Designing emergency preparedness resources for children with autism

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Abstract

Emergency preparedness is a fast developing field of education driven by the numerous disasters worldwide with more recent notable examples including the terrorist attacks of 9/11 in the U.S in 2001, the 2004 Indian Ocean Tsuanmi, Hurricane Katrina in 2005, the London bombings in 2005, the earthquake in China in 2008, the Great East Japan Earthquake in 2011, Hurricane Sandy in 2012 and more recently the Paris terror attacks in 2015. Whilst there is a growing literature focusing on the psychological implications of such disasters on children, there remains a lack of focus on disability, particularly neurodevelopmental disabilities such as autism. Due to the nature of autism it is likely that this group will have specific needs during disasters and emergency situations and may find such situations more stressful than their typically developing peers, as such they can be considered a more at risk group in such events. In this paper, I consider the need for an intervention for a nearly wholly neglected group in the field of education for emergency preparedness, children with autism, and report on phase one of a project aimed at designing resources for this group.

Introduction

Emergency preparedness can be defined as the capacity of individuals, communities and organizations to anticipate, respond to and recover from emergency or disaster situations (Nelson, Lurie, Wasserman, Zakowski & Leuschner, 2008; International Federation of Red Cross and Red Crescent Societies, 2011). There have been numerous emergencies and disasters worldwide throughout history, more recent notable examples include the terrorist attacks of 9/11 in the U.S in 2001, the 2004 Indian Ocean Tsuanmi, Hurricane Katrina in 2005, the London bombings in 2005, the earthquake in China in 2008, the Great East Japan Earthquake in 2011, Hurricane Sandy in 2012, the Paris terror attacks in 2015 as well as numerous other terrorist attacks worldwide. It is also noted that each year tens of millions of children witness disasters and conflicts worldwide and many are displaced due to these events (Penrose & Takaki, 2006; UNHCR, 2010; UNICEF, 2011, 2012; Masten, 2014). As a result there is a growing literature on the psychological implications for children and adolescents after natural disasters (Roussos et al., 2005; John et al., 2007).

Whilst it is evident that children are vulnerable during such events, children and adults with disabilities are often perceived at particularly high risk during emergency situations and disasters (Peek & Stough, 2010; Aldrich & Benson, 2008; Neumayer & Plümper, 2007; Cutter et al., 2003). Whilst there is limited research which looks at the risks to those with disabilities during disasters, it appears that the vast majority of the research is focused on mobility issues (e.g. Rowland, White, Fox & Rooney, 2007) and is largely US based research (e.g. Taylor, Hughes, Richard, Hoch & Coello, 2004; Murray, 2011). Furthermore, there is little research that looks at the direct experiences of people with disabilities, specifically autism, during disasters and as a result little is known about the experiences of this group from their perspective. Public documents from the UK inquest into the London bombings of 2005 do, however, identify the

experiences of one young man with autism, and how he sought help, and this has helped inform this work.

The public documents report on a young man with autism who was travelling on one of the trains which was bombed during the London bombings in 2005. This man was traveling alone on the train and was on the same carriage as one of the bombers. The public documents into the inquest show this man's statement which identified that he gained help by identifying himself as having autism, "I could hear people screaming and asking for help. I stood up from my seat and also asked for help. My ear was hurting. It was ringing. A lady, who was also on the train, who I now know to be Caroline Bridgeman, I told her I was autistic" (Coroner's inquest, 2010a, p.107). The lady who heard this man's calls stated that "he was saying 'Can someone help me, please? I'm autistic. Do you know what autism is?' and just asking for help" (Coroner's inquest, 2010b, p.10). She identified that he was distressed and herself and others then helped him by reassuring him. They also decided to get him off of the train first as he was becoming increasingly distressed.

It is not known whether this young man's clear and direct method of identifying himself as having autism and needing help is something he had practiced or prepared before the events of that day, however what does seem apparent is that it allowed him to get the support and help he greatly needed in that situation by identifying himself as having autism and by asking if anyone knew what it was. It is also apparent that the altruism of the other passengers helped him, and may too have helped them during the events of the disaster.

From the literature discussed above and the experiences of the young man with autism during the London bombings in 2005, there appears to be a lack of emergency preparedness resources for people with disabilities, specifically autism, and other

developmental disabilities, and therefore this could be considered an imbalance. This paper considers the need for an intervention for a nearly wholly neglected group in the field of education for emergency preparedness: children with autism and aims to begin to address the imbalance by identifying how resources can be developed for children and teenagers with autism. This paper then reports on the first phase of a longer project which aimed to identify how this can be achieved by utilizing successful resources previously developed for use with primary aged children in Essex, United Kingdom, and adapting them to be used for emergency preparedness with children and teenagers who have autism. It details the process of adaptation and design of the resources and includes a brief initial evaluation of the resources. Following this phase (detailed in this paper) phase two of the project will focus on publishing and fully evaluating the resources designed in phase one and phase three of the project will go on to explore the experiences of people with autism during disasters.

The needs of children with disabilities

Peek & Stough (2010) suggest that "disaster risk is socially distributed in ways which reflect pre-existing inequalities" (Peek & Stough, 2010, p.261; Wisner et al., 2004). They suggest that although groups who are considered vulnerable have been identified, and the social vulnerability paradigm has developed a focus of attention on these groups, research has tended to only focus on single factors such as age, gender or race (Peek & Stough, 2010; Phillips & Morrow, 2007) rather than more complex and multifaceted intersections between different vulnerabilities.

Although there is growing literature focusing on the psychological effects of disasters on children, which indicate that children are particularly vulnerable (La Greca et al., 2002; Weissbecker, Sephton, Martin & Simpson, 2008) there is a paucity of

research which has investigated the psychological effects of disasters on individuals with disabilities (Peek & Stough, 2010). The research that is available has indicated that like children, individuals with disabilities are at risk of experiencing negative effects such as distress, depression and anxiety (Rooney & White, 2007) but this research has largely focused on adults and the implications for children with disabilities may well be different and have rarely been considered (Peek & Stough, 2010). Research has suggested that children are more susceptible to a heightened risk of trauma and children with disabilities who are directly exposed being more at risk of longer term psychological implications and negative reactions (Christ & Christ, 2006).

The available literature recognizes that for children with cognitive impairments there are specific dangers presenting them during disasters, especially a sudden onset disaster with little or no prior warning, such as failing to recognize or understand the danger or threats (Kailes & Enders, 2007) and experiencing confusion and anxiety (Scotti et al, 2007). Additionally it has been identified that adults with disabilities as a group are least likely to evacuate (Dash & Gladwin, 2007). Similarly children with disabilities may also be less likely to leave the threatened area putting them at greater risk (Peek & Stough, 2010; Dash & Gladwin, 2007; Martin & Mims, 2009). Furthermore it has been suggested that they may be less likely to have evacuation plans (Spence, Lachlan, Burke & Seeger, 2007) therefore it is essential that children and adults with cognitive disorders are considered more when preparing for emergencies.

Peek & Stough (2010) suggest that children and people with disabilities often are not included in emergency preparedness plans, even at government level, whilst many professionals involved in disaster response may assume that parents warn and inform as well as protect during a disaster. This assumption, however, is dangerous, as children, including those with disabilities, spend varying amounts of time away from

their parents (Mitchell, Haynes, Hall, Choong & Owen, 2008; Phillips & Morrow, 2007) increasingly more so as they enter adulthood. This lack of inclusion in plans, coupled with the assumptions, leaves people with disabilities in a more vulnerable and unprepared state.

Research also indicates that emergency personnel have limited knowledge of disability and as such may not include people with disabilities in their own emergency plans (Fox, White, Rooney & Rowland, 2007; Rowland, White, Fox & Rooney, 2007). Whilst these issues place individuals with disabilities at risk, the research available focuses largely on disabilities that have a more obvious nature, such as mobility issues and health issues. There is less attention paid to those who are just as vulnerable but for different reasons, such as people with autism.

The particular needs of people with Autism
Autism is a lifelong, complex neuro-developmental condition that affects people in differing ways, and is considered to be a spectrum disorder. Historically, autism has been considered to have a triad of impairments which manifest as; social and emotional difficulties; language and communication difficulties; and difficulties with imagination/flexibility of thought (Wing & Gould, 1979; American Psychiatric Association, DSM-IV, 1994). More recently, for purposes of clinical diagnosis, this triad of impairments have been reduced to two main areas; social communication and interaction; and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association (APA), DSM 5, 2013). Despite this recent revision in the DSM 5 the triad of impairments remain as a description of autism for many (for example the National Autistic Society). Autism is comorbid with many other developmental disorders (MacNeil & Mostofsky, 2012; Mannion & Leader, 2013; Chen

et al., 2015) and often with associated learning disabilities (Gillberg & Coleman, 2000; Bernard et al, 2008). Studies suggest that between 5% and 40% of people diagnosed with autism will also have another hidden disorder of Epilepsy (Tuchman, Rapin & Shinnar, 1991; Rossi et al., 1995; Giovanardi-Rossi et al., 2000; Tuchman & Rapin, 2002) meaning that they could additionally be at risk of a seizure at a time of fear and stress if an emergency occurs. Hughes & Melyn (2005) suggest that whilst the prevalence for epileptic seizures in someone with autism is 46% the prevalence of abnormal brain activity is as high as 75% (suggesting that someone with epilepsy may experience abnormal brain activity without experiencing a seizure), further highlighting the additional risks faced by this group.

Children with autism may rely more on their parents or caregiver than other typically developing children (due to their differences and difficulties) and this may be especially so within the school environment. Similarly this would be true for adults with autism, and this would often include providing emotional support and explanations of unfamiliar events and situations as they occur. However, despite this group of individuals potentially having more support they also have more needs. It is highly likely that many people at the higher functioning end of the spectrum may be semi-independent during their teenage years and beyond, meaning that they may travel and spend varying amounts of time on their own or away from their carer/supporters. It is this group that could be considered the most vulnerable.

The literature indicates that for individuals with disabilities, particularly intellectual disabilities, disasters and their aftermath may be more stressful and they can be at a disadvantage in understanding and following instructions (Barile, Fichten, Ferraro & Judd, 2006; Peek & Fothergill, 2008; White, 2006). Furthermore emergency situations can include startling visual and auditory sounds, due to the disaster itself

and/or the alarm systems, as well as the presence of strangers including emergency personnel, all of which can have negative stress reactions on those with intellectual disabilities (Scotti et al., 2007). It is widely accepted that people with autism generally find startling sounds and changes in routine, including people, very difficult and overwhelming, making this group particularly vulnerable during an emergency situation or disaster. Compared to peers, children with autism's post disaster adaptive responses and behaviours are significantly hindered particularly in the areas if communication, daily living, socialization and motor skills (Valenti et al., 2012). Peek & Stough (2010) state that children with autism may become agitated by the systems used to alert people to emergency due to the visual and auditory sounds and they may also become agitated by the disaster sheltering. It is also noted that for individuals with autism, difficulties with processing information may hamper their recovery after a disaster as may the challenges they face regarding change (Peek & Stough, 2010).

Whilst literature exists focusing on post disaster outcomes with suggestions being made that a more coordinated and collaborative effort would support post disaster coping (Eisenman et al., 2009) little research focuses on pre-disaster preparedness in order to mitigate these outcomes for this group. Taylor et al (2004) conducted a study which sought to teach teenagers with autism to respond to a vibrating pager by handing out a card which helped them to seek assistance from members of the community. The focus was on if the teenagers got physically separated from their family, the card had their name on it, a statement identifying them as lost and their parents contact details on. Whilst very important, this was not trialled for supporting them during an emergency situation. Furthermore whilst this study did suggest that teenagers with autism could be taught to seek assistance, this was only when prompted by the pager and the study consisted of only three participants. It is evident therefore that what is needed are

materials that can prepare this group of children for seeking assistance without the need of a prompt. There is a growing awareness of the needs of people with autism during and after disasters with some organisations taking tentative steps to address the issue. One example being the US based science and advocacy organisation Autism Speaks, which set up an autism response team and online support forum for people with autism following Hurricane Sandy[1]. However despite there being a growing awareness there remains a lack of resources available to prepare people with autism before the event.

Due to autism being known as a spectrum disorder (Wing, 1988; 1996) those with autism do not fit neatly in to one group and a 'one size fits all' approach is not suitable. Engaging children with autism in emergency preparedness would require different approaches and different formats than would be needed to engage older teenagers and adults with autism. Likewise differences in approaches would need to be made dependent on the severity of the autism and the ability of the individual to understand the different concepts, therefore any materials and resources would need to be accessible to many and used in an individualised way.

It has been suggested that important and crucial elements of developing resources and interventions for children with disabilities should include; developing an understanding of the way in which different elements shape the environment around children with disabilities (Maste & Obradovic, 2008); developing a full understanding of the adversities they face both during and after a disaster; and identifying what their vulnerabilities to disaster are as well as what makes them resilient (Peek & Stough, 2010). Children have the right to be safe (UNCRC, 1989) and this includes children

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[1] https://www.autismspeaks.org/site-wide/fema

with disabilities, therefore children with disabilities should have equal access to resources, information and interventions which will support and aid their safety. Whilst some resources have been developed they largely are American (Debbaudt, 2006, 2012; Autism Society of Minnesota), and largely not inclusive in that they do not cross over with what is offered to typically developing children. As such, there is a need not only for UK based resources, but also more importantly resources which support inclusion and are developed and adapted from resources already in use by typically developing peers and for which there can be a shared understanding.

Designing resources

Considering the difficulties facing children and adults with autism during emergency situations it is evident that there needs to be some materials that can be used to prepare this demographic in order that some of the negative impacts they may suffer may be mitigated in some way. This project aimed to address this need by utilizing successful resources previously developed for use with primary aged children in Essex, United Kingdom, and adapting them to be used for emergency preparedness with children and teenagers who have autism.

The materials used for adaption were originally developed by Rosanna Briggs for Essex Civil Protection and Emergency Management (ECPEM), part of Essex County Council, in 2011 as part of their 'Developing Community Resilience through Schools' project. Through their project opportunities were identified for delivering teaching based materials which educated about emergency planning. The 'What If?'[2]

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[2] 'What If' resources created by Rosanna Briggs MBE, Deputy Head of Service (Civil Protection & Emergency Management in Partnership with Essex County Fire and Rescue Service & Essex County Council).

series of materials were developed for use in schools for educating primary school aged children in emergency preparedness in a fun and interactive manner[3]. The program received positive feedback from head-teachers and local authorities stating that the community was better informed, independent and empowered as a result.

Consultation with Autism experts

In order to adapt the 'What If?' materials for use with people with autism a group of experts in autism were consulted. The group consisted of a specialist consultant Educational Psychologist working in the National Autistic Society (NAS); a Person Centred therapist and trainer who specializes in working with people with autism and Asperger's syndrome and who is also a parent of an adult with autism; the manager of a London based charity which works with people with different disabilities and their families and has extensive experience working with people with autism. Each expert was consulted individually and the 'What If?' Book; the 'What If?' Calendar[4]; and the 'What If?' door-hanging pamphlet were presented to them to discuss their potential use for amendment for use with people with autism.

Feedback from Autism experts

The experts provided useful feedback on the resources presented to them and their appropriateness for use with children with autism. After considering the 'What If?'

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[3] http://news.bbc.co.uk/local/essex/hi/people_and_places/newsid_8416000/8416132.stm

http://www.crucial-crew.org/what-if/

[4] The 'What If?' books and calendar (as well as other resources) can be viewed online at: http://www.whatif-guidance.org/parents/

book, the experts concluded that the language within the book was too advanced for people with autism and needed to be simplified to be factual, simple and short. Furthermore it was suggested that less writing on each page was required so as to not be too overwhelming. The pictures were considered too 'busy', confusing and often too scary for someone with autism and it was noted that these need to be simplified and related directly to the written points.

The experts all discounted the 'What If?' calendar entirely for use with people with autism due to the tendency people with autism have to becoming fixated with things and taking things too literally. It was thought the calendar could cause children with autism to become highly agitated and anxious as they might expect there to be massive floods in January, severe snowstorms in February, power cuts in March, and industrial accidents in April, as depicted in the calendar.

The experts considered the 'What If?' door-hanging pamphlet to be useful, however careful consideration was advised as to the use of simplified factual language as well as the purpose that it would serve for people with autism.

After consultation with the experts and on reflection of the literature available and available resources for working with people who have autism, the 'What If?' resources were adapted for use with children with autism.

Adapting the 'What If?' resources for use with children with autism.
Social Stories™ are a popular technique in special education as a tool, originally devised by Gray (1998), to teach social skills, concepts and situations to children with autism. Whilst many other interventions do exist for use with people with autism aimed at addressing the many issues they have with social communication (as identified by Kanner, 1943) Gray (1998) suggests that Social Stories™ are particularly useful as a

simple intervention for use by teachers and other practitioners (Scattone, Tingstrom & Wilczynski, 2006). The resources being designed here are aimed at being used within school settings with children with autism and as such aspects of the Social Story™ technique have been incorporated it in the adaption of these resources.

The National Autistic Society (NAS), utilizing Gray's (2004) suggestions, state that when constructing a Social Story™ consideration should be given to the goal or purpose and then what the child needs to know in order to achieve this goal. They also recommend gathering information about the child, their interests, attention span and level of ability and understanding as each Social Story™ needs to be tailored to the individual with autism, as with autism, like many other developmental disorders, one size does not fit all. Typically Gray (2003) asserts that Social Stories are short, individualised stories which should be written from the view point of the child using first person language. For this project however the resources being designed are for use within schools, by many different children and are to be inclusive with already accessible resources. Therefore in this instance we have decided to not utilize this suggestion of Grays but do consider that the adapted resources can (and should) be personalized if the child wishes to do so.

Social Stories™ have been extensively used for many different purposes including problem areas (Kuoch & Mirenda, 2003; Rowe, 1999; Scattone, Wilczynski, Edwards, & Rabian, 2002), teaching appropriate behaviours (Swaggart, Gagnon, Bock, Earles, Quinn & Myles et al., 1995) and teaching daily routines such as sleeping in one's own bed (Bronwell, 2002) and hand washing (Hagiwara & Myles, 1999). The overarching aim of Social Stories™ is to provide clear and concise information about a specific situation and how to behave in that situation and as such their use could extend to familiarizing a child with unexpected situations and appropriate/safe responses.

Social Stories™ are constructed with careful consideration, often with one picture to one piece of short concise text and one aspect or step per page. Gray (1998) suggests that Social Stories™ should contain specific sentence types and structures to present the information which are detailed in figure 1 below.

Sentence type	purpose
Descriptive sentences	used to provide the 'where', 'who', 'what' and 'why' aspects of the story
perspective sentences	used to refer to other people's feelings, beliefs, opinions and ideas
directive sentences	used to offer a response or suggestion of behavior
affirmative statements	used to enhance the meaning or emphasize the importance of certain sentences
cooperative sentences	used to identify how other people can help the person in the situation
control statements	allow the person with autism to add meaning that is personal to them, should be used as this can assist in their ability to apply the information
partial sentences	may be used if appropriate, these are incomplete sentences allowing the person with autism to guess the next step in a situation, this however should be judged on the level of ability and understanding the person has.

Figure 1: Gray's (1998) suggested sentence types

Tarnai & Wolfe (2008) state that whilst Gray (2003) asserts a particular ratio of sentence types within a social story there is no empirical evidence to support this, furthermore there is indeed evidence to suggest that social stories not conforming to this suggested structure have higher efficacy (Reynhout & Carter, 2006). Therefore when

adapting the resources as part of this project, we have used many of the sentence types suggested by Gray but not conformed to the suggested ratio. Gray (1998) also stated that behavioural responses should be framed in positive ways for example stating what the person will do, not what they won't. Again, here, we have utilized some aspects of this technique and developed our own for this context. For this reason we have included both positive and (what could be viewed as) negative statements as literature also shows that people with autism need clear, concrete 'rules' and in the context of an emergency the 'don't' rules are essential, clear and direct.

What If? Book

The 'What If?' books already available were used to aid production of a 'What If?' version, using the Social Stories™ techniques, for children with autism regarding emergency preparedness. Consideration was given to the feedback from the autism experts consulted as well as Gray's (1998) suggested sentence structures when putting together the text. Starting with descriptive sentences the book clearly and concisely tells the reader the 'what' of the situation, ie: a fire, smoke, alarms. It then moves on to use directive and affirmative sentences as well as cooperative sentences all aimed at preparing the child for what to expect as well as how to behavior in such a situation (a brief example is below in figure 2).

Book: 'What If?' I have autism.........and there is a flood?	
Page 1	**There is a flood.** [SIMPLE IMAGE] **A flood might look like this.**
Page 2	**If I am scared I will say "please help me, I have autism and I am scared".** [SIMPLE IMAGE]

This is very important.

Figure 2: Example of adapted text for 'What If?' books for people with autism.

Whilst the books produced can be used by any child with autism, if there is a desire for the book to be individualized to the child, the suggestion is that it is preloaded on to a USB so that the child with autism, working with a parent or support teacher, can add control sentences and partial sentences to make their 'What If' book individual to them, enhancing its effects and meaning for them, and then can be printed. This way of delivering the book would also allow for the book to be adapted to different contexts that are unique to the child.

Door-hanging pamphlet

When considering the door-hanging pamphlet from the 'What If?' series the experts consulted had said that it was useful but needed simplifying for people with autism. Upon consideration the adaption of this resource could be two fold. Firstly it could serve as an information point for others who are trying to help the person with autism. For this purpose it would need some useful factual and concise information as to what autism is as well as how people with autism may react in emergency situations. In addition it could also serve as a checklist to the person with autism. Therefore this resource was adapted to have both of these elements incorporated. On the front page the 'What If?' branding would remain with the added "I have autism". Inside there would be two sides of useful information as to what autism is and how someone with autism may react in an emergency. The back page of the pamphlet is for the person with autism. It contains a few reminders of what they can do in any emergency situation as well as room for details of their emergency contacts, doctor and medical information.

ICE card

In addition to the two resources which were adapted from the currently available 'What If?' resources, an 'In Case of Emergency' (ICE) card was also developed to become part of the materials for autism using the 'What If?' branding. The development of this ICE card was particularly inspired and informed by the experiences of the young man with autism mentioned in the introduction, who was on one of the trains which was bombed during the London bombings in 2005.

In the UK there is very little in the way of resources which can be used in emergency situations by people with autism, however the NAS do produce an 'In Case of Emergency' (ICE) card which they state can be handed out by a parent or carer when in difficult situations. The card has the following text; *"This person has autism. Autism is a lifelong disability that affects social and communication skills. People with autism may behave in unpredictable ways as a result of their difficulty in understanding language and social situations. People with autism are likely to be extremely anxious in unfamiliar situations. Please help by being understanding, patient and tolerant"* *(National Autistic Society).*

Additionally icecard.co.uk produce ICE cards for general use as well as specific cards for various special educational needs, disabilities and medical conditions. Whilst on the front the graphics are clear and on the child autism version it states "please be understanding" there is no more information as to how to support the child with autism in an emergency. On the back of each card there are sections for personal details, 2 emergency contacts and doctor's details including medical information.

When considering the available ICE cards specifically designed for people with autism in the UK it is noted that both of these ICE cards, and others, have some features

which are useful, particularly the bullet points available on the NAS produced card and the clear colourful graphics on the icecard.co.uk card, therefore these were considered when producing the 'What If?' ICE card. However, what is noticeable is that whilst the information may seem useful, the experiences of the young man with autism during the London bombings suggest that a more direct and specific card identifying the person as having autism, providing a brief overview of autism and identifying how a person with autism may behave is more essential, especially in an emergency situation. His simple yet effective words of "Can someone help me, please? I'm autistic. Do you know what autism is?" (Coroner's inquest, 2010b, p.10) proved to be essentially in getting the help and support he needed and also it could be said helped those around him to support and help him.

The branding of the 'What If?' Series is useful for many reasons, especially as it links all of the 'What If?' resources together in an easily identifiable way, one which importantly is used by all children. It is for this reason that the same branding is used on the front of the ICE cards coupled with a declaration that the person has autism. On the reverse of the card (shown in figure 2) there are bullet points which state how the person with autism might react and how others can help them;
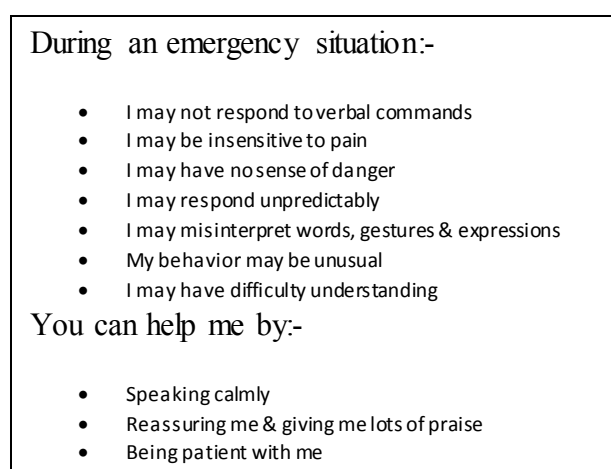
During an emergency situation:-
- I may not respond to verbal commands   - I may be insensitive to pain   - I may have no sense of danger   - I may respond unpredictably   - I may misinterpret words, gestures & expressions   - My behavior may be unusual   - I may have difficulty understanding
You can help me by:-
- Speaking calmly   - Reassuring me & giving me lots of praise   - Being patient with me

Figure 3: Reverse of ICE card designed for use by children with autism.

Whilst adapting the 'What If?' resources for people with autism it became apparent that the materials actually needed to be adapted to achieve two tasks, firstly to be resources for those with autism, but also to introduce autism to other children, thereby introducing them to what they can do for a person with autism if they come across them in an emergency situation. Therefore one recommendation from this work is that a further 'What If?' book is produced with the already established characters, Molly and Ben, and that during the emergency situation they find themselves in they come across a child with autism. In this way some of the characteristics of a child with autism can be gently introduced to other children as well as how to respond to a child with autism. This will help by educating typically developing children on how to help someone with autism in an emergency situation. As in all of the 'What If?' books there should be a summary page at the end of the book as well as possible questions and answers to ensure that the children have grasped the concepts of autism.

Follow-up feedback from experts

Following adaption of the resources, the expert group were again consulted and their feedback gathered. All experts felt that the developed resources were much better suited to children with autism and could be used with teenagers and some adults with autism with little adaption required. They all agreed that the adapted resources retained the connection with the originals in that they would be inclusive as planned. Comments were made with reference to minor elements of the language and these were adjusted accordingly. For example, attention was drawn to a line of text in the book that indicated an alarm *would* be heard. This was therefore adjusted to be factually correct,

that an alarm *may* be heard. A small number or these resources were then printed for distribution at a launch event in November 2015.

Evaluation of resources

On the 23rd November 2015 the 'What If…? I have autism' book and ICE card detailed in this paper were launched at an event hosted by Essex Fire and Rescue HQ in collaboration with ECPEM which brought academics and practitioners together. The launch event was attended by 49 delegates from different sectors who have an interest in autism and/or the general public. The sectors represented at the event included emergency services, counselling services, Transport for London, telecoms services, utility services, autism charities and schools. Presentations were given about the project and the design and production of the resources and delegates were invited to explore the resources and provide feedback through filling in an evaluation form and/or by providing a video interview. The evaluation form consisted of a rating scale for each of the resources (the rating scale was from 1-5 with 1 being poor and 5 being excellent) and 3 questions designed to gather written responses. The questions were; 'What do you think the impact of the resources will be for your organization?'; 'What do you think the impact of the resources will be for people with autism?' and 'What do you think the impact of the resources will be for the wider community?'. There was also space for further comments.

Of the 49 delegates who attended the launch event, 18 completed the evaluation form. 89% of responses rated the 'What If…? I have autism' book as 4-5 star out of 5 while 83% rated the 'What If…? I have autism' ICE card as 4-5 star out of 5. All responses can be seen in figure 4 below.

	Poor 1	2	3	4	Excellent 5
'What If? I have autism' book			11%	39%	50%
'What If? I have autism' ICE Card		6%	11%	33%	50%

Figure 4: Evaluation rating scale

Delegates were asked what they thought the impact of the resources would be for their organisation and the responses were all positive identifying the usefulness of the resources for;

"filling the gap" and "targeting an often forgotten condition".

The usefulness of the resources for children was recognised by many who responded, with some commenting that similar resources for adults with autism would be good. Many delegates commented on their plans to cascade these resources;

"brilliant resources which I can hand on to clients and practitioners",

"I intend to contact to request in house presentation to take place".

Delegates were also asked to comment on the impact the resources could have for people with autism and again the feedback was positive;

"really useful to pass on the important messages" and "helpful to begin a conversation".

Additionally the wider benefits the resources could have for someone with autism were also recognised;

"my clients (and adult son) with ASD will have a resource to help them think through what they can do in an emergency, and will provide their supporters/carers, teachers with useful clear drawings rather than abstract information".

Many delegates stated they would be passing on the information and the resources to other colleagues and some were going to pass the resources on to their library. Some delegates requested further in house presentations of the resources and talks tailored to their specific target audience.

Conclusion

Much of the research available in the area of emergency preparedness and autism is largely US based, there is a significant lack in UK based research as well as research specifically aimed at individuals with autism and other developmental disorders. Due to the many issues faced by individuals with autism it is imperative that there is a better understanding of the difficulties they may face in emergency situations. It is also essential that others gain knowledge to enable them to support people with autism to be as prepared as their typically developing peers. Emergency preparedness for people with autism needs to focus on two differing areas, firstly it is essential that there are materials for this group that are individualized to them and secondly it is essential that emergency personal, communities and other children are better educated about people with autism and how they will be affected during an emergency situation and how they may react.

It is evident that due to the nature of autism being a spectrum disorder it is unlikely that one resource will achieve the desired result for all children with autism, therefore it appears necessary that the resources are personalisable so as to be as individual as possible thereby increasing their potential.

In this first phase of this project some resources have been developed for use with children with autism using pre-existing successful resources for typically developing children and utilising the concepts of the Social Stories™ technique (Gray, 1998). The evaluation of the resources so far has been positive. Many indicated the potential for

these resources to have a positive far reaching impact, not just for children with autism, but for their parents, carers and teachers. It was also noted that there is the potential for these resources to benefit many organisations whose role it is to ensure the safety of the general public, that work with members of the public, or whose concern is ensuring the physical and/or emotional safety of all.

The second phase of this project will publish and test these resources with children with autism in primary schools in the UK to ascertain their effectiveness and usefulness in UK schools. Additionally these resources will also be tested with older children, teenagers and adults with autism in order that their effectiveness and usefulness for differing age groups can be identified and they can be adapted further upon feedback received. Finally a further evaluation of the resources will be conducted with further experts in the field of autism, as well as teachers and Special Educational Needs Coordinator's (SENCO's) from the schools that participate in the trail and evaluation of the materials in order that a comprehensive review of the resources can be achieved.

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