12:35:03 Hello, and welcome to everybody, and thank you for joining us at this really exciting autism care pathway webinar.

12:35:12 We've had an absolutely tremendous response, beyond our expectations we were hoping for 200 people, but we've had nearly 1000 registrations, which is really encouraging.

12:35:27 We'd like to thank all of you who have supported us and shared the flyer, and sharing with your colleagues and supporting what we're trying to achieve through this webinar.

12:35:41 Firstly, could I ask you if you could keep your video switched off please, simply because we have so many people joining us. And this is to ensure the best sound quality.

12:35:53 And if also you could please mute yourself, as well as turn your video off, because that will affect the sound quality of the presentations. The presenters that will leave their video on and unmute themselves as at the time they speak.

12:36:12 This is the agenda for this afternoon.

12:36:16 We'd like to invite you to watch the video after a comfort break at 1.40, we will have a question and answer session at 2.40 where the panel of speakers will be available to answer your questions.

12:36:33 As there are so many people that join this webinar, we do appreciate we may not be able to answer all the questions today, but we will take those questions and answer them on our website so please do look at the webinar page on the website, where

12:36:52 there will be all the resources from the webinar. There will also be a recording, transcriptions, PowerPoints and question and answers for everybody to access.

12:37:07 Please do post your questions on the chat function. I see everybody is already starting to chat.

12:37:14 We will be collecting your questions as we go along, and we will be presenting as many as we can to the speakers at the question answer session.

12:37:29 So we've got a very a nice combination of presentations.

12:37:36 First of all, it's a real privilege to have Professor Jonathan Green who is presenting on 20 years’ worth of successive research trials. The research trials are independent, but also connected.

12:37:49 It's the accumulation of that evidence which has brought us to this point where they were able to provide information on the best support services for children with autism and their families.

12:38:02 So I’m really delighted that Jonathan can present the scientific evidence to us today.

12:38:10 This is followed by Helen Harban who's a senior specialist lead speech language therapist working in the NHS , and she'll be talking more about the pragmatic, practical implementation.

12:38:23 So in their NHS Trust they've been embedding evidence-based practice into their services. Helen will talk about how they've done it and encourage other Trust to follow that

good model of service delivery.

12:38:39 I'm delighted we can hear from Louise Harrison who is going to present a parent perspective and it's important that we consider parent values, what are their aspirations for their children.

12:38:52 And we will hear from Amanda Haydock. It is a great compliment to have her join us as an autism advocate. Amanda represents the positive attributes of the autism community, their contribution to our community, their values and aspirations.

12:39:12 I'd also like to thank, Tanya Farley, and Kelly Warner Keith. They have made a tremendous effort to bring this together with all the organisation. Responding to all the emails and registrations and disseminated flyers.

12:39:27 So a real warm welcome.

12:39:31 Thank you to you for all your efforts.

12:39:33 Now I'm going to hand you over to Tanya, who will be introducing the speakers. Please continue to post your questions.

12:39:48 Thank you, Catherine. Good afternoon. We are delighted that Professor Jonathan Green co-founder of the PACT program has joined us today.

12:39:58 Jonathan is going to present new empirical evidence for a paradigm shift in the approach to autism intervention from reactive to proactive. A developmentally informed more rational approach to intervention.

**JONATHAN GREEN**

12:40:26 Welcome Jonathan.

12:40:42 Hello everyone. And just to check that you can hear me and see my slides. Can I have a thumbs up from Catherine, great pleasure to be here to talk to everyone today, and I want to start off by really thanking you and paying tribute to Catherine who has

12:41:06 been such a driving force behind the impact intervention and this collaborative program today.

12:41:16 And it's a pleasure to talk to you about the new autism, early detection care pathway that we have put together and to present the evidence on which we think this can be now promoted for colleagues.

12:41:37 So, what are the principles behind this evidence lead developmental approach?

12:41:46 Our theme really is to provide proven evidence to support from day one of an autistic child's life.

12:41:59 And really the principles behind this is to bear in mind that autism is both developmental and enduring as a condition, and the support programs we need to have in place, need to reflect this and that's really not how currently most services around the

12:42:19 world are organized as they tend to be somewhat patchy ,reactive and short term.

12:42:28 According to the health system in which they're located and the purpose of this approach I'm going to present to you is a more integrated developmentally informed care pathway and I hope I can convince you of the logic behind this and how it could work

12:42:43 in practice key is that we now have evidenced interventions and detection instruments to help support a proactive pathway of this kind. So, the idea of this is that we are proactive in our support for the developmental condition, in the hope that we

12:43:06 can head off later problems rather than have to react to them.

12:43:09 But we also have pulled into this service models from other areas of healthcare that have worked out how to look after enduring health conditions of different kinds.

12:43:22 And there are some principles that one can pull out from those Research Service models.

12:43:30 One is that whatever care we put in place has to be owned by the service users by the families by the autistic children by the autistic adults. In this case, it has to be owned it has to be developed in partnership with them.

12:43:52 So that's what so called self-management approach is a crucial aspect that I will talk more about.

12:44:01 We also need to have enduring support for families because we are talking about young children and their families here mainly in this pathway that this in this presentation.

12:44:12 We need sustained support what we call key working and I'll talk more about that.

12:44:17 And then we need a model of step care where you get the appropriate level of care that you need when you need it. And for as long as you need it but no longer so that this can be an efficient pathway that doesn't waste resource and uses the resource that

12:44:31 we have efficiently and to also help with that. There is the role potentially in the future of digital health technology.

12:44:43 And I'll allude to this but I think that's going to be a bit of a game changer as well for us.

12:44:48 So here's the model.

12:44:51 And in sort of summary terms. And this is what I'm going to be talking about today.

12:45:00 The model is published recently last month in the journal Lancet Child and Adolescent Health.

12:45:08 At the end of the presentation I'll give you the link to the reference for that publication.

12:45:24 But then if people contact myself or the organisers, we'll see what we can do to get you a copy of the paper.

12:45:33 Essentially what we're promoting here is a stepwise approach in development, starting pre diagnosis and this is one of the first innovations that this is proactive to early identified near a divergence in development for children, so that we get in place.

12:45:52 Early support before the diagnostic process.

12:45:56 And then we need support for families around the diagnostic process to orientate them to help them adapt to the new situation, and to sign post them to ongoing care and that's a crucial gap that needs filling on going to be talking about that.

12:46:15 Yeah, I'm very sorry to interrupt, but are you on two screens, because I think we're saying we're seeing you need to swap the screens, because I think we're seeing small slides and the Presenter View with black all around it and lots of slides, better.

12:46:30 Fantastic. Thank you. Okay, sorry about that i thought i got it right. But anyway, that's better for you.

12:46:39 That's perfect. Thank you. Okay, no problem. So,

12:46:45 yeah, so, to where I was with the family support around diagnosis and then post diagnosis.

12:46:54 And what we need is a developmentally informed intervention that's family focused, which will help family adaptation and empowerment, as well as building the child's developmental skills and I'm going to talk about that that's where PACT comes in.

12:47:13 And then finally, after that, there is a long term process of long term support, because as we know, we have to have engineering support through early development into adulthood, no doubt in the end.

12:47:30 And so, we need a system of case management, ongoing family support and step up care when needed.

12:47:36 So, this is an integrated the sequential pathway as you can see in development the way I'm going to present it is assuming reasonably early diagnosis and identification preschool.

12:47:52 But we recognize of course that many autistic children identified later than that in current services, and this kind of model can be adapted to later identification as well.

12:48:07 So let me take you through the steps of this intervention care pathway.

12:48:14 So we start with the pre diagnosis processes and in a way this is the most novel and innovative and some level controversial aspect of this pathway, which I'll talk with you about it fundamentally is to give early appropriate care where it's needed,

12:48:38 and to tackle this awful diagnostic bottleneck that families experience in health systems around the world I don't think there's any health system that's already cracked this, the diagnostic bottlenecks certainly a problem in UK.

12:48:56 And the first innovative thing we have is now surveillance instruments that are evidence to pick up early childhood neuro diversity or concern, which are pretty good at identifying young babies and toddlers who are at higher likelihood of developing autistic

12:49:16 development.

12:49:18 And these can be incorporated within health is during Community Health regular developmental surveillance infrastructures.

12:49:29 And obviously they're different around the world but we think this can be adapted internationally, and the particular measure, there are a number of measures that can do this but the particular one that we think has the best evidence at the moment is

12:49:45 the social attention and communication surveillance or sacs.

12:49:50 And this is a fairly simple but really robust and well evidence surveillance instrument that can be applied from the age of one year in infancy through the preschool years.

12:50:04 I'm not going to say any more about it but this is the instrument that we think has good evidence of predictive value.

12:50:13 And we are you know training or the originators of training on this instrument for those who are interested can get in touch.

12:50:23 After we've identified early neuro diversity and remember this is pre diagnosis, but with this surveillance technology, we can be reasonably sure that these are children at least have higher likelihood of developing autism.

12:50:41 We need appropriate care.

12:50:44 And the idea is to triage into a personalized evidence support for early child development.

12:50:52 And this is where the model that we've tested over the last decade or more called the IBASIS VIP comes in and I want to tell you a bit about that.

12:51:05 All the interventions that I'm going to talk about in this presentation are what we call parent mediated intervention so just going to say a word about this general model of intervention that applies to the PACT treatment as well.

12:51:20 This is a method of intervention that works, the therapist works just with the parent.

12:51:28 They don't work directly with the child, but they work with the parent in the context of their, the parents, direct interaction and family naturalistic interaction with their child.

12:51:40 And the idea behind this is that we can work with the parent in that way in a targeted way.

12:51:47 Targeted alterations and parental behavior appropriate to neuro diversity, then lead to improved child direct communication, that's the theory, whether this actually happens in practice as a matter of the evidence which are present to you.

12:52:03 And then the next bit of the chain, as it were, is that if the child has this otter diabetic experience.

12:52:13 Improved addict communication, they will generalize that into more general social functioning out in the community with other people in other contexts, and this generalization step is the crucial step to developmental improvement.

12:52:34 So this is the general model that we are aiming for.

12:52:40 This represents a real paradigm shift in the way we approach autism intervention.

12:52:46 It is done as I say with parents in the context of normative social development.

12:52:52 It's based on a transactional account of known developmental processes.

12:52:57 And in that way. It feeds into ordinary child social development across the neurotypical, as well as the autistic spectrum, working in this way, definitely does not imply there's anything wrong with the parenting, this needs to be emphasized the parents

12:53:15 work with us as co partners, they want to do the best they can to be the best parents they can be. We work with them to help them do that. And as you'll see in the evidence parents are wonderful at doing this, there's nothing wrong with parents or parents

12:53:29 need is the guidance to liberate their natural skills, and the information to do so.

12:53:36 This leads to a spin off, potentially, proud parents feeling empowered skilled up and much more confident to manage their child and family life which is a huge benefit.

12:53:49 It also is a spin off is quite efficient on professional time, in the sense that the once we've got this in place, the parent does a lot of the work to be honest.

12:54:01 In the course of their normal parenting and therapists time is relatively minimized. And this 24 seven therapeutic effect, we think is key for the intervention having long term effects, after the treatment dad does your see in the, in the evidence.

12:54:21 But this isn't straightforward. This is not simple psycho education, it's not coaching, it's not Tea and Sympathy, is not generic support, although it's all those things in a way, it's a really specific therapeutic technique where we produce really focused

12:54:40 change and parental understanding and responsiveness. And we do that using video feedback and so I want to emphasize this is quite a technical procedure, and it's rather specific and the way that it works.

12:54:54 And we found that video feedback is very helpful for that.

12:54:58 So I'm just going to show you the generic process that we that we do in these kinds of therapy.

12:55:06 We take a videotape of the parent with a child in a naturalistic setting. And then we play back this videotape itself with the therapist, and the parent together so just show you how this works.

12:55:34 Stop.

12:55:58 So here's the side here is the therapist with that parent showing this video click back and exploring it together.

12:56:10 Here is the therapist with that parent showing this video click back and exploring it together. VIDEO PLAY: He understands Nice.

12:56:13 Yeah, that's me got my insights from his play. Yes, first time Yes.

12:56:17 Yeah,

12:56:21 I think, at the very beginning, and that's something that's really quite interactive because I think he realized I did make the game more fun. Yeah. VIDEO PLAY END

12:56:36 So you'll see that this is a collaborative model they basically the parents and the therapist explore the video together, it's not the therapist, telling the parent, what to see although they clearly have knowledge and a manual progression in the

12:56:54 back of their minds but really the process for the parent is a mutual exploration. And it's important that the parent explores and discovers things about their child and that's what makes it exciting for the parent and really

12:57:08 lodges in their mind.

12:57:11 So the first method first context in which we use this method is the so called, IBASIS VIP the infancy intervention.

12:57:22 This is pre diagnosis, it's a home based manual intervention 12 sessions over five months with daily practice plans for parents and it follows a sequential a sequence of early developmental themes,

12:57:38 where the parent gets sensitized to the, the child's particular pattern of communication, any alterations or complexities related to the child's neuro diversity.

12:57:55 taken into account and the parents sensitized alerted to them.

12:58:00 And through this process, the parent really gets to know their baby and first the intentionality of their intervention of that communication, even though their communication maybe a bit a typical for the parents experience.

12:58:13 They are able to understand this difference and understand the intentionality is generalize to everyday activities linked with feelings.

12:58:24 And, and then develop interactive communication and talk.

12:58:29 And we have a lot of

12:58:32 adaptations we make early, within this kind of manual approach.

12:58:40 Fundamentally, we're after shifting the dyadic style, which is consequent on early on early neuro diversity and just to give you a little brief example of this, what we're hoping for.

12:58:54 Here is a baseline. This child is really young about eight months or so, You know, one of our treatment cohorts.

12:59:17 In one of our treatment cohorts.

12:59:29 See how mums working hard to engage baby.

12:59:33 And he's sort of reacting a bit passive.

12:59:37 And, and then.

12:59:39 This is what we hope for an endpoint.

13:00:13 You'll see how much more active the child's his face to face, and mum’s waiting watching nurturing him and responding and then entering into a social anticipation game with mutual enjoyment.

13:00:29 You'll all be familiar with this kind of thing. This is the context within which social /language learning where communication starts to take place and this is what we are promoting with the therapeutic work.

13:00:46 So that's the theory, that's what we do in the therapy, how does it work in practice. So, for this iBASIS intervention.

13:00:56 We did our first trial in the UK several years ago with babies, a higher likelihood of autism from nine months of age.

13:01:05 And when I present the results of these trials, it will be in in three sections Firstly, the way in which we've been able to shift parental direct response this parental behaviours.

13:01:19 Next is the way we've been able to then consequentially shift child died at communication.

13:01:25 And the third is this level of generalization to overall autism symptoms with a different person in a different context.

13:01:34 So there are three stages to our evaluation of how well the interventions work.

13:01:42 And here in the eye basis trial, the period of therapy is seen here on the left of the graph, up until this vertical dotted line.

13:01:51 This is the therapy. And at the end of therapy we see we've really shifted This is the heavy line here the continuous line is the treated group. The treatment as usual comparison group who didn't get the basis treatment is along this horizontal line here.

13:02:09 The difference between those two lines is the difference the intervention is made within this randomized trial.

13:02:17 So what you'll see is that we've made a big difference to parental direct response what we call non-directive, which is the targeted change we're hoping for.

13:02:29 And that that sustains that change sustains over the next few years, because we follow up the kids and about three and a half.

13:02:35 But maybe falls off a bit here, we have a change in measurement.

13:02:41 Then the next level of this is the child's communication with the parent and remember we don't actually work directly with the child at all so this this changing child communication is the consequence of the parental change.

13:02:58 And here you'll see we get a lag effect so that the child does change in their direct communication the amount of direct communication, but it it takes off just a slightly slower rate than the parent change which is what you'd expect, but it's sustained

13:03:16 right the way through.

13:03:18 And the difference between these two curves this area in here is statistically what we measure as the treatment effect and it's highly significant for those of you interested in the statistics.

13:03:32 So we've we get this sustained change in child biotic communication with parents.

13:03:39 And then the third thing which is our primary outcome if you like is whether that change is generalized out into other contexts with other people that's the key generalization.

13:03:51 And you'll see here this is measured on the A Dawson the AOC for those of you who are into more research side.

13:03:58 And here the line goes down because we're reducing severity of autism symptoms or autism related behaviours were improving social functioning and reducing severity of the.

13:04:12 The other behaviours.

13:04:13 And we've succeeded in reducing the severity here at the end of treatment.

13:04:21 And although it just doesn't quite the overlap here suggest that doesn't quite reach significance in its own right.

13:04:29 But the fact is that it's sustained through the next couple of years. And it's that sustaining. That gives us this significant effect. Over time, intervention effect over time.

13:04:41 So we do get a generalization effect as the result of this five months treatment.

13:04:48 So this infancy intervention was more recently, replicated in Australia with colleagues in Perth and Melbourne.

13:05:00 And they did the same intervention exactly the same, but with community identified children so these are children who've been identified with community concerns on this sax instrument that I mentioned earlier in the talk, again, the same five month intervention

13:05:17 and three follow up. And incense, what, in essence, what we found is exactly the same results as we got with the UK trial. Here is the outcome effect on autism symptoms and social functioning and you'll see this sustained reduced level of autism related

13:05:35 behaviours. So the significant trajectory here, over time, following up from the intervention.

13:05:45 And what happened? Additionally, in this trial was that they did a clinical best estimate that's what this stands for autism diagnosis from independent clinicians that three.

13:05:58 And they these clinicians had access to all the data, including the A das the parent child interaction and other measures.

13:06:07 And they did this formal diagnosis against DSM criteria.

13:06:12 And the key thing that they found these clinicians, was that for the parent child buyers who had received the intervention.

13:06:22 They were 60% less likely for the child to have developed autism.

13:06:28 The child still had some neuro atypicality in development, but they had gone below the autism threshold.

13:06:40 So that's a 60% reduction. These numbers are relatively small.

13:06:45 But this study was unequivocal in its result that this kind of early intervention seems to be able to reduce the amount of autism diagnosis above threshold.

13:07:05 This is the first, what we call pre-emptive pre diagnostic intervention, which, which has shown a phenotypic reduction in autism. It needs replication but it is a powerful result.

13:07:19 And it's consistent with other findings that we have on the improvement in the Autism.

13:07:28 many of you will be familiar with this paper that was published last year was, had a lot of publicity and some controversy. I don't have time today to go into all that I'm happy to do that in question and answer.

13:07:44 But, in essence, there were some concerns that we were as it were getting rid of autism.

13:07:49 But I think the key point that we were able to make was that it's not really that it's that what we're doing is providing really good focused early support the kind that all children benefit from.

13:08:02 And as a result of that.

13:08:05 The children were showing less distress associated with neuro diversity.

13:08:10

13:08:12 As I said I can't go into all that today.

13:08:13 The dialogue that we had with people around this but we think this is a significant result. It's not about trying to get rid of autism, it's about giving appropriate early care, which then has beneficial developmental consequences.

13:08:33 So that's the first part of the, of the pathway. It gives us evidence now for essentially starting a proactive care pathway that the earliest signs of neuro divergence before diagnosis, I'll come back to that point.

13:08:51 Then when we get to the diagnostic process around diagnosis, when the diagnosis has been made. We do need good family support.

13:09:03 And this is because families need an orientation to this change in their lives they need support, and they need signposting into terms of future care to get this is a crucial point, which there really isn't any good evidence care Packages at this sort

13:09:23 of around diagnosis point for families.

13:09:30 Although lots done it's largely on evidence. We are ourselves doing a group program for young families within an autism diagnosis just made, and that trial is in process to see if this combination of psycho education, and I emotional support therapy.

13:09:49 Will really give help for the families at this stage, and we'll have the results of that in a year or two.

13:09:58 Then we come on to the post diagnostics primary intervention, and this is where we want an intervention that's family focused strengths based to give sustained support for parenting for parent for empowerment and skills, but also sustained support

13:10:18 for the child's developmental progress, particularly around their social and communication development.

13:10:26 And that's the purpose, we think of the intervention of this particular part of the pathway.

13:10:34 Fortunately, the best evidence-based interventions at the moment, do precisely that.

13:10:41 And this has been recognized by the UK NICE committee and various other international bodies in who've reviewed the evidence.

13:10:50 And one of the social communications that is particularly family focused.

13:10:56 That has been shown to have these effects is indeed the, the PACT intervention that we've worked on with Catherine here in Manchester and collaboratively across the UK.

13:11:09 So a few words about PACT, which we now call the Paediatric Autism Communication Therapy because it can be applied into the early school years.

13:11:21 It's a slightly longer program than the one I've just described to you six to 12 months, focuses on the developmental dyad, as you know I've said before, targeting parental awareness and responsiveness to New York divergent development and social and social communication.

13:11:42 Just as it were, a difference from other autism interventions, we do not use a behavioural modification or behaviour learning principles in this intervention.

13:11:54 This is really very, very different to those kinds of behaviourally orientated autism interventions ,ABA and other interventions of that kind.

13:12:04 As I hope I've explained to you this works much more with the early developmental transactions that underlie, or actually all child social development stage, according to early communication precursors and as I said it uses video feedback.

13:12:26 So it works in these three levels as I've mentioned the work with a parent inducing change in the child's dyad, and then generalization.

13:12:37 And we've tested PACTed in a big series of trials, over the last almost 20 years now, the PACT trials.

13:12:48 This is one of the largest at the time we did it was the largest randomized trial in in autism, it certainly remains one of the largest to have been done.

13:12:58 over 150 children.

13:13:01 And what we did was to do this random allocation, you'll note that these are children at the beginning, who have caught what we called at that time core autism.

13:13:15 In other words, these are quite significantly affected kids about 80% of learning disability.

13:13:22 Only 25% of the beginning had phrase speech at the preschool level so these are quite significantly affected.

13:13:32 And they have a 13 months, 12 months intervention with the pact, which you'll hear about the nature of pact later, more clinically.

13:13:43 And then we followed them at 13 months after the end of the intervention and then six years after that, when by this time the children were in middle childhood mean age around 10 and a half.

13:13:55 And at this age, we achieved 80% follow up, which is pretty good after such a long time. And when we assess these children at that age, they were still the, the assessors the people who were doing the assessment we're still blinded to which treatment,

13:14:13 which group these two kids were in so we retain the blindness, even at the follow up stage.

13:14:21 We've published these, I'm sure you'll probably be familiar, many of you with these, the papers that we've published on this and other sense.

13:14:30 And the findings to, which are essentially raised similar to the iBASIS findings. So here is the effect of therapy on the targeted parental behaviour.

13:14:44 And this is mid-point, this is the end point of the trial.

13:14:48 And you'll see that we've. This is the blue line is the treatment as usual so these families in this arm of the trial we're getting a whole range of different therapists, we didn't constrain that at all.

13:15:01 And then this red line the families were getting other therapists if they wish them, but the pact therapy. In addition, and here you'll see the addition of the PACT therapy has resulted in a very significant treatment effect to improve the parents ability

13:15:21 to be aware of the child's communication and respond to it that's essentially what we are measuring here.

13:15:29 And this is a big treatment effect. And it over time, whether because of the way we measure it, or it just washes out that treatment of back to has diminished by the time we follow them up in middle childhood.

13:15:42 But this area between the curves this area in here is what we measure is the developmental impact of the therapy over time. And that is highly significant for these parental synchronous responses.

13:15:58 And then we come as we did before, to the child targeted child behaviour with the parents, so this is the direct communication, and you'll see his mid-point this is endpoint, This is follow up.

13:16:11 And the thing to notice here is that we haven't used it's not such a big change.

13:16:16 As with the parent, but it's a significant change, particularly in the so far as its sustained right the way through until 10 and a half. So remember this is the end of therapy.

13:16:28 But this change sustains itself, six years after the end of therapy until we followed them up, virtually undiminished which is extraordinary result.

13:16:39 And then when we come on to the autism symptoms, which we measured using the aid of the standard.

13:16:47 Autism phenotype behaviour measure what you'll see here is again a diminution of the expense severity of autism symptoms.

13:17:01 At the end of therapy, this is significant affect the end of therapy, and that effect is sustained right the way through until follow up. And as you can see, it's not diminished the actual treatment effect it sustains itself right the way through.

13:17:18 And this area under between the curves is highly significant

13:17:24 that effect. We also looked at in terms of parental reports of their child's language, social communication functioning repetitive behaviours, adaptive function, and also some of the teacher ratings.

13:17:40 And these all these ratings support. The blinded findings here of improved child functioning.

13:17:50 So this is a powerful results, particularly in the how well this is sustained over time.

13:17:58 It's actually a unique result there's no other therapeutic trial that, which has been done rigorously to have shown a treatment effect sustained over this time in autism.

13:18:08 So this is an important evidence behind how we can advocate a therapeutic pathway of the kind that all return to in just a minute.

13:18:20 You'll also have noticed but the effects we get in each of these trials these, this is the, the iBASIS is the baby trial. This is the Australian replication, and this is the PACT trial, the kind of effects we get on autism.

13:18:39 Symptoms phenotype here are very similar in their shape, which is a very interesting result developmentally This is done preschool This is done in early childhood and infancy, and you get the same kind of effect that each stage using this kind of therapeutic

approach.

13:19:00 We're also interested to know that was what happened. Then we wanted to know how it happened. How was this treatment effect actually

13:19:13 delivered for the, for the, for the child. And we've done these mechanisms studies which again are some of the largest in the field and publish these and, in essence, what we show is that it is this change in parental synchrony.

13:19:33 That is the is the thing that is responsible for the change in child direct communication, and we hypothesize this but it was really important to have shown it so changing parental synchrony as we define it is the thing that really makes the difference

13:19:48 and that supports the logic behind the pact and the basis therapies equally importantly, this change in child data communication. That is the thing that is that mediates the autism symptoms severity outcome.

13:20:08 It's not the parent change that mediates this.

13:20:12 Sorry, it's not the parent change that mediates this, it's this child dynamic change that mediates the autism functioning and what this suggests is the child is really internalizing, the different dynamic experience and able to apply that in other contexts,

13:20:31 and just generalizing their social communication functioning and the way that neurotypical children do and what ‘ve shown through this, is that neuro diverse children can do it as well given this kind of therapy.

13:20:48 We've also shown the same mediation approach. Actually mediates the long term effects to middle childhood so the child communication initiations are the thing that make the difference to six year symptom outcomes, six years after the treatment end.

13:21:09 And this is an important result in itself that suggests how important these communication initiations are in in long term developmental change, and they get embedded somehow in the child's development, which is very encouraging.

13:21:28 then more recently we've adapted PACT two kind of combined a home and education PACTage.

13:21:40 And this we thought would be a good idea to be able to disseminate the work further, but there were complications with this the in order to do home in education together and when we did it in education we did it with teaching assistants in the UK, who

13:21:55 worked with their children in the in the classroom.

13:22:00 And there were lots of issues around doing this, it's a good idea but the, the amount of dosage that we could put in, in terms of how many sessions with the parents and the educators was much lower than with clinic base PACT that we had tested before

13:22:16 the education context, while it's great to do this kind of thing it is complicated to really initiate and sustain an intervention of this kind.

13:22:26 And we did a lot of online therapy during this at a time when we weren't so familiar with online therapy, bottom line is that doing it like this has a bit of a reduced effect it has the same kind of effect on parents synchrony and child initiation, but

13:22:43 it this, these, these effects don't then mediate this generalized change in child symptoms in the same way.

13:22:52 And this is with this was good learning for us.

13:22:56 It suggests that there is a dose effect here, you do have to have a certain level of dosage, and the right environmental conditions to produce the developmental change that we've reported elsewhere.

13:23:11 Important to note that we did however improve parental well-being and child challenging behaviour both at home and school and those are important concerns for many families indeed.

13:23:24 So, this is the PACT parent mediated intervention, we've shown that we can do this kind of work across socio economic status Education, Culture ethnicity we've done it in South Asia, and other places.

13:23:42 And also with parents on who are themselves on the autistic spectrum. So, this looks very widely applicable across all these kinds of areas know have adverse effects that we've really recorded.

13:23:58 Apart from parents sometimes find the pressure of time, understandably is hard.

13:24:05 And we've done a lot of studies of patient experience and you're hurt hear a bit more about that in later talks from Louisa particularly today.

13:24:15 And we're doing PACT training, we've done PACT training in 21 countries now, and Catherine will talk more about the training procedures later this afternoon.

13:24:29 So my take home principles before I return to the pathway that autistic children of all kinds can respond to this kind of improved understanding and response from their parents and other adults, by increased social motivation engagement and communication.

13:24:49 Parents can develop these skills and feel better for it.

13:24:54 And children generalize these experience into improved social functioning elsewhere in their development.

13:25:06 And this is the best evidence route currently for improving long term child social functioning and sentence.

13:25:17 And this is why we advocate, this kind of intervention as this foundational treatment for post diagnostic support.

13:25:27 Then just to complete.

13:25:30 Just to finish off and complete the latter stages of the pathway.

13:25:34 So, after we've put in place this foundational family focused intervention that I've just described, which is aiming to empower families but set children's development off on the right foot, and for their later development into school years, etc.

13:25:53 We know that's not the end of the story.

13:25:56 As children go into school experience out of their families often difficulties arise autistic children are vulnerable to a lot of difficulties and co occurring conditions, and we need to be able to support families and children through that time.

13:26:16 The first way that we need to be able to support them and I'm not going to talk about this very much at all. But just to note that environmental modification, autism aware environments in school in social settings and later on in work environments are

13:26:31 going to be crucial to help good adaptation along the model I've described.

13:26:36 But we're also going to need to be able to provide specific treatments for co occurring conditions anxiety, depression, ADHD obsessive compulsive conditions behavioural challenges.

13:26:50 All of these things are quite common in autistic children currently we have some evidence based interventions for these range of conditions but we need more research on the specificity of them.

13:27:04 This is where we come to step up care because these treatments then need to be delivered by autism specialist services of one kind or another.

13:27:15 And we need to signal for families when they need that care, give them the care and then the step down bit is to win that care is finished, step down into the foundational case management subsequently so this is what we call step up, step down.

13:27:33 But it's against a background of the foundational care and support that we've put in place. Earlier in the pathway

13:27:43 digital technologies can definitely help.

13:27:48 We think for the future. Although these haven't really been implemented that much yet I'm not going to talk about them very much. But we've got some digital apps to help surveillance.

13:28:00 We have co owned health records digital health records which we can co partner with families early in the process after identification and embed into digital health systems.

13:28:15 And this is going to be a challenge for health systems to put this together but we think this is going to be crucial.

13:28:23 And then, smartphone apps can give community support to families for each other and with professionals.

13:28:30 And what we call digital navigators who are going to be able to be online caseworkers for families efficiently being able to link with them signpost support and respond efficiently to difficulties as they arise.

13:28:46 So all this use of digital health technology is there ready to be done it just needs health system change to implement it and let's hope that can happen over the next few years.

13:29:00 So, this is the model in summary, starting at the earliest stages of identification of neuro diversity, with pre diagnosis care family support around diagnosis, primary intervention and then ongoing case management and step up, step down.

13:29:18 You'll see it's a sequential model it'll take the families through their child's development. And we hope that it will be additive if you get each of these components, you should end up with better outcomes and as we implement this pathway we hope we

13:29:33 will be able to show that we're doing implementation.

13:29:38 Currently in the UK and Manchester in Cambridge, and this is the reference to the paper that we produced earlier this year which has the pathway model in detail in Australia, they are planning a national implementation of this pathway or something like

13:29:56 it.

13:29:57 And in low and medium income countries, particularly South Asia. We have colleagues and collaborations, which are going to introduce this kind of process into South Asia and that's very exciting adapted for low income settings, and two different health

13:30:16 systems. And if you're interested in reading more about how we're doing that. This annual research review in the Journal of child psychology and psychiatry has got a detailed description of how we how we do.

13:30:33 So that's, that's the pathway. That's my talk, thanks to my colleagues, who've been wonderful in collaborating with me and the team in producing these trial results is the PACT collaborating team.

13:30:51 And here is a thank you slide which has got more information about on the various interventions I've mentioned training impact training in the basis that that we're hoping we're planning to start in the, in the summer.

13:31:10 And my email is on the slide there if you want to get in touch with me. So, with that, thank you very much for your attention and look forward to q amp a when it comes a bit later in the talk.

**HELEN HARBAN**

13:31:28 Thank you, Jonathan for that ground breaking presentation, and we are warmly welcome Helen Harban. Helen is a speech and language therapist and clinical lead in workshop NHS.

13:31:40 We're excited to hear what she has to say about what she was experiencing in embedding PACT in their practical autism service, and their plans for future growth.

13:31:52 Thank you, Tanya. I think Kelly is going to help me out with the slides but I'll make a start.

13:31:58 So thank you, Kelly, so I'm just going to really summarize how PACT was introduced in developed in warrior cheer so we I'm in South worship NHS Foundation Trust, a very forward looking trust I would say, we started with a very small scale pilot project

13:32:13 with no additional funding I will say, going to talk about the impact of pants within Word cheer and how we embed it into our current any just provision.

13:32:23 Obviously it's a very exciting time. Currently, because NHS England have named PACT as a recognized intervention for autism so as it just feels like a really good appropriate time to have this webinar this afternoon to really encourage people to take

13:32:36 that step, particularly it within the NHS to make back to reality.

13:32:41 Okay. Next slide.

13:32:42 So how PACT started in workshop was, I had half a day a week, which wasn't a lot, and I focused on introducing it into the south of the county.

13:32:54 I became aware of PACT because of the autism literature. So I really felt it takes so many boxes for me about in so many ways. So I went to speak my manager, and she agreed that I could be trained as the as the first therapist, we didn't work in 2018.

13:33:11 So we decided after the, the training which, again, it just really grabbed me and I just thought we have to do this more actually we have to make this happen it's just, we've waited too long for an evidence based intervention for autism.

13:33:25 So we started very small scale with just two children, and then added another two children. So all together we had four nonverbal preschool children as our first PACT intervention targeted group.

13:33:40 And we decided to really focus on that very small number of children because of the time that I had available. We also decided to focus on preschool children.

13:33:51 And if we're honest therapist felt really stuck in terms of progress interventions had been tried, but it really felt that progress just wasn't being made.

13:34:05 So we targeted those that particular group of children, taking referrals from within speech language therapy team, obviously very much focusing on families who could commit, because it is a commitment at the end of the day.

13:34:19 So, the daily practice of half an hour, but also these fortnightly sessions which we offered over a six month period. We decided to offer it pre and post diagnosis so that the actual diagnosis itself didn't become a barrier, or a complete focus.

13:34:36 And we decided that we would obviously go for the face to face intervention because it was 2018 when I did my training and things really got moving in 2019.

13:34:46 So we went ahead with face to face intervention and started PACT. And we obviously agreed that we would review that after the pilot.

13:34:55 So, moving into 2020 and the next slide. How did it all go. I have to say, positive feedback, across the board from all for families who were all very different.

13:35:06 It really felt like high quality intervention, an absolute as Jonathan describe this true partnership working. It's not about involving parents. Parents are absolutely at the center of this intervention and combining their detailed knowledge of their

13:35:25 own children they understand the context, they know what the children have been doing the day before, what they've been experiencing with the skills of the therapist, It really did just.

13:35:37 I was so surprised that actually you know we didn't work. We could also make it work. It wasn't just all of the hard work that had been carried out in the research, it did actually work in practice which was fantastic and a real privilege to be part of.

13:35:54 As things described, there have been remarkable changes, not only in the children's development, but also parental confidence, and that feeling of empowerment.

13:36:04 And I was really struck particularly by one one parent who described initially that playing and interacting with their child felt like a war, and she felt she lost every battle, and that really felt so powerful, but at the end of the 12 sessions, her

13:36:21 comments were that the child loves interacting with me now, and he's a very different child. So I think getting that feedback back was was very very strong for me.

13:36:32 And it really made us feel we need to move this forward.

13:36:37 So, inevitably, there was a high demand for the therapy, which is understandable. During this time we gathered qualitative feedback from the families and asking them to document their views at the end of the sessions, and also obviously speaking to the

13:36:53 wider groups who were involved with PACT speaking to other professionals as well. But we really need the availability because demand, understandably, really, really increased.

13:37:05 Okay, so next slide.

13:37:07 What we tried to then do is increase our availability within this very small project also again with no additional funding.

13:37:18 So what we managed to achieve was we got agreement to train three more of the specialist therapists from within the autism team, we presented on every occasion possible to the widest speech language therapy team, stressing the principles, whilst they

13:37:34 weren't able to all access PACT training and deliver PACT in its entirety. We still felt strongly there were many principles that could be embedded within speech numbers therapy practice to improve the offer that was available within work share some

13:37:50 speech language therapy staff shadowed the pet session so came out on sessions, obviously with parental consent to really experience PACT in people's houses, and to see how then they could take that forward when the children finished the pact intervention

13:38:04 and returned on to their own caseloads.

13:38:08 Parent Child interaction therapy PC. It was also offered within work share that therapists felt that they were again, because of the pipe principles that were described, even a different model itself could be enhanced and improved by knowledge of pact

13:38:24 And again, any opportunity to present to my education colleagues or other education, wider group such as a clinical psychologist, we're also taken at every opportunity.

13:38:37 So, what happened next.

13:38:39 So look at the next slide.

13:38:42 We've got all these people ready to train lockdown. So, great timing we're all ready to go. However, we've tried to have a pragmatic and positive attitude as we find with PACT, we moved immediately to an online PACT offer, which was very interesting.

13:39:00 I felt initially that the face to face contact with the parent was absolutely key to develop that therapeutic relationship. So I was very interested to see how that would translate to move in online.

13:39:13 I was pleasantly surprised. It really did increase the availability the reach because I was no longer restricted to only being able to offer it in the south of the county because of travel consequences.

13:39:26 I was able to offer it across the whole of work share which obviously did really increase the reach and it was more equitable across the area.

13:39:35 I was lucky in that Southwest share NHS Foundation Trust resolved it issues very quickly. We had laptops we had work mobiles, we used WhatsApp for transferring videos so parents took the videos themselves at home, and then transferred to us using WhatsApp,

13:39:54 a platform, they were very comfortable with and very familiar with, so hopefully reduced a bit of stress there. We used Microsoft Teams to as our platform.

13:40:03 And again, people were becoming very quickly very familiar with that.

13:40:07 So interestingly what comments I got back from parents was that the online experience in some ways felt like it gave them more control.

13:40:18 They were in charge of the videos, they decided for themselves, which videos to submit. And they also commented that they could share the video footage with other members of the family.

13:40:30 after we've had the sessions, they reported going back and sharing it with the wider family and talking through the discussion that just happened.

13:40:43 It weren't sure we refocus some therapy time to enable us to deliver PACT from early bird so pair of base training program about autism, and that we will no longer able to do during lockdown because of restrictions.

13:40:57 So we did have some additional time to put into PACT which was much appreciate it.

13:41:02 One thing we did alter, and this was very much a consequence of lockdown rather than the 12 sessions that were initially offered, we reduce that down to six sessions, and then a review.

13:41:14 And that was very much because I'm sure looking back we remember the consequences of locked down and six sessions, took us three months ahead, and that felt like a reasonable amount of time that parents and therapists could look ahead and predict how

13:41:31 things were going to feel what we could commit to.

13:41:34 But committing to six months of therapy and six months of availability from families that felt like quite a high demand so we decided to alter the, the, the dosage down to six sessions, but with very much the option to review.

13:41:50 So for some children, parents felt and therapists also felt that at six sessions, parents were really on their way. And often they had then gone into school so that was a natural break for other families that we worked with six sessions felt like they

13:42:05 were just really getting going and. Absolutely. Definitely we needed to continue for the full six, the full further six, and families felt very much the same.

13:42:15 One of the other options we added in at the six month, six session review was the option to include educational settings. So one of the families felt very strongly that she was clear on what she needed to do family will clear as well grandparents were

13:42:30 all on board. But when they went into nursery communication was not obviously following a pact principal so she felt very strongly that nurse she would benefit.

13:42:41 So what we agreed was that the nursery could attend a PACT awareness session if you like held online, obviously, with myself and the parent attending very much as co host of the training which again gives a really nice balance from between the therapist

13:42:57 and the parent nurseries took this on board, and several actually offered as well to record footage of themselves in the setting with the child, and then join again online for a further PACT session to look at the video, look at the video evidence and

13:43:12 use that to discuss and work on things that they could see were really effective what, what were the things that worked during the session focusing on those principles and looking at all the positives that were happening and how could they do more of

13:43:25 that.

13:43:27 So we've got, again, high quality feedback going on throughout lockdown. And that really did give us encouragement to see where we should go next. So I think the next slide.

13:43:40 Also, Is this is an example of one of the techniques that used, which is very much freeze framing and a slide. So looking at the video footage that was happening but actually if you see something really interesting stopping the video and freezing it and

13:43:54 getting parents to look and see what they noticed and then having a discussion about what was going on, and having a real sort of in forensic look at the interaction and the play that's happening there so that's just an example of one of the things

13:44:08 that is really helpful to do, is an obviously online that that's very straightforward to do. Okay, so next slide.

13:44:17 Yes, one of the schools and get offered this experience of having the PACT session online. So really enabling them to to work with parents and outside agencies giving that consistent approach, and as adults they really felt they become much more aware

13:44:33 of limiting their language and making sure that it's purposeful and meaningful and interestingly as no longer being worried about silence because that can be exactly what's needed at times, and overall saying it was a very positive experience, enabling

13:44:52 them to celebrate as well as unpick some of the interactions. So obviously, any intervention is not going to be all straightforward. So the worst some challenges along the way.

13:44:59 Clearly not all families were able to commit to practicing for 30 minutes a day, and submitting videos in a timely manner.

13:45:07 And sometimes certainly during the first lockdown. It became difficult for some families, and it was just not practical to continue, but they were very much in the minority most families I think really appreciated that high quality intervention, at a

13:45:20 time when maybe there wasn't a lot of support going on. And I think parents really commented on that.

13:45:27 Of course there were it frustrations at times with connectivity, so that again potentially was a difficulty, but again, families overcame it we use other means if we have to do with illness at times, but again, minimized because of the online approach.

13:45:43 So even when people were self isolating as long as they were well, that could still continue with pets intervention.

13:45:50 However, of course one of the other issues was again demand outstripping capacity. So we needed to look at where we went with this. So in terms of. Next slide.

13:45:59 2022, and beyond.

13:46:02 We now have four pet therapist trained within worship, and within the autism team also two additional PACT therapists, trained, we've described as autism PACT champions to act as a point of contact within the area, so if people have got queries around

13:46:21 whether a child's appropriate to refer to want more information about PACT they are very much on him to give that advice in a very hopefully very approachable and accessible.

13:46:30 In total, when we started in 2019, up to early 20 to 30 families have now received PACT. And again, that is without any additional funding so I do feel it has made a difference within literature, but clearly there's a lot more work that needs to be

13:46:44 done.

13:46:46 I hope to originally, that there would be an impact on tribunal cases, as we go forward as many other trusts.

13:46:55 We in worship have a large number of tribunal cases where parents are really seeking funding from the local authority to implement. Other autism interventions that are significantly less robust than PACT so I'm really hoping that as PACT becomes more

13:47:09 widely known.

13:47:11 We can have that as an evidence base effective intervention that will stand up in tribunal if need be.

13:47:19 Clearly, we're promoting PACT wherever we can.

13:47:21 To have our surface have become PACT associate so becoming involved in delivering PACT training which is very exciting whereas in the very early stages of this business case for funding is absolutely on the horizon.

13:47:35 And in that, obviously we will be reverting back to offering 12 sessions, as the core offer in line with the research.

13:47:43 So moving on to summarize some of the, the benefits to professional services.

13:47:49 Obviously it is suitable for pre and post diagnosis which I feel is a significant issue it's not about getting a diagnosis to enable people to get access to PACT is there as a support going along, obviously enhancing our care pathway within

13:48:05 we're actually we're now able to offer this admittedly to a small number of families, but it's there now and it wasn't there before, because it's an evidence intervention, there's a lot of professional confidence going into offering the intervention,

13:48:20 the outcome measures because we parents set their own targets and using a very gentle video feedback using this Guided Discovery techniques progress is made across the board.

13:48:32 And you therapists using PACT has had to pass fidelity training. So it's not a question of just attending the course, and then Off you go.

13:48:41 it you know there is quality control which I think as a therapist, but also as a, as a family, hopefully gives it in a strong reassurance that people have had to hit a certain level of competency which is which is very important.

13:48:55 It really does give adults that empowerment to manage things going forward. And using the cascade techniques so people research then training, other people.

13:49:06 And then those people, training further people, and then moving on to the important adults within the child's everyday environment, whether that's parents carers, or other people within the educational setting as it's been touched on, and get just a professional

13:49:20 quote, that's giving a very structured individual pathway to intervention.

13:49:26 So moving on to benefits for the children.

13:49:30 Obviously being understood, understanding others just so important. And I feel that more than anything is about acceptance, acceptance of difference, looking at what makes the child's interests, and it's not about change.

13:49:44 It's all about developing those connections, and that social engagement so the children really want to engage and seek out by interacting with other people, and very much, focusing on the positive attributes within a very supportive environment because

13:49:58 understandably, it is quite exposing for families when they send videos to to therapists who may be at the start they don't know well at all.

13:50:18 And, and it is quite revealing so I think to have the confidence to do that, the sessions have to be extremely positive and extremely supportive.

13:50:15 We're looking at hopefully increasing the frequency and also the range of communication by parents becoming even more skilled at spotting those opportunities, and just seeing what the child is actually trying to communicate by reviewing and reviewing

13:50:30 the videos, and click clearly then improving relationships as well, and reducing some of those non functional maybe distressed repetitive behaviours as described earlier.

13:50:42 So many benefits there. So now, to conclude onto the most important person, which is the families here, and this is an example of one family's experience of PACT.

13:51:00 We haven't got sound on that Helen sorry.

13:51:03 No, I'm just hoping that my technical support can

13:51:12

**VIDEO PLAY**

*13:51:11 We feel incredibly lucky to be able to take part in these sessions, and I would actually say it's been quite life changing for us as a family. It's completely opened up our communication with our daughter, and she's gone from being completely non verbal*

*13:51:28 having very limited contact and really struggling with attention and frustration really that we can understand her to now we get excellent eye contact, and really meaningful and communication in terms of, she has very specific now in terms of what she's*

*13:51:46 trying to tell us. She can sit down and play with us for more than 30 minutes before we get lucky if we got two minutes. She actually get something out of us playing with her now.*

*13:52:03 And she's locked calmer because she knows me understand what she's trying to say. And this is also fed into school as well I would say to start in September.*

*13:52:24 and sort of said like, explain to us what you think's happening when we introduce them to PACT and got actually got them involved in doing PACT sessions with us and Helen, and their whole technique change, and within two days the feedback was totally different*

*13:52:28 Taylor would be Calmer, there was hardly any frustration and school calmer as well, and massive a massive impact both at home and at school.*

*13:52:39 And she's actually said some words now.*

*13:52:42 And so, I think for me, PACT, really should be rolled out to a lot more people it should be a lot more accessible. And I think it should be the starting point of speech therapy if you've got a nonverbal child be quite honest, and I think it's the techniques*

*13:52:58 and both benefit a lot of children and my frustration at the moment is the outside agencies that are coming to help Taylor, and every single one so far has never heard of PACT.*

*13:53:08 And so when I'm trying to get them to keep the consistency at school, I'm having to explain six months of training in a one hour meeting. And again, I appreciate it if everybody could consider it a bit more.*

*13:53:28 And, and, when they rolled out to a few more people in the UK.*

*13:53:34 And, and thank you very much to Helen for that.*

*13:53:36 And I will be forever grateful.*

**VIDEO END**

13:53:43 Okay, so I think that really just demonstrate the power of PACT, and also emphasize the importance of that therapeutic relationship. But interestingly, I've never been in the same room as Louisa.

13:53:55 So whether it's online, or whether it is face to face, PACT, hugely powerful and show huge benefit to so many families.

13:54:04 So to conclude. Now that we have an effective evidence based approach for autism that's been developed here in the UK. I just feel it's essential to make that a reality for all families who would benefit particularly within the NHS.

13:54:18 So I'm hoping that whether you're a parent carer a professional or a commissioner. I hope you feel maybe a bit more encouraged now to further investigate that.

13:54:30 And consider just what an incredible difference PACT could make to you. Thank you very much for your time.

13:54:33 Thanks Helen that was a really inspiring talk and I thought that parents really summed it up perfectly. And my guest suggest that we are actually quite short of time.

13:54:43 Should we just take a five minute break come straight back and just get on with a little quizzes, presentation, and then hopefully we'll have time for questions at the end.

13:54:51 If you're happy with that come

13:54:55 Yes, we've got five minutes I think that's probably a good idea to take a quick commercial break, I can actually share screen, and just play this video probably is everything to be five minutes so I'll just share that while people that come to break.

13:55:24 all the questions and we are going to get them all answered and sent out. Anyway, after the event if we don't get around to it.

13:56:22 nothing to gain.

13:56:27 Let's try some features are you getting your favourite scene, it all very,

13:56:35 Very good expression.

13:56:36 It was.

13:56:38 He can't touch the sides.

**PACT VIDEO**

13:57:06 The largest treatment trials been undertaken into social communication and treatment for autism internationally today. So, just from the point of view of a treatment trial and size that's a major milestone, the number of children that we've been rolled

13:57:20 into this trial over 150 is at least double anything else that's been done previously, and in the treatment trial world that we work in size is important.

13:57:33 configuring your trauma.

13:57:35 Yeah, so this is a one of a group of communication interventions that have been developed. Internationally, over the last decade, I would say.

13:58:00 Ours is similar but different to some of the other interventions, they all have as their aim to improve the communication skills of young children with autism. What we're particularly doing in our intervention is we're using our knowledge of normal development,

13:58:06 neurotypical children, and way they develop communication and language, and the seeing if we can apply this to the situation voices

13:58:41 partnership between the research organization, professional, and the family needs to take the best quality therapy into practice.

13:59:30 parent: child play video:

*13:59:36*

*13:59:40 Hello Jamie.*

*13:59:54 Hello snowman*

*13:59:52 snowman.*

*13:59:54 Hello.*

*14:00:12 Hello snowball*

14:00:48 My aim is to take therapy into the daily lives of children by working within the family home, the nursery school contacts or caregiver context, say that the intervention can pervade the daily lives of children, do you see as being different about this.

PACT therapist feedback with parent:

14:01:09 *He's, he's open to me, he's initiating.*

*14:01:15 It's his genuine interest in it, rather than the fullest and get on him. What do you see from his body language.*

*14:01:29 He's,*

*14:01:29 he's comfortable with me.*

*14:01:36 Very very comfortable.*

*14:01:38 In hindsight, having watched video. It was a better moment than you initially don't think we need to we need to wrap it up no caffeine continue.*

END OF PACT VIDEO (see full video link on the PACT website home page [www.pacttrainng.co.uk](http://www.pacttrainng.co.uk)

**LOUISA HARRISON**

14:01:53 Hi Welcome, welcome everybody back.

14:01:56 I'm now delighted to introduce Louisa Harrison Louisa is a parent teacher, or the PACT trainer.

14:02:03 And we, Louise is going to share her first hand experience as a parent, and professional addressing what really makes a difference to the lives of autistic people and how we can strive to achieve this.

14:02:18 Hi everyone, and thanks Tanya and thanks to all of you for attending this important event today. So let me start with some introductions. So I'm a mum, I have two teenage children.

14:02:28 I'm a teacher, but for the last five years, I've worked with families and schools as a PACT therapist. And I also deliver training to professionals.

14:02:38 And this is Frank, my 15 year old son, this is on his birthday last year, and PACT Well, this is what I'm going to talk to you about today.

14:02:46 From what our life was like early on, before we knew about it to where we are now.

14:02:51 I'll share my experiences of how PACT has helped Frank communicate, but also how PACT has worked for us in ways that stray very helpfully into other areas that are less to do with communication, and more to do with ensuring good outcomes into adulthood.

14:03:07 I'll highlight this through using video of me and Frank interacting together.

14:03:12 And using a video will also show you how the process works, how illuminating it is, how sensitive and supportive it is, and how empowering it is for those parents, teachers teaching assistants, caregivers, whoever it is that is with the child most, and

14:03:29 therefore knows the child best.

14:03:37 So, what was it like early on before we knew about PACT?

14:03:41 Well, Early on, it felt confusing.

14:03:44 Frank's communication was extremely limited, and very hard to figure out.

14:03:49 Yet I was desperate to understand him to know what he was thinking and how he was feeling.

14:03:54 I wanted him to be able to communicate effectively, and understand the world, so that he could feel happy and safe.

14:04:02 I wanted to get it right, but I wasn't sure how. Frank received a diagnosis of autism when he was three.

14:04:09 And this put me on a different trajectory, with no conventional milestones to look out for. No similar points of reference, with other parents. My instinct initially, and the instinct of many adults I now work with doing PACT, was to keep trying to

14:04:25 engage him.

14:04:27 But this often became an exhausting and frustrating task for both of us.

14:04:31 And as these pictures illustrate. Sometimes he engaged with me.

14:04:36 And sometimes he was just too interested in other things.

14:04:41 So I wanted to know how he might feel more inclined to share with me.

14:04:49 So this short video illustrates how I soon sense the answer.

14:04:54 And this realization has informed my beliefs about what makes a difference to autistic people ever since.

14:05:01 So, This is a family holiday on the beach.

14:05:26 You kick your feet.

14:05:44 So, Frank is with us, but not with us.

14:05:48 We're all enjoying being on this beach, but we're all enjoying it in different ways, we're chatting a bit and faffing about. And this is of no interest to Frank, he's enjoying listening to the sound of the waves.

14:06:02 And most of all, he's loving the wind blowing the windmills round and round and watching the sunlight catch on them.

14:06:07 And I realized that rather than getting Frank to share this with me in a way that I might with another child.

14:06:14 I had to find a way to join that felt right to Frank, not necessarily right to me.

14:06:20 And this is such a fundamental insight, it had to feel right to Frank, more than it felt right to me.

14:06:26 And then I came across PACT.

14:06:31 so PACT addresses everything that I've mentioned so far and it gave me the approach, I was looking for that felt just right. So how is that, how is it different from other interventions?

14:06:42 Well, lots of interventions a child centered, but PACT takes this to a deeper level.

14:06:47 It tunes the adult in to understanding the child’s precise focus. So for example, it's not just ‘oh he’s interested in the marbles’, say, but, rather, he's interested in the different colours of the marbles, or the way they sound when they roll, or the way

14:07:02 they look when they roll, or the way they feel when you put them in your hand.

14:07:07 So, when we come to this next point about adult adjustment. The adult then is sharing the child's interest in a way that exactly matches their focus, and that level of sensitivity and synchrony is what makes the difference.

14:07:22 For children that find it hard to communicate and therefore to trust others, we need to make it easy for them.

14:07:28 We need to adjust ourselves to share in the right way, at the right moment at the right pace, and with the right words.

14:07:42 And the effect of this is that interactions feel more comfortable to the child and in turn more comfortable and easy to the adult.

14:07:45 So it enhances that feeling of being in tune being together. PACT then is not about teaching, but about trust and building balanced secure relationships.

14:07:58 And the method used for being able to do this so effectively is what everybody doing PACT really values. Watching video of the adult child play shines a light on what exactly is happening. Moments that would otherwise be missed are captured, rewatched

14:08:14 and discussed. The therapist guides the adult to reflect :what was happening there? What did he do? how did you respond? How did you know to do that? And these discussions lead to moments of revelation and insight about what led to a positive interaction,

14:08:31 and how that can then be built on. To do this requires a collaborative approach. It's the adult who's the expert, the adult who knows the child best, and the therapist, guides the adults to moments of discovery.

14:08:47 So it's a partnership, and it's about doing with not doing to.

14:08:53 And finally, it's positive.

14:08:55 The focus is on what felt good. When it felt connected.

14:08:58 And those positive moments in play link to PACT strategies, which then become focused goals that the adult has in mind when they play with the child between sessions.

14:09:10 So, as a parent, I quickly became more confident. I felt I had easy to use strategies that worked effectively and never felt forced, and the quality of my interactions with Frank improved.

14:09:23 And the more that happened, the more he initiated.

14:09:26 And the more balanced and safer our interactions felt, the more he was then prepared to go with my ideas. And working as a PACT therapist, guiding this process is hugely rewarding.

14:09:39 You're empowering the adult to appreciate when they're getting it right.

14:09:43 You're building their understanding of how they can adapt to the child, and why that's important.

14:09:50 But also, you're enabling the adult to think about the child holistically.

14:09:55 Because through the adults tuning into the child's ideas and motivations, they’re not only enhancing shared attention, they're also gaining an understanding of what makes the child tick.

14:10:06 This lays the groundwork for a strengths based approach.

14:10:09 So as Frank has developed, I've tuned into his strengths and interests, and I've tried to nurture them.

14:10:16 And this is information that can be shared between family, friends, teaching staff, everyone involved with the child can notice and take opportunities here.

14:10:26 It can be weaved into lessons at school, for example, so we expand from Frank's base of knowledge and experience and interest. This helps him to engage in learning that he might otherwise find too abstract, and it can also be shared with people unfamiliar

14:10:41 to Frank, to help him feel able to trust them.

14:10:48 I'm going to share a video with you now, which I hope will show you a little more about how PACT works. You'll also be able to see what our communication together looks like these days.

14:10:58 To give you a bit of context, Frank, didn't say very much at all for a very very long time. And he's always found all aspects of communication very difficult, and still does to this day.

14:11:10 So this is about two and a half minutes long, and it's from a year or so ago when we were walking to school.

14:11:16 I'll just play it all the way through first without any explanation.

**VIDEO PLAY:**

14:11:33 59 ***F: miles that's a long way on the way to Burton.***

14:11:42 *Oh yeah, we went past, we went past Burton playground, on the way home almost 39 miles and 59 miles is a plus.*

*14:11:55* ***F: The other place also now. Oh yeah 20 more mile,***

*14:12:11* ***F: M6 motorway.***

*14:12:21 Yeah.*

*14:12:28 That's a very long way on the motorway.*

*14:12:34 Sometimes we can only go 50 miles an hour.*

*14:12:38* ***F: Which one? (looking up bird in a tree)***

*14:12:40 Oh yeah.*

*14:12:46 I don't know what that is.*

*14:12:52* ***F: I which one? I don't know.***

*14:12:57 It’s got a high note.*

*14:13:02* ***F: Which one?***

*14:13:10 I don't know which but I only know. I mean it could be pigeons and greenfinches.*

*14:13:11 I didn't know any more bird songs.*

*14:13:15* ***F: Warm***

*14:13:25 Oh, you'll definitely be warm for running home.*

*14:13:33 Oh, we made it.*

*14:13:43 We made it before the tractor,*

*14:13:48* ***F: where it goes?***

**END of VIDEO PLAY**

14:13:56 So, firstly I'm guessing, there were parts of that, maybe all of it, where you weren't at all sure what Frank was talking about.

14:14:03 But the important thing is, is that I'm sure. I know, and that's why PACT therapists work with the adult and not the child.

14:14:10 So there's a cascade effect in PACT: in the same way the adult is responsive to the child, rather than directing them. The therapist is responsive to adult knowledge, rather than directing them or telling them.

14:14:33 So, in PACT we think about what's happening in the video. So how would I describe the interaction in this video? Well, Frank is hopping from topic to topic at his pace, he’s not constructing sentences very well.

14:14:36 It's often taking him a long time to get his words out. Should I worry about that? No, because Frank is generating his own spontaneous language, with no prompting and no demands.

14:14:48 He's relaxed. He's not under any pressure, and he's communicating with confidence on his terms in his way. And this is what PACT can achieve.

14:14:58 And if someone had shown me this video when he was three years old, I would never have believed it could happen.

14:15:04 So, how am I involved, how do I keep it going? Well help to keep it going? Well Frank chooses the topics, and I go with each one. And within each topic, I'm using PACT strategies to keep the conversation going.

14:15:18 So I'll just show you an example.

14:15:22 Just watch this clip here. VIDEO PLAY

14:15:29 M6 motorway to Barrington, VIDEO STOP

14:15:39 So, what am I doing here?

14:15:42 I'm giving Frank time to say what he needs to say, so he doesn't feel rushed. I'm waiting. I'm reducing my expectations. And I'm letting him lead. And these are all strategies within PACT that adults learn, and just before this moment.

14:15:57 Here, you can just see it now. Look, he's glancing to me.

14:16:01 What does that glance signal? He's sharing with me that he's finished.

14:16:05 So by me matching his pace and letting him lead on this topic he's initiated a social cue, a glance. I know he's ready for me to acknowledge him.

14:16:16 So this requires sensitive observation from the adult, and this is how we maintain synchrony by really tuning in to all signals, however fleeting.

14:16:26 and these are further strategies that we learn.

14:16:28 I'll just play on from here.

14:16:31 Oh yeah, we went past went past Burton playground way on the way home.

14:16:38 So, here I acknowledge what he said, by naturally repeating back, but adding a new word I say, oh yes we went past Brereton playground on the way home, and Frank then repeats back ‘past Brereton playground’.

14:16:52 So here, I'm expanding vocabulary, expanding his vocabulary and building on his topic. And this kind of interaction leads him to want to say more. Watch here.

14:17:03 39, miles and 49, miles is a plus a plus at the other some also now. Oh yeah 20 more 20 more miles.

14:17:17 So Frank is now talking about different distances on this journey that come up on the satnav. Again, a therapist wouldn't know this, but I do, so I can then describe and explain what's happening, and the therapist can guide me to understand how to respond

14:17:32 best to help Frank stay engaged, and to help him be more reciprocal. So I said, Oh yes, 20 more 20 more miles. And here I've learned how to model to Frank what he means to say that in a natural conversational style.

14:17:47 So he never feels corrected.

14:17:50 Now I just want to show you something else.

14:17:56 what happens here? VIDEO PLAY

14:17:59 Which one?

14:18:01 Oh yeah, VIDEO STOP

14:18:07 which one. Frank is asking a question, and I should add it took years for Frank to be able to ask a question, but now he's able to confidently seek information that he's interested in.

14:18:20 He's changed the topic, just like that.

14:18:23 But I move on with him. And this helps maintain the interaction.

14:18:28 Let's see what else happens here. Just watch here. VIDEO PLAY I don't know what that is.

14:18:38 I don't know.

14:18:42 it's got a high note.

14:18:46 Which one?

14:18:48 Which one?

14:18:50 I don't know which bird, I only know. I mean it could be pigeons and greenfinches.

14:18:56 I didn't know any more bird songs. VIDEO STOP

14:19:00 So Frank gets a bit anxious and frustrated.

14:19:03 Why, because he can't cope with me not knowing which bird it is. I'm not sure he understands that I don't know everything.

14:19:10 And we have this problem quite often, but the style of communication supports this issue, because through his lived experience. I can teach him naturally, that I don't know.

14:19:21 So I try and put it into language that he'll understand. I only know woodpigeons and greenfinches. And after this walk to school, at other moments. I'll try to generalize by taking opportunities to point up other things I don't know.

14:19:35 So this is an example of how PACT supports social understanding - areas outside of communication.

14:19:41 And one final example of this. I mentioned outcomes at the start.

14:19:46 Frank changes topic because he hears Birdsong, so he's sharing with me that he's interested in birds. So aside from me trying to maintain the conversation for as long as possible

14:19:57 Why is it important to go with this?

14:20:00 Well, we all have interests, don't we, some of our interests become hobbies, and some hobbies lead to developing friendships with like-minded others, and some hobbies, can lead to realizing a talent, which might lead to a job.

14:20:13 When the stakes are so high for autistic people.

14:20:17 When the things they find difficult can hamper their chances for a smooth transition into adulthood shouldn't we be engaging in active noticing, and then taking seriously all opportunities to nurture strengths and interests and find outlets for them.

14:20:32 So Frank now names all the birds we hear when we're out and about. It's amazing how he can tune in and distinguish which bird is which. And that’s also a reminder that when we talk about sensory difficulties, we must also talk about sensory strengths

14:20:47 and across this short video Frank's interests are clear: birds journeys and distances and running.

14:20:54 And these are all things that we try to nurture and things that we can see could become key elements in his life, as he gets older, through hobbies, and even paid work.

14:21:07 So, to conclude, in my view, it's just different. Frank is just different. My life as a mum is just different from what I was expecting all those years ago.

14:21:18 Sometimes it feels harder. Sometimes it feels easier. But ultimately, it's just different.

14:21:24 And I hope I've shown how as a parent and a professional I see how PACT supports this difference. How it puts families on the right track feeling more confident.

14:21:35 Also, how it can support not only communication, but can build social understanding within the child's lived experience and looking ahead, can pave the way for how we think about meaningful outcomes.

14:21:51 Thank you, Louisa I think that was very powerful and illuminating, and I think you've raised the principles for all parenting.

**AMANDA HAYDOCK**

14:22:01 And so finally, I want to introduce Amanda Haydock.

14:22:06 Amanda is a professional and an autistic advocate, representing the priorities and values of the autistic community.

14:22:16 She aims to celebrate individual attributes and promote a more supportive environment to help autistic people realize that you need potential. Thanks.

14:22:28 Thank you. And so this talk is about where we've come from and where we're going in autism intervention and around the neuro diversity movement as a whole, from an artistic person's perspective.

14:22:45 The Who am I, and you might notice that I use the term artistic rather than have autism, with autism or on the autism spectrum. As I along with 96% of autistic people prefer this terminology.

14:23:01 Being autistic is part of my identity. I'm not separate from it and know what I want to be.

14:23:07 Neither is being autistic my whole identity. I acknowledge that I'm also why a female a climber, and a therapist amongst many other things.

14:23:18 I spent about 42% of my life so far, knowing I'm autistic. And that's been a journey of acceptance, much like the one I'm going to talk about today.

14:23:29 I was diagnosed as autistic in 2009. When theory of mind was the domino theory of autism, and we all refer to ourselves as having aspect is.

14:23:40 journey towards both acceptance and celebration of myself and my autistic identity.

14:23:54 I really wouldn't be where I am today were it not for autism, and I hope I've already had a positive impact on others journeys towards acceptance and celebration of themselves or their autistic child.

14:24:08 As I just alluded to, I'm a pact therapist and originally trained in other relationship based approaches, such as the DIR floor time model. I also have a master's in autism from the University of Birmingham.

14:24:23 And I used to run an early intervention service from my home for several years. And if more recently set up spectrum connection CIC, where we provide PACT two families all over the country.

14:24:36 And I've received grant funding to provide back to lower income families in Greater Manchester.

14:24:42 I also have an interest in using AC with autistic children, and we're branching out into this tool as we develop our service.

14:24:51 So, what are the priorities of the autistic community.

14:24:56 To answer this question, autistic are conducted a survey, asking autistic people what their priorities for autism research are. The number one priority for autistic people was in regards to mental health interventions.

14:25:11 And the second highest priority was in regards to developing the communication and language skills of autistic people autistic people have the same innate needs as every other human being, in order to be able to self actualize.

14:25:27 According to the directors of the self determination theory.

14:25:31 These intrinsic motivations drive and sustain us. And these needs have been defined as the need for autonomy, the need for competence and the need for relatedness intrinsic motivation is incredibly important in becoming self motivated people who are confident in their abilities. Although PACTs is primarily a communication intervention. I would also argue the supports the mental health of autistic children as being able to autonomously communicate and meet their needs could be a protective factor against distress

14:26:08 behaviours and mental health issues.

14:26:12 When we think about these things as long term goals for our children. Then we start thinking about the behaviour that's right in front of us and start thinking about the bigger picture where we come from, in terms of autism, autism intervention.

14:26:29 Most interventions for autistic children have focused primarily on shaping behaviour to mold autistic children into being more like neurotypical people.

14:26:40 This need to mask or behave in more neurotypical ways can actively harm autistic people.

14:26:47 It is a factor in mental health difficulties in autistic adults, and it starts right from childhood shaping and changing autistic people's behaviour, does not meet our needs for autonomy.

14:27:02 Most interventions for autistic children have focused on extrinsic motivation in one form or another.

14:27:08 For example, when using pecs we teach your child to hand over a card to receive the reward of the item research over many years in many different contexts has shown that extrinsic motivation cannot sustain and maintain positive change in anyone, including

14:27:26 autistic people.

14:27:28 Nobody learns at their best when someone's trying to change them, rather than meeting them where they are.

14:27:35 Most importantly interventions were so focused on doing to autistic people rather than joining with autistic people to learn about their priorities.

14:27:45 A lot of assumptions were made about what autistic people needed to exist in the world. Priorities which were highly misguided.

14:27:54 The autistic researcher Damien Milton has developed the idea of the double empathy problem that neurotypical people have historically had the opinion or belief that autistic people like empathy.

14:28:07 However, they also like understanding of how autistic people communicate and social a lack of empathy towards the needs and goals of autistic people interventions that are based on the belief that neurotypicality is inherently somehow better than neuro

14:28:22 diversity will perpetuate this double empathy problem.

14:28:28 So where are we now in our autism intervention journey.

14:28:32 We have come a long way in our understanding of autism.

14:28:38 PACT focuses on intrinsic motivation. It's acknowledges that every human being wants to connect with others. Practice a great example of an intervention is done with autistic children, rather than two, and is solely focused on their interests, their motivations

14:28:57 and the ways that they communicate. Rather than harnessing these things in order to change them. We are fully accepting them, celebrating them and joining them.

14:29:05 The research shows that the most important factor in communication development further down the line is that children can initiate this vital skill leads to autonomous communication, and the ability to self advocate.

14:29:22 And as you've heard from the research PACT demonstrated a reduction in repetitive behaviours. However, these are never targeted during intervention, and in fact in some ways are encouraged, such as when repeating games the child's loads and really engages

14:29:36 in its therefore more likely that autistic children, demonstrate a reduction in distress related behaviours.

14:29:52 If we think about what neurotypical people do when they feel stressed or when they have a breakdown in communication, they chew their nails they taught their feet, peace will come down.

14:29:55 These repetitive behaviours are a sign of distress support people to be their best selves and these distress related behaviours reduce.

14:30:06 We should always look at the reasons behind children's behaviour and be responsive to all kinds of communication.

14:30:14 This is why I would argue that pact also makes the highest priority for autistic people and supporting them until how we cannot overstate the mental health and well being benefits to autistic children that come from feeling heard and understood connected

14:30:31 and accepted, and then being able to engage in things with other people that bring them joy or comfort, or to feel understood as to what they're specifically communicating.

14:30:43 When we work with families, we aren't really trying to teach them about autism. But we are really trying to show them how their autistic child is ready and willing to connect.

14:30:54 If we meet them where they are.

14:30:56 If we accept autistic children, exactly as they are, join them in their passions, understand their meaning and everything has meaning. We will show them the true depth of relationship that their child is capable.

14:31:11 We support people to get into their child's world on their level. And when we do this, we see an almost magical connection between people, that enables both parties to see one another's perspective.

14:31:24 It's really hard enough just filtering, all the sensory and emotional stimuli around us, without people actually believing that we also like empathy presuming competence and seeing the world from an artistic person's perspective closes the double empathy gap.

14:31:42 What are we going in autism intervention.

14:31:45 Well, PACT works because through it we're supporting autistic children, autonomy, the ability to act on their own free well unconstrained by neurotypical expectations.

14:32:00 We're building confidence and increasing their ability to self advocate was supporting autistic children's relatedness, the ability to connect with others and have rich and meaningful relationships where they feel fully seen and heard.

14:32:13 And when supporting autistic children's competence, the ability to communicate with confidence, and put themselves out into the world, exactly as they are.

14:32:24 And pre-emptive support is vital. And we need to focus on empowerment and self advocacy in autism intervention.

14:32:32 So, as I just said pre-emptive support is vitally important to support autistic children to feel heard at the earliest possible point in their lives. This is what early intervention should be all about providing sensitive child focus and developmentally

14:32:49 informed support at the earliest possible time to support families to accept that child's neuro diversity.

14:32:57 This pre-emptive support should never be about trying to change your child, but instead should focus on making the world an easier place for our children, when the world is less overwhelming more predictable less demanding and tailored to individual needs.

14:33:14 Then children can grow and develop at the pace that's right for them.

14:33:19 Just imagine the confidence and skills of potentially an entire generation of autistic children should this be the case.

14:33:27 Imagine the mental health benefits to near divergent children and their families should this be the case. Imagine the downstream effects on school policies, the neuro diversity movement and the beliefs and expectations for autistic people should this

14:33:43 be the case.

14:33:46 The autistic community is made up of millions of people, so many of whom have been harmed by practices that sort of change at all costs. And towards a misguided ideal of neurotypicality.

14:34:00 Yes, there are difficulties that come along with being autistic. But so many of them are due to misunderstandings expectations and demands from the earliest possible point in autistic children's lives, we need to pay attention to the environment, relationships,

14:34:16 developmental trajectories intrinsic motivation and targets informed by sensitive discussion with autistic people.

14:34:24 This paper which is co authored by autistic people highlights the need for intervention to meet autistic children's deepest needs, including those for autonomy relatedness and competence.

14:34:36 We need to change the narrative around autism have a whole paradigm shift and cultural change in that thinking about it at all levels and understand that it's just a different way of being human.

14:34:50 And from there we can support autistic children to be the best version of themselves, they can possibly be. We can support them to feel heard to initiate, and to understand themselves so that they can be strong self advocates.

14:35:05 What can you do to take steps towards becoming a better ally to autistic people and support the neurodiversity movement, right across children's life spans.

14:35:16 You can use identity first language. This is preferred by the vast majority of autistic adults, so use the term autistic unless a specific person tells you they prefer otherwise.

14:35:29 Use correct terminology that's preferred by the autistic community, such as non speaking rather than non verbal complex communication needs rather than low functioning distressed behaviours rather than challenging behaviour abiding loves rather than special

14:35:45 interests. We need to take the judgment, out of the way we talk about autistic people, and focus on how we can make life easier for them.

14:35:54 Focus on connection, above all else, above all your goals above independence of absolutely everything connection is the place that everything else grows from when seeking advice.

14:36:10 Listen to autistic adults above everyone else, we are child growing up, and we might have insights that nobody else has. It's especially important to listen to non speaking autistic people, you have a vastly different range of experience than I do. See

14:36:27 people on online, listen to their experiences and their knowledge to support you to better know your autistic child, and then listen to parents and carers before you listen to professionals, they often have to fight to get their voices heard, and yet

14:36:42 they know their child better than anyone else.

14:36:46 We're making goals focus on things that are important to autistic people don't make arbitrary goals that focus on masking or coping, or even independence, unless that's what the person themselves once support that regulation through relationships that

14:37:02 are safe and accepting and think about how you can make the world, an easier place to be in focus on emotional regulation, and self advocacy support children to initiate communication rather than respondent.

14:37:16 This is the way we grow confident assertive communicators presume competence, just because you can't see evidence of knowledge, understanding, or competence, it doesn't mean children aren't capable of these things.

14:37:32 All we can directly see our motor movements and a lot of our non speaking autistic children, but we need to make the least dangerous assumptions about them.

14:37:43 In the same vein, we need to provide access to a range of communication strategies as early as possible.

14:37:49 There are millions of non speaking autistic children that don't have access to robust, communication, such as AC devices. Perhaps because we don't routinely assume competence.

14:38:02 Be willing to be wrong. Listen to autistic people listen to families and change your mind based on what they're telling you believe in people over systems and seek change and openness at all levels.

14:38:17 Accept autistic people for exactly who they are right now. Have fun with them on their terms, learn how they communicate. Let them know regularly and often how much they mean to you, and how much joy they bring into your life.

14:38:32 Don't try and change them, but they're exactly who they're meant to be. And it's our job as adults to change the world for them.

14:38:40 Now that we know better, we need to do better.

14:38:44 The evidence is clear that if we support children at the earliest possible point, they will develop the skills necessary to be autonomous and assertive communicators, that can self advocate, the focus should be on well-being, on listening to children and

14:39:01 their parents/ carers, acceptance celebration and accommodation of neuro diversity in all its forms.

14:39:10 It is a fundamental human rights that all people have freedom of opinion and expression. So to be autonomous communicators.

14:39:18 We need trust at every level from trusting parents, trust in professionals, and most of all, trusting our autistic children.

14:39:26 We need to give space for learning for stepping back and observing, but this time is precious.

14:39:32 Early Childhood should not be filled with cramming and fear and too much therapy, in an attempt to make our children be less autistic.

14:39:42 Early Childhood should be a place of learning of authenticity of wonder of just the right amount of just the right kind of relationship based intervention that enables understanding and growth in acceptance and sharing Joy with our autistic children.

14:40:00 It is possible for our autistic children to be autonomous, connected and competent, we just need to accept celebrate and meet them exactly where they are.

14:40:10 Thank you.

14:40:15 Thank you, Amanda, that was absolutely fabulous. And so I'm conscious that we've come to the end of the presentations, and I think we're going to try and take Question and Answers now.

**QUESTIONS & ANSWERS**

14:40:28 So there are lots of questions one of the first, I think that has come up is. Jonathan what are the implications of the new evidence for UK autism services?

14:40:47 Yeah.

14:40:48 Thanks Tanya, and

14:40:52 just let me thank the wonderful speakers.

14:41:01 Yeah, so what's the implication I've asked, I've tried to answer some of the questions already in the chat so people can look there.

14:41:12 I think what I'd say about the national strategy is that we're in a window of opportunity that the national autism team part of NHS England are really interested in this care pathway that we've been talking about today.

14:41:31 And the approach that we've been talking about around.

14:41:35 What we've called parent mediated intervention that you've heard about family focused.

14:41:40 This is just in their minds and on the agenda. So, it is a window of opportunity.

14:41:46 They have funded a few pilots around the country I alluded to that in my talk of putting this kind of care pathway into practice.

14:41:57 I think the process of health system change is inevitably slow, but we need, what we call in the trade a theory of change we need a plan, basically. And we need to just take a step by step.

14:42:27 in the NHS executive are really got this on board now and it has the attention of politicians. So, I'm positive basically but it'll be slow but sure.

14:42:33 Another question should parent carriers be looking for intervention around the point of identification.

14:42:42 Well, for me, I mean I think, as I said in my, in my talk, and that is one of the new things that we think now we have evidence to in good faith and promote.

14:43:00 In other words, if you're going to put this kind of really early intervention support in before diagnosis.

14:43:08 You've got to be sure, in any area of health care but in autistic development or neuro diversity for sure that it's going to be appropriate.

14:43:19 It's going to have good outcomes, it's not going to have adverse effects.

14:43:24 And it's going to be on balance beneficial for families, whether or not their child goes on to be autistic. And that's an important aspect that I didn't talk about so in all those ways when we've done these what we call pre-emptive pre diagnostic interventions.

14:43:45 We've looked at all that, and we think now we have the evidence to say yeah, it is worth doing that.

14:43:51 And the public health implications of that about how health systems are organized a pretty substantial. That's obvious.

14:44:00 And it's not going to be totally easy to introduce that. But we think that's the appropriate thing and what we're working at now quite hard actually is to work out practical ways of doing this in the community that are going to work.

14:44:17 equitably for people. So it's not a postcode lottery.

14:44:21 And, yeah, we're working on that so short answer yes I think it is appropriate. And we're working on how we can best do that with the evidence we've got.

14:44:36 And I think, Helen what impacted Introducing the new PACT intervention have or existing pressures in your service, and how this intervention become more accessible to families and carers?

that's an interesting one I think that within the NHS the demand is always going to outstrip our capacity in terms of the diagnostic bottleneck that Jonathan described, and that is a focus inevitably currently, hoping that we had a SEN inspection which has an action plan linked to it, which we're hoping will improve things as we go forward in the next few years. I think it's given another tool, and having an evidence based tool is hugely advantageous.

14:45:17 And as I said, I'm really hoping that we shift the focus as PACT becomes more recognized within the UK, even more than it is now obviously with these sorts of events and hoping that parents will be requesting PACT, to go on the HTTPS for PACT to be delivered.

14:45:36 Without a waiting list, as opposed to other interventions with less robust evidence base so that is my hope, but it really feels good to have something in our toolkit that we can now offer, even at the moment it's if it's a small number of families that we’re able to support but hopefully, as we rolled out and get this business case delivered, and we really hope we feel very positive about the future.

14:46:04 Thank you having any question for Louisa.

14:46:11 How did you find giving a particular path to the other adults in Frank's life. Is it something that I would assume would be good for e.g. grandparents to know about, but it also doesn't sound feasible to have the additional adults attending sessions.

14:46:28 Yeah thanks. It's a great question.

14:46:31 Obviously you know practice highly individualized and it is all about that particular adult working with that particular child. So two things I'd say one is.

14:46:41 It's a, it's amazing how much kind of rub off there is a few like so within our house, although I was the person doing the PACT sessions, my husband and my daughter just sort of over time just noticed that I was communicating in a slightly different way

14:46:54 so if I used more comments, rather than asking lots of questions, they realized they witnessed that Frank would respond more, so they would then start to do it.

14:47:05 And so that kind of thing definitely happens. And in kind of for wider family members that obviously aren't so available and also I would possibly include school staff into that category as well, they're all kind of sort of common strategies and principles

14:47:21 that you can't explain, particularly in the context of that particular child. So, I can tell Grandma and Grandpa, and you know the teaching assistants that school that, you know, just wait, just give Frank a bit more time to get his words out you know

14:47:36 some autistic people find being asked questions, but Frank isn't with Frank it's highly sensitive so notice what he's interested in, and then just drop in a comment.

14:47:46 And if he doesn't respond.

14:47:47 Don't worry about it. And if he does, then brilliant you can build on that. So you can actually pass on some kind of child specific strategies that that work because you're right you know for all family members to start doing their own PACT sessions could

14:48:03 get a bit unwieldy

14:48:08 reason that's actually great, and also question for London which I thought was going to be very interesting.

14:48:17 And I've lost it so I'll come back to that in a minute. So another point, and I think probably from Catherine Amanda. What about older autistic people?

14:48:28 How does that work for them?

14:48:48 I’ll answer then maybe, Amanda would like to add to this, we have the research trials, we've only tested the results up to 11 years. And that was because of the criteria and the research programme.

14:48:42 However, I think the principles about good quality communication are universal.

14:48:55 And we're taking that communication to a very high standard which is very adapted to the individual.

14:49:05 And a lot of those principles are equally applicable to older people.

14:49:11 And I think can be particularly valuable for people who are compromised in their communication, were communication is difficult for them. They have difficulty conveying their needs and that feeling that being heard or expressing their needs and wishes, and to be in an environment that's supportive is very powerful.

14:49:31 And as we've said already, there is evidence that person initiation is a key factor, being autonomous and empowered by being able to initiate more, whether it's nonverbal signals or verbal language, it doesn't matter. As long as their meaning is conveyed, and received and responded to. So those are some very key principles that we know are grounded in the research findings, and could be taken forward, even though we haven't tested the age range above 11 years.

14:50:09 Amanda Do you want to add anything?

14:50:12 And I guess it becomes sort of a nice model about how you interact with people in general, it is autism specific, I think that's why there's no evidence of any kind of adverse effects, because it's just how we should really interact with everybody. And, you know, and that attuned kind of way and the way that we really try and understand the other person's perspective and what they're trying to communicate.

14:50:42 And so I don't see why those principles couldn't be used with a child, older than 11, but I guess it's just that the evidence isn't there yet.

14:50:55 Perhaps I could just comment, and to agree with that and to say that.

14:51:02 The thing about these treatments is that a lot goes into them in terms of working out the details of how you do this and how you train therapists, etc.

14:51:11 And the details of how one might apply these principles to adolescents and adults, it really hasn't been worked out like that yet and we know that that is would be a great thing to do.

14:51:26 You know, there are only 24 hours in the day, unfortunately, so.

14:51:32 But that is a task for the future is to operationalize these kinds of principles into effective support for adolescents and adults.

14:51:41 Great job to do for someone.

14:51:45 Great. The other thing is shown here. Somebody asked about being used for 11 plus but also without learning disability.

14:51:54 I seen that can be pretty good.

14:51:58 Yeah, I think that's, that's true. I did answer this in the chat actually but just to briefly say that, you know, whoever made the comment is absolutely right that to pick picked up that in our initial PACT trial.

14:52:20 We purposefully and this is going back to 2004 or something so as long time ago that we purposefully looked at children who had significant autistic development.

14:52:28 I mean, the terminology is difficult here but at that time we were talking about quotes core autism.

14:52:35 And why did we do that because we thought, if we're trying to introduce a therapy of this kind.

14:52:41 Let's make you know let's go for the kind of kids that we actually do see in our clinics, who have most effect and distress and difficulty in lots of ways.

14:52:53 And so we, in a way, made life hard for ourselves by going for that group, to be honest.

14:53:02 But, and we showed effects in that group. Subsequently in Catherine could comment you know we have done a lot of this work with autistic people with children with ordinary cognitive ability.

14:53:17 And, yeah, the same principles apply. And then the I basis. This is the work that I presented for the babies.

14:53:25 There is no cognitive exclusion. So we've shown that we can do this across the cognitive range of the children and we've had no evidence that cognitive ability makes a difference to how they respond actually.

14:53:38 So that's an interesting one. So, yeah, it's perfectly applicable, but that's the reason why in our first trial.

14:53:46 We, we took that group.

14:53:51 Okay.

14:53:53 And there was just a question that came up about.

14:53:57 I'm currently speaking with, I found the therapist details on the pact website is this the best way to go. I'm sure consuming. She has all the qualifications and training to deliver the intervention most is the game that you want to back down please.

14:54:11 Yeah, so, on the website.

14:54:14 We have information, which is under locations. So find a PACT therapist.

14:54:22 And there you can look at all the professionals we've trained, and there should be little markers where they are on a map of the UK, but also internationally.

14:54:32 Now we are asking professionals to register and get their consent, so they fill out a form, and give their consent for their information to be shared on that website so we're still building it.

14:54:42 But we have got a large number of PACT therapists there on that find a PACT therapist so that's the first place to look. But also do feel free to email us if you have any questions or have any personal, you know, difficulties finding a therapist.

14:55:00 I think because it's moving towards face to face and online as well as face to face that we may be are less constrained by location, it is more now accessible to all independently of your geographical location.

14:55:15 So, it will try and help you as best we can.

14:55:19 And we can try and connect people with NHS trusts and all other other practices, you know, depending on your preferences.

14:55:29 Right, so gorgeous that we are trying to stick to time and I know that Cathy is going to wrap this up, and we are actually moving on to 55 so.

14:55:40 So, it's up to you, I think.

14:55:48 So just, just to summarize, and also on the website you'll see information about trading.

14:55:56 So there are two levels of trading, level one is an E learning. It takes about 90 minutes, and it is offered by Hawker for publishers.

14:56:08 And this has some video interactive tasks to demonstrate good communication technique for supporting autistic children. It also shows, and videos of the different stages of path just illustrating has some information about those stages.

14:56:28 And in addition, there's a video of a full PACT session so it shows a therapist style.

14:56:34 This is an introductory training, which is available for anybody who's interested in, in part and wants to know about the path principles and but it's a requirement also to progress a level two, if the professional wants to become an accredited practitioner,

14:56:54 and the level to training the registration is on, or perhaps training website that's the website.

14:57:02 And that's a two day live training, and there's post course supervised practice, and it comes complete with a manual and the platforms.

14:57:16 So the next steps well first of all I wanted to thank everybody. And a big thank you to all the presenters, I just thought they were absolutely wonderful.

14:57:26 And, you know just really enjoyable and very thorough and very thought provoking, I think, to triangulate it together between the science, the practice practical application then it chess.

14:57:44 Parents values, and then young people and adults, autistic adults, you know, bring them into this whole picture of what do we do to bring about the most valued outcomes.

14:57:56 And I think, to work together is, is the skip the strongest basis for improving those outcomes of something that is worthwhile.

14:58:07 And so our next steps are. And please do go to the website this is this is the website on the webinar page there will be a link where all the resources will be available from this webinar.

14:58:21 So they'll be recording full recording, they'll be transcript for anybody who wishes to translate it, they'll be the PowerPoints, and we will post on their answers to the questions we haven't been able to address that you've.

14:58:34 Thank you for all your chat contribution is the very lively very interesting. And it's been a B. We can try to read through it as we go along, but we will have to go back to that and take our time to answer those questions.

14:58:49 And just to say that the global PACTs implementation is already in 21 countries including Italy, France, Australia Denmark China, Hong Kong Brazil and beyond.

14:59:00 So, it is, we're having him to have the impact globally across different countries and cultures.

14:59:09 We have a strong associate membership. These are all our trainers and advisors who deliver training internationally, who support.

14:59:22 We give feedback to them and updates and support the extending the reach, so that we can get to the maximum reach for the benefit of autistic people.

14:59:49 And I think this is just really valuable to have your input and interaction. And so please we've, we've got some social media we've got a Facebook kept international which is open to the public.

14:59:58 We've got Twitter at pet autism and Instagram account.

15:00:04 When you do continue that interaction, could you please use the hashtag, which is the ACP W 2022 autism care pathway webinar so that we can all contribute to the discussion.

15:00:22 And finally, we just like to say we do have ongoing training data level two training.

15:00:28 Please look on the website, we've got a training course in June September, there's international training for example Australia, America. In October, there's also dates for all the other countries that that provide PACT training.

15:00:42 So, it's constantly updated as we get new dates so please do keep looking on the, on the website whether be new information.

15:00:53 And just to say, thank you very much for supporting us thank you for joining this webinar, we know some people who've registered are unable to make it but we will post the recording so they can they can join us by locate the recording.

15:01:12 And, and there And a big thank you to everybody, all the presenters.

15:01:18 So I can, if you wish carry on with the video.

15:01:27 I think you'll probably play from the beginning again actually but just if anybody wants to make make final comment before I close the webinar and play the video.

15:01:43 Okay, I'll go ahead with the, with the video, thank you very much.

15:02:04 nothing to gain this one.

15:02:09 Let's try some pages, are you really terrible, getting your service seen it all day.

15:02:17 Very good expression, because if you can't touch the sides.

15:02:47 Largest treatment trials been undertaken into social communication treatment for autism internationally today. So, just from the point of view and treatment trial, and its size, that's a major milestone, a number of children that we've been rolled into

15:03:02 into this trial over 150 is at least double anything else that's been done previously, and in the treatment trial world that we work in size is important, because you're trying more accurate.

15:03:16 Yeah, so this is a one of a group of communication interventions that have been developed internationally over the last decade, I would say.

15:03:48 Ours is similar but different to some of the other

15:03:43 jobs, similar but different to some of the other interventions, they all have as their aim to improve the communication skills with young children with autism.

15:03:52 What we're particularly doing in our intervention is we're using our knowledge of normal development, neurotypical children, and way they develop communication and language and seeing if we can apply this to the situation borders.

15:04:19 condition is to build a solid partnership between the research organization, professional, and the firm needs to take the best quality therapy and make it accessible to all children.

15:04:32 We want to have a visible effect on the lives of children and their families.

15:04:40 So the aim of our interventions to work with parents to help them get sensitized to the what the particular way that autistic children communicate, so that they can respond to that communication sensitively.

15:05:39 No man.

15:05:43 No man.

15:05:55 Somebody I would play with living for half an hour a day.

15:06:01 Play with living for half an hour a day and trying to achieve the objectives in the program, and.

15:06:10 and little by little. Initially I felt like I was just watching and waiting didn't and observing and being ready. And surely, which was difficult for me because he just wanted to, you know, say things and do things for her but.