephone: +44 (0) 207 265 7352 | Email: info@ihv.org.uk

www.ihv.org.uk