

INPLASY PROTOCOL

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None declared.

Exploring the resilience of adults with autism spectrum disorder: A Scoping Review protocol

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Review question / Objective: This review aims to explore resilience in the context of autistic adults. To fulfil this aim, the review has the following objectives:

- To explore how adults with autism experience and perceive their resilience.
- To identify how empirical research has defined and measured resilience in populations of adults with autism.
- To identify how resilience in autistic adults can be understood in terms of the resilience process.
- To identify factors that can support the resilience of adults with autism.

Condition being studied: Autism is a lifelong neurodevelopmental condition that has core features of intense interests, affective and social interaction difficulties, and a preference for repetitive behaviours (American Psychiatric Association, 2013). Resilience has been defined as an outcome, and/or a process through which people use resources to adapt positively to adversity, stress, or trauma (Windle, 2011).

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 08 April 2022 and was last updated on 08 April 2022 (registration number INPLASY202240049).

INTRODUCTION

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- To identify factors that can support the resilience of adults with autism.

Rationale: To our knowledge, the literature on resilience pertaining to autistic adults has not been systematically examined. Currently it is unknown, how resilience is experienced and defined by autistic adults. It is also unknown how the concept of resilience has been operationalised and measured in this context of autistic adults.

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METHODS

Search strategy: The following databases, PubMed, PsychInfo, Scopus, Web of Science, and Cinahl, will be searched, for titles and abstracts. Searches will use the following key words, and they associated MeSH terms: ‘autism’ OR ‘autistic’ OR ‘pervasive Develop*’ OR ASD OR ‘Asperger*’ OR ‘autism spectrum disorder’ AND Adult*OR grown-up OR mature OR old* AND Resilien* OR Adapt* Bounce back* OR accept* OR cop* OR Adjust* OR ‘protective factors’. In addition, the following journals will be hand searched for items that meet the eligibility criteria: Journal of Autism and Developmental Disorders, Autism, Autism and Research.

Participant or population: The review will include empirical studies that involve participants who are diagnosed with any type of autism with or without common comorbid conditions that include intellectual disability, ADHD. Studies will be included if they also include participants without autism. The data from people who are examined as neurotypical ‘controls’ will

be included in the review. Where other populations are included however, who don’t have autism, there will be an attempt to isolate the data of the autistic people.

Intervention: This review does not focus on the examination of interventions. It will include studies that focus on resilience. It will not include studies that focus on related constructs for example: self-efficacy and hardiness.

Comparator: This review does not involve comparators.

Study designs to be included: Studies that use any design including qualitative, quantitative, or mixed methods will be included.

Eligibility criteria: Studies will be included if they are empirical studies, of any design and methodology, that involve people diagnosed with any type of autism with or without common comorbidities. Participants must be over 18 years and the studies must focus on resilience. Studies that do not meet the inclusion criteria will be excluded as will papers that focus on concepts related to resilience.

Information sources: Empirical studies published as journal articles, dissertations, and conference presentations, that are identified from the electronic databases and handsearching. The grey literature will not be searched. Authors may be contacted to obtain data on autistic adults who are involved in studies that report mixed populations.

Main outcome(s): This review examines the concept of resilience. Therefore the main outcomes are resilience and positive adaption.

Additional outcome(s): Additional related outcomes may be revealed as a result of examining the resilience literature, including: quality of life. Self-efficacy, Educational attainment, Employment, Social Participation.

Data management: Items identified through the searches will be downloaded to Endnote. Four authors working independently will be involved in selecting studies for inclusion, screening them for eligibility. Then, they will meet to discuss their agreement. If disagreements cannot be resolved through discussion, another researcher who is knowledgeable on the review topic and the methodological processes will review the item and determine its eligibility.

Quality assessment / Risk of bias analysis: The strengths and weaknesses of included studies will be assessed using The Critical Appraisal Skills Programme checklists. These will be used to determine the risk of bias, inconsistency, publication bias, imprecision, etc. CASP has been recommended by the World Health Organisation (Noyes et al, 2017). Two researchers will work independently of one another will appraise the papers using CASP. They will then meet to review and discuss together the results of their appraisals. If there is disagreement between them about their appraisal, a third researcher who is knowledgeable about using CASP and a topic expert, will review the results and determine through discussion the final result.

Strategy of data synthesis: Independently two researchers will work to extract the study data into a bespoke table that identifies the following: Study ID, country of research; aim of study; participant details; diagnosis of autism; how resilience was defined; measured, methods used, results, and conclusion. The two researchers will work together to confirm the accuracy of data extraction. Two researchers will work independently to identify themes that are relevant to the review aims, through repeated examination of the extracted data. These researchers will then discuss the initial themes with a third researcher and the themes will be finalised.

Subgroup analysis: It is unlikely that there will be need for subgroup analysis in this review.

Sensitivity analysis: There is no need to predetermine the sensitivity of analysis in this review.

Language: English.

Country(ies) involved: Ireland and USA.

Keywords: ASD ; Autism Spectrum Disorder ; Asperger's ; Adversity; Positive psychology; Adaptation; Resilience; Resiliency.

Dissemination plans: The review results will be published in a peer review international journal and presented at a conference.

Contributions of each author:

Author 1 - Sally Whelan - Author 1 conceived the review; designing the review; coordinating the review; data management; analysis of data; interpretation data; writing the protocol and review.

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Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., ... & Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of clinical epidemiology*, 97, 49-58.

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