



Autism Specific Transition Resources (T-Res Study) Report 5 Evaluation of our website and resources

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The closures and restrictions on movement that have been implemented in response to the COVID-19 pandemic have wide ranging impacts on us all. For autistic children and young people, adapting to change at such a rapid rate can be very difficult. Our project involved the development of a transition package to guide parents and educators in preparing autistic children and young people for the resumption of regular daily routines following the easing of COVID19 restrictions. These resources were developed based on research focusing on the needs of children with autism, their parents, teachers and other professionals working with them such as occupational and speech and language therapists. Although a majority of students have seen declines in skills and abilities since the onset of the pandemic, a minority had seen improvements in some areas such as life skills, academics and emotional regulation. Therefore, it is important that a broad range of resources are provided to cater for the full spectrum of challenges that may be faced by children and their families since the onset of the Covid-19 pandemic in Ireland.

On development of these resources, we checked to see if they were useful. To do this, we sought the views of the people who were most likely to use them (parents, teachers, therapists). Adults identifying as autistic were also sought to participate. The process involved showing participants a brief video tutorial of selected resources, providing access to all of our published resources and then

interviewing them (via video call). A range of approaches have been employed across disciplines in order to evaluate the efficacy of resources as can be seen throughout the literature in the area. Studies have used quantitative (O'Neill et al., 2020; Owens et al., 2008), qualitative (Taherian & Davies, 2018; Vesterinen et al., 2019) and mixed (Lei et al., 2020; Nicolaidis et al., 2016) methods. Critically however, previous research has highlighted the importance of the 'user voice' in developing learning technologies (Parsons et al., 2011). Furthermore, there is often a conflict between the expectations of an end user for a resource versus what is actually possible to implement. This can lead to rejection of the technology (Moran et al., 2011). Autistic populations in particular, are often excluded from assessment and design of technology that is actually created for them. Inadequate products can result from this lack of inclusion in the development and assessment process (Millen et al., 2010). Furthermore, resources developed for autistic children must be acceptable to parents, carers or professionals in order to ensure continued use. This is especially true in dependent populations. Researchers have incorporated parental involvement in the design (Rabba et al., 2020) and evaluation (Kokkoni and Gallowa, 2021; Rabba et al.) of resources for their children. Rabba et al., advised including stakeholders in each stage of resource assessment. They outlined a four stage approach, (1) cooperative researcher-stakeholder planning, (2) cooperative researcher-stakeholder-based action, (3) stakeholder observation, and (4) cooperative researcher-stakeholder reflection. This detailed assessment meant that the researchers were able to develop prototypes of the online resource in conjunction with the participants. Six key topics arose during the study; understanding autism, accessing services, support, gaining funding, combining it all, and future progress.

In keeping with best practice, T-Res has involved stakeholders from parents to teachers, therapists and autistic adults in the identification of areas of need as well as the assessment of resources. The current report outlines the assessment only. Information on other stages of the T-Res project can be seen in previous reports.

Method

Design

This research entailed a qualitative user study to assess the resource toolkit. Data were gathered through semi-structured interviews in November 2021.

Participants

Participants for this study comprised 15 experts or experts by experience. Some participants were identified as having more than one role (eg. Parent of autistic child and teacher). Experts included seven teachers, one occupational therapist and seven participants who worked in another autism-related role. Experts by experience consisted of one adult who identified as autistic, four parents and two siblings of autistic children. All identified as female. Recruitment was conducted through emails to participants in previous rounds of the study, emails to relevant organisations and social media advertisements. Convenience sampling, word of mouth and snowballing were also employed with participants engaged through the networks of the research team and earlier participants. All participants were aged over eighteen years.

Procedure

Restrictions due Covid-19 had first been implemented in Ireland in March 2020 and had changed on numerous occasions since. Participants were provided with brief pre-recorded tutorials which explained the toolkit and website more broadly and also explained selected resources from the toolkit in more detail. The questions in these interviews were on efficacy, usability, aesthetics and other areas related to user experience of the resources. Each participant was interviewed individually. Interviews were conducted through video call using Zoom software and recorded. These recordings were then transcribed by a third party and thematically analysed based on the methods as outlined by Braun and Clarke (20xx).

Results

Following analysis of the data set, five themes were extracted, with relevant subthemes: 1) Covid Specific Challenges, 2) Strengths, 3) Weaknesses, 4) Suitability. See table 1 below for a summary of each theme and its relevant subthemes. The following subsections will describe each theme and its sub themes in further detail.

Table 1

Thematic Summary

Theme	Subthemes
1) Covid Specific Challenges	a) Difficulty of Covid b) Anxiety and Covid c) Public Health and Covid
2) Strengths	a) Website layout and design b) Resource layout and design c) Centre of information d) Evidence based
3)Weaknesses	a) Website layout and design b) Resource layout and design c) Amendment to Resources
4) Suitability	a) Target group b) Respectful of individuals with autism

1. Covid Specific Challenges

The disruption caused by the Covid-19 pandemic has created major disruption and anxiety for autistic children and their families. As such, there is a demand for supports that can be used by parents, teachers and other professionals that are cognisant of the pandemic and the specific challenges that it has caused. Participants identified how they feel T-Res can fill a unique gap in the wake of the Covid-19 pandemic, whereby the resources have the potential to communicate information about the pandemic and public health advice in a way that is straightforward and user friendly for autistic children and their families:

1.1 Difficulty of Covid

Participants spoke about the disruption that Covid and related social restrictions have brought to autistic children and their families. One participant spoke about how Covid has caused some of the autistic children they work with to regress:

'Our young people have really, really suffered over COVID; they've really, really gone back lots of steps' (P5)

The same participant also went on to discuss an increase in parents of autistic children looking for resources and supports, as the progress of their children is declining rapidly due to the pandemic. She highlighted how the pandemic has created this demand, but that websites like T-Res have the potential to meet the demand:

'Some of our parents have really been reaching out for us to help. I mean this week alone I've got six new referrals already because parents are really finding it hard at home and a lot of the young people's mental health and their own progression rate has declined a lot. So, it's great to see more resources coming up, especially of this kind, because like I said, I don't think there's anything like it.'

1.2 Anxiety & Covid

Some participants noted that the language used around the pandemic and the increased need for hygiene has caused a rise of Covid related anxiety in some autistic children and their families. One participant noted how they try to steer clear of using Covid related visuals in their home as much as possible:

'We don't go too far into lots of visuals around COVID if that makes sense' (P4)

Another participant noted how autistic children can often have a diagnosis of an anxiety disorder. It's important not to provide such children with unnecessary information regarding the pandemic as it may needlessly increase their anxiety. Therefore, some of the resources regarding Covid-19 and hygiene may not be suitable for use with such children:

'There's a cohort of autistic children who have really high anxiety around hygiene, you know, they may have a co-occurring OCD or something like that (Public Health toolkit). So, you might not be using something like that with that kind of group' (P10)

1.3 Public Health & Covid

Participants commented that the public health advice relating to Covid is constantly in a state of flux, which can be a source of stress and worry for both themselves and the autistic children they work with. One participant stated the usefulness of the Covid-19 related visuals on T-Res:

'There's so much noise out there on media and 'Do this, don't do that' and then they'll go 'Okay, do that.' And you're like 'What is going on?' So, to have a visual like this to go 'Right, this is what's required of me' is really, really helpful.' (P7)

While some participants noted that T-Res communicated public health advice directly and clearly, others noted the importance of keeping the information on the website as up to date and in line with public health policy as possible:

'So that young people can be asymptomatic so that I suppose maybe is it that you say something like you're required to have a test to rule out COVID-19 or I'm not exactly sure what language again' (P8)

2. Strengths

Participants identified aspects of the website and resources that stood out to them as being strengths of the project, or aspects that set T-Res apart from other similar existing websites/resources.

2.1 Website layout and design

One participant noted the website is easy to navigate, even for participants who wouldn't have much experience with researching resources or supports online:

'I think it's not too difficult a website to navigate for parents who just wouldn't have a lot of confidence with stuff like that.'

Some participants noted that the layout of the website was straightforward, and the website easy to use to find resources that are relevant. One participant noted the ease at which they could find relevant resources on the website:

'When you go on it it's not overwhelming, it's easy to find what you're looking for' (P5)

Participants spoke about how the website is suitable for use with individuals working with autistic children and, depending on their ability, some autistic teenagers may also find the website accessible, as highlighted by one participant:

'Anybody working with an autistic child or adult or even an autistic teenager I suppose depending on their skill level' (P13)

2.2 Resource layout and design

Participants spoke about the language used in the resources. Most participants noted that the language used in the resources was easy to understand and direct:

'Yeah, I thought it was easy to understand. Again, the use of language was nice and straight to the point, simple.'

Some participants spoke about the tone of the resources, specifically the resources related to Covid-19. One participant spoke about how it is useful that the resources frame information related to Covid-19 in terms of keeping people safe rather than framing the information in a way that will panic autistic people:

'Sometimes with supports for autistic people during COVID, sometimes they can be a little bit negative or it feels pessimistic after you get off it, or a bit doom and gloom. There's nothing really in the resources that felt like that. It was just about keeping people safe.'

Participants spoke about the visuals used in the resources. Most participants agreed that the visuals used were aesthetically pleasing and attractive, and would be suitable for use with autistic children who may have specific sensory needs (rephrase):

'I think the language is good and plain and universal. You know, any of the imagery used is very neutral and doesn't detract from the information or anything.' (P12)

One participant, who has had experience teaching autistic children, spoke about how the resources were much easier to understand than the PDFs

'I feel flash cards and posters and stuff like that it's easy peesy to understand as compared to reading a PDF file'(p11)

2.3 Centre of information

Several participants noted a particular strength of the website is that it provides a centre of information relevant to individuals with autism as well as parents, teachers and therapists who work with individuals with autism. The fact that the website contains resources that are specific to T-Res, as well as links to other relevant sites, organisations, and supports such as the HSE website, Middletown Centre for Autism and AsIAM.

One participant noted that while some of the information and resources available on the T-Res website may be found on other websites, the advantage of the T-Res website over the other sites is that all information is available in one spot together, creating a sort of hub of information and resources for parents and professionals”

‘I think some of them (other websites) are certainly similar to ones I’ve seen, but the value in what you have done is everything is in one place now.’

Another participant said that especially as a result of the Covid-19, it is useful to have a website that combines information about Covid with relevant supports and resources for working with autism:

‘I think in relation to COVID it’s good to have nearly like a one stop space to go to’

Another participant who works as a therapist in the HSE noted that a particular strength of the T-Res website is the fact that it is an Irish website, bringing together relevant resources and supports for Irish autistic children and professionals in the area:

‘What you do have is this unique opportunity where it is an Irish website linked to AsIAM and is sort of tailored to the Irish experience’ (P15)

2.4 Evidence based

Some participants acknowledged the importance of resources being evidence based and of being informed by best practice when working with individuals with autism. A speech and language therapist noted a strength of the resources is the fact that they're evidence based:

'It aligns with the current research that we have around visuals and how important they can be for people to plan or to manage certain situations. So, from that point of view it is certainly evidenced based.' (P12)

A teacher in an ASD class also noted the fact that many of the resources on the website are evidence based and follow the format of techniques that have found to be effective with children with autism:

'They are all best practice. You know, using the visual schedules, the anxiety text.' (P13)

3. Weaknesses

Participants also identified aspects of the website and resources that they did not like, and felt could be improved upon.

3.1 Website Layout and Design

Some participants noted that the website, while straightforward and easy to use, lacked aesthetic appeal, looked outdated in parts, and could benefit from being updated:

'I just felt the layout was just more old school and that it could be maybe designed in tiles or something like that, that sort of format.' (P8)

One participant commented that the home screen in particular was unattractive to look at, which presents a problem as it is the first page that people see when visiting the website. She recommended rearranging the page so that the pictures were more interspersed with the written section, as the large chunk of words were off putting:

'I think the home is a bit off-putting... Just the first bit of it, where it's just all words, and you have to scroll down then to see the pictures.'(P10)

3.2 Resource Layout and Design

While most participants noted that aspects of the resources were attractive and useful, some also noted aspects of the layout and design of the resources that may need to be improved upon. One participant noted the name of the project was confusing and unappealing, and that it does not necessarily communicate who the website and resources are for or about:

'The only thing is the name of it. T-RES. So, I don't know will it... not get as many hits but I don't know, I don't know. That's just a personal kind of thing, that's all. So, I'd see T-RES and go 'Oh, what's that?' And I might skip on by it. But then I can see the writing underneath, Autism Transition Resources. Which is for an autistic person, it's probably... I would probably just need to go to see Autism Transition Resources first rather than the T-RES, does that make sense' (P7)

One participants commented that some of the language in the resources and supplementary material that's describing autistic children and adults may be outdated and need to be updated:

'The language is a bit... so, it does say children with autism an awful lot, rather than autistic – and I think... and you know, use of autism spectrum disorder'

Most participants noted that the resources were visually attractive and laid out well. However, some participants identified issues with the colour and layout of some of the resource, for example a teacher made the following statement about the colours and images used in the resources:

'I think maybe little cliparty things on it to make it more colourful possibly maybe not on a white background, have a kind of a pale yellow or a pale blue because sometimes people find the white background a bit glary.' (P14)

One participant noted the importance of adapting each resource to the wants and needs of each individual child, rather than trying to force the routine of every child into a previously determined schedule, which has had no input from the child themselves. Therefore, the issue of the resources being editable arose:

'first of all, to get the child's input in terms of what the visual schedule might be like for them for the day, to get them to feed into how the structure would look if they were going to create a routine,'
(P10)

3.3 Amendment to Resources

Some participants commented on some gaps they had observed in the resources, and suggested some potential resources that could help make the project more comprehensive. One participant mentioned that it may be worthwhile adding a resource on mindfulness to manage and teach coping mechanisms for stress and anxiety:

'I think if I may add, I think there could be a competent of mindfulness as well added' (P11)

Another participant who works as an autism therapist in the HSE, described scale commonly used to measure emotional feeling in autistic children that may be useful to include in the resources:

'I suppose a big thing that I felt was missing was just that piece around - and again managing emotions. So, something like an emotional feeling scale like the incredible 5-point scale, I don't know if you've seen that before.' (P8)

4. Suitability

Participants identified who they felt would benefit the most from the website and resources, as well as the profile of the children who would benefit the most from interacting with these resources in a school or home environment.

4.1 Target Group

One participant who works as an Advanced Autism Practitioner noted that the resources would be of particular use with most individuals who work with autistic children, including parents, teachers, SNAs and other professionals in the area:

'Really useful and really needed. And as I said, I do think it's going to be amazing for school aged kids and their parents and teachers and SNAs and principals and professionals that work with children'

(P3)

There was a lot of variability in terms of participants' opinion of the age of children that would most benefit from these resources, for example, one participant noted that some resources were more suitable for younger children, whereas some were suitable for older children/teenagers.

'The schedule Monday to Friday I would certainly say is an older child, possibly secondary school...

The first, then, next, is for younger children, we use those a lot in even right up to second class, possibly third depending on the child.' (P14)

The same participant also noted that some elements of the resources would be suitable for all age groups, indicating that the resources can be adapted to suit the age range/ability level of the group that the resource is being used with:

'Certainly, I think for primary school up to sixth class, from infants up to sixth. There's elements of it, you know that you could use right across the whole primary school'

4.2 Respectful of individuals with autism

Some participants highlighted how it is important for a project like T-Res to maintain respect for the autonomy of autistic people and children, as some resources can be too prescriptive (?) in nature,

and disregard the wants and needs of each individual child. It is important to give children as much control and autonomy in a given situation as possible:

'Because often times, I think what happens is, people come in with their own idea of what the schedule should be, and that wouldn't always work out. Because a child has their own ideas, and they need to have their own autonomy really, I think - while trying to keep a balance. I think there was a line – it was actually when I was looking at the other resources around anxiety, I just thought of that too, just to someone build in the idea of balance into your resources, for families. Or for anyone who's looking at them. That what you're looking for is to try and promote balance in the person's life, by giving them as much control and autonomy themselves, over their day.' (P10)

Another participant commented on the recent shift in approaches and resources for autistic people to be more respectful of their autonomy. This participant spoke about how in her opinion, T-Res adopts this standpoint, and for this reason she would be happy to recommend T-Res to parents of autistic children:

I suppose the way autistic people are referred to and talked about in these resources is respectful. There is a big push now for neurodiversity pharma approaches and resources to be respectful in that way. I definitely think that ticks those boxes as well. (P12)

Summary and Conclusions

The T-Res project followed a collaborative approach to resource development. As such assessment of the resources was an important component of the project. The assessment provides useful insight into strengths of the resources as well as areas for improvement. Accessibility of the website and suitability of the resources was a strength noted by participants as well as the use of best practice in the development of resources using formats and methods known to be effective. Gaps in provision

of some anxiety related resources, a need to maintain up to date information regarding public health advice were noted as areas for improvement. Continued care needs to be given to the language used throughout the resources and also the “branding” of the website.

A particular strength of T-Res noted throughout the assessment is the fact that it’s an Irish website servicing Irish autistic people and professionals in the area. It was noted that while some of the resources may not be particularly novel, and may share some features with other similar websites, the strength of T-Res is that it is creating a hub of information across organisations, in an Irish context. Distribution of the resources was also identified as an issue by some participants, as most of them had never encountered T-Res before, and some had difficulty finding the website through a Google search.

While the findings are useful in confirming utility of the resources and identifying further areas for development it should be noted that there are a number of limitations particularly regarding participant recruitment. There was low recruitment of therapists working in autism in this study with only one occupational therapist recruited, and no psychologist. Recruitment of autistic adults for this assessment of resources was also low despite the attempts of the authors. Only one participant identified as autistic. However, they were still awaiting formal diagnosis at the time of the study. It had been hoped that the inclusion of autistic participants in the evaluation would have reduced the likelihood of developing inappropriate resources (Millen et al., 2010). In keeping with previous research in the area (Parsons et al., 2011), user voice has been central to this evaluation as the resources are designed primarily to be used by parents or professionals with autistic children. Furthermore, parental or caregiver input should help to encourage uptake of the resources (Kokkoni and Galloway, 2021; and Rabba et al., 2020)

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