

JAYMIE HUCKRIDGE BSc Hons

EXPERIENCES OF RESPONDING TO SUICIDALITY

Section A: Opening the door and keeping it open:  
How do people respond to suicidality and what  
aspects of care do they prioritise?

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Section B: Identifying suicidality in autistic people  
and discussing it with them: A qualitative study

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## **Summary of the Major Research Project**

**Section A:** A systematic literature review, which synthesises and critically evaluates qualitative research into how “supporters” (professionals and non-professionals) describe their responses to adults experiencing suicidality when risk is identified, and what aspects of care they prioritise. The quality of the eleven identified papers is assessed and findings are considered within the context of limitations and generalisability. The findings are considered as they relate to psychological theory, their implications for practice and policy, and suggestions for future research are made.

**Section B:** Uses grounded theory methodology to explore how suicidality is identified in autistic adults, and how it is discussed with them, as understood by people who have completed these tasks (including carers, voluntary sector, health care professionals). The generated theory found discussions take place when an overwhelmed autistic is provided with a safe environment to express distress. Supporters draw upon various knowledge to negotiate stages from identification of suicidality (usually through direct disclosure from the autistic person), to planning, exploring meaning and providing immediate responses to reduce distress. Risk assessment runs parallel to these processes. The theory is discussed in relation to diathesis stress theories of suicidality and existing literature, and clinical and research implications are described.

**Section C:** Appendices

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## **Section A: Literature Review**

JAYMIE HUCKRIDGE BSc Hons

### **EXPERIENCES OF RESPONDING TO SUICIDALITY**

Opening the door and keeping it open:  
How do people respond to suicidality and what  
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## Abstract

**Background:** Suicide prevention is a global public health priority, and guidance has been developed to support professionals and non-professionals in responding to suicide risk. However, guidance is inconsistent, with little evidence as to how it is being implemented.

**Aim:** To synthesise and critically evaluate qualitative research into how “supporters” (professionals and non-professionals) describe their responses to adults experiencing suicidality when risk is identified, and what aspects of care they prioritise.

**Method:** Electronic databases were searched, with 11 research papers identified. Research quality was assessed using Kmet, Lee, & Cook’s (2004) quality criteria.

**Findings:** Professionals made direct and indirect initial enquiry, but often “shut the door” on further discussion. Non-professionals reported responses including not taking suicidality seriously and seeking support. Establishing trusting relationships, fulfilling formal processes, and clarifying diagnosis were priorities. A ‘system of responding’ was suggested, where people in an individual’s network fulfil different roles. The papers are presented in the context of their limitations and generalisability.

**Implications:** Clinical implications included allowing professionals adequate time to build a relationship with their clients, ensuring formal processes are meaningful, and conceptualising suicidality beyond diagnosis. Further research on non-professionals is needed, and improving access to support, knowledge, and skills for this group.

Key words: *review, suicide, suicidality, qualitative.*

## **1. Introduction**

### **1.1.Suicide**

In 2018 there were 5,821 suicides registered in the UK (Office for National Statistics, 2019), with “suicide and injury or poisoning of undetermined intent” being the leading cause of death for males and females aged 5-34, and for males up to the age of 49 (Office for National Statistics, 2019). The World Health Organisation (WHO, 2016) estimates that for each of these deaths, more than 20 additional suicide attempts are made, and three quarters of people who complete suicide are not in contact with services (Hewlett & Horner, 2015). Such alarming statistics mean that suicide prevention has become a major public health priority (Erllich, 2016).

### **1.2. Preventing suicidality<sup>1</sup>**

A number of high-profile responses with the aim of preventing suicide have been launched nationally and internationally, including World Suicide Prevention Day (International Association for Suicide Prevention (IASP), 2019a), the UK’s ‘Zero Suicide Alliance’ (ZSA, 2019), and the British Psychological Society (BPS) position statement on suicide, which states that “no civilised and caring society should tolerate this level of despair, hopelessness and avoidable tragedy” (BPS, 2017). In the UK, suicide prevention is central to the government’s mental health strategy, with a ministerial role established (Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention) with the explicit task of developing suicide prevention policy and initiatives (UK Government, 2019). Most recently, the National Health Service (NHS) Long Term Plan (NHS, 2019a) highlights suicide prevention as a priority for the NHS.

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<sup>1</sup> Suicidality includes suicidal ideation, plans, attempts, and completed suicide. The term is fully explored in section 1.4.

These prevention initiatives face many challenges, not least that suicide is a complex phenomenon, with diverse risk and protective factors identified in research, including personality and individual differences, cognitive and social factors, and negative life events (BPS, 2017). This means that suicide prevention efforts require collaboration from multiple domains of society, including organisations such as health and social care providers, education, private businesses, and wider systems and institutions such as politics and the media (World Health Organisation, 2014). Despite high-profile commitment and investment in suicide prevention initiatives, including public education and media campaigns, there is little evidence of their effectiveness, with only education of physicians and restricting access to lethal means found to actually reduce suicide (Mann et al., 2005). A review by Bolton, Gunnell, and Turecki's (2015) found that a range of tools have been suggested for supporting practitioners to assess and manage suicide risk, including psychometric tests for assessing risk, implicit association tests, neurocognitive tests, antidepressants and other psychotropic drugs, psychotherapy (specifically cognitive behavioural therapy (CBT), dialectical behavioural therapy (DBT), and problem solving therapy), electroconvulsive therapy (ECT), and online resources. They conclude that the most effective routes to reducing the risk of suicide remain unclear, despite considerable investment in researching this area.

### **1.3. Asking and talking about suicide**

Central to many suicide prevention initiatives is the promotion of improving knowledge and developing the skills of individuals who may be able to identify risk of suicidality in others, and act to support the person and reduce their suicidality. This has included:

- *Campaigns and resources aimed at the public*, for example publications from Rethink (2016), Mind (2017), the Campaign Against Living Miserably (CALM, 2019), and

Samaritans (2019). Such campaigns and resources usually promote a framework of initiating a conversation about suicide, actively listening, and supporting the person to find appropriate professional support. Open access training courses such as Mental Health First Aid (MHFA; Mental Health First Aid England, 2019) and Applied Suicide Intervention Skills Training (ASIST; Livingworks, 2019) also share similar frameworks and can be accessed by professionals or members of the public.

- *The development and dissemination of guidance about assessing and managing suicidality for mental health practitioners and organisations.* Many organisations have published such multi-disciplinary guidelines, including IASP (2019b) and the National Institute for Health and Care Excellence (NICE, 2019). A review of such publications by Bernert, Hom, and Roberts (2014) found that the majority (>70%) consistently recommended assessment of similar known established risk factors, interventions (e.g. restricting access to means), and make suggestion for postvention practice (an intervention conducted after a suicide, generally support for those bereaved). However, they also found inconsistency in some aspects of the content of these documents, with relatively few making recommendations for measures and other tools for assessing and managing risk, protocols for safety planning, or addressing broader professional practice issues (e.g. confidentiality, training).

Common across all these publications and resources is the suggestion that members of the public, professionals, and organisations having direct and supportive conversations about suicide reduces the risk of an individual completing it. This suggestion is informed and supported by research, with a review by Dazzi et al (2014) finding positive outcomes of directly acknowledging and talking about suicide including the potential to reduce suicidal ideation (SI) and improving mental health in treatment-seeking populations. However, Berman and Silverman (2017) suggest that despite this apparent consensus that asking about suicide is

appropriate and helpful, little is known about how this question should be asked, and what exactly we are trying to explore when we do ask.

#### **1.4. Psychological theories of suicidality**

To further consider what might be helpful to explore in these conversations, it is useful to consider the psychological theories of suicide that have been developed to offer insight into how suicidality may be predicted and managed, thus providing possible areas for discussion and action. Barzilay and Apter (2014) provide an overview of the history of these theories, summarising the following models:

- *Classical psychodynamic theories*, which conceptualise suicidality as a response to early negative attachment, the result of negative feelings toward the body, or a product of internalised aggression.
- *Psychological pain theories*, which posit suicidality as an attempt to escape unbearable emotional pain.
- *Cognitive theories*, which emphasise the cognitive aspect of suicidality, including the role of maladaptive schemas.
- *Diathesis-Stress theories*, where suicidality is explained as the interaction between predisposing vulnerability factors and a triggering stress factor.

Historically, these theories of suicide did not adequately explain why an individual may experience SI but not attempt suicide, or how SI may progress to a suicide attempt. This led to the development of new ‘ideation to action’ theories of suicidality to better account for this (Klonsky, Saffer, and Bryan, 2018). Such ‘ideation to action’ theories include:

- **Interpersonal Theory of Suicide (IPTS; Joiner, 2005)**, which suggests SI is the result of an individual failing to have their need to belong met (thwarted belongingness) and

feeling they are a burden to others (perceived burdensomeness). Suicide attempts are the result of acquiring the capability to act on suicidal ideation, by overcoming the fear and pain involved in self-inflicted harm and death, usually through experiencing painful events.

- **Integrated motivational–volitional model (IMV; O’Connor, 2011)**, which posits a *Motivational Phase*, where feelings of defeat and entrapment caused by difficult life events are central to SI, with other moderators such as belongingness, burdensomeness and low positive future also integrated. The model also proposes a *Volitional Phase* where moderators including increased capability, impulsivity, imitation, and access to lethal means account for SI progressing to suicide attempt.
- **Three-step theory (3ST; Klonsky and May; 2015)**, which proposes three steps:
  - A combination of pain and hopelessness cause SI.
  - SI escalates from modest to strong when pain overwhelms connectedness to loved ones, valued roles, or an individual’s sense of meaning or purpose.
  - Ideation progresses to attempt when the person has the capacity to attempt suicide. Klonsky and May (2015) include additional factors such as a genetic high threshold for pain or low fear of death; as well as contributors such those described above for IPTS; and practical contributors such as knowledge of, expertise in, and access to lethal means.

Klonsky, Saffer, and Bryan (2018) suggest that the empirically supported aspects of these ‘ideation to action’ theories (broadly, that pain, hopelessness, and related variables result in SI, progressing to a suicide attempt when the person has capability for suicide) should be incorporated into assessment and intervention, but they suggest no specific actions as to how practitioners operationalise this. Joiner, Van Orden, Witte, Selby, et al (2009) encourage clinicians to integrate theory into practice by exploring their client’s feelings of belongingness,

burdensomeness, and acquired capability (especially previous suicide attempts), either through face-to-face discussion or administering standardised questionnaires that assess these constructs (E.g. Rosenberg's five item scale to assess perceptions of mattering to assess burdensomeness). These theories also advocate for practitioners to focus on preventing individuals from reaching the point where they have "higher-risk" thoughts (i.e. perceived burdensomeness and thwarted belongingness; Kleiman, Law, and Anestis, 2014).

Despite having a range of tools, theories, and guidance available, practitioners have described assessment of suicide as being "semi-intuitive" (Waern, Kaiser, and Renberg, 2016) and the pressure of responding to suicidality can mean that even experienced practitioners find their therapeutic frame and collaboration with the client derailed, as crisis management becomes the priority (Fowler, 2012). Responders may also struggle to make sense of inconsistent or unclear advice around risk assessment measures, tools for suicide management, protocols for safety planning, addressing confidentiality, and legal issues (Bernert et al., 2014). This could mean that despite having received information on good practice, practitioners may be required to "fill in the gaps", respond intuitively as situations arise, or that different practice may take place across different settings and professions. Despite the assessment and management of people experiencing suicidality being described as one of the most stressful tasks for mental health practitioners (Jobes, 1995), there is no clear idea of how this sensitive issue is currently being managed at a broader level within the healthcare system and what aspects of guidance are prioritised by practitioners. For non-professionals, suicide attempt survivors have reported that family members have a range of helpful and unhelpful reactions, including stigmatising statements, avoidant reactions, and asking questions (Frey, Hans, and Cerel, 2016). Identifying the reactions of non-professionals when faced with a person experiencing suicidality could also inform prevention initiatives, so that more helpful recommendations can be developed for all types of responders.

## 1.5. Suicide or Suicidality

Beck, Kovacs, and Weissman (1979) described suicidality as including completed suicide, suicide attempts, and suicidal ideas. These concepts have since been frequently used collectively under the term *suicidality* in research, as well as in international publications about suicide prevention (e.g. World Health Organisation, 2015; National Strategy for Suicide Prevention (Center for Mental Health Services (US) and Office of the Surgeon General (US), 2001)). The National Strategy for Suicide Prevention also includes ‘suicidal plans’ within its definition of suicidality, making four possible constructs included within this term:

- *Suicidal ideation*: thoughts pertaining to suicide.
- *Suicidal plans*: thoughts around method of carrying out suicide.
- *Suicidal attempt*: an unsuccessful attempt to engage in behaviour with intended outcome to die.
- *Completed suicide*: death occurring as a result of direct behaviour intended to end one’s life.

This review will explore a broader concept of suicidality that includes all four of the above constructs, rather than focusing on one individually. This was carefully considered and felt most appropriate and useful as:

- The term is widely used as a term in literature and practice.
- Focusing only on completed suicide may exclude research into behaviours and thoughts that are closely related to suicide which could support prevention initiatives.
- Mościcki (2001) discusses the difficulty of completing research on suicide exclusively, as large sample sizes are required because base rates of suicide attempts and deaths are low in the general population.



- Research with people who complete suicide is not possible.

However, there are some limitations to exploring *suicidality*. Meyer, et al. (2010) suggest that research exploring the all-encompassing and “not clinically useful” *suicidality* has often been clouded by the lack of clarity and consistency in definitions used. This potentially means that comparing the incidence and prevalence of suicidality across different populations may be problematic, as each report may be referencing a different aspect of this multi-dimensional term. Even within more specific subcategories of suicidality, there appears to be variance in understandings of each term. For example, Valtonen, Suominen, Sokero, Mantere, Arvilommi, Leppämäki, and Isometsä (2009) reported that less than a third of their sample of patients reporting suicidal ideation (SI) were consistently identified as such across a range of common psychometric measures used to assess SI, finding only low to moderate consistency in definitions used within the questionnaires.

### **1.6. Rationale and aims**

This review aimed to synthesise research findings into how people respond to individuals experiencing suicidality. As the majority of people who complete suicide are not in contact with services (Hewlett & Horner, 2015), this review sought to include anyone who may have responded to someone experiencing suicidality, including professionals, family members and carers, and members of the public. As such, this review will discuss the responses of supporters, meaning anyone who may have contact with a person experiencing suicidality. This is a well-established approach in suicide prevention policy and practice, which encourages consideration of the collective concept of “gatekeepers”, or people from a wide range of backgrounds that someone in distress may turn to for help (Snyder, 1971). This “gatekeeper” role of identifying and responding to people at risk of suicide is completed by both professionals and community

members, who hold unique insights that should be shared so that good practice can be adopted across the system, and challenges responded to (WHO, 2018).

Taking this broad scope is critical, as the NHS Five Year Forward View (Mental Health Task Force, 2016) notes that members of the public are now central in the delivery of health and social care, with the WHO publishing a whole toolkit to ensure that resource and expertise in communities is understood and utilised as part of suicide prevention (WHO, 2018). National suicide prevention training frameworks use this "gatekeeper" approach (e.g. Isaac et al. 2009) and include the insights of both professionals and non-professionals (e.g. Mental Health First Aid England, 2020), and there are targets that at least 10% of people in the general population should be formally trained in responding to suicidality (Mental Health First Aid England, 2019b).

Gaining insight into how people respond to suicidality will further support the development of guidance, training requirements, psychological theory, and offer the potential to share good practice and challenges across settings and professions, as well as guidance for non-professionals. The review set out to answer the following questions:

- How do supporters respond when faced with a person experiencing suicidality (i.e. when they suspect suicidality or suicidality is disclosed, what do they say or do, how do they acknowledge the person's suicidality, and how do these conversations unfold?)
- What aspects of care or processes to be followed do supporters prioritise when responding to suicidality?

## **2. Method**

### **2.1.Scope**

Terms to identify the reactions of supporters were developed to reflect the various ways that responding might be described for professionals and non-professionals; a list was initially created from literature reviewed when developing the project, and finally synonyms for these words identified. A number of papers were reviewed to develop the search terms for suicidality, so that it included all aspects of the broad definition previously described, including those included under the umbrella of ‘suicidality’, synonyms, as well as more specific terms like ‘self-poisoning’. Only papers including adults (aged 18 and over) were included, and searches were limited to qualitative results only in line with the aims of this review (rationale further described below). Barroso et al (2004) note that only identifying qualitative papers can be challenging, and their recommendations for developing search terms were followed so that the databases was thoroughly checked.

## **2.2. Systematic search**

A systematic search was completed using the electronic databases PsychINFO, Medline, PubMed, Web of Science, and Google Scholar. These Boolean search terms were combined: [suicid\* OR self-harm OR self-injury OR self-directed violence OR self-mutilation OR deliberate self-harm OR DSH OR non-suicidal self-injury OR NSSI OR self-cutting OR self-burning OR self-poisoning OR parasuicide] AND [interview\* OR discuss\* OR respon\* OR react\* OR ask\* OR question\* OR assess\*, manage\* OR screen] AND [qualitative OR grounded theory OR phenomenological OR thematic OR case study OR narrative OR discourse].

Further articles were identified by manually searching the reference lists of relevant papers. Titles were initially reviewed, and when a paper was thought to be potentially relevant, its abstract was read.

### 2.3. Inclusion and exclusion criteria

Clear inclusion and exclusion criteria were developed to ensure that all literature included was relevant to the research aims. Searching was not limited to a time period to maximise the scope of the review, but may have been limited by the databases used.

#### **Inclusion criteria**

- Studies in the English language.
- Studies where the suicidal person was an adult (18 years or older), as supporters' approaches may change when responding to children or adults (e.g. it has been noted that antecedents of suicidality may be different for children; University of Manchester, 2017), and there are also differences in service provision for children and adults.
- Papers where the acknowledgment and response was face-to-face contact (e.g. not including conversations that take place online), as the findings from these different approaches may not be transferrable to one another, due to such dramatic differences in format including an inability to get non-verbal cues.
- Studies which were from the perspective of the supporter or provided insight into processes completed by the supporter independently of the suicidal person's reports of the response. Research suggests that individuals with a history of suicidality themselves have memories of the event lacking in detail, with a recall bias towards first person, internally focused memories (Chu, Buchman-Schmitt, and Joiner, 2015).
- Qualitative studies. Hjelmeland and Knizek, (2010) suggest that most research about suicide focuses on *explanations*, usually framed in terms of linear "cause-effect-thinking" and argue that qualitative research allows for a shift in focus to more on *understanding*. The number of papers synthesising the findings of qualitative research has increased dramatically in recent years, as the value of the rich insights they provide

into the experiences and perspectives of participants has increasingly been recognised as an important source of evidence to inform practice, research, and policy (Tong et al., 2012). For the PsychInfo website, qualitative studies could be identified using the search tool, and for the other databases, additional search terms were used and are detailed in the next section.

### **Exclusion criteria**

- Studies that *did not include processes*, for example research exploring the emotional experiences of those supporting a suicidal person, or their attitudes and beliefs about suicide, or how they conceptualise suicidality.
- Studies that focused only on barriers and facilitators to a person making an intervention.
- Studies about supporting *children and young people* (people under 18 years of age).
- Studies that were exclusively from the perspective of the suicidal person.
- Studies about euthanasia or assisted suicide, which are issues that have been subject to separate debate and shifts in public attitudes over time (e.g. Attel, 2017), as well as implicating additional individuals in the act of suicide.
- Studies that evaluated specific frameworks for supporting people experiencing suicidality, or summarised guidelines for suicide assessment/management.
- Non-qualitative studies.
- Poor quality papers, scoring below 75% in the quality criteria outlined by Kmet, Lee, and Cook's (2004). As this tool gives equal weighting to all items on its checklist, all papers were also considered in terms of their overall methodological robustness, as there was the potential that papers with methodological issues could get a high score. No papers fell below 75% but were reviewed to ensure that they didn't have central methodological weaknesses not captured by the tool.

Eleven papers were identified (summarised in Table 1), with the search strategy summarised in Figure 1.

Figure 1. Flow chart illustrating systemic literature search

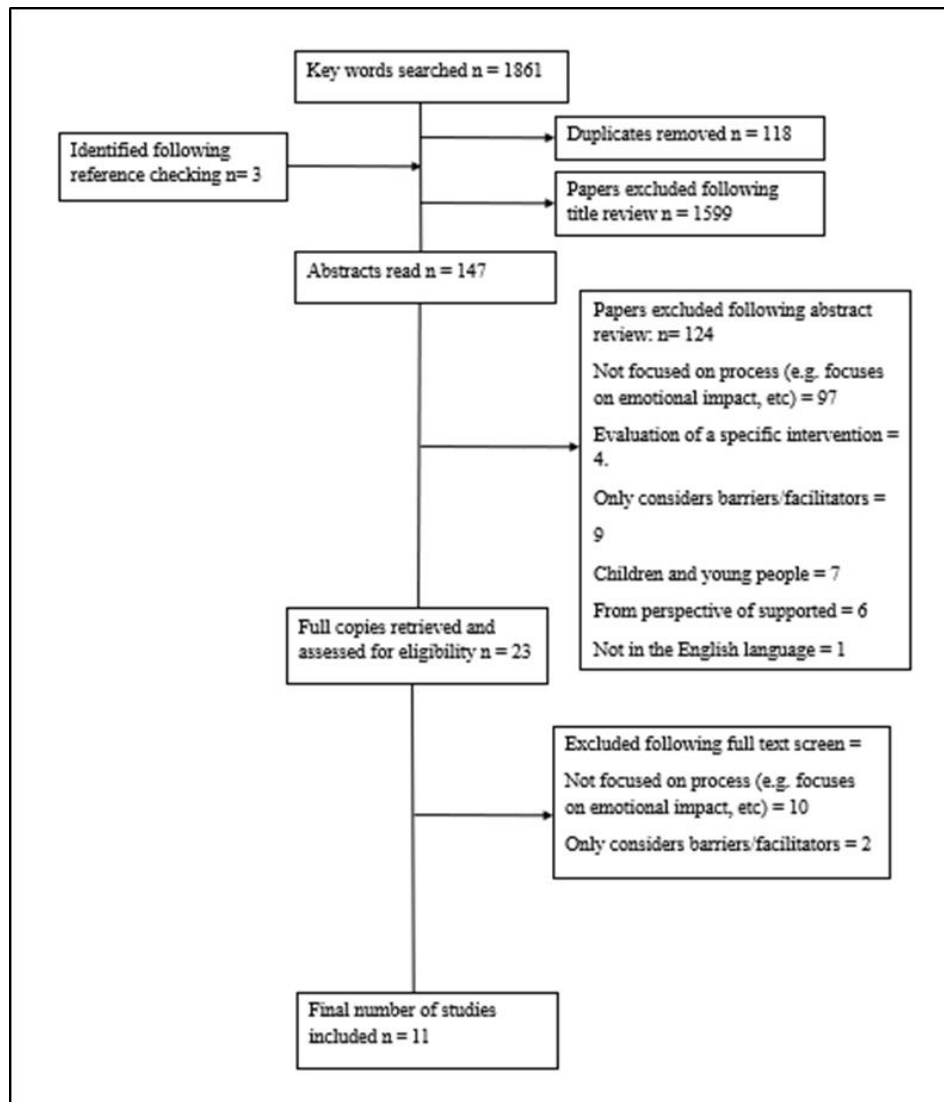


Table 1: Key information by study

Study	Study Aims	Participants professions and settings	Sampling	Participant demographics	Study design	Analytical method	Key findings
Garcia-Williams and McGee (2016). USA.	To qualitatively describe the self-reported responses college students have engaged in, at any point in their lifetime, when a friend or family member disclosed being suicidal.	461 undergraduate college students, with 126 completing the qualitative part of the survey.	Random (simple and stratified) and non-random (purposive and snowball) sampling strategies. Mixed strategies used because of the challenges associated with recruiting a diverse sample of undergraduate students.	<p><b>Participant genders:</b> 94 female, 32 male</p> <p><b>Participant ages:</b> Mean age 19.9</p> <p><b>Participant ethnicity:</b> 57 European American/White 26 Asian American 16 Hispanic/Latino, 18 “other”</p>	Qualitative online survey	Thematic analysis	<p>Five main responses emerged, which were not mutually exclusive:</p> <ol style="list-style-type: none"> <li>1. <i>Provide social support</i>, including giving the suicidal person reasons for living, destigmatising suicide (e.g. sharing personal experience), and emphasizing support.</li> <li>2. <i>Information</i>, which included help seeking from professional and nonprofessional sources</li> <li>3. <i>Telling someone</i></li> <li>4. <i>Crisis support</i>, including calming the person down, promise-making, talking the individual down/talk them out of it, and using force</li> </ol>

							Other responses were noted including using aggression, creating distance, and keeping the disclosure secret.
Hagen, J., Hjelmeland, H., & Knizek, B. L. (2017). Norway.	To explore mental health professionals' experiences of treatment and care of suicidal patients.	<p><b>Profession:</b> 4 psychiatrists 4 psychologists 8 mental health nurses</p> <p><b>Setting:</b> 2 hospitals and 10 different psychiatric wards across 2 hospitals in Norway. 11 working in an acute ward or a crisis unit, and in other wards (general psychiatric ward, rehabilitation ward, unit for psychosis, or another specialized ward).</p>	Purposive and convenience sampling was used.	<p><b>Participant genders:</b> The therapists were 3 females and 5 males. The nurses were 7 women and 1 man.</p> <p><b>Participants ages:</b> 28-60.</p> <p><b>Professional experience:</b> Between 2-30 years, with 13 professionals having &gt;10 years of experience.</p> <p><b>Ethnicity:</b> Not provided</p>	Qualitative semi-structured individual interviews	<p>Three step analysis:</p> <ol style="list-style-type: none"> <li>1. Initial analysis using inductive principles from 'systematic text condensation' (Malterud, 2011, 2012).</li> <li>2. Data read through theoretical perspectives.</li> <li>3. Steps 1 and 2 combined to ensure that findings were grounded in the empirical data</li> </ol> <p>The first author conducted all steps of the analysis, then all authors read the transcripts and were involved in the process of interpreting data.</p>	<p>Two approaches identified:</p> <ol style="list-style-type: none"> <li>1. <i>Connection and care.</i> Characterised by a relational approach, focused on establishing a trust/collaboration to promote connection to life, openness, and treatment compliance. Person is positioned within a medical model with emphasis on diagnosis/treatment, particularly for therapists. The 'burden' of caring and setting boundaries is discussed.</li> <li>2. <i>Duty and control.</i> A more formal approach. Focus on professional role and responsibilities, making 'clarifications; of diagnosis and risk.</li> </ol> <p>Therapists more concerned with formal and legal aspects of care, while nurses are more</p>



							concerned with emotional aspects.
Høifødt, T.S. and Talseth, A.G. (2006). Norway.	To explore the lived experiences of newly educated physicians' in treating patients at risk of suicide	<b>Profession:</b> 13 newly educated physicians  Setting: General practice	Participants part of an existing project on the development of psychiatric competence.	<b>Participant genders:</b> 7 males, 6 women  <b>Participants ages:</b> All around 30 years old.  <b>Professional experience:</b> Participants had completed their 18-month post-graduation internship.	Qualitative design, using a phenomenological-hermeneutical method.	Hermeneutic approach.	Three main themes and ten themes were noted:  1. <i>Striving for relatedness</i> , which included relating with the patient and establishing a relationship.  2. <i>Intervening competently</i> : having adequate professional knowledge; performing professionally; having professional values; evaluating one's own competence.  3. Being emotionally involved: accepting one's own vulnerability; feeling morally indignant; feeling powerless and accepting one's own fallibility.
Kjølseth, I. and Ekeberg, O. (2012). Norway.	To investigate the extent to which, how, and to whom, elderly people gave warning prior to suicide, and consider how these warnings were responded to.	<b>Participants:</b> 63 informants were interviewed:  Relatives: 4 spouses, 19 children, 3 siblings, and 8 daughter/son-in-laws.	172 municipal medical officers in ten counties in southern Norway were asked to report regularly to the project manager all definite suicides among those aged over 65 in their region. The medical officer acquired information on the deceased's closest	<b>Participant genders:</b> Not provided.  <b>Participants ages:</b> Not provided.  <b>Professional experience:</b> Not provided.  <b>Ethnicity:</b> Not provided.	"Psychological autopsy study" based on qualitative interviews.	Interviews were transcribed almost verbatim.  Systematic text condensation method was used, based on elements from phenomenological analysis and grounded theory and modified by Malterud (2001; 2002).	The interviews contained four main themes regarding reactions to the warnings: 1. <i>Not taken seriously</i> . 2. <i>Helplessness</i> . 3. <i>Exhaustion</i> . 4. <i>Acceptance</i> .  Warnings were given to relatives (11), home-based care nurses (5), and GPs (2).

		17 general practitioners	relatives, his/her GP and the home-based care nurse, if any.				
		12 home-based care nurses.	Written information on the project and a request to take part in the interview were sent to potential informants.				
Lees, Procter, & Fassett, (2014). Australia.	Explore the experiences and needs that mental health-care consumers had of suicidal crisis, the degree to which those needs were met, the role that mental health nurse engagement played in that context, and the key factors suggested to impact on the quality of care.	<b>Professionals:</b> 87 mental health nurses completed a survey, with 11 completing follow-up interviews.  Setting:  The interviewed nurses were from adult hospital inpatient (n = 7) and adult community (n = 4) settings in South-Eastern Australia.  Data collection also included interviews with 'consumers' – people who had recovered from recent suicidal crises during	Nurse participants were recruited via email and personal invitation utilizing the researcher's 'insider' status as a recent employee of the mental health service.  Consumer participants were recruited via their current mental health services community case managers.	<b>Participant genders:</b> 6 female, 5 male  <b>Participant ages:</b> Average age of 48 year,  <b>Professional experience:</b> average of 12 years' experience as mental health nurses. All but two of the interviewed nurses had postgraduate qualifications in mental health.  <b>Participant ethnicity:</b> Not provided	In-depth, semi structured interviews.	Drew upon adapted forms of critical discourse (Blommaert & Bulcaen 2000), constant comparative (Glaser 1965), and classical content analysis (Leech & Onwuegbuzie 2007). Analysis occurred during and at the completion of the data-collection sequence. This involved the iterative development of themes drawn from the qualitative interview and survey data.	The data showed that nursing care most prominently involved detention, formal observation, medication, and management within a multifaceted social and physical inpatient unit environment.  While only minimal therapeutic interpersonal engagement was reported by consumers, nurses reported an emphasis on building rapport, active listening, empathy, boundaries, relating as equals, genuineness, compassion, unconditional positive regard, trust, time, and responsiveness.

which they had received mental health nursing care (n = 9), but this review will focus on the supporter data.

<p>McCabe, R., Sterno, I., Priebe, S., Barnes, R. and Byng, R.. (2017). UK.</p>	<p>To analyse how psychiatrists ask questions about suicidal ideation and how patients respond in community mental health care.</p>	<p><b>Profession:</b> 319 psychiatry visits.  46 general practitioner visits.  <b>Setting</b> Secondary mental health care in urban, semi-rural, and rural areas of the UK.  Primary care.</p>	<p>Psychiatrists and supporting patients meeting DSM-IV criteria for schizophrenia/ schizoaffective disorder/ major depressive disorder were asked to participate. Consecutively attending patients were approached by a researcher.  A convenience sample of from 2 practices for primary care.</p>	<p><b>Participant genders:</b> Not provided  <b>Participants ages:</b> Not provided  <b>Professional experience:</b> Not provided  <b>Ethnicity:</b> Not provided.</p>	<p>Psychiatry and primary care clinics were audio-visually recorded.</p>	<p>qualitatively analysed using conversation analysis</p>	<ul style="list-style-type: none"> <li>• A gateway closed yes/no question was always asked.</li> <li>• Psychiatrist moved onto next topic when patient responded no.</li> <li>• 75% of questions were negatively phrased (expectation of no suicidal ideation).</li> <li>• 25% were positively phrased, (expectation of suicidal ideation).</li> <li>• Patients more likely to say they were not suicidal when question negatively phrased.</li> </ul> <p>25% of patients responded with a narrative rather than yes/no, conveying ambivalence. Psychiatrists tended to pursue a yes/no response.</p>
<p>Reeves, A., Bowl, R., Wheeler, S.</p>	<p>To explore how counsellors deal with</p>	<p><b>Professionals:</b> 20 qualified and experienced</p>	<p>Opportunity sampling: used pre-existing data.</p>	<p><b>Participant genders:</b> Not provided.</p>	<p>The study used pre-existing data from an evaluation of the psychodynamic</p>	<p>Discourse analysis, with the discursive object of ‘suicide’– how the expression of</p>	<ul style="list-style-type: none"> <li>• Explicit references to the discursive object (suicide) were rarely made by</li> </ul>

and Guthrie, E. (2004). UK.	suicide risk, and the implications for their clients.	counsellors, completing a training programme in psychodynamic interpersonal therapy.  <b>Setting:</b> Primary care		<b>Participants ages:</b> Not provided.  <b>Professional experience:</b> Not provided.  Ethnicity: <b>Not provided.</b>	training programme, where counsellors were presented with 'standardised client actors' to simulate suicidal client discourse. who had been 'primed' to present with depressive symptoms, somatised symptoms or suicidal thoughts. Counselling 'sessions' were videotaped pre and post training.  The pre-training video sessions were used in this study.	suicide was made by the clients in the transcribed interviews and subsequently responded to by their counsellors (both implicitly and explicitly).  The videos were viewed, and general 'response' notes were made. The videotapes were then transcribed fully.  In total 16 transcripts were completed.	client or therapist, and it was more often referred to in metaphor. <ul style="list-style-type: none"> <li>• The counsellor facilitates the client's expression of suicidal ideation by enquiring about whether the client has 'any thoughts of harming himself'.</li> <li>• Few counsellors asked direct questions to ascertain the risk the client posed to themselves.</li> </ul> <p>Counsellors responses were primarily reflective, and three types of interpretative repertoire seem to emerge – meanings, metaphors and figures of speech that help construct different aspects of the discourse.</p>
Vandewalle, J., Beeckman, D., Van Hecke, A., Debyser, B., Deproost, E. and Verhaeghe, S. (2019a). Belgium.	To uncover and understand the core elements of how nurses in psychiatric hospitals make contact with patients experiencing suicidal ideation.	<b>Professionals:</b> 26 nurses  <b>Setting:</b> 12 wards across four psychiatric hospitals. 5 participants came from closed wards, 21 from open wards.	Head nurses on the wards invited potential participants.	<b>Participant genders:</b> 9 males, 17 females  <b>Participants ages:</b> 3 were <25 years, 11 were 25-34, 6 were 35-44, 4 were 45-54, 2 were >55.  <b>Professional experience:</b> Length of employment	A qualitative grounded theory study using interviews.	The grounded theory data analysis was inspired by the Qualitative Analysis Guide of Leuven.	Nurses' interactions with patients experiencing suicidal ideation are captured in the core element ' <i>promoting and preserving safety and a life-oriented perspective</i> ', which represents the three interconnected elements.  1. <i>Managing the risk of suicide</i> -using protocols, initiating

in years provided: 9 <5 years, 9 had 5-14 years' experience, 4 had 15-24, 4 had >25.

**Ethnicity:**  
Not provided.

caring contact to develop an emotional connection. Making agreements.

2. *Guiding patients away from suicidal ideation*, by creating hopeful conditions e.g. by encouraging physical activity, doing things with patients, listening, and believing.

Searching for balance in the minefield.

<p>Vandewalle, J., Beeckman, D., Van Hecke, A., Debyser, B., Deproost, E., &amp; Verhaeghe, S. (2019b). Belgium.</p>	<p>To understand what constitutes contact between nurses and patients experiencing suicidal ideation, how contact is established in practice, and how this contact can be improved for the benefit of suicide prevention.</p>	<p><b>Professionals:</b> 19 nurses</p> <p><b>Setting:</b> Nurses were based across four psychiatric hospitals. 5 were from closed wards, 14 were from open wards.</p>	<p>Nurses were recruited on wards in four psychiatric hospitals where adults experiencing SI are regularly admitted. Researchers contacted head nurses who approached potential participants. Interested nurses were emailed to schedule an interview.</p>	<p><b>Participant genders:</b> 7 males, 12 females</p> <p><b>Participants ages:</b> 1 was &lt;25 years, 6 were 25-34, 6 were 35-44, 45 were 45-54, 1 was &gt;55.</p> <p><b>Professional experience:</b> Length of employment in years provided: 4 &lt;5 years, 7 had 5-14 years' experience, 5 had 15-24, 3 had &gt;25.</p> <p><b>Ethnicity:</b> Not provided.</p>	<p>A qualitative approach inspired by the principles of grounded theory (Glaser, 2002).</p>	<p>Grounded Theory, guided by the Qualitative Analysis Guide of Leuven (QUAGOL)</p>	<p>Analysis identified two interconnected core elements:</p> <ol style="list-style-type: none"> <li>1. <i>Creating conditions for open and genuine communication.</i></li> <li>2. <i>Developing an accurate and meaningful picture of patients.</i></li> </ol> <p>These represent nurses' attention to relational processes like building trust as well as their predominant focus on assessing suicide risk. Nurses put other emphases in their contacts with patients depending on whether their approach is guided more by checking and controlling suicide risk or by</p>
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							acknowledging and connecting with the person.
Vannoy, S.D., Fancher, T., Meltvedt, C., Unutzer, J., Duberstein, P. and Kravitz, R.L. (2010). USA.	To describe the vocabulary and narrative context of primary care physicians' inquiries about suicide.	<b>Professionals:</b> 152 physicians  <b>Setting:</b> Primary care	Secondary analysis of data from a previous study.	74 visits were to male physicians, and 34 visits were to female physicians.	Secondary analysis of data from a randomised control trial.  In the original study, standardised patient visits were completed with physicians (who provided informed consent for these visits to take place), and audio recorded using concealed equipment.	Transcripts were subject to coding and discussion by all authors, with focus on three stages in the suicide inquiry process: inquiry, context, and response.	<ol style="list-style-type: none"> <li><i>Inquiry.</i> 3 categories of linguistic content: direct inquiries that used the word 'suicide' or 'killing', indirect inquires related to self-harm, and indirect inquires related to hopelessness or passive death ideation. 'No problem wording' was common.</li> <li><i>Context.</i> Most inquiries were preceded by in context-blocks.</li> </ol> <p><i>Response.</i> Supportive follow-up statements common. Other responses deterred discussion.</p>
Vannoy, S.D., Tai-Seale, M., Duberstein, P., Eaton, L.J. and Cook, M.A. (2011). USA.	To identify patterns in physician-patient communication regarding suicide to inform quality improvement interventions.	<b>Profession:</b> 35 physicians.  <b>Setting:</b> Primary care working with patients 65 years and older and their primary care physicians.	Participants identified by office managers and approached to take part in the study.	<b>Participants ages:</b> Not provided.  <b>Participant genders:</b> 74 visits were to male physicians, and 34 visits were to female physicians.  <b>Professional experience:</b> All physicians had completed their training, but no further	Video-taped clinical encounters in which suicide was discussed.	Thematic analysis.	<p>Three patterns of conversation were identified:</p> <ol style="list-style-type: none"> <li><i>Arguing that "life's not that bad,"</i> where the physician strives to convince the patient that suicide is unwarranted.</li> <li><i>Engaging in chitchat,</i> where the physician addresses psychosocial matters in a seemingly aimless manner with no clear therapeutic goal.</li> </ol>

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details provided.

**Ethnicity:**  
Not provided.

*3. Identify, assess, and...?*  
Which is characterised by acknowledging distress, communicating concern, eliciting information, and making treatment suggestions, but lacks clearly articulated treatment planning or structured follow-up.

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Table 2: Checklist for assessing the quality of qualitative studies (Kmet, Lee and Cook , 2004)

	Garcia-Williams and McGee (2016)	Hagen et al (2017)	Høifødt et al. (2006)	Kjøiseith & Ekeberg (2012)	Lees et al (2014)	McCabe et al (2017)	Reeves et al (2004)	Vandewalle et al (2019a)	Vandewalle et al (2019b)	Vannoy et al (2010)	Vannoy et al (2011)
1. Question / objective sufficiently described?	2	2	2	2	2	2	2	2	2	2	2
2. Study design evident and appropriate?	2	2	2	2	2	2	2	2	2	2	2
3. Context for the study clear?	2	2	2	2	2	2	2	2	2	2	2
4. Connection to a theoretical framework / wider body of knowledge?	1	2	2	2	2	2	2	2	2	2	2
5. Sampling strategy described, relevant and justified?	2	2	2	2	2	2	1	2	2	2	2
6. Data collection methods clearly described and systematic?	2	2	2	2	2	2	2	2	2	2	1
7. Data analysis clearly described and systematic?	2	2	2	2	2	2	2	2	2	2	2
8. Use of verification procedure(s) to establish credibility?	2	2	0	1	0	1	0	2	2	2	2
9. Conclusions supported by the results?	2	2	2	2	2	2	2	2	2	2	2
10. Reflexivity of the account?	0	0	2	0	0	0	1	2	1	0	0
Total %	85%*	90%	90%*	85%*	80%*	85%*	80%*	100%*	95%*	90%*	85%

\* Scores <75% are good quality (Kmet et al., 2004). Scoring: 2=yes, 1=partial, 0=no, N/A=not applicable



### 3. Results

The quality of the 11 studies was assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet, Lee and Cook, 2004). Papers were generally assessed as being of good quality (all above 75%, where above 55% is acceptable and above 75% is good), all had clear research objectives, usually guided by several research questions capturing different aspects of the study's intentions. The context for the study and the wider knowledge they were related to were well integrated throughout the papers, and although there were no examples of integrating psychological theory, this was considered appropriate as most of the papers were designed and written by people working in other professions. The papers identified used a range of approaches to capture responses to suicide. Qualitative interviews were the most popular approach, with studies including semi-structured interviews (Hagen et al., 2017, Lees et al., 2014), and narrative interviews using a phenomenological-hermeneutical method (where the researcher's pre-understanding due to culture, language, history, etc, is acknowledged, (Lindseth and Norberg, 2004)). The studies acknowledged theoretical frameworks and guidance for completing a range of approaches including thematic analysis, systematic text condensation, Hermeneutic approach, grounded theory, critical discourse, conversation analysis, discourse analysis, constant comparative, and classical content analysis. Data analysis was described thoroughly by all studies in terms of these frameworks. Ten papers included the responses of professionals, and two included non-professionals.

Ten out of the 11 studies included professionals, with the most frequently included being nurses and primary care physicians, with five studies including these groups. This frequency is perhaps to be expected as nurses in hospitals are likely to have the greatest contact with 'at risk' people, while physicians in primary care are often viewed as "gatekeepers" to wider

support services (Sripa, Hayhoe, Garg, Majeed and Greenfield, 2019), and may be the first point of contact for many people in distress. For other professionals, two other studies included psychiatrists, one including counsellors, and one including psychologists. The included studies represented both primary and secondary care services, providing an insight into responses across the healthcare system. It was notable that the responses of non-professional supporters were not well represented in the literature, with only two studies identified that included them (although some other papers considered the emotional impact of a non-professional supporting a suicidal person). The two studies about non-professionals identified for this review included undergraduate students in one study (Garcia-Williams and McGee, 2016), and relatives in another (Kjølseth and Ekeberg, 2012).

The “gatekeeper” position of physicians means that they are often on the front line in terms of responding to people in distress, and so it is perhaps appropriate that research to date has included a considerable emphasis on them. However, more insight into how other types of professionals and non-professionals respond to suicidality will be valuable to ensure that people experiencing suicidality are well supported wherever their need is identified. One study did consider the reactions of counsellors, which included somewhat different responses to physicians (e.g. the use of metaphors) and suggests that completing this further work with a range of professionals would be valuable. It was also found that practitioners would often encourage the person to return to them if their suicidality became worse. This response has implications for service commissioners and managers, to ensure that services are appropriately flexible to allow such actions to be completed.

All studies including professionals provided information about service context and reflected a broad range of staff experience from newly qualified to experienced (although a paper about

responding to older adults (Kjølseth and Ekeberg, 2012) did not include information about staff experience). Participant demographics were considered as part of this review and sought for each study, so that responses could be reviewed within these contexts. Age and gender were generally well reported, but ethnicity data was not provided for any studies including professionals, and only for the study using college students. While data analysis was well described in all papers and theoretically sound, researchers generally did not explicitly address the likely impact of their own personal characteristics (such as age, gender and professional status) on the interpretation of data, and where this was acknowledged, there was not any meaningful description of processes completed to try and address this. This was especially striking as several of the studies did not make clear reference to verification processes that were used to ensure data was properly scrutinised. One paper did provide an example of good practice in this aspect of qualitative research (Vandewalle et al., 2019a), where the lead researcher is described, the potential impact of their position is acknowledged, and thoughtful consideration of reflexivity is documented, including the use of supervision by other researchers from diverse background. Despite this shortcoming, the conclusions made by the studies are presented in the context of limitations for all papers.

The studies included in this review were completed in Belgium, Norway, UK, Australia, and the United States of America (USA). This international context was carefully considered in relation to suicidality, and studies were included based on the following rationale:

- The prevalent religion of a country is a major factor in the epidemiology of suicide (Bertolote and Fleischmann, 2002), and all countries are majority Christian.
- In the WHO's rankings of the overall health system performance of its member countries (measuring improvement in the health of the population (levels attained and

distribution), responsiveness, and fairness in financing), the included countries were ranked within the top 20% (Tandon et al., 2000).

- Suicide is ‘legal’ in all these countries.
- All countries included have representation in the International Association for Suicide Prevention (IASP; 2020), and are member states of the World Health Organisation (WHO; 2020a), meaning that they have committed themselves to working towards the target of reducing suicide 10% by 2020 (WHO, 2020b).
- The countries included fall within the highest 60% of countries for suicide worldwide (WHO, 2017).

Each of the research questions will be considered in turn, with the papers contributing to findings in each section critiqued where appropriate to ensure that results are appropriately contextualised. While there were clear similarities in how different groups of people responded to suicidality, there were also some instances where different roles were fulfilled by different people, suggesting a larger system of care, which will also be discussed. The results of this review will then be contextualised by collating and critiquing broader information about the settings and participants.

### **3.1. How do supporters respond when faced with a person experiencing suicidality?**

The studies contributing to this aspect of the review used recordings of practitioners at work, either using standardised clients (Reeves et al., 2004; Vannoy et al., 2010), where actors simulated patients, or video recordings of interactions of genuine outpatient visits (McCabe et al., 2017; Vannoy et al., 2011). This was viewed as a strength, as the data is not from reports of practitioners themselves, who may feel pressure to appear competent if asked to retrospectively recall how they responded to suicidal clients. However, it is important to consider that in these studies the practice documented was completed in the context of the practitioner

being alerted that they would be recorded. This means that the practice observed may not be completely representative of what happens under natural conditions, and may have encouraged the person to respond in what they perceived to be the most ‘desirable’ way.

### **3.1.1. Professional responses**

#### **3.1.1.1. Framing the initial enquiry – Direct Vs Indirect**

Several approaches to introduce the subject of suicide were identified for different professionals. Vannoy et al’s (2010) exploration of physician responses to suicide identified the broadest range of enquiry methods, with direct enquires (i.e. including the words ‘suicide’ or ‘killing’), and two types of indirect enquiry – one related to self-harm (the most common approach) and one related to exploring hopelessness or passive death ideation (less common). This paper also found that most suicide inquiries by physicians took place following “in context blocks ” noting that physician-patient conversation often jumps from topic to topic, but in the case of their study the suicide inquiry was usually preceded by information that was relevant to suicide (i.e. discussing psycho-social concerns).

McCabe et al (2017) found that psychiatrists usually initiated conversations with a closed ‘yes/no’ question. Furthermore, they found that 75% of questions were negatively phrased (where an expectation that there was no suicidal ideation was indicated in the psychiatrist’s questioning). The Vannoy et al (2010) paper also found that this “no problem wording” was often used, where the physician indicates they assume or would prefer a ‘no’ response (“You’re not thinking about suicide, are you?”). Interestingly, a number of patients in the McCabe study (25%) responded to such questions with open narrative rather than closed yes/no answers, and in such instances, the psychiatrist continued to pursue an explicit closed answer. For newly qualified physicians (Høifødt et al., 2006) responses were generally more direct, including investigating thoughts, plans, and known risk factors such as current life situation and losses.

They also reported paying close attention to if and how patients talked about the future. Only one paper exclusively explored the approaches of non-medically trained professionals (counsellors). In this paper, Reeves et al (2004) found that client and counsellor appeared to ‘collude’ in not naming suicide explicitly, often using metaphors to explore the subject. A common approach was to ask if the client has had any “thoughts about harming themselves” although a few counsellors did ask direct questions to ascertain risk.

#### **3.1.1.2. Further exploration of suicidality**

In the Vannoy et al (2011) paper, the metaphor of a doorway leading to treatment being open or shut is used to describe physician’s initiation of conversations about suicide. This included the patient ‘knocking on the door’ (raising suicidal thoughts), followed by the physician ‘opening the door a crack’ (asking questions about such thoughts), only to ‘shut the door’ by not completing further assessment. This pattern could be found in other studies, where professionals would follow the general guidance (e.g. Dazzi et al’s review) and ask about suicide but had difficulty in framing and being explicit in asking the question, using metaphors and asking questions that encouraged the person to answer negatively. McCabe et al (2017) found that psychiatrists often moved on to the next topic if the patient responded ‘no’. Vannoy et al (2010) found that supportive follow-up statements were common, usually to encourage future disclosure (“if anything changes, please call us”) or seek reassurance (“are you sure?”).

#### **3.1.2. Non-professionals**

Only two papers were identified exploring the responses of non-professionals, but these did not directly address initial enquiries or how these were framed. They did provide some insight into how non-professionals may respond to suicidal individuals.

The Garcia-Williams and McGee (2015) paper found that the students interviewed indicated some flexibility in terms of how they approached the situation depending on the suicidal person. They found that when faced with crisis situations where dangerous behaviour was identified, participants focused on “talking the person down” (full details of the content of this were not provided), trying to get the person to make promises to keep themselves safe, and using force to take any means of suicide from the person.

The Kjøseth and Ekeberg (2012) paper found that relatives were the most likely people to receive warnings of suicide from elderly people, which is consistent with statistics indicating individuals who complete suicide are not in contact with professionals. While, most papers including professionals positioned the supporter as responsive and open to exploring the person’s suicidality, papers with non-professionals suggested less helpful or understanding responses. This paper identified not taking suicide seriously as a response. This was the only paper to consider a very specific population of people at risk of suicidality (older people), and could suggest that when faced with different populations responses can be variable. For older people supporters may be less responsive (for example, Stoppe et al. (1999) found that some physicians disclosed that they would not assess risk of suicide of older patients due to concerns it might encourage thoughts of suicide, and older suicidal females have been shown to receive the least sympathy compared to younger females (Stillion, White, Edwards, and McDowell, 1989)). This study combined interviews with other sources such as medical journals and police reports to present as clear a reconstruction of the response as possible (“a psychological autopsy study”), and as such may present a useful picture of the genuine responses of relatives. One participant in the Garcia-Williams paper also used aggression as they felt the suicidal person was ungrateful for their input, also suggesting unhelpful responses are possible.

## **3.2. What aspects of care or processes to be followed do supporters prioritise when responding to suicidality?**

### **3.2.1. Priority 1: Establishing a trusting and collaborative relationship**

In secondary care services, establishing trust and collaborating with the patient was central to many responses from professionals. Hagen et al (2017) found that both therapists (defined as psychiatrists and psychologists) and nurses in hospital settings shared a focus on establishing a trusting relationship with patients, with participants indicating that this was important for the patient's connection to life, but also to promote treatment compliance. Interestingly, it was nurses who appeared to be more concerned with these emotional aspects of care, with therapists more concerned about formal and legal processes. Lees et al (2014) and Vandewalle et al (2019b) also found that nurses invested in relational processes such as building rapport and trust with patients when faced with suicidality, so that they could communicate openly with patients and "develop a picture of them", with Vandewalle et al (2019a) identifying the processes that nurses completed to achieve this including doing things with patients, listening, and believing. Lees et al (2014) also added setting boundaries, relating as equals, genuineness, compassion, unconditional positive regard, trust, time, and responsiveness to these processes. It was striking that this finding seemed to be an attempt to respond to the domain of thwarted belongingness proposed by Joiner's IPTS and O'Connor's IMV, and the lack of connectedness to others proposed by 3ST, by focusing on building connections that are open and reliable, and the ideation to action theories of suicidality would endorse this priority as a useful response to reduce SI.

While this priority was particularly present for nurses, newly qualified physicians in primary care also indicated that they strived to establish a trusting relationship with their patients in the event of recognising their suicidality (Høifødt et al., 2006), particularly noting that knowing



the patient over time was helpful in building this, while adding that substance use was a barrier to maintaining this throughout a session. The study related to newly qualified physicians also found that they explored current life situation, losses, and paid attention to how the person talked about the future, which also suggest that building a relationship increases the likelihood of exploring domains proposed by the ideation to action theories such as low positive future, valued roles, or an individual's sense of meaning or purpose.

The focus on establishing trust with the suicidal person was also noted in the study with non-professionals, with Garcia-Williams and McGee (2016) finding undergraduate students also placed importance on giving the person a reason to live, destigmatising suicide, sharing lived experience, and emphasising that they will be supportive.

### **3.2.2. Priority 2: Fulfilling formal protocols and processes**

Practitioners in secondary care settings also appeared to prioritise responding in accordance with their organisation or professional protocol, especially in terms of record keeping. The nurses interviewed by Vandewalle et al (2019a) reported using suicide prevention protocols including restricting access to means, enforcing seclusion, and completing observation, while Lees et al (2014) also found these formal processes were prominent in nursing responses to suicidality, also including providing medication. Hagen et al (2017) noted that therapists' sense of doing the job well was closely related to completing and documenting clinical procedures and "covering your back", but that they sometimes questioned the usefulness of these procedures. This may also be reflected in the McCabe et al study, where it was found that physicians continued to pursue a concrete 'yes/no' answer in the event of receiving a narrative answer.

However, this finding while useful in highlighting the pressures facing practitioners, should be considered carefully, as the study combined psychologists and psychiatrists in the category of “therapists”, which may be problematic, as psychologists and psychiatrists have different roles and responsibilities, and as such may have different priorities in terms of responding to suicidality. Psychiatrists often hold responsibility for managing the formal and legal aspects of care, for example in the UK “responsible clinicians” have historically been psychiatrists, and while an amendment to the Mental Health Act in 2007 allowed other professionals to fulfil this role, most of these roles continue to be fulfilled by them. In the same study, Hagen et al discuss that nurses appeared to put ethics of care first, recognising the importance of performing their formal and legal obligations, but emphasising the importance of talking to the suicidal person and offering proximity.

Interestingly, both nurses (Vandewalle et al., 2019a) and college students (Garcia-Williams and McGee, 2016) also reported “making agreements” with the suicidal person to try and prevent them from ending their life. While this is not a formal process for non-professionals, ‘No suicide contracts’ (NSCs) are a tool commonly used by nurses in community crisis situations (Farrow, 2004) and as such felt appropriate to include under this priority.

### **3.2.3. Priority 3: Clarification of diagnosis**

Some studies with professionals indicated that the diagnosis of the person experiencing suicidality was often central to the response of professionals. Hagen et al (2017) found that the inpatient setting meant that suicide is understood within a medical model, with practitioners placing emphasis on clarifying diagnosis with their response based on that diagnosis, as well as seeking to make clarifications of diagnosis and risk. Again, this was particularly prominent for “therapists” (psychologists and psychiatrists). Newly qualified physicians (Høifødt et al.,

2006) reported that when the patient had a ‘serious mental illness’ they found the situation easier to manage and discussed making a diagnostic formulation as part of suicide risk. Diagnosis did not seem to be a consideration for non-professionals.

#### **3.2.4. Priority 4: Supporter seeking further support**

The two studies that included the responses of non-professionals included important additional information in terms of thinking about the range of responses, and the needs of supporters at different levels. Kjølseth and Ekeberg (2012) found that helplessness was a key response of people responding to warnings of elderly suicide. Garcia-Williams and McGee (2016) indicated that providing information (for example encouraging the person to seek counselling or other help) and telling someone (e.g. the suicidal person’s support network) were both popular responses. These are in line with the recommendations of Mental Health First Aid (MHFA), where encouraging the person to access appropriate support services is one of the five steps (Mental Health First Aid England, 2019). Support seeking in professionals was not discussed.

### **3.3. A system of responding**

Although professionals and non-professionals seemed to share some aspects of how they prioritised responding to a person experiencing suicidality, the papers also suggest a system of care where different people have different roles and responses to supporting a suicidal person. Based on the identified papers, this could include non-professionals encouraging the person to find mental health support, primary care physicians acknowledging and exploring suicidality, secondary care nurses building a trusting relationship with the person to ensure compliance to treatment and better connect them to life, and “therapists” – psychologists and psychiatrists holding responding to the formal and legal aspects of care.

#### 4. Discussion

Following collation and critique of the findings, the results are considered in relation to wider literature, psychological theories of suicide, and their implications for clinical practice and research.

The metaphor of “opening the door and keeping it open” adds further weight to Berman and Silverman’s (2017) assertion that further exploration of how to ask about suicidality is needed. ‘Keeping the door open’ would facilitate supporters to practice in line with the recommendations the ‘ideation to action’ theories of suicide suggest, offering the opportunity to observe a shift from general negative thinking (which might be disclosed initially) to more specific thoughts related to burdensomeness and belongingness. Exploring such domains requires more than ‘yes/no’ questioning, and it is interesting that where practitioners pursued a clear ‘yes/no’ answer, the suicidal person often responded with a narrative response, indicating a desire for space to explore their feelings beyond disclosure only.

This review found that time was important in making connections with suicidal individuals, and it is important to build relationships with people to enable helpful responses. This may be particularly difficult in primary care, where appointments are on average under 10 minutes, and although this is increasing, will only reach 15 minutes in 2086 based on current trends (Irving, et al., 2017). The UK has also seen an increase in the number of part-time and locum GPs (General Medical Council, 2018), which could also have implications for GPs “getting to know someone”. Mental health primary care services are delivered in line with NICE guidelines that suggest as few as six to eight sessions (NICE, 2009).

Training non-professionals in information and skills to improve mental health, prevent suicide, and build resilient communities has been suggested as a priority in national policy documents (Mental Health Task Force, 2016; Public Health England, 2015), but only two papers were identified considering this group. Particularly striking for non-professionals were feelings of helplessness and needing to call for help from professionals. Inaccessibility or availability of professional support could account for people turning to relatives, which could contribute to perceived burdensomeness, cited by ideation to action theories as key contributor to SI (especially if relatives are unable to respond in a way that is helpful). Research by Peters, Murphy, and Jackson (2013) found that prior to the suicide of a loved one, many people had identified the risk but were unable to access professional support, and yet that is recommended by guidance aimed at the general public. The ideation to action theories of suicide also suggest that access to services more broadly would be helpful, for example following a traumatic event, as these experiences increase a person's capability for suicide, and adequately supporting someone through a difficult event could later mean their capability for suicide is reduced.

Practitioners placed emphasis on diagnosis, but certain diagnostic labels can be stigmatising and may impact on the care provided by professionals if these are actively being considered in deciding the best approach. For example, patients diagnosed with borderline personality disorder (BPD) have been found to receive less empathy from nurses than other patients (Fraser and Gallop, 1993). Using the ideation to action theories of suicide as a basis for formulation may allow for better distinction between SI and suicide attempt.

Completing research into how diversity impacts on responses, particularly with groups who are known to be at a high risk of suicide, would be helpful. For example, there is a growing body of research suggesting that adults with autism are a high-risk group for both experiencing suicidal thoughts and completing suicide (e.g. Hedley, et al., 2017; Hirvikoski, et al., 2016),

but no exploration of how this vulnerable population is responded to when they display suicidality appears to have been completed. The ideation to action psychology theory would suggest that people from minority groups may be at increased risk of SI and attempt, as experiences of discrimination may mean that their sense of belongingness is reduced, while difficult experiences caused by this discrimination may increase their capability for suicide.

An implication of the 'system of care' suggested by the papers, where different people fulfil different roles in responding to suicidality, is that services need to be commissioned and managed to allow the multi-disciplinary and multi-agency working such an approach requires. While this review focused on direct responses to suicidality, the 'ideation to action' psychological theory would also suggest that this system of care includes wider service providers than only those directly dealing with suicide, as overcoming the fear and pain involved in completing suicide is key, and usually cultivated following painful events. Multi-agency working has been described as challenging for practitioners who may have to navigate working with different approaches, issues of power and hierarchy, and roles and identities (Robinson and Cottrell, 2005).

#### **4.1. Clinical Implications**

- Training and supervision specifically around asking about suicide and 'keeping the door open' may be useful to build practitioner confidence in "following through" with their questioning.
- This review suggests that there is great value in allowing practitioners to build relationships with clients, and service commissioners and managers should ensure there is capacity to do this. Additionally, skilling practitioners in approaches to "get to know" clients could be a useful training priority. An example of such an approach could be

“problem-free talk” (George, Iveson, & Ratner, 1990), where clients are invited to explore non-problem areas of their lives.

- Improving the accessibility of services so that non-professionals are better supported when they attempt to support someone experiencing suicidality. This could include provision to support responders, and resources for identifying support. There are already existing resources that could be promoted to offer this, such as NHS Direct (NHS, 2019b).
- Expanding training and information on responding to suicidality for the general public, as there was suggestion that non-professionals can respond in ways that may be unhelpful.
- Opportunities for practitioners to reflect on their use of formal processes in supervision or training may be helpful, to allow for exploration of whether these processes are being used as intended – to ensure accountability and provide evidence-based guidance – or whether they are also distracting from meaningfully supporting a suicidal individual. This could be facilitated through research or quality and improvement projects, so that cultures in specific environments can be identified and addressed. Procedures could also be reviewed to encourage assessment of the domains suggested in the ideation to action theories of suicide, which may provide a more effective indicator of risk, and allow practitioners to more appropriately respond.
- The emphasis practitioners placed on diagnosis has several implications. In terms of producing guidelines for professionals, recommendations for supporting individuals experiencing suicidality should be flexible to the needs of different people. As noted in the review of suicide management guidelines by Bernert, Hom, and Roberts (2014), advice given generally encourages consideration of risk factors, and completing assessment of suicidal intent, which may encourage some individualisation of

approaches, but having specific guidance on approaches for different types of needs may be helpful. Using the ideation to action theories of suicide as a basis for formulation would allow for distinction between SI and suicide attempt. It would be useful to encourage practitioners to be flexible in terms of their thinking about diagnosis, which may encourage a less person-centred approach. This could be facilitated by encouraging formulation, as well as challenging the stigmatising aspects of labelling people in this way. Producing accessible information about the ideation to action theories discussed in the introduction so that non-psychologists (professional and non-professional supporters) can integrate them into their responses, may be useful.

- If the current ‘system of care’ suggested by this review is to be maintained, resources must be allocated to support teams to complete multi-agency and multi-disciplinary work. If an alternative system is to be put in place, this should be designed with professionals across the system and include local communities to consider how skills and knowledge can be shared across the system.

#### **4.2. Implications for research**

- Only two papers were identified about non-professionals, highlighting a need for further research in this area, especially as most people who end their life by suicide are not in contact with professionals.
- Completing research into how diversity impacts on responses, particularly with groups who are known to be at a high risk of suicide, would be helpful. For example, there is a growing body of research suggesting that adults with autism are a high-risk group for both experiencing suicidal thoughts and completing suicide (e.g. Hedley, et al., 2017; Hirvikoski, et al., 2016), but no exploration of how this vulnerable population is responded to exists. The ideation to action psychology theory would suggest that



people from minority groups may be at increased risk of SI and attempt, as experiences of discrimination may mean that their sense of belongingness is reduced, while difficult experiences caused by this discrimination may increase their capability for suicide.

- It would be interesting to complete further research specifically exploring the responses of psychologists separately to psychiatry colleagues, to see if they discuss the priority of attending to formal documentation, diagnosis, and the legal aspects of care.

### **4.3. Limitations**

This review included papers from several countries, and while they have similar demographics (particularly around religion, one of the major factors in the epidemiology of suicide), and the WHO and IASP both advocate for building a global knowledge base, they also note the usefulness of exploring individual country's resources and situation. The limited papers that included non-professionals mean they are underrepresented, but do highlight unique findings for this group.

This review did not include the perspectives of people who have experienced suicidality. While this provides a useful insight into practice within the context of different professional and non-professional approaches, it is not able to evaluate how meaningful these approaches are for the individuals being supported.

## **5. Conclusion**

While there is an abundance of guidance around the most effective ways of responding to a person experiencing suicidality, this review sought to explore how people (including professionals and non-professionals) actually respond and what they prioritise when they are faced with this challenge. The review found that professionals (physicians and counsellors) often follow the accepted approach of asking about suicide, but had difficulty in framing and being explicit in asking the question, using metaphors and asking questions that encouraged

the person to answer negatively. Building a trusting relationship, fulfilling formal protocols, clarifying diagnosis, were prioritised as responses across a range of other professionals and non-professionals, with non-professionals additionally seeking help to manage the situation. There was also the suggestion that in some situations (in the case of the paper focused on older people in the review) suicide may not be taken seriously. This review adds further weight to the suggestion that research should now focus on how suicidality is discussed and investigated, and it will also be helpful to consider diversity in future research, and how the characteristics of both the supporter and supported affect reactions, particularly for groups who are known to be at higher risk of suicidality. For non-professionals, it is essential that appropriate services are available for directing the suicidal person to, as this was a key response this group identified, but there are known barriers, not least availability of services, which will impact on accessing meaningful support. This review also suggested that a system of care exists, with different roles for different people involved in supporting the suicide. If this system is to be sustained, the challenges of multi-agency work must be addressed, or if it is to be changed, this should be done with the involvement of stakeholders including staff and local communities.

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**Section B: Empirical paper**

JAYMIE HUCKRIDGE BSc Hons

**EXPERIENCES OF RESPONDING TO SUICIDALITY**

Identifying suicidality in autistic people  
and discussing it with them: A qualitative study

Word count: 8259

## **Abstract**

Autistic adults have increased risk of suicidality, and little is known about how the people who support them identify this or discuss it with them. Fifteen people who have discussed suicidality with an autistic adult took part in interviews and focus groups, including carers, voluntary sector, and healthcare staff. A theory generated using grounded theory methodology (GTM) found discussions take place when autistic people feel overwhelmed and are provided with safe environments to express distress. Supporters draw upon various knowledge as they negotiate processes of identification, exploring meaning, providing immediate response to reduce distress, and planning. Risk assessment runs parallel to these processes. Results are discussed in relation to theories of suicidality and their implications for clinical practice and research.

Key words: *autism, suicide, suicidality, grounded theory*



# 1. Introduction

## 1.1. Autistic Spectrum Condition (ASC)

Autism is a lifelong developmental condition that affects how a person communicates with and relates to others and experiences the world (National Autistic Society, 2019). Since early descriptions of autism in the 1940s, the term has seen shifts in its conceptualisation (Wolff, 2004). The fifth edition of the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) includes ‘autistic spectrum disorder’ (ASD), described as presenting in early childhood and characterised by “persistent difficulties with social communication and interaction” and “restricted and repetitive patterns of behaviours, activities or interests” (including sensitivity to sensory input) which cause “significant impairment in social, occupational, or other functioning”. However, such conceptualisations continue to be debated for failing to adequately consider diagnosis across the lifespan, and differences in presentation between genders (Wing, Gould, and Gillberg, 2010).

ASDs will be referred to as autistic spectrum conditions (ASCs) in this paper, as this recognises both the disabling aspects of autism and a profile of potential strengths (e.g. Wilkinson, 2011). In line with the preferences expressed by the autism community (Kenny et al, 2016), this paper will use identity-first language (‘autistic person’), while also recognising some individuals prefer person-first language (‘person with autism’). Individuals without autism will be referred to as ‘neuro-typical’.

Prevalence estimates for ASCs have increased in recent decades (Maughan, Iervolino, and Collishaw, 2005), and it is estimated that 1.1% of the UK population is autistic (NHS Digital, 2012) with higher rates of diagnosis in males (Halladay, et al, 2015), although females may be

underdiagnosed (Loomes, Hull, and Mandy, 2017). Presentations may differ between genders (Werling & Geschwind, 2013), where females display fewer social problems (Mandy et al, 2012), as traditional female social roles may ‘camouflage’ autistic behaviour, while their “special interests” may be similar to their neurotypical peers (Gould and Ashton-Smith, 2011).

Autistic adults are disadvantaged in terms of employment opportunities, social relationships, physical and mental health, and quality of life (Howlin and Moss, 2012) and often have poor life skills, report isolation, and are at higher risk of experiencing abuse (Balfe and Tantam, 2010). Autistic people often report difficulty accessing the support they need or that support available is not adequate (Camm-Crosbie et al, 2019). There is a ‘mortality crisis’ for this population, who die sixteen years earlier than the general population on average (Autistica, 2017).

## **1.2. ASC and suicidality**

It is suggested that autistic individuals are at high-risk of experiencing suicidality<sup>2</sup> (e.g. Cassidy et al, 2014; Hirvikoski, et al., 2016). While there have been studies suggesting that ASC is an independent risk factor for suicide (e.g. Chen et al, 2017), others report that risk is only increased in the event of comorbidity with other psychiatric disorders (e.g. Horowitz, et al, 2017; Demirkaya, Tutkunkardaş, and Mukaddes, 2016). Research has suggested that autistic females are at higher risk of suicidality than males (Hirvikoski et al, 2019; Kirby, et al, 2019), in contrast to the wider UK population (Office for National Statistics, 2019). Other factors increasing the risk of suicidality in autistic people include diagnosis of higher-functioning

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<sup>2</sup> Suicidality includes suicidal ideation, suicidal plans, suicidal attempts, and completed suicide.

autism (without a learning disability; Richa, et al, 2014, Veenstra-VanderWeele, 2018), a history of self-harm (Zahid and Upthegrove, 2017), familial suicidality (Demirkaya, Tutkunkardaş, and Mukaddes, 2016), and experience of abuse (Richa et al, 2014), although many of these are also cited as antecedents of suicide for the general population (e.g. abuse; Molnar, Berkman, and Buka, 2001, familial suicide; Tidemalm, et al, 2011).

### **1.3. Identifying and responding to suicidality in autistic people**

Many organisations have published suicidality commentary (e.g. British Psychological Society (BPS), 2017; Department of Health, 2012), but none acknowledge increased risk for autistic adults specifically. Similarly, there are a wealth of resources to support the general public and professionals to identify and respond to suicidality (e.g. Samaritans (2019), Mental Health First Aid (MHFA; Mental Health First Aid England, 2019) and Applied Suicide Intervention Skills Training (ASIST; Livingworks, 2019)), but these do not make any suggestions as to how the recommendations could be adapted for supporting autistic people. Resources aimed at supporting autistic people generally focus on engagement and diagnosis (e.g. NICE, 2016; Royal College of General Practitioners, 2018), summarise descriptive data about risk factors (e.g. Cassidy, 2015), or provide very brief generic advice (e.g. Autistica, 2019).

Psychological theories of suicidality also provide frameworks for predicting and managing suicide risk. Barzilay and Apter's (2014) review of psychological theories of suicidality summarises the following models:

***Psychological pain theories***, which position suicidality as problem-solving behaviour, with the individual attempting to escape unbearable pain, resulting from failure, rejection, and loss

(“psychache”, Shneidman, 1993). Autistic individuals are more likely to face rejection and victimisation from peers (e.g. Maiano et al, 2016; Sasson, et al. 2017), and may have low self-esteem due to being “devastated” by their diagnosis (DePape, and Lindsay, 2016).

*Cognitive theories*, which emphasise the cognitive aspect of suicidality, including the role of maladaptive schemas (e.g. Beck, Brown, Berchick et al., 1990). Gaus (2007) suggests this may be especially relevant for autistic people, as cognitive inflexibility may mean they hold strongly to negative schema, which have been reinforced through social difficulties, as well as being potentially unreceptive to new information that could inform the development of more helpful schema.

*Diathesis-Stress theories*, where suicidality is explained as the interaction between predisposing vulnerability factors and a triggering factor. In their commentary about suicidality in ASC, Lai, Rhee, and Nicholas (2017) suggest these theories (with particular focus on the Interpersonal Theory of Suicide (Joiner, 2005; Van Orden et al, 2010), and the Integrated Motivational-Volitional Model of Suicidal Behaviour (O’Connor, 2011)) are the most useful as they account for differences between ideation and attempt. Joiners’s theory suggests domains such as perceived burdensomeness and thwarted belongingness lead to *ideation*, while the addition of acquired capability for suicide (capability to overcome self-preservation reflexes) results in *behaviour*. How autistic people relate to these is unclear as diminished social reciprocity and theory of mind (“being able to conceive of mental states: that is, knowing that other people know, want, feel, or believe things” (Baron-Cohen, Leslie, and Frith, 1985)) may mean that they are less relevant. However, Jaswala and Akhta (2019) note that literature around autism often reinforces the assumption autistic people lack social interest, but this assumption is frequently contradicted by the testimony of many autistic people themselves. Autistic people

may be at increased risk of experiencing feelings of thwarted belongingness or burdensomeness, with Sasson et al (2017) finding that neurotypical people have consistently negative first impressions of autistic people, resulting in reduced intention to engage in social interaction. Acquired capability may also be increased in autistic people who may not fully understand the permanence of death (e.g. Koehler, 2016). Suicidality in autistic people has been described as characterised by rigid, detailed, and pervasive thinking patterns, like other special interests they might have (Weiner et al, 2019).

O'Connor's (2011) theory describes ideation as couched in a pre-motivational state (environment, life events) and influenced by motivational factors (defeat and humiliation), with volitional aspects (e.g. capability, impulsivity, planning, access, imitation) leading to behaviour. These volitional aspects may be particularly relevant for autism, and a comprehensive consideration of the theory's relevance to autism is provided in Table X.

<b>Area of model</b>	<b>Relevance to autism</b>
<b>Pre-motivational Phase:</b> Background factors and triggering events	<b><i>Diathesis + Environment + Life Events</i></b>  Autistic people are at increased risk of experiencing traumatic life events across their lifespan (Kerns et al, 2015; Mehtar and Mukaddes 2011; Taylor and Gotham, 2016), and report difficulty adapting to change (Balfe and Tantam, 2010). Autistic people also report aversive sensory experiences in daily life of environments (e.g. light, sound), particularly if they have a lack of control over them (Robertson and Simmons, 2015).
<b>Motivational Phase:</b> Ideation/Intention formation.	<b><i>Defeat and humiliation, entrapment.</i></b>  <ol style="list-style-type: none"> <li><b>1. Threat to self-moderators</b> (<i>Social problem solving, coping, memory biases, ruminative processes</i>).   Social problem-solving impairment has been suggested for autistic people (Goddard, et al., 2007), who also demonstrate impaired episodic memory and are less likely than neurotypical people to mentally reexperience past events from their own point of view (recalling them from a third-person point of view; Lind and Bowler, 2010). Rumination has been shown to be more prevalent in autistic adults, and is significantly associated with depression in autistic people (Crane, et al, 2013). Suicidality in autistic people has been described as characterised by rigid, detailed, and pervasive thinking patterns (Weiner et al, 2019).</li> <li><b>2. Motivational moderators</b> (<i>Thwarted belongingness, burdensomeness, future thoughts, goals, norms, social support, attitudes</i>)   Wood and Gadow (2010) propose autism related stressors that could have implications for an individual’s sense of belongingness and burdensomeness including social confusion, peer rejection and victimisation, and prevention or punishment of special interests. Autistic adults are also disadvantaged in terms of employment opportunities, social relationships, physical and mental health, and quality of life (Howlin and Moss, 2012). Autistic people have difficulty accessing support, and describe support available is not adequate (Camm-Crosbie et al, 2019). They are often supported by caregivers who also experience high levels of psychological distress and poor quality of life (Herrema, at al, 2017). Autism-related deficits have been shown in episodic future thinking (e.g. Lind and Bowler, 2010; Terrett, et al., 2013).</li> </ol>
<b>Volitional Phase:</b> Behavioural Enaction.	<b><i>Capability, impulsivity, implementation, intentions (planning), access to means, imitation</i></b>  Autism has been conceptualised as a product of executive dysfunction, due to traits such as need for sameness, difficulty switching attention, a tendency to perseverate, and a lack of impulse control (Rajendran and Mitchell, 2007). Autistic people have been shown to be at higher risk of impulsive behaviour including rapid food consumption, emotional outbursts, aggression, and self-injury (Pavlina et al., 2018). Autistic people have been reported to show greater compulsive use of the Internet (MacMullin, et al., 2016), where pro-suicide resources including detailed “how-to” instructions are easily accessed (Recupero, et al., 2008).

*Table 1: The Integrated Motivational-Volitional Model of Suicidal Behaviour (O’Connor, 2011) and its potential relevance to autism.*

Joiner et al (2009) posit that these theories can be integrated into practice by questioning individuals about the suggested domains. While there have been calls for discussing suicidality with autistic adults (Bennett, 2015), identifying changes in mood can be challenging (Stewart et al, 2006). For example, facial expressions are often difficult to interpret (Bieberich and Morgan, 1998). While difficulty in processing and expressing emotion has been suggested in ASC, evidence to support this has been inconsistent, leading to suggestions these difficulties may not be a universal feature, but are heightened in autistic individuals due to high incidence of co-occurring alexithymia in this population (difficulties in recognising, distinguishing between, and expressing different emotions; Kinnaird, Stewart, and Tchanturia, 2019).

#### **1.4. Rationale for the current study**

This uncertainty as to how relevant and applicable existing suicidality practice guidelines and psychological theory are to autistic populations presents a significant question as to how suicidality is currently being identified and discussed with this vulnerable group. Establishing how carers and practitioners are currently managing this issue has the potential to provide insight into good practice that can be more widely shared, and highlight challenges for improving guidelines and theory, and suggest areas for this growing field of research to consider in the future.

This research explored how carers and practitioners are currently identifying and discussing suicidality with autistic adults. Three research questions were developed to consider different aspects of this aim:

1. How are carers and practitioners currently identifying risk of suicide in autistic adults they support?

2. When risk is identified, how are conversations about suicidality initiated with autistic adults?
3. What areas would a carer/practitioner explore with autistic adults when discussing suicidality, and how do these relate to psychological theory?

Suicide prevention is a major public health priority, and NHS England (2016) made the ambitious commitment to reduce suicides by 10% nationally by 2020/21. The UK charity Autistica published a report calling for increased focus on early death in autistic people, specifically highlighting the need for action to reduce suicide (Autistica, 2017). Ensuring that autistic people are considered as part of this commitment is couched in the NHS core value of “everyone counts”. Autistic people, carers, practitioners, and researchers have also placed a high priority on research exploring practical, social and emotional issues, and particularly research in adult populations (Pellicano, Dinsmore, and Charman, 2014).

## **2. Methodology**

### **2.1. Design**

A qualitative non-experimental design was used, with semi-structured interviews and focus groups, analysed using grounded theory methodology (GTM) (Glaser & Strauss, 1967; Urquhart, 2013).

### **2.2. Rationale for qualitative design**

Qualitative research methods include interviews (group or one-to-one), participant observation, and document analysis, with a focus on self-reflexivity of the researcher, making sense of



context, and obtaining ‘thick’ descriptions of phenomena (Tracy, 2013). Historically, qualitative methods have been poorly utilised in suicidality research where the focus has been more on *explanation* than individual *understanding* of phenomena (Hjelmeland and Knizek, 2010). While qualitative research has increased in recent years, there are still gaps in knowledge, with calls for more qualitative research to provide richer accounts of suicidality (Cutcliffe, 2013). A qualitative methodology allowed the lived experience of participants to be captured in the richest way possible.

### **2.3. Rationale for Grounded Theory**

During project development, three qualitative methods were considered; discourse analysis (Potter and Wetherell, 1995), Interpretive Phenomenological Analysis (IPA, Smith and Shinebourne, 2012), and GTM, Glaser & Strauss, 1967; Urquhart, 2013). GTM was selected, as this study explores social processes in identifying and discussing suicide, and there is little current knowledge of how these processes are completed with autistic people (despite having a range of tools, theories, and guidance available, practitioners have described assessment of suicide as being “semi-intuitive” (Waern, Kaiser, and Renberg, 2016) and that therapeutic frames and collaboration with the client can become derailed, as crisis management becomes the priority (Fowler, 2012)). By collecting and analysing the data simultaneously, GTM allows for emergent themes to be explored from a range of perspectives, so that a theoretical framework of how suicidality is being identified and discussed with autistic adults can be created.

### **2.4. Rationale for using focus groups and interviews**

Lambert and Loisel (2007) found that data from focus groups and individual interviews is frequently combined in qualitative research for several practical and pragmatic reasons, which resonated for this study. This included that some participants may not have been prepared or able to participate in a focus group, and that combining methods improves data completeness as the different methods reveal multiple aspects of a phenomena and create richer understandings. Especially for a sensitive subject like suicide, it was important from an ethical perspective to offer a range of participation methods.

## **2.5. Epistemological position**

While GTM was originally suggested as coming from a positivist epistemological position (Glaser and Strauss, 1967), where the theory *emerges* from the data, interpretivist positions have also been used and promoted as the method developed. For example, Charmaz (2008), suggests that a constructivist-interpretivist position is more useful as this understands the theory as *generated* by the researcher, who brings their own assumptions and expectations. This study used the original method of data analysis, as it provided clear and systematic guidance for analysis of the large amount of anticipated data, for a researcher relatively new to qualitative methodology. After consideration throughout the development of the project, the lead researcher identified themselves as holding a ‘critical realist’ position (Collier, 1994), considering the theory as *generated* from the data through an interaction between objective reality and researcher interpretation.

## **2.6. Patient and Public Involvement (PPI)**

During the initial project development, a focus group was completed with staff from an autism service in the hosting NHS Trust, and a staff member from a voluntary sector autism support

organisation. This group considered the research questions, recruitment, and participant safety and other ethical implications of the research, and the discussion shaped the initial proposal for the research.

A meeting was also completed with the NHS Trust service user involvement team. The team made recommendations for the project, including in relation to improving the accessibility of project documents, and recruitment procedures. A service user consultation was commissioned specifically for the project, and some autistic service users already engaged in research around suicide took part in a focus group. The service users gave complete approval to the project, and made further recommendations for language, accessibility, and dissemination of the project results. All recommendations were actioned.

## **2.7. Ethics**

Ethical approval was gained through the NHS Research Ethics Committee and Health Research Authority (HRA) (Appendix A), and from the NHS trust hosting the research (Appendix B). Difficulties in recruiting carers meant that a request to amend the project's ethics application was made to both committees (requesting recruitment sites were increased) during data collection (Appendix C). The research was developed and conducted to ensure compliance with the British Psychological Society's code of ethics and conduct (BPS, 2009). Participants were given an information sheet in advance (Appendix D) so that they could provide informed consent, providing full details of safeguards in place (including data protection), their right to withdraw at any time, and information about accessible support services should the study raise difficulties. Consent was checked at the start of focus groups and interviews and recorded using a consent form (Appendix E). Following the interviews and focus groups, participants were

debriefed, and invited to discuss any concerns. All participants provided positive feedback, with five participants contacting the lead researcher after the study to share further positive feedback. For focus groups, additional safeguards were in place, including opening and closing check-ins (all safeguards are listed in the focus group/interview schedule, Appendix F).

## 2.8. Inclusion and Exclusion criteria

Clear inclusion and exclusion criteria were developed (Table 1).

*Table 2: Inclusion and exclusion criteria for study*

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<p>To be included in the study, participants must:</p> <ul style="list-style-type: none"> <li>• Have supported an adult with autism (aged 18+ and without learning disability) in the last 24 months.</li> <li>• Have discussed suicide with the person they supported.</li> </ul>	<p>Individuals were excluded from the study if they were:</p> <ul style="list-style-type: none"> <li>• A professional who had worked with a client who died by suicide in the 12 months prior to participation in the study, or where there is was an on-going investigation or review into a client death by suicide.</li> <li>• A carer who had experienced bereavement by suicide in the 24 months prior to participation in the study. The increased time for carers reflected the personal nature and the lack of formal processes to ensure this has been adequately supported.</li> <li>• A carer with a diagnosis of autism, due to potential risk of rumination.</li> </ul>

## 2.9. Participant recruitment

All participants were recruited through services operating within the hosting NHS Trust.

Carers were recruited from a voluntary sector autism service, although other carer forums were contacted following initial low numbers. The difficulty in recruiting carers was striking and may reflect the great demands placed upon them by caring responsibilities. Information, including the information sheet, was sent to these organisations and distributed to appropriate

carers. Interested people were encouraged to contact the researcher for more information and to ask questions, to make an informed decision about participating.

Professionals were recruited through contacts held by the project's Trust-based supervisor. Prospective participants were sent the information sheet and were invited to take part in a focus group or interview depending on their availability and preference.

### **2.10. Participants**

As this research took place within specialist teams within a small geographic area, reporting participant demographics was carefully considered, as identification of specific individuals and teams would compromise participants' anonymity. Participant data has therefore been collated to protect participant identities.

Two female carers took part in the research (supporting their adult children, one transgender female, one male), 2 staff from a voluntary sector-based autism support organisation, and 11 members of staff from an NHS service including autism assessment and support team, general practice, mental health support teams, and a crisis service working closely with the police. Professionals included clinical psychologists (1), nurses (4), speech and language therapist (3), therapy assistants (2), voluntary sector workers (2), and general practitioners (1).

### **2.11. Interviews and Focus Groups**

Two focus groups and 7 interviews were completed. One group was the voluntary sector staff, the other was the NHS autism assessment and support service. Open questions were used, with the aim of encouraging rich responses (Charmaz, 2014). The initial interview/focus group schedule was reviewed by project supervisors and the PPI consultation

group (Appendix F). Focus groups and interviews lasted from 55 minutes to 86 minutes (mean 65 mins).

## **Procedure**

Data collection and analysis was completed simultaneously, so that early findings can influence the development of the project, including possible lines of enquiry and sampling, as described in the GTM approach by Urquhart (2013).

- Interviews/focus groups were completed in either office space within the Trust or the supporting voluntary sector organisation (for the voluntary sector staff and carers). Participants contributed to *either* a focus group *or* an interview, following the structure described in the interview/focus group schedule (appendix X).
- Early focus groups were used to generate initial data that was then explored in further detail in the individual interviews (aided by the memos from the substantive (open) coding phase (described below) and the reflective diary completed by the lead researcher). For example, lines of enquiry added to the interview schedule included exploring diversity within the autism community in later interviews, as early focus groups raised gender as a consideration, and as GPs were being discussed so frequently in early focus groups, a GP was recruited and interviewed to gain their insights. Following the first carer interview, great effort was made to recruit further carers by reaching out to wider voluntary sector and trust partnership boards.

## **Data analysis**

Data analysis was completed in three stages:

- Following each interview, recordings were transcribed, and *substantive (open) coding*, was completed line-by-line (Appendix H) to ensure the researcher was fully immersed in the data, with early ideas recorded as memos (Appendix G). Coding was expanded to sentence by sentence after the first 4 transcripts and paragraph by paragraph after the 6<sup>th</sup>.
- *Substantive (selective) coding*, where data is coded into core categories. Constant comparison of the data was completed, moving back and forth between datasets when developing codes and categories to test whether new data support these generated theoretical categories. (Appendix J).
- The relationships between codes were conceptualised into a theory (Appendix K and L).
- Recruitment and data collection ceased at the point of theoretical sufficiency, where enough data was collected to offer sufficient depth for theory development (Dey, 1999).

## 2.12. Quality assurance

Researcher bias was considered for both the lead researcher and supervisors at all stages of data analysis. The lead researcher kept a research diary throughout the project (Appendix M), for reflection on preconceived ideas, values, and motivations. A reflective meeting was also completed for the lead researcher and project supervisors, encouraging self-reflection and consideration of biases. Extracts of data and coding were reviewed by project supervisors to improve reliability. The generated model was also sent to participants (Appendix N) to invite their views on its development and to ensure it was representing their experiences. Two participants responded (Appendix P), indicating the theory was a good representation of their

experiences. The feedback request was sent during the global Covid-19 crisis, which may account for the lack of response from NHS staff.

### 3. Results

Eight core categories (selective codes) emerged from the analysis, comprised of several sub-categories (axial codes). Table 2 summarises these, and the theory and its interactions are presented in Figure 1, and described in the text below, with anonymous quotes (categories are highlighted in bold, subcategories are underlined).

*Table 3. Summary of categories and sub-categories.*

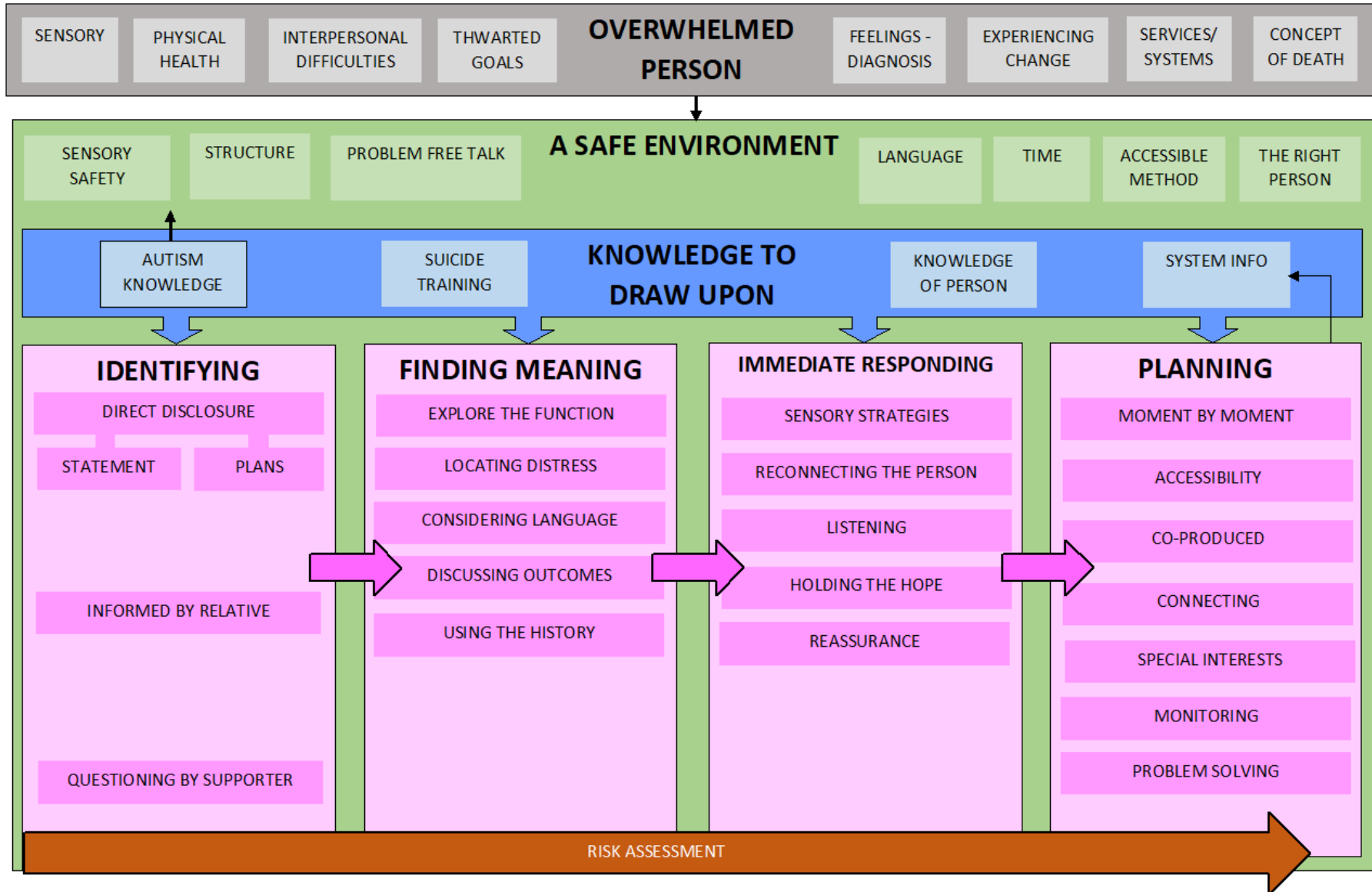
<b>Core Category</b>	<b>Sub-categories</b>
Overwhelmed person	Experiencing change Interpersonal difficulties Feelings towards diagnosis Sensory stimulation Negotiating systems Thwarted goals Physical health problems
Safe environment	The right person Problem free talk Creating sensory safety Accessible methods A clear structure Adequate time
Knowledge	Autism knowledge System information Knowledge of the person Suicide prevention training
Identifying	Direct disclosure Questioning by the supporter Informed by a relative
Finding meaning	Explore the function Locate the source of distress Using the history Discussing outcomes



	Considering language
Immediate responding	Sensory strategies Reconnecting the person Holding the hope Reassurance Listening
Planning	Moment by moment Co-produced Accessible Special interests Problem solving Monitoring Connecting
<u>Risk Assessment</u>	<u>Completing a risk assessment</u>

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Figure 1: A model illustrating how suicidality is identified and discussed with autistic adults



## **Overwhelmed person**

Participants understood that conversations about suicide were completed when the autistic person was overwhelmed by life. Experiencing change was the most commonly discussed antecedent and included experiencing and anticipating change and having difficulty problem-solving when faced with these changes. Common examples included experiencing or anticipating loss, and particularly changes of routine.

*“The times I know when her suicidality will increase are Christmas holidays and summer holidays... her routine changes. It can be as simple as I cut my hair, and so looked different, and that sent her into spiral.” (GP)*

Interpersonal difficulties were a common source of distress that led to expressing suicidality. This included conflict with family members, friends, and services, as well as loneliness and isolation.

*“Interpersonal events are huge. So being misunderstood. Or criticised,” (Nurse)*

*“Thinking that she’s not popular and that she’s made enemies.” (Carer to daughter)*

The autistic person’s feelings towards diagnosis were related to this, with participants understanding that the person they support has an awareness of their difference. Being newly diagnosed was noted as a challenging time when these feelings are prominent.

*“It will often be related to having had a new diagnosis, they think they don’t fit in to society so well.” (Voluntary sector worker)*

Negotiating systems was a source of distress, particularly the benefits system, waiting for professionals to provide support, or previous difficult experiences with services.

*“When money is being cut... having to go through that process. That is one of the main triggers.” (Voluntary sector worker)*

*“Not being able to understand the processes of the system... that it’s going to take a bit of time. Which then builds up into there’s no point in me carrying on, because you’re not going to help me out.” (Therapy assistant).*

*“A lot of trauma from unsatisfactory contact with services, where they’d been labelled as difficult.” (Nurse)*

It was striking that most participants shared examples of autistic individuals being overwhelmed by sensory stimulation prior to the conversation about suicide. This was often the result of inappropriate environments including distressing levels of light and sound in healthcare (e.g. ward environments) or home environments (e.g. noisy neighbours).

*“Maybe the frustration around the sensory side. I can’t cope within this environment.” (Therapy assistant).*

Thwarted goals were frequently a precursor to discussions about suicide, where the autistic person was unable to complete a desired goal. Difficulty at university was a frequent example, when the person did not meet their perceived academic potential or was unprepared for university life. Being unable to secure employment was also used as an example.

*“Well she was openly suicidal, she had been through a year at university, and had failed... she’d always been told that she could have an academic career.” (Carer to daughter)*

*“He wanted to join the Navy, but they wouldn’t have him because of his autism. He’s constructed this persona, and the Navy would have fit it.” (Carer to son).*

Physical health problems, including health conditions, could also be a including difficulties with sleep.

*“A lot of people have a clinically significant physical difference. So pain, fatigue, gut issues, and all of that kind of thing.”* (Speech and language therapist)

### **Safe environment**

Conversations were facilitated by creating a safe environment for the autistic person to talk. Creating this environment allowed the autistic person to build trust and feel relaxed, which helped to “disarm the performance” or any “masking” behaviour. There was a feeling that conversations had taken place because the supporter was “the right person”, having established a trusting relationship with the person, or showing autism knowledge.

*“Just the fact... that someone has heard them enough to say “Yeah, you are this highly sensitive person, and you know, you don’t just have to be that stereotypical male... You can see that performance undoing a little bit as you ask the questions.”*  
(Nurse)

*“The problem is it’s got to be the right person. This is the big difficulty.”* (Carer to son).

Problem free talk was understood to be a powerful tool in building trust by helping to “find a way in” and “build a connection”. This particularly focused on any special interests the person might have and using humour and informality.

*“I might ask “what do you enjoy doing?” You know, “I remember once you talked to me about that videogame” ... We can use that.”* (Voluntary sector worker).

*“If you’ve met them previously, you’ve got some background knowledge, you can bring up things you know that person likes. The older lady, I know she likes her*

*teddy bears, so as an ice breaker I can ask about her favourite bear... So how can I help them feel relaxed to talk to me and get enough information?" (Nurse)*

Creating sensory safety was understood to be central to this, considering factors such as quiet spaces, lighting, taking the person outside. Considering physical contact was also raised, with participants being mindful of eye contact and adapting physical contact based on the persons sensory and emotional needs.

*"We ask "are the lights alright?", "is the sound OK?". [They think] "oh my goodness – "I've never been asked that question" ... I think that is an instant "you get me". (Voluntary sector worker).*

*"I've done assessments walking alongside people, who couldn't do face to face, so we just walk outside..." (Nurse).*

While face-to-face conversations were the main method described, participants also discussed using accessible methods particularly offering alternatives to face-to-face conversation, including writing things down, using scaling charts, emails, and texting based on individual needs.

*"Maybe a diagram or something.... I might do a rating of numbers." (Nurse)*

*"I've had sessions where people have barely said anything and then they've emailed me the most exquisite explanation of what they're going through... They can't articulate it until afterwards." (Nurse).*

Providing a clear structure for the conversation, including a clear introduction outlining the aims and intentions, and allowing adequate time or using time well.

*“Say “So what we’ll do first is talk about our services, then talk about your life....  
I can see people getting more relaxed, “right, now I know what to expect here””*

(Voluntary sector worker)

*“You can do a lot in 15 minutes... If I’ve got someone who is distressed or I need  
more time, I overrun, ... or I can schedule more time to see them.” (GP)*

## **Knowledge**

All aspects of the conversation, from creating the safe environment to the four stages of responding, are informed by having knowledge to draw upon.

Autism knowledge and holding this knowledge in mind throughout, informing the approach, but also providing a framework for the safe environment and building trust.

*“So I can often be one of the first people they meet who has autism knowledge. I  
often find a lot of the time I’ll speak to people that have been going through all of  
this and no one in their personal life knows about autism, and sometimes the people  
themselves don’t.” (Voluntary sector worker)*

System information, with the most frequently discussed having access to medical records, which provide information including diagnosis, previous service use, and previous suicidal ideation.

*“It might be through looking at their care notes that you know they have ongoing  
thoughts of suicide,” (Nurse)*

Knowledge of the person, their family, community, and any other identities that is also used. This included having knowledge of other aspects of their identity, gender (including transgender), mental health diagnosis (particularly personality disorder), knowledge of their

workplace, community, or family. Some of this knowledge was from working with the individual directly, or having access to the system information described previously.

*“You have that picture of them as part of a community... you know the area of town where they are from, the support systems around. If they went to a certain school or place that employs a lot of people, I’ll probably know someone else who works there, so my contextual picture is probably a lot more holistic” (GP).*

Having accessed suicide prevention training, this was generally described as providing a helpful framework for intervention and understanding the boundaries of their roles.

*“So the training was really clear that it only allowed us, or gave us the skill to ask the question and ask the further question “have you got a plan?” and from there we were taught to just pass it on.” (Voluntary sector worker).*

## **Identifying**

Most participants reported that the discovery of suicidality was the result of a direct disclosure by the autistic person at a time of distress. This was either in the form of a statement for example (e.g. “I want to kill myself”) or by sharing plans, for example “I’m going to take an overdose”.

*“What I have noticed is people with a diagnosis of autism can be quite vocal... That might be the first words that come out of their mouth “I’m suicidal”.” (Nurse)*

*“He just burst out with it. He said that there was no point in living, that his life had no meaning” (Carer to son).*

*“They might say that they’ve done something, like taken too many, they might just say about an action... “ I took loads of olanzapine.”” (Nurse).*



Sometimes this disclosure was prompted by questioning by the supporter, usually as part of a standard risk assessment or when exploring mental health history. In these cases, the autistic person continued to make direct and open statements indicating suicidality. Supporters described questioning the autistic person in a direct and ‘concrete’ way, although many expressed that they would use this approach with neurotypical people.

*“There’s a kind of real directness that people appreciate. I might have to give examples... Like maybe giving them an example of a suicidal thought.”* (Nurse)

A less common route to identifying was being informed by a relative of the person that they had received warning of suicide intent, verbally or in a written note.

*“The young guy – his mum will tell us, and the older lady I mentioned, she lives with her mum so she will often tell us as well.”* (Nurse)

### **Finding meaning**

Participants made great effort to explore the “function” of the autistic person’s suicidality. Many noted that this exploration most frequently found that the disclosure was often a means for the person to express overwhelming pain and distress, rather than a clear wish to end their life.

*“In the background, I might just be thinking is this as serious as the person is saying? And it might be. But sometimes it’s not. It’s like chronic distress that they’re trying to express.”* (Nurse).

*“So you’re threatening your life – what does that actually mean? ... And then you might be able to break it down... we can see that down the line, perhaps if this was put in place, that would change your thought.”* (Therapy assistant).

*“What does suicide mean to you? Do you actually want to be dead forever? Never to be here again. Or you want the arguments with your mum to stop?” (Nurse).*

A key process to finding meaning was participants making an effort to locate the source of the autistic person’s distress.

*“And what’s happened? What’s shaken up their world so much that they’re contemplating hurting themselves?” (Nurse)*

Knowing the history (including taking the history of suicidality) was also used to make a judgement as to the function of the suicidality and the level of risk.

*“And take a history. Understanding when they started, what the triggers were, how they keep themselves safe.” (GP).*

Discussing outcomes, to ensure that autistic person fully understands the consequences of a suicidal act, for example describing physical consequences of a failed overdose, or death meaning that the autistic person will be unable to participate in their special interests.

*“I told her that if she tried doing that, she would end up failing, but being ill, and turning, being a vegetable. And that worked” (Carer to daughter).*

*“If you did, you wouldn’t be able to be playing on your PlayStation, or that favourite TV program you like watching, you wouldn’t be able to watch that anymore, there might be a community group... do you realise that you wouldn’t be doing that anymore?” (Therapy Assistant).*

Considering language used including continuing to use direct words and concrete examples, presenting suicidality as a scale, and reflecting back what they are noticing in the moment.

*“My assessment is depending on the person, an ongoing assessment of what language they use. How they speak to me, what terms they use. I work it in to that.”*

(Nurse).

### **Immediate responding**

Participants emphasised the role of using sensory strategies to ground the person, for example, using tools like sensory boxes, or facilitating a mindfulness exercise. “Forming a cocoon” around the person and ensuring that their basic needs are being met.

*“Getting our sensory boxes out and exploring those kinds of things. And does that make a difference. And taking breaks, all of that. A coffee... I might do a little grounding – mindfulness practice.”* (Nurse).

Reconnecting the person with their resources, including with their special interests, by taking an interest in them. Reconnecting them with coping strategies they have learned including “advice” from counsellors.

*“After she’s seen the counsellor, I get her to tell me what the counsellor has said, so I can remind her about it.... That’s a positive strategy.”* (Carer to daughter).

Holding the hope, by focusing on the positive and sharing stories of hope.

*“So what we did with client, is I said to him that we would hold the hope for him until we could give it back. And we made a picture to show him all the things that were being put in place in the meantime, so he could still hold on to, life.”*

(Voluntary Sector Worker).

*“I’m a storyteller, I give real life stories of what happens when people finally come to find themselves.”* (Nurse).

*“Try and remind her of things that have happened, you know other things that are maybe more hopeful and more positive and talk to her about the friends she has got.” (Carer to daughter).*

Reassurance was of their value in society, their strengths and skills, and that they are liked and loved.

*“I tell him how important he is to me, and I tell him that he is a decent person, that people like him and care about him... That his perception of being useless is completely wrong, that’s just a feeling he has, but that’s not an accurate feeling, really he does matter.” (Carer to son).*

Throughout responding it was felt that unconditional listening was the most valuable tool at the supporter’s disposal, even in the face of the autistic person sharing unlikely plans or unusual ideas.

*“She’d heard something on the internet... It was about cyanide in apple pips, and she convinced herself that if she bought enough apples, and extracted the pips, there would be enough cyanide to kill herself, and she went and bought about six bags of apples.... What I do now, when she talks about these ideas, I just listen, and I realise it is an expression of the pain she is going through”. (Carer to daughter)*

## **Planning**

Participants described completing planning with the suicidal person, to keep them safe. This plan was frequently shared with other parts of the system either through contacting another person directly and sharing it, or uploading it to a record system so that it becomes part of the system information held.

Participants described planning as being 'moment by moment' problem solving, thinking about how the person might occupy themselves and ensure their basic needs are met in the short term (usually the following hours or days).

*“If someone is phoning in a crisis you’re not talking about what you can do in a week’s time, you’re talking about the next hour, the next few hours.” (Nurse).*

This plan is co-produced with the autistic person, encouraging their suggestions as to what it might contain so that they feel “safe, supported, heard, and cared for”, checking in at the end to make sure the plan meets their needs.

*“You might plan out the next few days, what are you going to eat? Have you got any food at home? Is the central heating working? Maybe plotting out a timetable if that’s the kind of thing they like... And fill it with meeting basic needs.” (Clinical Psychologist)*

This was central to ensuring that the plan is accessible to the person, by getting their view on what the barriers might be in terms of them actioning the plan independently, such as looking at alternative ways of contacting services if telephone contact is difficult. Making a visual plan, by writing it down or drawing it out was a frequently used approach to ensure it is accessible, but also to ‘remind them of the human connection’ established during the conversation.

*“And we said “what would you do if you felt unwell?” and he said “oh, I’d ring the doctor”, and there is absolutely no evidence at all that he would get out of his chair and walk to the phone.” (Speech and Language Therapist).*

*“Even if I just start writing down what we’re saying, you can see that connection coming back... It’s quite grounding I think, so sometimes those practical things and*

*then if I leave her with something I've written down she's got it there for where I go and then it's still permeance.” (Speech and Language Therapist)*

Special interests were again central to this aspect of the process, with the person being encouraged to participate in activities they enjoy.

*“It's engaging them in activity that they like, isn't it? And I think part of that comes back to self-actualisation as well. Because if you have a tendency to have a loss of identity, then it kinds of exacerbates those feelings of not being grounded”.*

(Therapy Assistant)

Connecting the person to other parts of their support system was also important, for example, the GP connecting them with community resources, and the voluntary sector workers connecting them with their GP, but also family or other networks (“low demand social interaction”). Suggesting apps, helplines and other services that they might access. Connecting also included the supporter reaching out to other people for support for themselves. The plan was connected back to the collective knowledge about the person, so that it could be drawn upon for the next conversation.

*“Or of they have a psychiatrist or psychologist, I've often – I'll get permission from the person – “Is it OK for me to make contact with your psychologist?” (Voluntary sector worker).*

*“I might put it on their front sheet as well, so when we go into someone's notes reminders will come up.” (GP).*

Problem solving including thinking about managing physical health, responding to sensory distress (suggesting aids such as headphones and weighted blankets), and resolving practical issues, with a focus on solutions that limit disruption or change for the person.

*“Something practical, even if it’s really small, I think they need to be able to see something happening.”* (Speech and language therapist)

*“What can we do now? What do you want to do? Shall we take you home, are we going to go back to A&E? Shall we talk to mum? What can we do? When are you due to see your care team? What distractions can you use?”* (Nurse)

Ongoing monitoring was integrated into the plan, either by carefully observing the autistic person’s behaviour after the event and attempting to limit time they are alone, restricting their access to means of ending their life, and offering follow-up meetings at an agreed time or date.

*“Really closely supervising him. Because he likes to be on his own at times like this... And it’s basically just making sure there are no more attempts... I ask him how he’s feeling.”* (Carer to son)

### **Risk assessment**

Throughout the core processes described (identifying, finding meaning, responding, planning) participants were completing a risk assessment, which then directly influenced the planning. This was felt to be complete when they had enough information about thoughts, level of intent, suicide plans, history, triggers, and protective factors.

*“I feel like I just carry on asking enough questions until I am confident that I can decide what their level of risk is or what my response needs to be.”* (Clinical Psychologist).

## **4. Discussion**

The generated theory suggests that the stages proposed by models such as Mental Health First Aid (asking directly about suicide, listening non-judgementally, giving reassurance,

encouraging the person to seek help, and encouraging the use of self-help strategies) are broadly being used with autistic adults, but adapted by knowledge of autism and individuals (e.g. using concrete language, integrating special interests), and with emphasis on having a ‘safe’ environment to complete these conversations. This may reflect that some participants report having accessed training in such models.

Participants generally identified that the person they were supporting was suicidal as this was explicitly disclosed, or they were direct in asking about suicidality, in line with guidance for the general population. Although this is somewhat contrasting to suggestions that autistic people may be less able to express their emotions, it could suggest that disclosure is made at “breaking point”, and that detecting distress at an early stage is difficult.

For antecedents to conversations, the findings can perhaps be most appropriately aligned with the domains proposed by diathesis stress theories of suicidality. Interpersonal relationships were understood to be a source of distress for this population, with reports appearing to mirror the domain of thwarted belongingness (Joiner’s Interpersonal theory of suicide). The participants understood that connecting with the person’s special interests, showing understanding, and providing sensory safety allowed them to build connections that increased their sense of belonging and feeling understood. This finding is supported by research showing that while autistic people are more likely to report feelings of loneliness, describing both intrinsic (e.g. challenges with social interaction) and external barriers (e.g. environments) to social relationships, offering quieter settings and alternative engagement methods can support them to participate socially (Ee et al, 2019).

Diagnosis also contributed to this sense of thwarted belongingness. Low personal and external acceptance of autism (where autism is accepted by others and the self as an integral part of that individual) predicts depression, and experiences of “camouflaging” relate to higher rates of



depression (Cage, Di Monaco, and Newell, 2017). Participants described being able to ‘disarm’ some of this camouflaging by engaging in non-judgemental talk and providing space for people to share interests.

Events and issues that may lead to ‘pre-motivational state’ (O’Connor, 2011) were identified including life events and environment. These included physical health, with many medical conditions being more common in autistic adults (Croen, et al, 2015). Bereavement was also discussed as a pre-motivational event and there is a such a shortage of literature on bereavement and autism that a chapter dedicated to the subject (Forrester-Jones and Broadhurst, 2007) is based on research completed with the general population and people with learning disabilities. Based on the difficulties that characterise autism, the authors suggest that obsessions, lack of understanding, and resistance to change may be prominent bereavement responses for autistic people.

Motivational factors of defeat and humiliation proposed by O’Connor’s (2011) theory were also responded to by participants. This research particularly advocates for improving support around learning and employment, as perceived failure in these areas was identified as a source of distress. In a review of autistic students’ experiences of higher education, Gelbar, Smith, and Reichow (2014) found a high prevalence of anxiety, loneliness, and depression, risk of academic failure, and the need for support to reach their potential. Furthermore, only 32% of autistic adults are in any kind of paid work (National Autistic Society, 2016). This research also found that the welfare system is a common challenge for autistic people. The National Autistic Society (2011) has expressed concern that welfare assessment processes are not accessible for, or sensitive to, the needs of autistic people, issues that may increase perceived burdensomeness. Participants suggested that ensuring that autistic people are reassured of their value and skills is received as a helpful approach.

#### **4.1. Clinical Implications**

- A core component of the theory was the autistic person becoming ‘overwhelmed’, and earlier identification of practical and emotional issues may reduce the risk of this taking place. The Autism Act 2009 and the Care Act 2014 place a responsibility on local authorities to assess the needs of autistic individuals as early as possible.
- Participants described success in offering accessible methods of engagement and having resource to provide these (e.g. mobile phones for texting, tablet computers, guidance around using email, drawing materials, sensory boxes). It may be helpful to offer these and promote resources that support autistic people with problem solving independently (e.g. Brain in Hand app; Brain in Hand Ltd, 2019). The generated theory also suggests that a wealth of information is held by individuals within the autistic person’s network, and as requested by participants, should be readily available on NHS records as per the Accessible Communication Standard (NHS England, 2016b) so that it can be shared across the system. ‘Passport’ style tools are also used to help autistic people communicate their needs to healthcare professionals (e.g. NAS, 2017), and the police (National Police Autism Association, 2019).
- The generated theory suggests that conversations about suicidality with autistic people occur when a safe environment is established, and the supporter has adequate knowledge of the person. Supporters described having adequate time to “get to know the person” as required to do this.

#### **4.2. Implications for policymakers and commissioners**

- The generated theory suggests that supporting autistic people experiencing suicidality includes a number of unique considerations and issues, for example supporters may be required to manage discussion of more unusual disclosures (also found by Demirkaya

et al, 2016). At present, these specific autism considerations are not adequately represented in guidance or training around suicide, and it may be useful to produce more specific guidance for people supporting these populations, informed by the experiences of service users, carers, and professionals, who demonstrated a wealth of unique knowledge in this study.

- The generated theory suggests that the autistic person often becomes ‘overwhelmed’ by distress caused by services or systems. The NHS Long Term Plan (NHS, 2019) and Department of Health and Social Care’s (DHSC) ‘Think Autism’ strategy (DHSC, 2018) both advocate for training in autism for health and social care services, and such training has been shown to decrease stigma and increase competence and knowledge about autism in various organisational contexts, including universities (Gillespie-Lynch et al, 2015). Rolling out this training may enable services and systems to better understand and meet the needs of autistic people. Employers and educational establishments should be included, as participants identified these as central to thwarted goals. There are existing resources that could be used to inform such organisations (e.g. CIPD, 2018; Fabri, Andrews, and Pukki, 2014).
- The generated theory suggests that sensory needs are central to autistic people becoming overwhelmed, consistent with literature (Robertson and Simmons, 2015), and this should be held in mind when designing service environments.

### **4.3. Research Implications**

- The generated theory suggests that supporters use several approaches when supporting autistic people (e.g. focusing on problem solving), which they understood as helpful, but evaluation of these is needed.

- The generated theory hypothesises that knowledge of an individual's characteristics or situation (e.g. gender or diagnosis) informs the approach used by supporters. Research into how different characteristics might affect how suicidality is approached for both supporter and the autistic person may be useful to provide more detailed insight into this phenomenon.

#### **4.4. Strengths and Limitations**

This research engaged a wide range of supporters, reflecting diverse professional backgrounds from across the potential network of an autistic person. However, it did not seek to consider the experiences of autistic individuals, which may have provided further insight into the usefulness of some of the approaches described. No participants shared experience of supporting an autistic person who had completed suicide, and such participants may offer alternative views. This is important as participants in this study generally reported the expression of suicidality as related to a need for support in problem solving, but the literature suggests that autistic people are at a higher risk of *completing* suicide.

While effort was made to interview diverse participants, most were female and British, and while women form the majority of the adult social services workforce (NHS Digital, 2018) and are more likely to be carers (Carers UK, 2019), the findings cannot reflect how characteristics such as ethnicity and culture might play a role. Only two carers were included, and there was a risk that their experience may not be well represented by the theory. While this should be held in mind, in feedback provided by a carer during the quality assurance processes, they reflected that the generated theory had captured their experience well.

### **5. Conclusions**

This study sought to develop a theoretical understanding of how suicidality is identified and discussed with autistic adults. The generated theory showed that these discussions are taking place in the context of an autistic person feeling overwhelmed and provided with a safe environment to express this. Supporters then draw upon a wealth of knowledge to follow a path from identification of suicidality to planning, where they explore meaning and provide an immediate response to reduce distress. Risk assessment runs parallel to these processes. The approaches described by participants appear to connect with diathesis stress theories of suicidality, and while similar components are used in guidelines for managing suicidality there are important distinctions in how autistic people are most helpfully approached. The implications of this research were discussed and several suggestions for how practice can be improved were made. If actioned, the generated theory would suggest that there may be less frequent or less severe presentations of suicidality in autistic people, and that their distress would be managed more effectively.

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## Section C: Appendices

**Appendix A: HRA and Health and Care Research Wales (HCRW) Approval Letter**

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## **Appendix B: Confirmation of Capacity and Capability from hosting NHS Trust**

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## Appendix C: Approval of amendment to ethics application to increase recruitment sites for carers

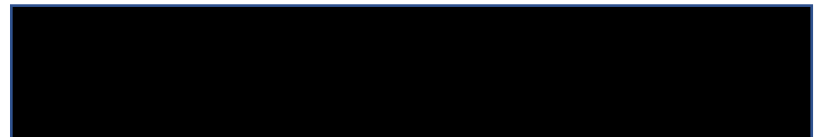
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## Appendix D: Information Sheet

Information sheet version 4

IRAS ID: 251997

14/03/2019



### Information Sheet

#### Identifying and discussing suicidality in people with a diagnosis of Autism Participant Information Sheet

*Hello. My name is Jaymie Huckridge, and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, I would like to explain why the research is being done and what it would involve for you. Please talk to others about the study if you wish, to help you decide whether or not to take part.*

*This research is supervised by Dr Dawn Howard ( [REDACTED] ), and Dr Julie Steel (Canterbury Christ Church University).*

*This information is split in to two parts: Part 1 tells you the purpose of this study and what will happen to you if you take part, and part 2 gives you more detailed information about the conduct of the study. You will be given a copy of this information sheet to keep, and a copy of the consent form for you to complete if you choose to take part.*



## **Part 1**

### **What is the purpose of the study?**

*This study looks at how suicide is identified and discussed with adults who have a diagnosis of autism by the people who support them, including their carers and professionals from across their network. There is growing research to suggest that people with a diagnosis of autism have a higher risk of both experiencing suicidal thoughts and completing suicide. However, there is little research or guidance on how to identify suicide in people with a diagnosis of autism, and how to best discuss it with them when it is identified. I hope that the findings will help to highlight good practice in this area, provide some ideas of how to better support people with a diagnosis of autism with suicidal feelings, and also help direct future research in this area.*

### **Why have I been invited?**

*You have been approached to take part in this study as you are either a carer to an adult with a diagnosis of autism, or a professional who works with a person with this diagnosis. I would like to hear about how you have identified and managed suicide risk with the person you support.*

### **Do I have to take part?**

*It is up to you to decide whether to join this research. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. In the event you decide to leave during a focus group or interview, any information recorded up to that point will be used as part of the research.*

### **What will happen to me if I take part?**

*If you decide to take part in this research, you will be invited to take part in a focus group or interview about the subject, with other people who support someone with a diagnosis of autism. This will be a one-off focus group lasting for up to two hours (1 hour for an individual interview), with regular breaks. In the focus group/interview, you will be asked some questions about how you have approached discussing suicide with the person you support or work with, and how you have identified suicidality. You will not have to answer any questions you do not want to, and are welcome to take a break at any time (there will be a separate space for you to go to).*

*The focus group/interview will be tape-recorded and transcribed so that the information can be analysed. Any identifiable information will be removed from the transcript.*

### **Expenses**

*Your travel expenses can be reimbursed up to a maximum of £10 in addition to a £10.00 gift voucher as a thank you for taking part. Light refreshments (tea, coffee, juice, biscuits and fruit) will be provided during the focus group.*

### **What will I be asked to do?**

*You will be posed a series of questions about how you have identified and managed suicidal feelings with the person you support. You will be asked to share your experiences around this, but also your ideas about how people with a diagnosis of autism could be better supported. You will not be pressured to speak, and can leave the group/interview at any time.*

**What are the possible disadvantages and risks of taking part?**

*The focus group/interview may touch upon experiences that might be distressing or uncomfortable. You do not have to discuss anything that may affect you in any of these ways. Should you become unduly distressed during the focus group, please let me know. You can take a break or stop the interview at any time, and there will be a separate room for you to go to. Should it become apparent that the focus group is distressing for you, I may ask if you would like to stop your participation in the group. We can discuss this together and see what might be best for you as a participant. I will check in with you at the end of the focus group/interview, to make sure that you are comfortable and feel safe. I will ask you about your experience of the focus group/interview, your current mood, how safe or at risk you feel, and the level of support that is available to you if you feel you require it. If you feel you need to plan support to feel safe I will stay with you until we have planned this. If you feel you need to extend the debrief later we can also schedule this. Contact details for support services are on this form and will also be on the debrief form, for example:*

**National Autistic Society helpline** (Information helpline, open Monday-Thursday 10am - 4pm  
Friday 9am - 3pm): Tel. 0808 800 4104

**Samaritans 24- hour helpline:** 08457 90 90 90

[REDACTED]

**Survivors of bereavement by suicide helpline:** 0300 111 5065

For employees of [REDACTED] Trust:

**Employee Assistance Programme:** [REDACTED]

**What are the possible benefits of taking part?**

*The findings of this study could potentially improve people's understanding of how suicidal thoughts and risk can be best identified in people with a diagnosis of autism, and how it is most helpfully discussed with them. At the moment, there is no guidance around this, so this research will contribute to a growing research base to increase understanding. As the study uses focus groups, you will also hear the views and experiences of other people who may have been in similar situations.*

**What if there is a problem?**

*Any complaint about the way you have been dealt with during the research or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.*

**Will information from or about me from taking part in the study be kept confidential?**

*Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.*

This completes part 1.


*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*

## **Part 2**

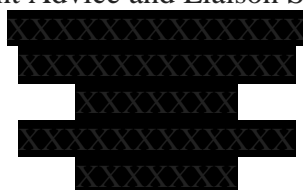
### **What will happen if I don't want to carry on with the study?**

*You are in no way obliged to take part in this research. If you do decide to take part, you have the right to withdraw your consent at any time without giving a reason. In this event, the information recorded up to that point will be used as part of the research.*

### **What if there is a problem?**

*If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070 or email me using [j.huckridge1055@canterbury.ac.uk](mailto:j.huckridge1055@canterbury.ac.uk). Please leave a contact number and say that the message is for Jaymie Huckridge and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Fergal Jones, Research Director, Salomons Centre for Applied Psychology – [fergal.jones@canterbury.ac.uk](mailto:fergal.jones@canterbury.ac.uk), tel: 01227 927114. You can also contact the  Patient Advice and Liaison Service using the following details:*

Patient Advice and Liaison Service



### **Will information about me from taking part in the study be kept confidential?**

*All focus groups are confidential, a group agreement will be proposed that all participants will be asked to agree to. The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else. The groups will be audio-recorded and typed up, stored securely and password protected. Anything that could identify you will be removed from these transcripts (e.g. if you mention the street you live). To assure the quality of my work, my research supervisors will have access to the anonymised written up interviews.*

*Canterbury Christ Church University will keep your name and contact details confidential and will not pass this information to any other organisations. Canterbury Christ Church University will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from Canterbury Christ Church University and regulatory organisations may look at the data you provide to check the accuracy of the research study, but only without any identifying information, and will not be able to identify you or find out your name or contact details.*

*Canterbury Christ Church University will keep identifiable information about you from this study for 3 years.*

*When you agree to take part in a research study, anonymised information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.*

*Canterbury Christ Church University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Canterbury Christ Church University will keep identifiable information about you for 10 years. Any information you discuss in the focus groups will be made anonymous and will not be identifiable.*

*Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.*

*You can find out more about how we use your information by contacting Jaymie Huckridge, using the details included at the end of this form.*

### **What will happen to the results of the research study?**

*The results of this study will be typed up into a report, and should you request, an overview of the research will be sent to you. Any identifiable information will be removed from the final report.*

*The final report will be submitted as part of my doctorate in clinical psychology, and I hope submitted to an academic journal so that the results can be shared with interested researchers and practitioners.*

### **Who is organising and funding the research?**

The research is funded through Canterbury Christ Church University and the NHS.

### **Who has reviewed the study?**

*All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS ethics panel, and approved by a research panel at Canterbury Christ Church University.*

### **Further information**

Please feel free to contact me should you have any more questions about this study:

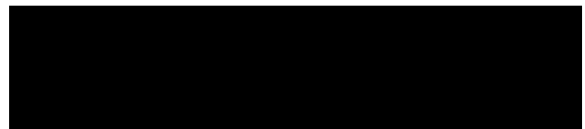
Jaymie Huckridge  
 Tel. 01227 927070  
 Salomons Centre for Applied Psychology  
 Canterbury Christ Church University  
 Tunbridge Wells  
 Kent  
 TN1 2YG  
 email: [j.huckridge1055@canterbury.ac.uk](mailto:j.huckridge1055@canterbury.ac.uk)

**Appendix E: Consent Form**

**Version 4**

**IRAS ID: 251997**

**14/06/2019**



**CONSENT FORM**

**IDENTIFYING AND DISCUSSING SUICIDALITY WITH AUTISTIC PEOPLE**

Please read the *participant information sheet*, and complete the following form:

1	I have read and understood the participant information sheet for the above study.	INITIAL:
2	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	INITIAL:
3	I agree to take part in this study.	INITIAL:
4	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without it affecting my rights in any way.	INITIAL:
5	I understand that the focus group will be digitally recorded and written up for the purpose of the research, and I hereby give permission for the focus group to be recorded.	INITIAL:
6	I understand that any information that might identify me will be removed from the transcript.	INITIAL:

7	I understand that anonymised quotes from my focus group/interview may be included in publications.	INITIAL:
8	I understand that the content of the focus group/interview is confidential as long as the researcher is not concerned about my safety or the safety of others.	INITIAL:
9	<p>I confirm that I meet the criteria (below) to participate and agree to take part in the above research study.</p> <ul style="list-style-type: none"> <li>• I have supported an autistic adult (aged 18+ and without a learning disability) in the last 24 months.</li> <li>• I have discussed suicide with the autistic person I supported.</li> <li>• I am not a professional who has worked with a client who died by suicide in the previous 12 months, or where there is an on-going investigation or review in to a client death by suicide.</li> <li>• I am not a carer who has experienced a bereavement by suicide in the previous 24 months.</li> <li>• I understand that discussing suicide can be distressing and have considered the possible impact on me. I do not consider that participating will cause distress that would place me at risk.</li> </ul>	INITIAL:
10	I confirm that my anonymised information can be provided to researchers running other research studies in this organisation and in other organisations. The information will only be used for the purpose of health and care research, and cannot be used to contact me or to affect my care.	INITIAL:
11	I understand data collected during the study, may be looked at by individuals from Canterbury Christ Church University and [REDACTED] I give permission for these individuals to have access to the data collected from my participation in this study	INITIAL:
12	I wish to receive a summary of the results at the completion of the study (you may change your mind about this at any time)	YES/NO

Name of participant: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

If have answered 'yes' to item 9, please provide your email address:

\_\_\_\_\_

Name of person taking consent: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix F: Focus group/interview schedule

### FOCUS GROUP SCHEDULE

In line with the grounded theory approach, this will be revised as new insights are gained from analysis of each focus group.

AREA TO EXPLORE	ACTIVITY
<b>Introduction from the facilitator</b>	Introduce research project, housekeeping, and structure for the session.
<b>A “go-round”, to make introductions and “temperature check” the room</b>	All participants (and the facilitator) complete a go-round, to introduce themselves:  <i>‘My name is... and I got here today by [transport]’.</i>  This allows each group member to say something early in the session, without it being too exposing, and also allows the facilitators to detect any anxiety or other issues in a safe way.
<b>A group agreement – introducing “ground rules” such as confidentiality.</b>	The facilitator introduces the group agreement. This will include phones off/silent, leave and have a break any time (if outside for 5-10 minutes facilitator will come and check you are ok), confidentiality, and respect for when others are talking. Check with the group if they all agree to work with this agreement.
<b>Introductory question</b>	Question:  <i>What made you want to talk about your experience?</i>

<p><b>Questions about identifying suicide in autistic people – signs, symptoms and events</b></p>	<p>Questions:</p> <p><i>How did you come to know that the person you were supporting was experiencing thoughts of suicide?</i></p> <p><i>Were there any specific events that took place before you realised about the person’s suicidal thoughts?</i></p> <p>What other factors do you think contributed to the person’s wish to end their life?</p>
<p><b>Questions about starting a conversation about suicide with autistic people – when, where, and how?</b></p>	<p>Questions:</p> <p><i>How long was it between identifying the suicidality and having the conversation? If there was a significant amount of time, what was happening between identifying and discussing?</i></p> <p><i>Who initiated the conversation about suicide with the person you were supporting?</i></p> <p><i>What was the aim of your conversation? (To reduce likelihood of suicide? To understand the issues the person is facing? To reassure you or them?)</i></p> <p><i>Did you have a clear idea of what you wanted to explore?</i></p> <p><i>Did you feel confident to approach this subject with the person you were supporting? Did you feel you had enough information/knowledge/skills?</i></p> <p><i>How directly did you approach the subject with the person you were supporting?</i></p> <p><i>How did the person you were supporting respond to the conversation?</i></p> <p><i>What was difficult about having the conversation?</i></p> <p><i>Did you approach the conversation differently to how you would with someone who does not have autism? What adjustments did you make?</i></p> <p><i>Did the conversation go as you expected? What stood out for you?</i></p>
<p><b>Questions about the areas that conversations about suicide would cover and risk management</b></p>	<p>Questions:</p> <p><i>What did you explore during the conversation? Who introduced different subjects?</i></p> <p><i>Who led the conversation?</i></p> <p><i>Were there any subjects that you avoided raising with the person? Why?</i></p> <p><i>How did you make a decision about risk, and how likely the person was to end their life?</i></p>



	<p><i>Endings: How did the conversation end? Were any actions agreed? Did you sign-post to or seek advice from anyone else (individuals and organisations)? How did you decide what to do next?</i></p> <p><i>Do you feel that you were able to effectively support the person? What helped you to do this, or what prevented this?</i></p> <p><i>What do you think would have helped the person to improve their mental health?</i></p>
<b>Ending question – key messages</b>	<p>Question:</p> <p><i>Based on our conversations so far, what would be the main advice you would want to pass on other people supporting autistic adults, to better identify and discuss suicide?</i></p>
<b>Debrief and go-round (temperature check)</b>	<p>Check-in: How was the focus group?</p> <p>Go-round: what might you take away from the group today?</p> <p>Debrief – and provide debrief sheet.</p> <p>Thank participants for taking part.</p>

## **Appendix G: Examples of theoretical memos**

*Removed from electronic copy.*

## **Appendix H: Example of open coding**

*Removed from electronic copy.*

## **Appendix J: Example of selective coding**

*Removed from electronic copy.*

## **Appendix K: Example of early plan of model**

### **Events “tipped from crisis to crisis”**

Frustration

Unprepared for independence/dependent – problem solving

Diagnosis – new – relating to others – experienced as different

Loneliness/Isolation – don’t fit in with society

Interpersonal – with services/family/friends

Don’t fit in with services

Know they are different

Hopelessness

Rejection

Other identities/bpd/overweight/mh conditions

Sensory triggers – personal environment

Change – bereavement – autism specific

Overwhelmed

Practical issues – central heating

Formal processes (e.g. benefits, waiting for professionals to take action)

Anticipation of these things

Difficulty imagining the future.

Disturbance of rituals

Physical health – sleep

Understanding of death/severity of method

Misplaced in services

Missing out of milestones in life

Options minimize

### **Creating a safe environment for disclosure – building a connection**

Sensory safety

Going outside/walking

Talking about special interests – “finding a way in”

Finding what works/building own confidence asking

Allowing adequate time

Getting to know the person

Allowing difficult emotions to be named

Problem free-talk, humour, and informality

Structure – explaining plan for session

Using language

Camouflaging women – disarming the performance

Getting the right person in front of them

Writing things down – scaling, emails, texting etc

Getting language right

Removing police officers “the right person”

Eye contact

Physical contact – using/adapting

### **Pre-existing knowledge base**

General MH info

Using referral/file

Pre-warning from colleague

Knowledge/understanding of autism – holding in mind

Knowledge of local area/family/person

Training in suicide

### **Direct discovery**

Explicit – not wanting to live – matter of fact

Changing the question

When taking history

Leaving a note – info from relative

Listening

Sharing plan

\*unusual plans and taking it seriously

Exploring areas

Direct question “blunt” – “just ask”

Routine risk assessment - current historical

### **Sharing possible outcomes**

Using specialist interests

Threatening

### **Finding meaning**

Locating the source of person’s distress

Calm and low key

Self-harm – self-soothing behaviour – understanding function of behaviour

Exploring meaning of language used

Exploring other parts of identity/risk factors Gender/other identities

Death as a special interest

Scaling

Timescale – now or later

Seeking info from family

## **Reducing distress**

Sensory strategies – grounding

Outside intervention (e.g. telephone call from friend)

Special interests

Low demand social interaction

Distraction

Reframing – perspective

Reconnecting with coping strategies including therapy guidance

Offering reassurance – I love you, Peer stories, you have things to offer

Reassurance - Holding the hope, positive. Stories of hope. List people who like them.

Ensure basic needs are being met 'form a cocoon'.

Assessing risk – prompted by having a plan – alarming because of directness – asking until confident – access to means?

Applying knowledge of distress for anyone

Practical support

Problem solving

Distract and divert

Checking-in – do things feel better?

## **Detailed Moment by moment short-term planning – bringing it back to now**

A co-produced plan

Seeing people – friends, family, wider internet family

Written visual down plan – for client – reminder of human connection

Praise yourself

Exploring alternatives for accessing services

Limitations to role

Seeking advice

Exploring accessibility/practicality of plan – not just a rehearsed script – e.g. doctors -seek reassurance for plan/gauge response

Physical health inc. health conditions, sleep, exercise

Paperwork

Safe, supported, heard and cared for

Practical comforts - Headphone, weighted blankets

**Aftercare**

Restricting access to means

Monitoring

Using special interests

Contribute to existing knowledge

Connect with other carers/parts of system – inc making complaints, self-care, finding support that fits, places to check in,

Keeping self-covered

MDT working

Digital apps/helplines/services

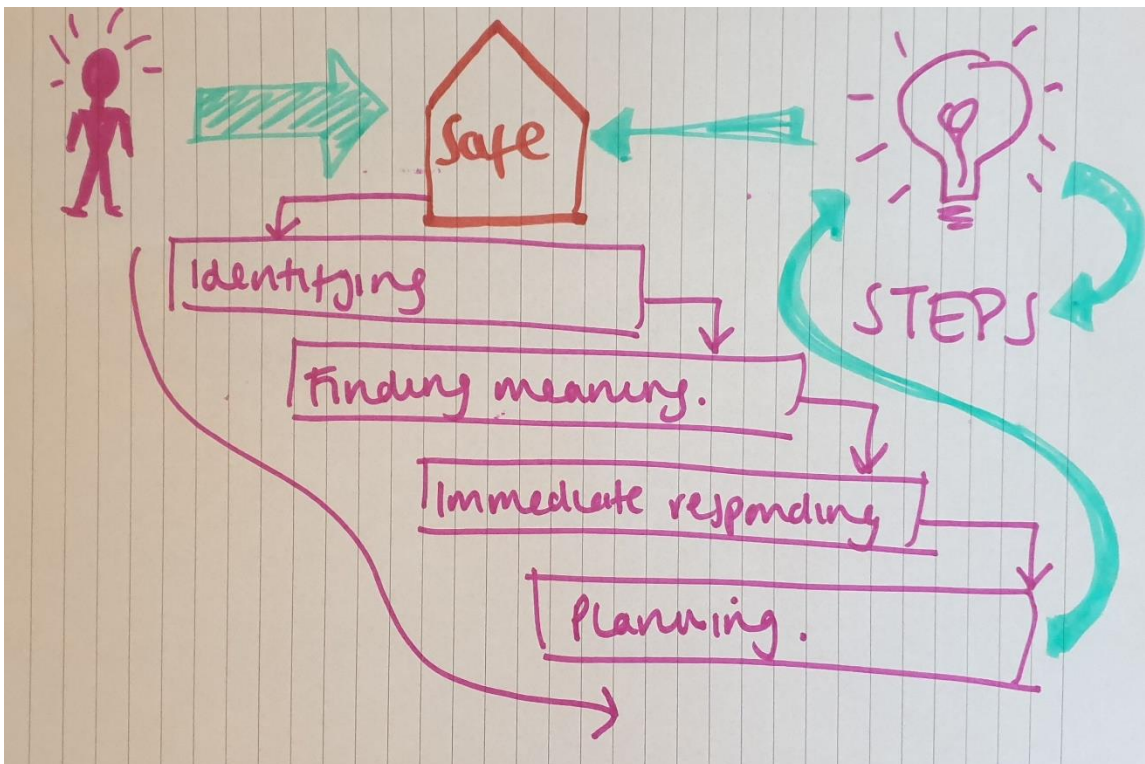
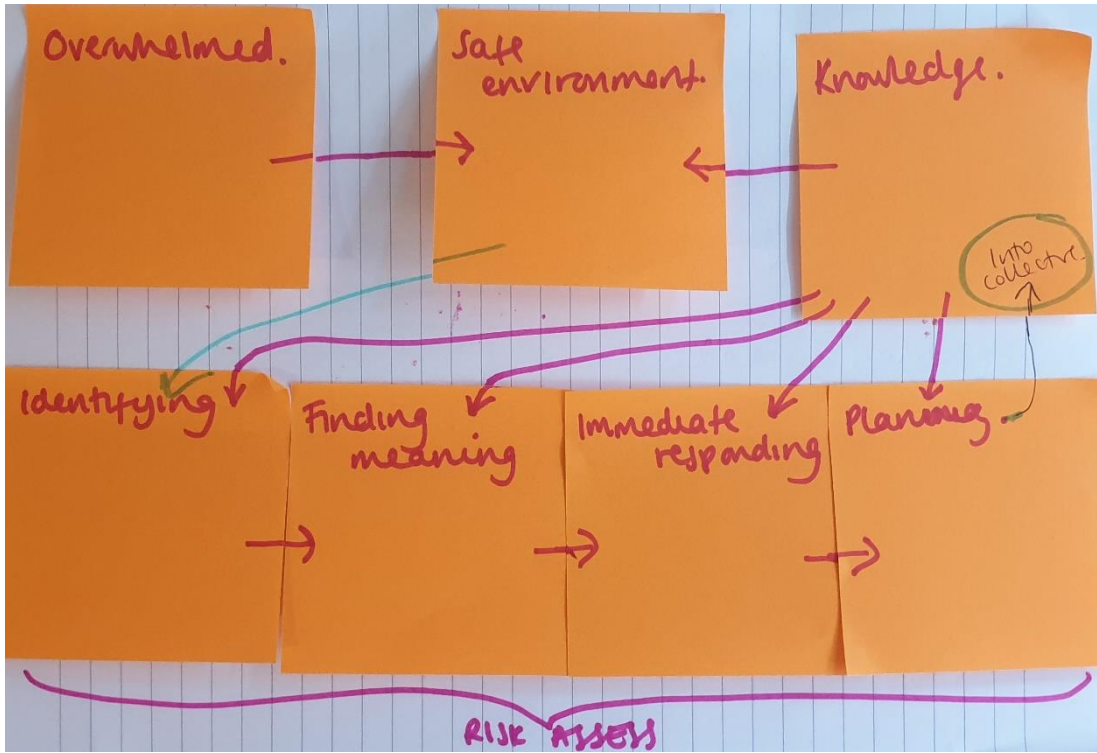
Continuity of care

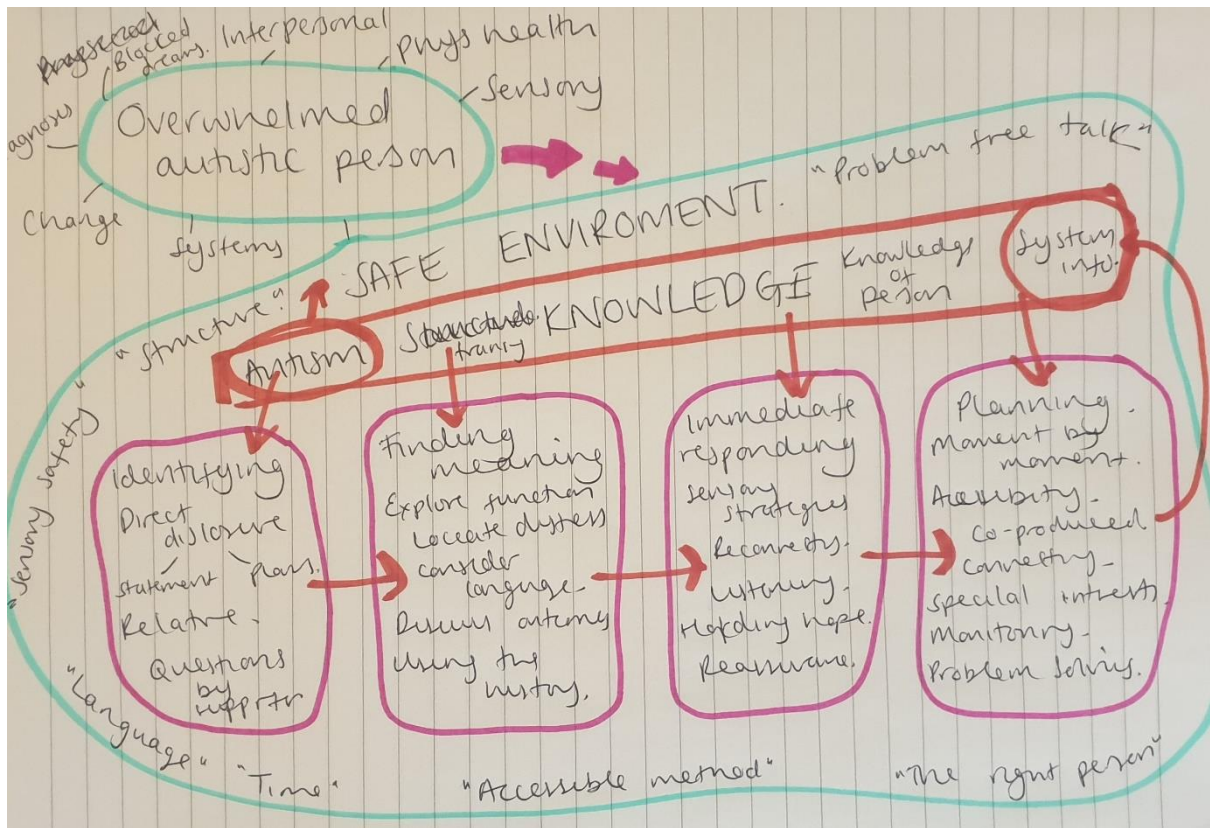
Avoiding approaches that increase instability/change

Updating medical record

**Appendix L: Example diagrams of theory development**







## **Appendix M: Research diary**

*Removed from electronic copy.*

## **Appendix N: Model information sent to participants for feedback.**

Dear Participant,

Thank you so much for taking part in my study on suicidality and autism.

I've now been able to analyse the data collected across the focus groups and interviews, representing 15 participants and many hours of insights. From this data, a model has been developed, which provides a theory explaining how suicidality is discussed with autistic people. At this stage I am sharing the model with you and would be really interested to hear your thoughts on it. I've attached a brief summary of to this email, and I will also send you a full summary of the study when it has been completed.

The attachment first includes a diagram of the different themes that came up and how they fit together, and then each part of the diagram is described below it. If you are able to have a look at the findings, I would really value any feedback you have on them. This could include:

- Whether you think the model captures your experience of discussing suicidality with an autistic person, and the information you shared in your interview/focus group.
- Any strengths you feel the model has.
- Any limitations of the model

All comments will be highly valued and will be used to tweak the model where possible, used in future presentations of the model, and to shape future research in this area. It would be great if you could send any feedback to me by Monday, 13th April 2020.

Best Wishes,

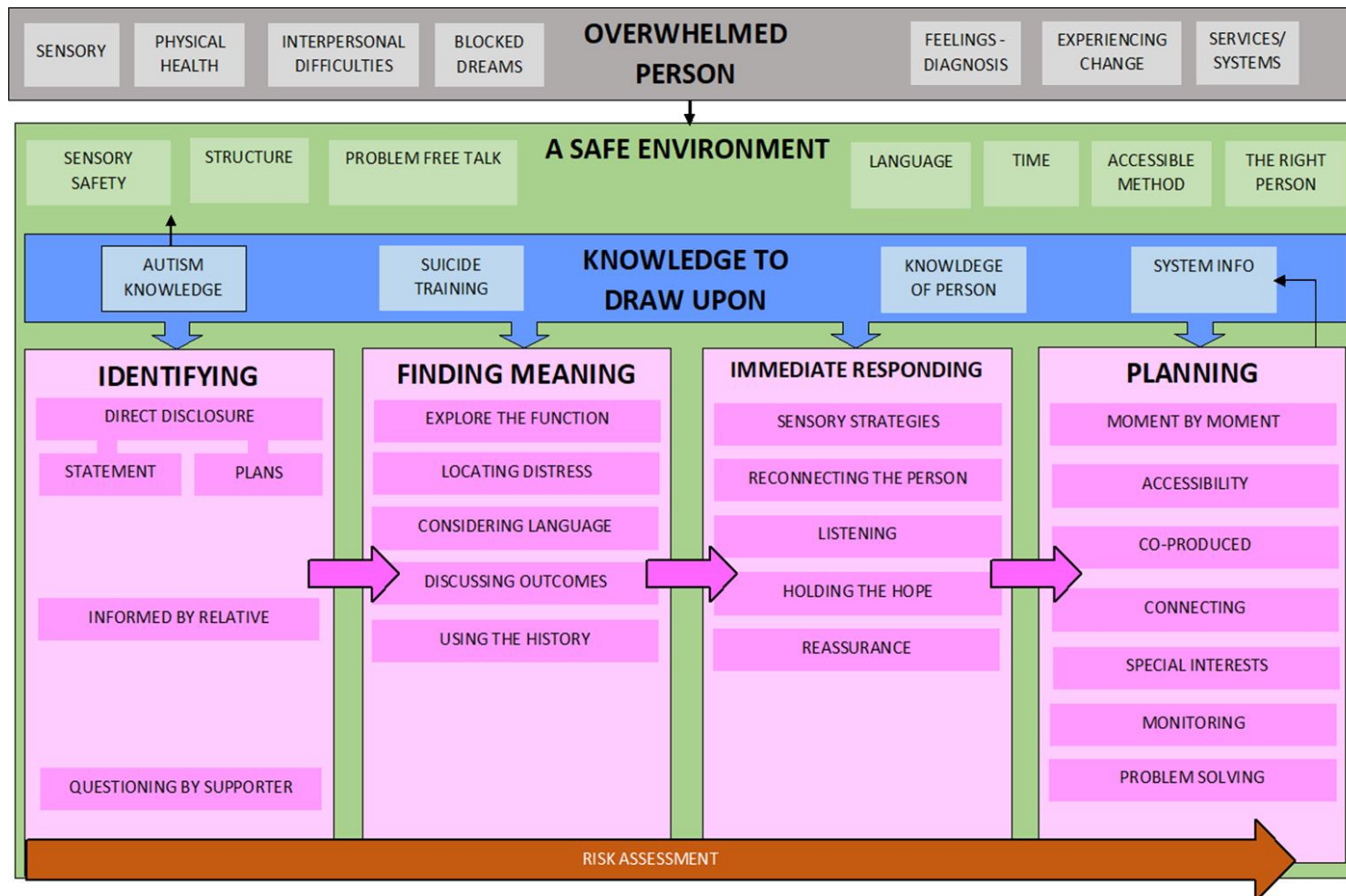
Jaymie

[Attached: early model, included in following pages]

Please send any feedback to Jaymie Huckridge: [j.huckridge1055@canterbury.ac.uk](mailto:j.huckridge1055@canterbury.ac.uk)

### Preliminary results for participants to review

From the data collected in this study, a model was developed which attempts to describe how conversations about suicidality are completed by supporters of autistic people, including professionals and non-professionals:



## **Overwhelmed person**

Participants understood that conversations about suicide were completed in the context of the autistic person being overwhelmed by various aspects of life. Experiencing change was the most commonly discussed antecedent of conversations and included experiencing and anticipating change and having difficulty problem solving when faced with these changes. Common examples included experiencing or anticipating loss, and particularly changes of routine.

Interpersonal difficulties were also a common source of distress that led to expressing suicidality. This included conflict with family members, friends, and services, as well as loneliness and isolation caused by rejection.

The autistic person's feelings towards diagnosis were related to this, with participants understanding that the person they support has an awareness of their difference. Being newly diagnosed was noted as a particularly challenging time when these feelings are prominent.

Negotiating systems was a major source of distress for autistic people, particularly trying to make sense of the benefits system, or waiting for professionals to provide support, or previous difficult experiences with services.

It was also striking that all participants shared examples of autistic individuals being overwhelmed by sensory stimulation prior to the conversation about suicide taking place. This was often the result of inappropriate environments and particularly distressing levels of light and sound in healthcare (e.g. busy ward environments) or home environments (e.g. noisy neighbours).

Blocked dreams were also frequently a precursor to discussions about suicide, where the autistic person was unable to complete a desired goal. Difficulty at university was a frequently used example, when the person did not meet their perceived academic potential or was unprepared for university life. Being unable to secure employment was also used as an example.

Physical health problems, including health conditions could also be a factor including difficulties with sleep.

## **Safe environment**

Conversations were facilitated by creating a safe environment for the autistic person to disclose their feelings of suicidality. It was understood that creating this environment allowed the autistic person to build trust so they felt relaxed, which also helped to “disarm the performance” or any “masking” behaviour they might complete. There was a feeling that conversations had taken place because the supporter was “the right person”, having established a trusting relationship with the person, having (and showing) autism knowledge.

Problem free talk was understood to be a powerful tool in creating this trust by helping to “find a way in” and “build a connection”. This particularly focused on any special interests the person might have and using humour and informality.

Creating sensory safety was understood to be central to this, considering factors such as quiet spaces, lighting, taking the person outside. Considering physical contact was also raised, with

participants being mindful of eye contact and adapting physical contact based on the persons sensory and emotional needs.

While face-to-face conversations were the main method described, participants also discussed using accessible methods particularly offering alternatives to face-to-face conversation, including writing things down, such as using scaling charts, emails, and texting the person based on their individual needs.

Providing a clear structure for the conversation, including a clear introduction outlining the aims and intentions, and allowing adequate time or using time well.

### **Knowledge**

All aspects of the conversation, from creating the safe environment to the four stages of responding, are informed by having knowledge to draw upon.

Autism knowledge and holding this knowledge in mind throughout, informing the approach, but also providing a framework for the safe environment and building trust.

System information, the most frequently discussed was having access to medical records, which provide information including autism diagnosis, and previous access of services, including previous suicidal ideation.

Knowledge of the person, their interests, their family, community, and any other identities that is also used. This included having knowledge of other aspects of their identity, including gender (including gender diversity), mental health diagnosis (particularly personality disorder), knowledge of their workplace, local community, or family situation. Some of this knowledge was from working with the individual directly, having access to the system information described previously.

Having accessed suicide prevention training, and this was generally described as providing a helpful framework for intervention and understanding the boundaries of their roles.

### **Identifying**

Most participants reported that the discovery of suicidality was the result of a direct disclosure by the autistic person at a time of distress. This was either in the form of a statement for example “I want to kill myself” and “There is no point in living”, or by sharing plans, for example “I’m going to take an overdose”.

Sometimes this disclosure was facilitated by questioning by the supporter, usually as part of a standard risk assessment or when exploring mental health history. In these cases, the autistic person continued to make direct and open statements indicating suicidality. Supporters described questioning the autistic person in a direct and ‘concrete’ way, although many expressed that they would use this approach with neurotypical people.

Another less common route to identifying suicidality was being informed by a relative of the person that they had received warning of suicide intent, verbally or in a written note.

### **Finding meaning**

Participants made great effort to explore the “function” of the autistic person’s suicidality. Many noted that this exploration most frequently found that the disclosure was often a

means for the person to express overwhelming pain and distress, rather than a clear wish to end their life.

A key process to finding meaning in the suicidality was participants making effort to locate the source of the autistic person's distress.

Knowing the history (including taking the history of suicidality) was also used to make a judgement as to the function of the suicidality and the level of risk.

Discussing outcomes, to ensure that autistic person fully understands the consequences of a suicidal act, for example sharing the physical consequences of a failed overdose, or death meaning that the autistic person will be unable to participate in their special interests.

Considering language used including continuing to use direct words and concrete examples, presenting suicidality as a scale, and reflecting back what they are noticing in the moment.

### **Responding**

Participants emphasised the role of using sensory strategies to ground the person, for example, using tools like sensory boxes, or facilitating a mindfulness exercise. "Form a cocoon" around the person ensuring that their basic needs are being met.

Reconnecting the person with their resources, including with their special interests, by taking an interest in them. Reconnecting them with coping strategies they have learned including "advice" from counsellors.

Holding the hope, by focusing on the positive and sharing stories of hope.

Reassurance was of their value in society, their strengths and skills, and that they are liked and loved.

Throughout responding it was felt that unconditional listening was the most valuable tool at the supporter's disposal, even in the face of the autistic person sharing unlikely plans or unusual ideas.

### **Planning**

Participants described completing planning with the suicidal person, to keep them safe. This plan was frequently shared with other parts of the system either through contacting another person directly and sharing it or uploading it to a record system so that it becomes part of the system information held.

Participants described planning as being 'moment by moment' problem solving, thinking about how the person might occupy themselves and ensure their basic needs are met in the short term (usually the following hours or days).

This plan is co-produced with the autistic person, encouraging their suggestions as to what it might contain so that they feel "safe, supported, heard, and cared for", checking in at the end to make sure the plan meets their needs.

This was central to ensuring that the plan is accessible to the person, by getting their view on what the barriers might be in terms of them actioning the plan independently, such as looking at alternative ways of contacting services if telephone contact is difficult. Making a visual plan,



by writing it down or drawing it out was a frequently used approach to ensure it is accessible, but also to 'remind them of the human connection' established during the conversation.

Special interests were again central to this aspect of the process, with the person being encouraged to participate in activities they enjoy.

Connecting the person to other parts of their support system was also important, for example, the GP connecting them with community resources, and the voluntary sector workers connecting them with their GP, but also including their family or other network ("low demand social interaction"). Suggesting apps, helplines and other services that they might access. Connecting also included the supporter reaching out to other people for support for themselves. The plan was connected back to the collective knowledge about the person, so that it could be drawn upon for the next conversation.

Problem solving including thinking about managing physical health, responding to sensory distress (suggesting aids such as headphones and weighted blankets), and resolve practical issues, with a focus on solutions that limit disruption or change for the person.

Ongoing monitoring was integrated into the plan, either by carefully observing the autistic person's behaviour after the event and attempting to limit time they are alone, restricting their access to means of ending their life, and offering follow-up meetings at an agreed time or date.

### **Risk assessment**

Throughout the core processes described (identifying, finding meaning, responding, planning) participants were completing a risk assessment, which then directly influenced the planning. This was felt to be complete when they had enough information about thoughts, level of intent, suicide plans, history, triggers, and protective factors.

## **Appendix P: Feedback about model from participants**

**From a voluntary sector worker:**

*Thanks so much for the update and sending over the summary of your research. I've found it accessible and easy to read (incredibly interesting too!). - The model is a great visual representation of the results and the categories reflect the key topics in conversations very accurately.*

**From a carer:**

*I was so impressed with your summary. I've read it several times, hoping to contribute something valuable, and all I can say is that I am amazed by how you have extracted logic and order from all those chaotic emotions and responses.*

***NOTE: Feedback was requested at the time of the global Covid-19 pandemic, which may account for low response rates from NHS based participants.***

**Appendix Q: Summary report for participants and stakeholders**

## **Summary report: Identifying suicidality in autistic people and discussing it with them: A qualitative study**

### **Background**

Autistic adults have increased risk of experiencing suicidality including having suicidal thoughts, making suicide attempts, and completing suicide. Current guidance and theory informing how to best identify and respond to suicidality may not be transferrable to the unique needs of autistic people, and little is known about how carers and professionals are managing these complex tasks with autistic adults they support.

### **Aims**

This research sought to explore how carers and practitioners are currently identifying and discussing suicidality with autistic adults.

### **Method**

Fifteen people who have discussed suicidality with an autistic adult took part in interviews and focus groups, including informal carers, voluntary sector workers, and healthcare professionals) including nurses, clinical psychologists, speech and language therapists, and GPs. Interviews and focus groups were transcribed and analysed using grounded theory methodology (GTM) (Glaser & Strauss, 1967).

### **Results**

The theory describes identifications of suicidality and discussions as taking place when the autistic person is **overwhelmed**, by experiencing change, interpersonal difficulties, their feelings towards diagnosis, negotiating systems and services, sensory stimulation, thwarted goals, and physical health problems.

For these discussions to happen, the autistic person is provided with a **safe environment**, with “the right person”, with the supporter using problem free talk,

creating sensory safety and providing accessible methods of engagement, a clear structure, and allowing adequate time or using time well.

All aspects of the conversation, from creating the safe environment to the four stages of responding, are informed by having **knowledge** to draw upon. This includes, autism knowledge, system information, knowledge of the person, and having accessed suicide prevention training.

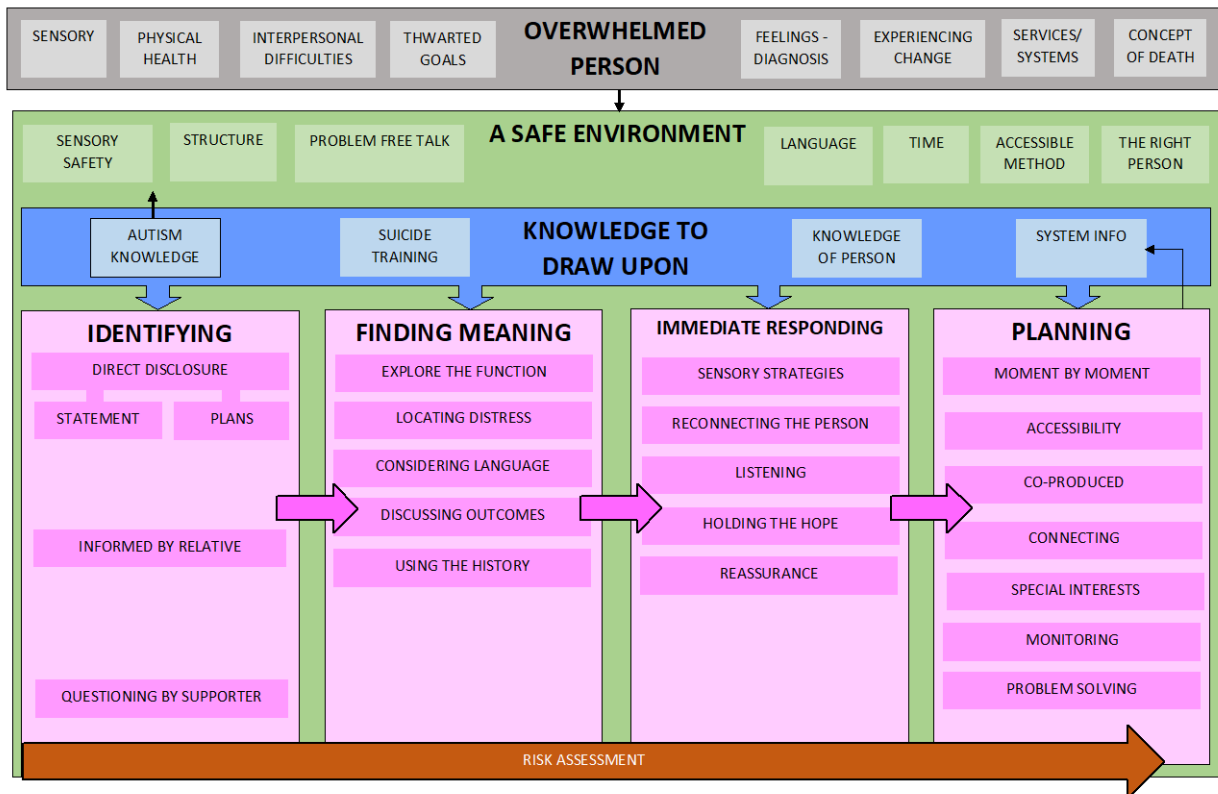
Most participants reported that **identifying** suicidality was the result of a direct disclosure by the autistic person at a time of distress, and that sometimes this disclosure was prompted by questioning by the supporter, usually as part of a standard risk assessment or when exploring mental health history. A less common route to identifying was being informed by a relative of the person that they had received warning of suicide intent, verbally or in a written note.

Participants made great effort to **find the meaning** of the person's suicidality, by exploring the "function", locating the source of the autistic person's distress, knowing the history, discussing outcomes, and considering language.

Participants provided an **immediate response** by using sensory strategies to ground the person, reconnecting the person with their resources, holding the hope, offering reassurance and unconditional listening.

Participants described completing **planning** with the suicidal person, to keep them safe, which was done 'moment by moment', co-produced with the autistic person, checked for accessibility, and including the person's special interests. Connecting the person to other parts of their support system was also important, and problem solving was also understood to be important. Ongoing monitoring was integrated into the plan.

Throughout the core processes described (identifying, finding meaning, responding, planning) participants were completing a **risk assessment**, which then directly influenced the planning. The following model shows how these different aspects are connected:



### Selected clinical implications

- Ensuring assessment of the needs of autistic individuals, for early identification of support needs, so that practical and emotional issues can be promptly addressed before reaching ‘breaking point’.
- Offering accessible methods of engagement and having resource to provide these (e.g. mobile phones for texting, tablet computers, guidance around using email, drawing materials, sensory boxes).
- Ensuring adequate time to “get to know the person”.

- Information on how best facilitate communication and engagement for the individual is key and should be readily available on NHS records.

### **Selected implications for policymakers and commissioners**

- Training around suicide and wellbeing should include autism specific guidance.
- Developing platforms for sharing information between individuals and organisations, or making information 'person held'.
- Holding in mind sensory needs when designing service environments.
- Increase awareness amongst employers and educational establishments on good practice in supporting autistic employees and students.

### **Selected research Implications**

- While the ethical implications would need to be carefully considered, it would also be helpful to interview autistic people themselves, as well as supporters who have been in contact with autistic people who have completed suicide.
- Consideration of how different characteristics might affect how suicidality is approached for both supporter and the autistic person.

**Jaymie Huckridge**

**Trainee Clinical Psychologist**

**Supervised by Dr Julie Steel and [REDACTED]**

### **References**

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. London: Routledge.

**Appendix R: MRP Information Sheet**

Name of Trust/location:



Type of project: Major Research Project

Year completed: 2020

Title: Experiences of responding to suicidality

Trainee: Jaymie Huckridge

Supervisors: Dr Julie Steel, [REDACTED]

**Section B Abstract:**

Autistic adults have increased risk of suicidality, and little is known about how the people who support them identify this or discuss it with them. Fifteen people who have discussed suicidality with an autistic adult took part in interviews and focus groups, including carers, voluntary sector, and healthcare staff. A theory generated using grounded theory methodology (GTM) found discussions take place when autistic people feel overwhelmed and are provided with safe environments to express distress. Supporters draw upon various knowledge as they negotiate processes of identification, exploring meaning, providing immediate response to reduce distress, and planning. Risk assessment runs parallel to these processes. Results are discussed in relation to theories of suicidality and their implications for clinical practice and research.

Key words: *autism, suicide, suicidality, grounded theory*

**Awards available for MRPs: please complete boxes below**

The following awards are available to MRPs receiving a Pass or Pass with Minor Corrections on first submission within this academic year (01 August to 31 July). MRPs can be considered for more than one award, but will not receive more than one award. Please indicate below which awards your MRP can be considered for.

Eligible?	Award details
No	My MRP is in the area of Children, Young People or Families* and can be considered for the <i>Lucy Fildes Award for best research relating to Children, Young People or Families</i> (NB this award is available to all doctorate project within the Salomons Institute, including PhDs) <i>*MRPs on Families do not need to be Child or YP-based</i>



Yes	My MRP employs qualitative methods in a significant element of the work and can be considered for the <i>Paul Camic Award for Best Qualitative Research</i>
Yes	Available to all MRPS: <i>Lavender Award for Research that Makes a Difference</i>

**Appendix S: Letter to Research Ethics Committee confirming study has ended**

*Removed from electronic copy.*

**Appendix T: Letter to R&D department confirming study has ended**

*Removed from electronic copy.*

**Appendix U: Notes for submitting to the Journal of Autism and Developmental Disorders**

**Instructions for Authors**

**Editorial procedure**

**Double-Blind Peer Review**

**MANUSCRIPT FORMAT**

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.

## APA Style

Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The blinded manuscript containing no author information (no name, no affiliation, and so forth).
- The Author Note

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## Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- Commentary: Approximately 20-25 double-spaced pages maximum, with fewer references and tables/figures than a full-length article.
- A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.

- A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures.

Style sheet for Letter to the Editor:

- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The blinded manuscript containing no author information (no name, no affiliation, and so forth):-

- 6 or less double spaced pages with shorter references, tables and figures

- Line 1: "Letter to the Editor"

- Line 3: begin title (note: for "Case Reports start with "Case Report: Title")

- Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

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### **Review your manuscript for these elements**

#### 1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Blinded Manuscript without contact information and blinded Abstract, and References

Appendix

Figure Caption Sheet

Figures

Tables

Author Note

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### **Manuscript Submission**

#### **Manuscript Submission**

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

#### **Permissions**

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

#### **Online Submission**

Please follow the hyperlink “Submit online” on the right and upload all of your manuscript files following the instructions given on the screen.

Please ensure you provide all relevant editable source files. Failing to submit these source files might cause unnecessary delays in the review and production process.

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#### **Title page**

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone and fax numbers of the corresponding author

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### **Abstract**

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

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### **Keywords**

Please provide 4 to 6 keywords which can be used for indexing purposes.

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### **Text**

#### **Text Formatting**

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

### **Headings**

Please use no more than three levels of displayed headings.

## **Abbreviations**

Abbreviations should be defined at first mention and used consistently thereafter.

## **Footnotes**

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

## **Acknowledgments**

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

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## **Body**

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
  - Introduction (The introduction has no label.)
  - Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
  - Results (Center the heading.)
  - Discussion (Center the heading.)



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## **Headings**

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

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## **Footnotes**

Center the label "Footnotes" at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

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## Author Note

The first paragraph contains a separate phrase for each author's name and the affiliations of the authors at the time of the study (include region and country).

The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".)

The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study.

The fourth paragraph states, "Correspondence concerning this article should be addressed to..." and includes the full address, telephone number and email address of the corresponding author.

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## Terminology

- Please always use internationally accepted signs and symbols for units (SI units).

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## Scientific style

- Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.
- Please use the standard mathematical notation for formulae, symbols etc.: *Italic* for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) **Bold** for vectors, tensors, and matrices.

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## References

### Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

Ideally, the names of six authors should be given before et al. (assuming there are six or more), but names will not be deleted if more than six have been provided.

### Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

- Journal article Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. *Journal of Film Writing*, 44(3), 213–245.
- Article by DOI Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. *Journal of Molecular Medicine*, <https://doi.org/10.1007/s001090000086>
- Book Calfee, R. C., & Valencia, R. R. (1991). *APA guide to preparing manuscripts for journal publication*. Washington, DC: American Psychological Association.

- Book chapter O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), *Gender issues across the life cycle* (pp. 107–123). New York: Springer.
- Online document Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association.  
[http://www.psych.org/edu/other\\_res/lib\\_archives/archives/200604.pdf](http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf)  
. Accessed 25 June 2007.

For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

[EndNote style \(Download zip, 4 kB\)](#)

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