

# The Power of the Voice of Women with Autism Spectrum Disorder (ASD): Their life experiences in their transition out of college

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### Introduction & Background

The past decade has seen a rise in the number of students with ASD arriving in higher education. In more recent times, we have seen an increase in the number of studies exploring the challenges facing students with ASD as they navigate the university environment (Quinn, Gleeson & Nolan, 2014; Anderson et al, 2017; Gelbar, Smith & Reicho, 2014; Glennon, 2001).



Figure 1. Challenges facing students with ASD within university.

Higher education plays an important role in preparing persons for employment and life opportunities (Briel & Getzel, 2014), however there is very limited research or literature exploring the outcomes for these university students as they graduate and progress from higher education (Howlin & Taylor, 2015). Of the evidence that does exist, no spotlight focuses on adult women with ASD who have successfully graduated from higher education. Much knowledge is anecdotal or autobiographical in nature, with little known about their needs, leading to a lack of support and understanding. What is known, shows that women with ASD are subjected to systemic disadvantage in most areas of their lives, they experience exclusion socially, in their personal lives, and in access to healthcare.

With more and more women being diagnosed with ASD worldwide, it is important that we begin to consider this large cohort of women and explore their needs, their life challenges and their experiences. Such a call has been identified by the autism community as a key problem to be addressed by research (Pellicano et al. 2014).

Autistic voices can be crowded out by professionals who see ASD through their own experience. Therefore, with an evident gap existing within the literature exploring the needs of this marginalised group in society, this research aims to better understand the everyday life and occupational experiences of these women with ASD at the 'high functioning' end of ASD, who appear to face particular challenges which are currently unknown.

### Aim

Therefore, the aim of this poster and the research is to address the gap in the literature, and endeavours to explore the life experiences of women living with ASD, who have progressed through higher education. It seeks to better understand their transition experiences out of higher education and explore whether their diagnosis of ASD impacts on their transition, their future prospects and their everyday life.

### Methodology

In order to truly explore the life experiences of the women, a research methodology that would centralise the women's voices, give essence to their life, and allow for multiplicity of meaning and experiences was essential and as a result a qualitative method was employed.

### Philosophical Framework: The Feminist Approach

A feminist approach was chosen as the guiding philosophical framework. The approach influences all stages of the research, from the topic, to the design, the process and the outcomes. The study focuses on the needs of women and their realities and is specifically designed for women, rather than just being about them (Peters, Jackson & Rudge, 2007). The women in the research are considered 'experts' in their own lives and are empowered within the research process (Ollivier & Tremblay, 2000). The aim is to help create a sense of empowerment for these women with ASD who have been marginalised within society, where the dominant discourse focuses on men with ASD (Kirkovski et al. 2013). It creates a platform from which their voices can be heard, and moves beyond 'knowledge for its own sake' but using the knowledge for change and power (Patton, 2002, p. 129).

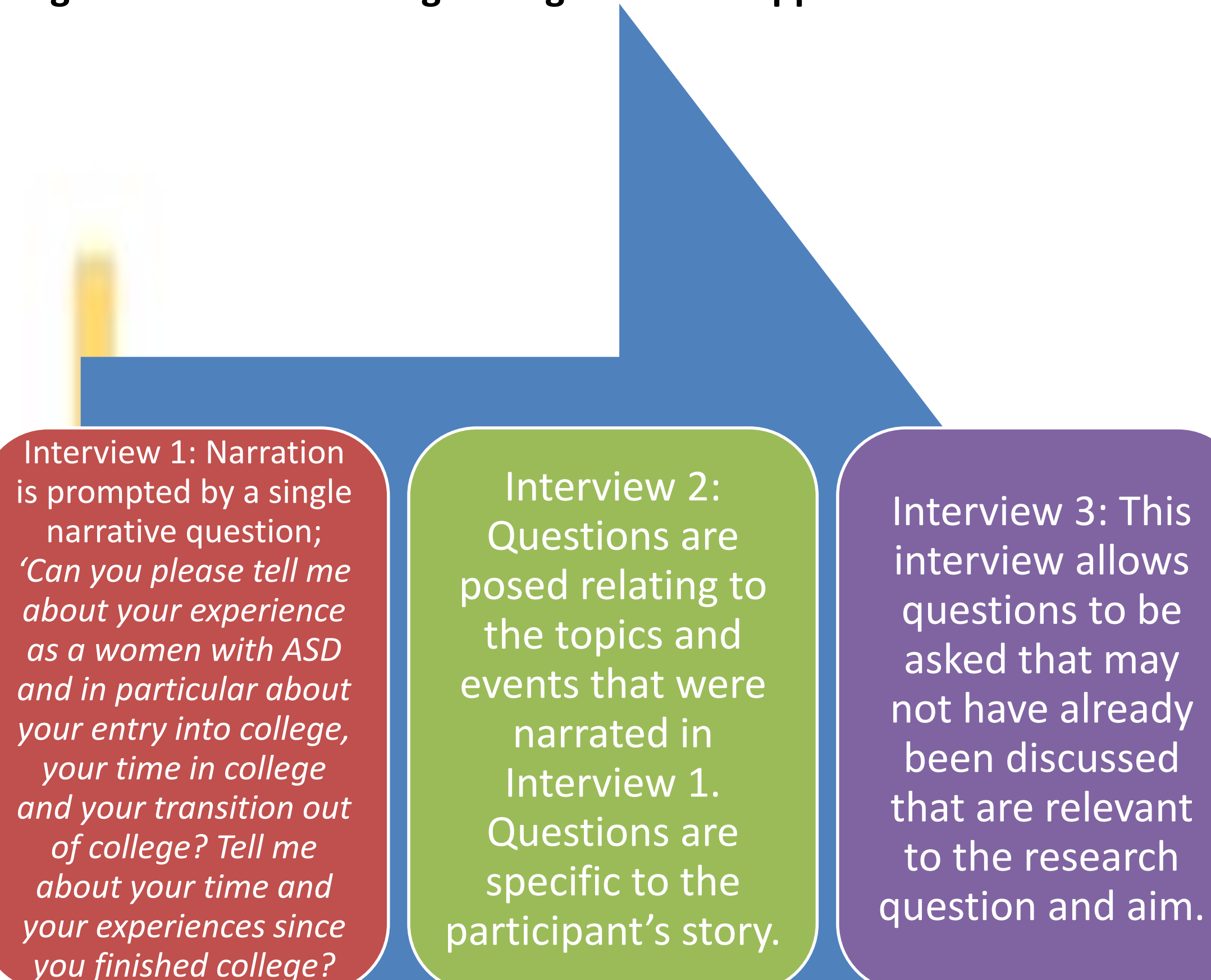
### Research Design

The **Narrative Inquiry** approach was chosen as the research method to best answer the guiding research questions and allows the voice, the stories and the deep experiences of the women to be heard.

*Narrative Inquiry provides an approach for understanding human experience that is consistent with the ways in which individuals make sense of their shared lived experience (Gergen, 1994, 1999).*

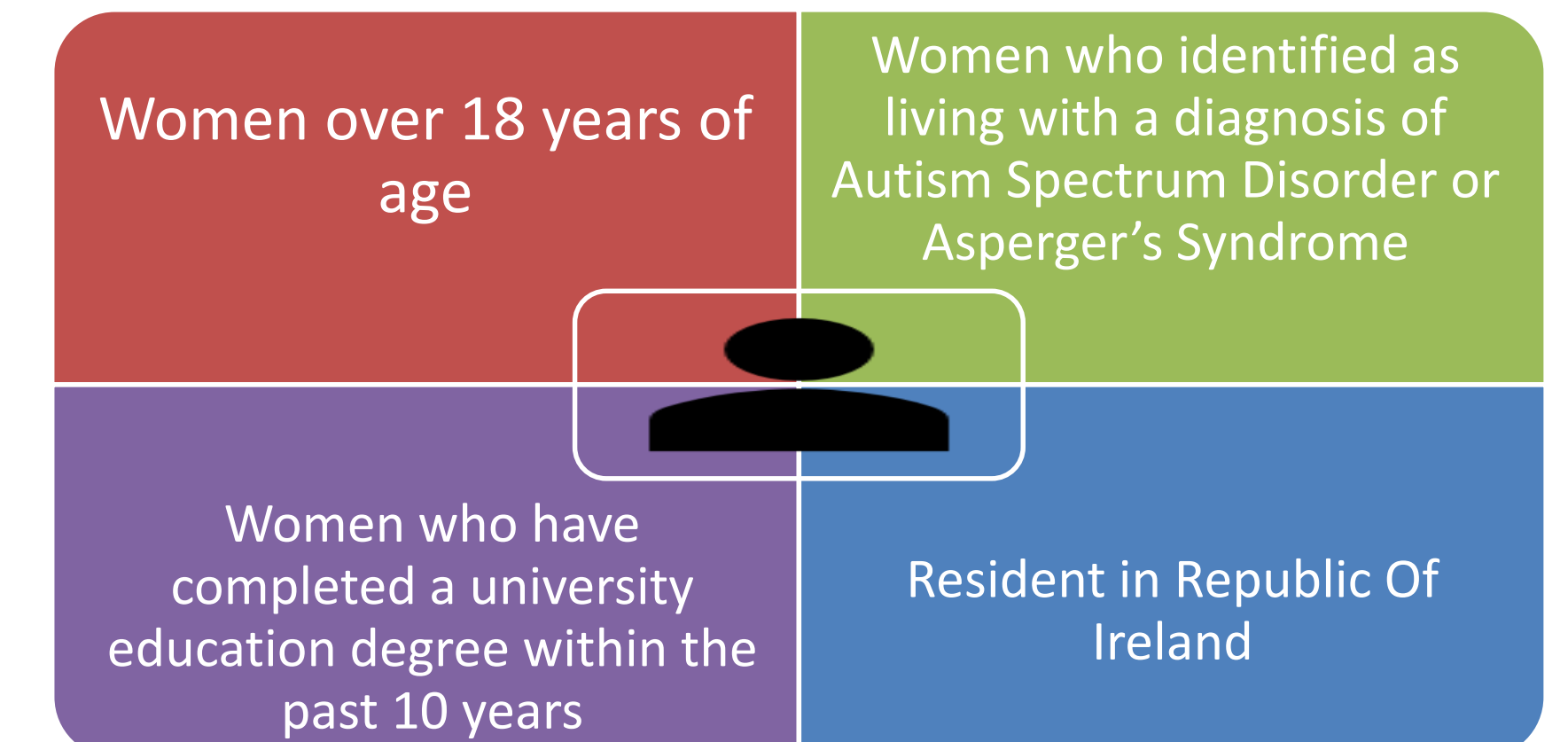
The Biographic-Narrative Interpretive Method (BNIM) developed by Chamberlayne, Bornat and Wengraf (2000) was chosen as a method as it offers a method for both data generation and collection using the specific BNIM interview technique, and also offers an analytical technique for analysis of the narratives (Wengraf, 2006). The study utilised three interviews to seek the experiences of the women and the format is detailed below:

Figure 2: Research Design using the BNIM approach.



### Sampling

A **purposive sample** of 20 women was selected for this Study. Inclusion criteria were:



### Results

The study is currently ongoing, some of the initial themes that are emerging are identified below:

Themes emerging	Sub-themes emerging
<b>Difficult Transitions</b>	Finding a job –unemployment Floating at sea-waiting for something to happen Life is everywhere-no pattern Struggle with life situations-anxious with new things
<b>Mental Health issues emerging</b>	Drank a lot Admitted to hospital
<b>Managing Social relationships and communication</b>	Like an alien Never made friends Wanted to find my husband Fired by my boss-miscommunication
<b>Busy world</b>	Sensory difficulties Tonnes of voices
<b>Questioning everything...</b>	What I was studying? What I was doing in work? Need to change things Why I needed to get good grades? Expectations...

When all the data is collected each participants story will be co-constructed into their own story and further thematic analysis of the women's experiences will be generated.

The initial findings highlight the diverse and distinctive challenges faced by women with ASD; including mental health difficulties, unmet support needs in education settings and the workplace, and challenges with managing social interactions and relationships. Their life stories are truly unique and highlight the need for all health professionals to work in a client centered way to best support the needs of these women.

### Conclusion

Given that women with ASD are a burgeoning population, we must consider that we need to address their needs and listen to voices.

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