

# An Evaluation Report of the Right Click Parent Training Programme

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## INTRODUCTION:

Autism Spectrum Disorder (ASD) is characterised by pervasive social communication and restricted, repetitive and stereotyped behaviour repetitive (APA, 2013). The Center for Disease Control and Prevention (2009) report rising autism diagnosis rates, with as many as 1 out of every 110 children being diagnosed with ASD. The recent reported increase in prevalence of 1 in 88 in the USA differs from the steady rates of 110 in the UK (Taylor, Hershel & Jick, 2013). Identification of autism and early interventions are critical for improving outcomes and quality of life (National Research Council, 2001).

Parents of children with autism are reported to have poorer psychological outcomes than parents of children with other disabilities. Increasingly studies affirm that providing care for a child with autism has a negative effect on caregiver wellbeing (Benson & Karlof, 2009; Hayes & Watson 2012; Stuart & McGrew, 2009). Lai, Goh, Oei and Sung (2015) report more parenting stress and depression symptoms, engagement in more maladaptive avoidance coping in parents of children with autism than parents of typically developing children. Parents displaying maladaptive stress tend to criticize themselves for problems they faced, vent negative emotions and distract themselves from thinking about problems (Piazza et al., 2014; Wang et al., 2011). Stahmer and Pellecchia (2015) call for a need to examine the role of parent-implemented strategies in improving family functioning and stress.

Parent training in typical developing children with disruptive behavior has a long established record as being an effective evidence-based treatment. Within this population there are a limited number of evidence-based parent training programmes. There are limited evidence-based practices in the field of ASD and this too can be applied to parent training programmes. An additional factor relates to the concept of what amounts to parent training in the field of autism. There are numerous and wide ranging parent training interventions thus the parameters are less well established or delineated and therefore harder to draw comparisons as studies often are not comparing the same interventions. Further, parent training in autism is linked to interventions that do not share similar treatment principles to target behaviours. Bears et al (2015) explored the disparity of autism parent training conceptualization and formulated taxonomy of this (see figure 1). They propose that parent

training in autism falls within two main components, *parent implementation*, which is skill-focused where the child is the direct beneficiary and *parent support*, which is knowledge-focused, where the child is the indirect beneficiary.

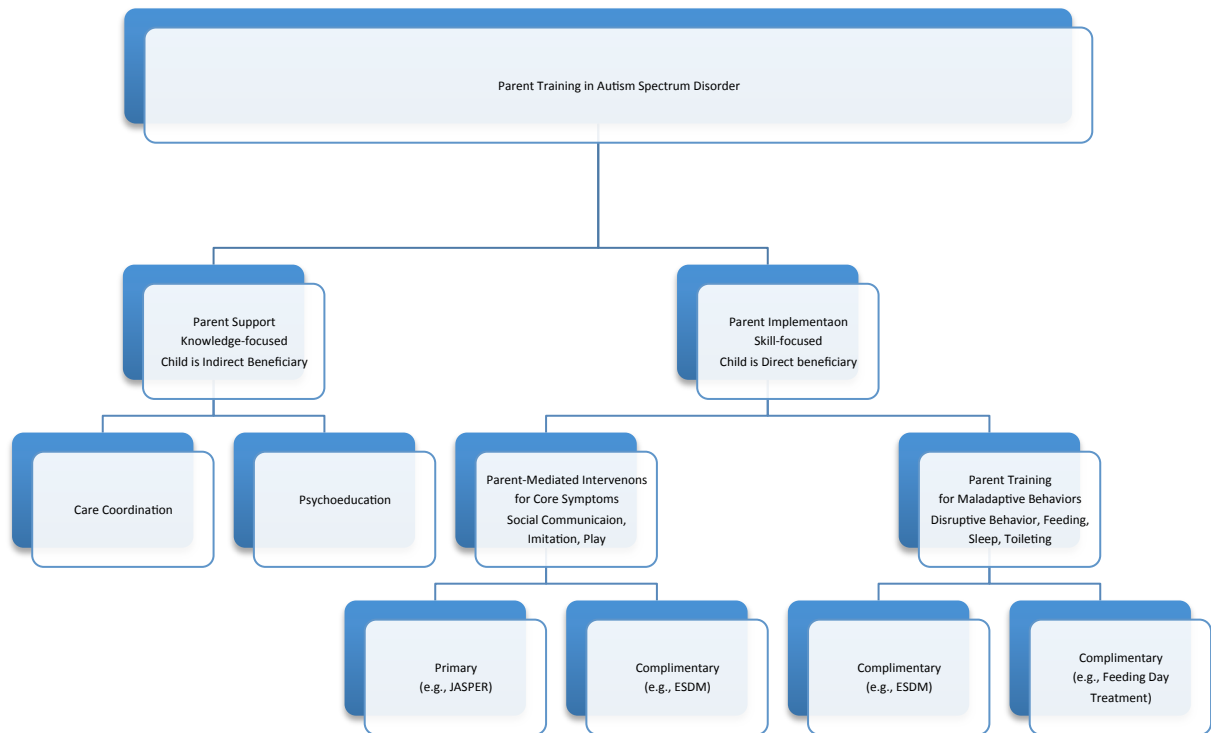


Fig. 1 Taxonomy of parent training in autism spectrum disorder

Figure taken from (Bearss, Burrell, Stewart & Scahill, 2015)

Parent training has been associated with positive changes in young children with ASD (Beaudoin et al., 2014), with substantial but inconsistent gains in communication, socioemotional functioning, symptom severity, and play. This is also associated with high satisfaction and skill improvement from following parental reports. The use of digital delivery methods to deliver evidence-based parent training programmes has been steadily increasing as a viable alternative to more traditional face-to-face training and clinical treatments. Breitenstein, Gross and Christophersen (2014) conducted a systematic review of published articles over a 12 year period (2000 – 2012) of research studies using digital

delivery methods of parent training. The review identified 11 articles that met the criteria and the studies were analysed based on delivery method used, dose (participation rates of intervention completion) and efficacy for improving parent and child outcomes. Telehealth is defined as a delivery model using technology to provide services over a geographical distance (Boisvert & Hall, 2014). This method enables therapeutic services to be delivered at a distance enabling individuals to receive professional support irrespective of where they reside. Wainer and Ingersoll (2014) claim that the use of computer and Internet-based technologies to deliver health information has the potential to address many barriers to parent-mediated interventions. There is currently a paucity of research reporting the efficacy of this methodology in online parent-mediated programmes intervention.

Boisvert and Hall (2014) identified two research studies in which telehealth procedures were used to train or coach parents with young children (under 6 years) diagnosed with autism. The first study trained parents to facilitate target communication skills and was delivered by speech–language pathologists (Baharav & Reiser, 2010). Following this parents reported that services delivered by telehealth at home were as valuable as sessions directly delivered by the clinician. The second study evaluated the Early Start Denver Model (Vismara, et al., 2013) with nine families with ASD. They reported that telehealth delivery showed parents were skilled at using teachable moments to promote children’s spontaneous language and imitation skills. Further, they found that the majority of parents reported that they found weekly videoconferencing sessions and the website video modules were the most helpful. Based on these preliminary findings Boisvert and Hall (2014) suggest that the use of telehealth is a viable means to provide training to parents with young children diagnosed with autism.

To date there is a paucity of studies reporting the impact of telehealth parent training on parent coping and wellbeing. These reported studies are based on parent-training programmes that assess evidence-based treatments via an online telehealth platform. Further, these parent-training programmes require teaching input with the support from a clinician. However, there are no studies that report the perceptions of parents who self-refer to a non-clinician led telehealth parent-training programme.

Scottish Autism operates an advice line that receives over 1000 enquiries a year. Right Click was developed to provide a way of directing parents to more detailed information that could be accessed flexibly. This is a five-week self-referring online programme, for parents of young children, teens or adults. Right Click is delivered through weekly/unit instalments that parents work through remotely at their own convenience. The programme covers a range of topics through video discussions and supplementary resources. The opportunity to access an Autism Advisor during the programme enables parents to seek more sustained support should they need it. Parents can re-refer as often as they wish.

*The Present Study* used parents as key stakeholders and a phenomenological approach to examine parent perceptions of Right Click, an online, telehealth training programme that supports parents in their understanding of ASD. As the Right Click parent programme is designed as self-referring and self-directed learning support; the specific research questions for this study included (1) What are parents' general perceptions of Right Click? (2) How does Right Click support family wellbeing and parent coping? (3) How do these experiences inform receptivity of Right Click as a parent intervention?

## METHOD

A phenomenological approach was used to elicit stakeholder experiences after completion of a self-directed online parent programme. The overarching research aim of this research was to explore parent's experiences of the Right Click programme. To answer the question of how parents find, respond and evaluate the Right Click parent training programme.

### *Participants and Recruitment*

A Study Advert was sent out to all attendees of Right Click. 18 attendees responded to the Study Advert and agreed to a telephone interview.

### *Participants*

18 participants agreed to a telephone interview and each interview followed a loose semi-structured format of the same open questions. Interview transcripts were included for analysis if participants met the inclusion criteria a) were attendees of either the young child,

adolescent or adult Right Click programme, b) their child was diagnosed or going through the process of diagnosis and c) they were able to recall their experiences of being an attendee on the Right Click programme.

Table 1: shows the Participants included in the analysis.

Participant	Gender of child	Age	Age of diagnosis	Time for Diagnosis	Diagnosis	Post diagnostic support
1: Mother	Male	4	2 ½	1yr	Lower functioning autism	Envelope with information
2: Mother	Female	9	8	1yr plus	Asperger Syndrome (Private)	No immediate support
3: Mother	Male	6			ASD	No immediate support
4: Father	Male	4 ½	2		Middle spectrum autistic	Pile of papers (Autism Centre)
5: Mother	Male	16	8	3 yrs	Asperger Syndrome	OT
6: Father	Male	4	2 ½	1 yr	Autism spectrum disorder	Envelope of leaflets
7: Mother	Female	11	8	6 months	Asperger Syndrome	Parents attended 1 yr CAMHS
8: Mother	Male	15	14		High Functioning Aspergers	No support Dismissive
9: Mother	Male	8	7		Autism	
10: Mother	Male	9	5			SaLT (private)
11: Mother	Male	15			Asperger Syndrome	No support
12: Mother	Male	15		process	Autism with LD	
13: Mother	Male	3				OT
14: Mother	Male	6 ½	6 ½	1 yr	High ASD ADHD	
15: Mother	Male	3		Process (1yr)		SaLT

## *Procedure*

All participants attended one of three Right Click parent programmes.

***Online Parent Training:*** The Right Click parent training programmes are open to any parent/carer whose child has a diagnosis of ASD. All participants actively registered to one of three programmes: Young Child, Teen or Adult. Each programme ran over a 5-week period. Parents self-register for one of three programmes:

Right Click: Young Child Programme is focused on providing support to parents of young and recently diagnosed children. This includes topics on autism awareness and daily skills development such as: Eating, Sleeping and Toileting.

Right Click: Teen Programme is focused on providing support to parents of teenagers. This includes autism awareness and and topics discussed include: Developing skills for independent living, Supporting siblings and Talking about relationships.

Right Click: Adult Programme is focused on providing support to parents of adults. This includes those supporting individuals with autism into adulthood and topics discussed include: Promoting happiness and wellbeing, Positive living and relationships and Planning for the future.

## **Data Collection**

### *Questionnaires and Interview*

Parents were invited to take part in a semi-structured interview.

***Semi-structured Interviews:*** Parents' experiences of using the Right Click online programme were assessed through loose semi-structured interviews lasting between 12 and 51 minutes. Participants were interviewed several months after completion of one of the Right Click programmes. The semi-structured interviews consisted of questions pertaining to their:

- experiences of diagnosis, post diagnostic support and finding Right Click
- overall experiences of Right Click
- the most useful and least useful aspects of the Right Click programme
- suggestions for changing the programme

- views on important messages for other parents

**Sampling Strategy:** Purposive sampling was used, as informants who have the best knowledge concerning their experiences of Right Click are those who have been through the programme. A Study Advert containing a link to the Participant Information Sheet was sent out to all previous attendees of Right Click. They could opt to respond either via an anonymous questionnaire or telephone or Skype interview.

**Qualitative Analysis of Interviews:** All interviews were conducted via the telephone and audio-recorded. Recorded interviews were transcribed verbatim. Once each interview was transcribed each was reviewed to establish whether it met the inclusion criteria and only those that met the inclusion criteria were subjected to analysis. Qualitative content analysis is a widely used method of eliciting meaning from text. Qualitative content analysis is a method available for analysing data and interpreting its meaning (Schreier, 2012). From the 18 telephone interviews 15 met the inclusion criteria and were included for analysis. Qualitative content analysis facilitates contextual meaning in text through the development of emergent themes derived from textual data (Bryman, 2001). As a research method, it represents a systematic and objective means of describing and quantifying phenomena (Schreier, 2012). Qualitative content analysis was selected as the method of analysis as it is most often applied to verbal data such as interview transcripts (Schreier, 2012).

**Objective:** The purpose of this research was to evaluate a self-directed, internet-based, distance-learning programme aimed at offering support to parents in their understanding of autism and how to apply autism strategies.

**Research questions:** What are parent's perceptions of using Right Click? What factors influence parents who seek out Right Click as a self-directed online parent training resource?

**Ethical Approval:** This study was approved by the University of Strathclyde, School of Education Ethics Committee.

## RESULTS

### *Respondents of Right Click*

Three respondents completed the questionnaire and 18 respondents agreed to a telephone interview.

Table 1: Number of Respondents for the Questionnaire and Interview

Response mode	Number of Participants		Right Click Programme		
	Total	included	Young Child	Teen	Adult
Questionnaire	3	3	X	X	X
Interview	18	15	X	X	

Of the 18 telephone interviews three were excluded, as the parent was unclear in their ability to differentiate the Right Click from other resources they had participated in. Of the 15 participants there were two fathers and 13 mothers of a child with autism.

### FAMILY LIFE AND FINDING RIGHT CLICK

Parents were asked how they experienced family life and how they discovered the Right Click programme. The main overarching theme to emerge from parent's experiences was that, they were all, to varying degrees experiencing an *erosion of their family life as they once knew it*. This overarching theme subsumed three main themes, the *process of diagnostic recovery*, being on the *brink of collapse* and seeking *the missing pieces* (see Table 2). These main themes and subthemes are expanded with illustrations from participants.

Table 2: Main Themes and Subthemes for Family Life and Finding Right Click

<i>EROSION OF FAMILY LIFE AS WE KNOW IT</i>	
PROCESS OF DIAGNOSTIC RECOVERY	LOSS, TRAUMA AND BEREAVEMENT EMOTIONAL TIPPING POINT
BRINK OF COLLAPSE	OVERWHELMING STRESSORS FAILURE TO STAY AFLOAT



THE MISSING PIECES	WHO'S THERE TO CATCH US SEEKING ASD GROUNDING COPING MECHANISM
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*Process of diagnostic recovery:* The first theme to emerge from their experiences was how they went through *a process of diagnostic recovery*. Initially parents (n=13) reported experiencing some form of *loss, traumatic response and bereavement*. One participant expressed the initial shock of the diagnosis and the impact this had “its been quite a difficult and traumatic journey really.... you are traumatised by the whole thing, you cant really face even contemplating it.” Other participants (n=3) reported a loss of employment, as can be seen here “I just felt that I couldn't be working full-time, so I gave up the job”, similarly the impact of how parents need to invest time in educational support activities shown here “He started school last August and I was working up until June last year. I had to stop because my employer couldn't support the hours I had to do. I needed to get more involved in his school life and with the specialists than I was able to when I was working.” A further aspect related to loss was social withdrawal, illustrated here “there are certain things we choose to avoid, going out for meals and things like that” leading the family to feeling isolated and can be demonstrated in one participant's comments “It's been really quite lonely at times.”

The second subtheme to emerge within the *process of diagnostic recovery* was expressed as feelings of being at the edge of an *emotional tipping point*. This stemmed from either the parents perceived impact on his or her mental wellbeing or their child's emotional dysregulation. First, parental mental health (n= 7) was summed up by one participant's comments “I just felt. There had been quite a lot of changes in our life that with mental health, that as you gradually come to terms with the whole thing” and specifically here from another participant “between my husband and I, it took a lot out on each other, I've been not very well, depression, having to go to the doctors about that, our mental health has been affected.” The pervasive impact can be shown here from another participant “I think you are in a constant state of anxiety, and a constant state of this isn't right, there was an impact on every minute of every day.”

Participants (n=8) referred to experiences of supporting their child through often-extreme crisis resulting in emotional dysregulation. A commonly reported experience were child meltdowns and can be seen here through this expression pertaining to frequency “a

daily basis, frequent meltdowns, on the surface she seemed to cope in school, but clearly she's not because of her anxiety levels but she can hold on to it, in school, but when she comes home, the slightest thing will send her to a meltdown", this frequency was echoed by another participant here "there is never a day that there is not a meltdown" and severity by another participant "we've been through some horrendous meltdowns." Parents also referred to emotional dysregulation through aggressive behaviours within the home. An example is given here from one participant "She's very aggressive verbally and physically, it's a worry, especially when we have a wee one as well, constantly looking for ways of making things simpler for her, easier for her." Parents also reported how tackling issues around aggression then led into deeper emotional wellbeing difficulties such as "Then you think well I'll talk to him and he's getting that way when he doesn't want to talk and he's aggressive as well, swears and quite unpleasant. And I had it out with him one day and that's when he said he'd been having suicidal thoughts."

*Brink of collapse:* The second main theme to emerge from parent's (n=8) experiences of family life was expressed through feeling as if they were often on the *brink of collapse*. The level of stress was referred to by many of the participants and can be seen in this example "It was really, really, kind of stressful at the beginning, and we still have those moments where you think, I can't cope with this. This is really, really, difficult and you get really, really, worked up yourself, we still have those moments" other participants referred to the impact this had on their partners "my wife was having anxiety attacks, she's had a lot of issues, she's had a melt down, she's struggling to cope with him." The fragility of families was also highlighted, such as "I'm the giver in this relationship and the day I stop giving is the day that my family falls apart. That'll just be the way it is."

*The missing pieces:* The third main theme that emerged from family life and finding Right Click related to the processes involved in parents (n=15) seeking support around what could be described as *the missing pieces*. A recurring question voiced by participants was *who's there to catch us* now that our child has been diagnosed with autism. Participants (n=9) expressed a sense of shock when they discovered no one was there to catch them, as shown here by one participant "There was no one really to catch us. We weren't shocked at the diagnoses, but we had no clue of the world we were now involved in. What it meant? What support was available?" Most parents (n=13) expressed that "there was no immediate support" whilst a common practice was to be given an information pack, as described here by

one parent “We got handed a large package, a large envelope with lots of paper in it. We were kind of told of all these things that were available.” Other participants expressed the negative impact this practice had for them at the time given in this example “ Once we got the diagnoses, there wasn’t really any immediate support there. You get an envelope of leaflets through the post, you know, that was it, a reading list, and at that time, you are traumatised by the whole thing” a second illustration of a similar response “They just kind of basically gave me a pack. It was an enormous brown envelope, full of stuff, with like websites and that, and we just got, ‘this is how far we go with you.’ They just offered the diagnosis and away we went. So we didn’t really know where to go from there. We were left with all this amount of stuff; this was too much; we were overwhelmed with information over-load. I felt a bit lost.”

Following the initial diagnosis participants (n=15) reported that they began *seeking ASD grounding* parents expressed a desire to be informed as shown here “I just felt that it was important to go out and find as much information as you can” and they actively engaged in seeking out information from a variety of sources, such as “searches on autism websites” whilst one participant explained "I did a lot of research myself. I was searching on the web site and come across it and thought that would be quite useful.” The third subtheme within *the missing pieces* emerged through many participants desire to alleviate stressful experiences via a *coping mechanism*. A number of participants expressed that when they found life challenging they tried to find solutions, but previous experiences of feeling as if others had failed them in the past, they resisted typical routes as shown here “I just thought the GP has never been supportive; they were no help with the diagnosis, and then when I went for some help regarding Disability Living Allowance, she was very dismissive.” When seeking help for solutions other sources (n=4) recommended Right Click to them for example “It was a Social Worker who runs a group for parents and we got together and signed up for it as a group.”

## EXPERIENCES OF RIGHT CLICK

Parents were asked how they experienced the Right Click programme and the majority of participants (n=14) expressed an overwhelmingly positive experience. From the four loose questions; how was your experience, most helpful and least helpful aspects and any changes you might make, three main themes emerged. Each of these main themes a

*lifeline of support, lost in translation and from remoteness to closeness* contained three subthemes (see Table 3). These main themes and subthemes are expanded with illustrations from participants.

Table 3: Main Themes and Subthemes for Parental Experiences of Right Click

<i>MAIN THEMES</i>	<i>SUBTHEMES</i>
A LIFELINE OF SUPPORT	THE CORE OF IT FEEL GOOD FACTOR PLEASE CAN I HAVE MORE
LOST IN TRANSLATION	THE ENGAGEMENT FACTOR YOU’VE TOLD ME NOW SHOW ME NO LIGHT BULB MOMENT
FROM REMOTENESS TO CLOSENES	NEEDING SOMEONE AS A GUIDE FEELING LIKE A FAILURE FAMILY HETEROGENEITY

*A lifeline of support:* The first theme to emerge from parents’ experiences of the Right Click was that this felt *like a lifeline of support*. Initially the majority of participants (N=14) expressed praise for this as a resource for parents with many putting out a disclaimer stating their reluctance to criticise, shown here “I think that it is a brilliant resource that they do it. So it’s a really, really useful thing, so as long as that can be stressed.” A common initial response from many of the participants was positive and is shown in this example “I thought it was fantastic, I was really impressed. I thought the overall format, the way they had it split up over weeks, so you weren’t overwhelmed with too much stuff, so you could do it in your own time” similarly here by another participant “It is a brilliant system, is the fact that it is done online is fantastic. The fact that it is done in weekly chunks is great because everyone is busy, everyone has busy lives.”

The first subtheme contained within this *lifeline of support* focused upon the *core of it*, that is the core aspects of the Right Click programme. Regarding the intervention content parents (n=14) mostly agreed that “It was really, really informative, the videos were really helpful” (YC Mother) whilst more specific comments varied on which aspects parents found

most informative for them. One parent explained, “The first few chapters were good. At the beginning it was a bit overwhelming, but they are the things I remember most” (YC Mother). Another participant referred to understanding autistic processing with “how my son thinks, his thought processes, was the most helpful for me” (YC Father).

With the second subtheme some participants (n=7) referred to the benefits being “immeasurable” contributing to the overall *feel good factor*. “There were lots of ‘ah-ha’ moments, like with potty training, it helped us to know that we weren’t going mad” (YC Mother). A number of participants (n=6) referred to their overall experience of “it was just so reassuring, we were reassured by what they were saying and by the way they reassured you that if one strategy didn’t work then it was ok, because everyone’s child is different” (T Mother) and another stating how important it was for her “That’s the overall feeling I got, it gave me a bit of confidence back” (T Mother). One participant spoke of how positive it was to hear the presenters with Scottish voices and how that for her gave her more closeness as illustrated here “It felt like having a Scottish expert in your room chatting away to you, it was just bliss” (YC Mother).

For the final subtheme *please can we have more* participants (n=11) referred, mainly with a positive excitement to extending, deepening and adding aspects to Right Click. One participant explained how she would like more information on areas most relevant to her circumstances by stating “I would love them to have a section on there about girls, because it is so different to boys. I’d also love to have some more on the AS” (YC Mother). One participant explained how they would like more depth to certain topics of interest to them as shown here “It would have been good; I know it’s difficult when it’s a generic course, you know, if there was more depth to some of the topics” (T Mother). This was echoed by another parent who suggested, “It would be good if there was a way of clicking on something to let them know you want more of something. That’s the only way I can think of how to improve it” (T Mother).

A final component contained within *please can we have more* was adding sections to, or creating more Right Click programmes. An example of adding a section came from one participant who explained how she wanted “A bit more about pre-diagnosis. The programme is really focused for parents whose child is already diagnosed” and another parent who suggested, “I definitely think autism and more negative behaviour, such as ODD, PDA and aggression. And how families can cope with aggression, verbal or physical”. A recurring

suggestion came from participants who had accessed the young child Right Click, but expressed how their child “is a Tween, she’s in between the teenager and the young child and there seems to be a bit of a gap for children of that age. So anything for her age group up to teenager. That’s the only thing I’d change. It was a fantastic course, it was great, I really enjoyed doing it, but if anything could be changed it would be that” (YC Mother).

*Lost in translation:* Although the majority of participants were mostly complimentary about the content and speakers (n=13) there were also a few less positive (n=2) experiences contained within *the engagement factor*. The majority of parents reported positively with expressions such as “I think that it is a brilliant resource” and another “a really, really useful thing. The presenters are lovely, they’re very calm and very warm.” Contrary to this one participant spoke of how she felt “one of the speakers, one was very, very good, the other one was very robotic, I switched off, it was monotone.” Whilst a number of participants expressed that “It’s not easy to be sat and spoke at, and its not any easier when its online” and how they found it hard to stay engaged at times, as can be seen here “It’s an engagement thing, maybe break up some of the long ones. Have short 20minutes, but they are broken up and they make it sort of bite size” (YC Father). Whilst suggesting how they think improvements to Right Click could be implemented, participants also recognised limitations of such a comprehensive programme “It’s always going to be hard to pitch at the right level so if you make it shorter and a wee bit more dynamic then people aren’t going to switch off” (YC Father). Some suggestions of how to make this even more engaging was expressed by one parent “I know it’s all down to costs, but maybe have a couple of little animations, some other presenters or perhaps slightly different people, just to mix it up a bit” (YC Mother).

The second subtheme *you’ve told me now show me* was mentioned by a number of participants (n=6) who felt that they wanted more role-play or actual demonstrations and is shown here “To actually see the sort of actions and reactions.” Another illustration can be seen by one expression “It would have been really useful to see them playing out what they were talking about. Like a playroom and you could actually see these things played out rather than actually hearing or reading it and interpreting it for yourself” (YC Mother).

The third subtheme related to how for a couple of participants (n=2) there had been *no light bulb moment* as expressed here by one parent “Nothing really stood out, nothing that was a massive light bulb moment” (YC Father). This was later clarified with a further

comment on his level of support offered post diagnosis as shown here “I think we’ve been lucky, as we’ve been signed up for a lot and we’ve managed to get a lot.”

*From remoteness to closeness:* The third main theme from *remoteness to closeness* related to some of the conflicting views of an online platform when compared to a traditional face-to-face delivery formats. For many participants (n=10) having Right Click online worked really well for them, shown here “I searched around for an online course and Right Click was one of the good ones. One of the best things for me was, it was online and you could just do it at your own pace. And that you could pick and choose what bits to watch and focus on” (YC Father) and for another parent “It is a brilliant system, it’s that fact that it is done online is fantastic” (T Mother) and for one parent “It was so good to be able to not have to get all the children ready to take out, because normally I have to go out for appointments to get information. This meant I could find things out at home, in my own time” (YC Mother). These positive experiences of an online platform were also counteracted by other participants (n=6) views of needing a human interactive touch, shown here “It’s great that it’s putting that stuff out there, but as a mum I don’t have the head space, I need someone to help with that” (YC Mother). A few other participants (n=3) felt that having the Right Click as a group face-to-face experience would have suited them better, as demonstrated by this parent “Delivering it face-to-face, that would be amazing” (YC Mother) and here “having a face-to-face delivery would have been perfect” (T Mother).

The first subtheme *needing someone as a guide* a number of participants (n=6) expressed that although they appreciated the content and the opportunity of being able to access Right Click, for them they missed human contact, as shown here by one participant “I really needed to talk to someone. I know they said you’d have someone to support you, but it was all done by email, but they said call, but I got the impression that they would prefer not too. I would like human interaction. I don’t get that; you just want someone to speak to. I really needed that” (YC Mother). Some participants expressed feeling inspired into action “As you watched it you think, *I could try this and that*. But because it was online I became overwhelmed” (YC Mother). This need for a guide to support them through the process to a successful outcome is shown through this expression by one parent “I had no one to say ‘OK, there’s loads of things here, you can’t tackle them all, you know what lets pick one” (T Mother).

For the second subtheme *feeling like a failure* a number of participants (n=5) referred to the impact the time limitation had on successful completion as illustrated by this participant “If I’d have had more time then maybe I could have accessed more of it” (YC Mother). Another participant expressed that the time to complete the programme was too much of a pressure, as shown here “I needed it over a longer time. Having it over 5 weeks when you have a family and are trying to dip into it is hard, so maybe having it over a longer time. Perhaps over a couple of months instead of 5 weeks” (YC Mother). Further, one participant shows that this failure to complete Right Click had a negative impact for her and expressed that this might also have a negative impact on other parents, shown in this illustration “I wasn’t able to do it all, it makes me feel like I’ve failed a little bit. I think if some people try it and they don’t finish it then they might not go back to it” (YC Mother).

For the third subtheme *family heterogeneity* participants (n=4) referred to how not only is the child with autism unique, but so is the family. One participant refers to “The beauty of it is that it is online and open to anyone, as some of the guys in the group can’t drive, so they can’t get to face-to-face things” (YC Father). Further, it was recognised how difficult it is to get it right for everyone due to every family being unique and requiring a spectrum of need as demonstrated here “Autism is non-class specific so you’ve got to try to appeal to the lowest common denominator in society and the highest” (YC Father).

## IMPORTANT MESSAGES FOR PARENTS

In the final part of the interview, participants were asked if they had anything else they would like to add or any important things they wanted to say. A number of the participants (n=13) responded to how they felt other parents might benefit from important messages they had from living and supporting a child with autism.

Table 4: Main Themes and Subthemes for Key Parental Messages

<i>MAIN THEMES</i>	<i>SUBTHEMES</i>
EMANCIPATE, EMPOWER AND LIBERATE	HEAR OUR VOICE TRIGGERS FOR CHANGE “DO IT” AND LET’S BUILD ON IT
A ROAD LESS TRAVELLED	BREAK OUR FALL



*Emancipate, empower and liberate:* The first main theme to emerge was *emancipate, empower and liberate* and this contained three subthemes, related to participation, voice and mechanisms for change. The first subtheme was how parents (n=9) wanted others to *hear our voice* and expressed strong messages for other parents of children with autism to learn from each other, through a shared experience as explained by one participant “We’ve been through this and I know peer-support is vital” (YC Mother). One parent expressed “It would be good to have parent examples. I think that’s where you get your main support, from other parents. Experts are not living this, they might have experience, but they are not living it” (T Mother).

The second subtheme to emerge *triggers for change* stemmed from participants (n=7) experiences of feeling a sense of isolation and relaying how they moved forward from this point. An example of this can be seen through one parents illustration “It got to the point where I felt alone, wondering if there was any one else out there going through this. I started doing the blog, at least to get it out of my system, and then I set up a Facebook page as well” (YC Mother).

The third subtheme “*do it*” and *lets build on it* emerged from a number of participants (n=11) wanting to share their positive experiences of Right Click “It’s so worth while. There's nothing I can say negative about it” (T Mother) by recommending it to other parents as shown here through this illustration “I recommend it all the time and tell as many people I can to do it. I met a parent from my daughters school and I said to her, you have to get on it” (YC Mother). A number of participants expressed that they didn’t really want the experience of Right Click to finish after the 5 weeks, but to be able to access more support, as shown here “It would be great if there was another stage or if you could meet up as a group once you’d been through it or go through it with others” (T Mother). Another suggestion from one parent expressed that Right Click would benefit others, not just parents, as shown in her expression “It would be really good for Teachers too, to get something out of it” (T Mother).

*A road less travelled:* The second main category to emerge was expressed through participants (n=14) voicing experiences of being on *a road less travelled*, which contained three subthemes. The first of these subthemes was the need to have someone to *break our fall*. Participants recalled how they experienced stunned shock when receiving their child's diagnosis and how they needed support at that time. A recurring expression of how parents felt unsupported is demonstrated here from one parent "The fact there is nothing there, no-one there to catch us." One participant expressed the need "There's nothing outside the medical centre. They tell you your child is autistic and that's it, but what we need is for them to say 'go and speak to these people', but there's no one. What we need to know about are the people to catch you" (YC Father).

For the second subtheme *painful lessons along an unknown road* most of the participants (n=13) spoke of the struggles they had experienced, whether that was reflecting on previous experiences or an on going situation. Parents wanted to share these painful lessons, but to also use these to support others who might be going through similar challenges. Many participants recognised that having a child with autism can be stressful as demonstrated in this comment "Having children with autism is very, very difficult. The first time you are going through it is very stressful in your family. Although a lot of families make it through, a lot of them separate. You have to agree strategies with your partner. I think if you can make it through that, it will be ok in the end" (YC Mother). This was a strong message to emerge from participants that it would be a helpful addition to have messages from parents who can offer hope as shown here "To give reassurance for parents, that you'll manage it. It's something we didn't have, it's not knowing what will happen that's really, really, scary" (YC Mother) and similarly from another participant "Tell people, yeah, it's going to get tough, but your going to be ok in the end. That makes things better" (T Mother).

The third subtheme *guide us on our journey* contained strong messages from participants (n=9) relating to their desire to have someone to support them, a key person that could act as a support, a guide. Even when parents recognise that professionals have made efforts to offer them some level of support, they still have a desire to be in safe and knowledgeable hands, as demonstrated by this participant "I appreciate that the professional got all the information together, but it is not specific. What we need is for them to give us a phone number. To say, this is the name of your autism support. The best thing to do is go and speak to these people. Take your child along and they are experts and they know what to look for. And I can go to someone and they say, your next steps are..." (YC Father).

Further, some parents expressed that they could see the potential benefits of Right Click, but not having the self-resources meant that for them it felt as if they had failed to achieve this potential, as demonstrated by this parent “What you’ve got to remember is that parents who have autistic children, they are getting it from all angles, but you’re battered down. It felt like a kick,...you know.. I could do that, but I really needed someone’s support to help me do it” (YC Mother).

#### RIGHT CLICK QUESTIONNAIRES:

Only three questionnaires were collected and completed over the study timescale. This reflects an extremely low return rate from participants. One participant from each Right Click programme (young child, adolescent and adult) completed the questionnaire. Therefore, it was not possible to draw any conclusions from these responses. However, a preliminary analysis of the qualitative responses showed that they did not elicit any additional themes gathered from the qualitative content analysis from participant interviews.

#### **Conclusions, Implications and Recommendations:**

*Overwhelming Positive:* The implications to be drawn from this qualitative evaluation is that there was overwhelming recognition that Right Click is a beneficial resource for parents of children with autism. Parents felt reassured and a desire for more ‘Right Clicks’ so they could access a more tailored experience or one they could access at different stages of their child’s development. Parents were eager to find support and gain as much information on autism as they could. Therefore, having a well-informed resource for parents to provide accurate information is fundamental as an aid to support better family and child outcomes. Adding to the suite of ‘Right Clicks’ would enhance its reach and scope, but requires time and investment.

*Strategic Potential:* Parents on the whole found Right Click themselves, which is an indication of their readiness and need to be informed or a lack of strategic awareness that this is a reliable information hub for parents. Although Right Click is an open and internationally available resource, it has the potential to form part of a Scotland wide, tailored post-diagnostic support for parents. This would require strategic developments to support Right Click’s potential as a post-diagnostic support to be embedded within health provision.

*Promote Parental Coping:* A clear message to emerge from parent experience of receiving a diagnosis for their child was that for the majority they felt isolated with very little support to cope. The literature on parental coping clearly demonstrates that parents of children with autism report highest levels of stress and additional mental wellbeing difficulties (i.e. depression). Even from this small sample the factors that influenced wellbeing can be seen through the trajectories of support provided post diagnosis. This study was unable to fully elicit factors and their correlation to parent coping. Therefore, further research exploring the most effective factors offered by Right Click in this area would be beneficial means of targeting parental wellbeing.

*Blended Delivery:* For some parents the self-directed facility permitted them to work through the programme in their own time whilst skimming content that was of little relevance to their personal circumstance. Therefore, for most, the online accessibility worked effectively. However, for some parents there was a strong desire for human interaction. The facility of Advisory support was recognised, but the need to have one person they could build a relationship with seemed fundamental to their success in being able to make a difference to the outcomes for their child. This appeared to be connected to a number of parental experiences of lack of family support and feelings of isolation. There is an ever increasing amount of information online and parents reported feeling overwhelmed with information, when many had a shared experience of being given ‘a big envelope of information’ pointing them to helpful places and resources. A common message was that parents needed that ‘one person’ to guide them. Therefore, the ideal would be to have a suite of Right Clicks with a person who could assess which programme is the right one for their need, at any given time. This one person could act as a guide to reassure parents, to prevent them being overwhelmed and to systematically work through support guidance given in the programme, ultimately raising better outcomes for the family and for the child with autism. This of course is not the aim of Right Click as it was not designed to provide this blended, intensive supportive telehealth service. However, the implications of this should be considered.

*Limitations:* This study is limited in its generalisation and transferability because of its limited scope, due to limited number of respondents. A replication of this qualitative study with a different cohort of parents would allow for comparative replication, to see if any additional themes emerge. This qualitative study would benefit from triangulation with qualitative data. The author intends to present these findings to either the participants,

depending upon receptivity and or to a representative stakeholder sample in order to evaluate trustworthiness.

### **Recommendations:**

From the interviews participants clearly see Right Click as a useful, valuable resource and recognised that, certainly for Scottish families (predominant sample) that it is the most extensive one stop resource available of its kind for parents. All except one participant interviewed claimed to have learned new and informative information. Of particular importance is the emotional reassurance that Right Click provided, with parents expressing that even if the content wasn't quite in line with what they needed at that time, they still felt that the impact was "immeasurable" and "reassuring". Therefore, it is reasonable for the developers to endorse Right Click as a valuable support to parents of children with autism.

It is recognised that parents of children with autism, autistic children, each family unit and each trajectory of support will be heterogeneous and as such providing an all-encompassing support programme meeting all needs is an ambitious task. However, participants of this study have made valuable suggestions for adjustment and or development based upon the impact each has had from their experience of Right Click. It is recommended that the author provide a list of each of these or a discussion regarding these in order for the developers to consider in future design and development of programmes.

Further research is required to explore the differences between how parents perceive concepts of support, training and intervention-based training. A more robust mixed method design with pre-post measures would provide information pertaining to Right Click having any form of evidence-base. Further research is required to carry out an assessment of the effects of Right Click on parental stress and other well-being outcomes such as self-competence and empowerment. However, Right Click appears to be different or unique from other telehealth programmes in that it is an open parent resource providing useful and accessible information. Other telehealth online parent programmes for parents of children with autism are systematic parent mediated training programmes aimed at delivering training to parents to provide evidence-based interventions. Right Click does not offer this type of intervention and it is recommended that a more systematic analysis of factors and outcomes be investigated.

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