

Resilience in Children and Young People with Disabilities: A Systematic Review with Embedded Primary Research

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Background

As research into resilience is gaining momentum, policy makers and practitioners are showing an increasing interest in the concept of resilience and its influence on quality of life¹. There is however, little focus on resilience and children with disabilities. Children with disabilities are considered more vulnerable², and at higher risk of adversity (including from their disability itself) and from abuse by others. It is important, therefore, to develop an initial evidence base by exploring the concept of resilience in the context of children with disabilities, by reviewing existing literature and current policy documents relating to children with disabilities.

Design

A mixed method systematic review design will be used to address each aspect of the review. This will be based on the Evidence for Policy and Practice Information and Co-ordinating (EPPI) Centre (Institute of Education, London) and the EPPI Centre Guidance³. The evidence will be in four streams; policy, conceptualisation, interventions and measures.

Review Streams and Questions

Aim: The aim of this systematic review is to conceptualise resilience in relation to children with disabilities. The systematic review will consider national policies, interventions and measures, in order to aid the understanding of the concept of resilience and address the following questions:

Stream 1: General Literature

1. How does mixed method evidence conceptualise resilience?

Stream 2: Policies

1. What do the policies say about resilience and children with disabilities?
2. How does this relate to the conceptualisation of resilience?
3. How does this relate to the programme theory underpinning the policy?

Stream 3: Measures

1. What tools are being used to measure resilience?
2. What concept of resilience is underpinning the tools?
3. What are the psychometric properties of the measures found?

Stream 4: Interventions

1. What interventions have been developed and tested to promote resilience for children with disabilities?
2. What concept of resilience has been used in these interventions?
3. What is the programme theory underpinning these interventions?

Quality Screening Exercise

Systematic and extensive searches of CINAHL (1980 to 2011), MEDLINE (CSA EARLIEST to 2011), psychINFO (CSA earliest to 2011), ASSIA (Earliest to 2012), Ovid Nursing Full Text Plus (1995 to 2012), Cochrane Library, Web of Knowledge, Google/Google Scholar, websites, references from journals.

Searches of policy documents, best guidance documents and websites using PDF searches of previously agreed search terminology.

Systematic and extensive searches of CINAHL (1980 to 2011), MEDLINE (CSA EARLIEST to 2011), psychINFO (CSA earliest to 2011), ASSIA (Earliest to 2012), Ovid Nursing Full Text Plus (1995 to 2012), Cochrane Library, Web of Knowledge, Google/Google Scholar, websites, references from journals.

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In Depth Appraisal (CASP) – Excluding policy documents

Documents/journals or websites, which include evidence to conceptualise resilience in relation to children with disabilities.

Policy documents, which include information of resilience in relation to children with disabilities

An assessment of the psychometric features of measures not included in Windle, Bennett & Noyes review⁴ and a description of previous measures used for measuring resilience in children.

Quantitative/ Qualitative and mixed method studies which include an intervention to promote resilience for children with disabilities.

Mixed Method Synthesis

Synthesis 1
1. Quality assessment
2. Data extraction
3. Findings

Synthesis 2
1. Data extraction
2. Findings

Synthesis 3
1. Quality assessment
2. Data extraction
3. Findings

Synthesis 4
1. Quality assessment
2. Data extraction
3. Findings

Synthesis Objectives

1. Does the concept of resilience in the literature match the definitions and programme theory of resilience upon which policies are based?

2. Does the concept of resilience in the literature match the definitions and programme theory behind the interventions that promote resilience?

3. Does the concept of resilience in the literature match the definitions and theory behind the measures?

Primary Research – focus group, small group or individual interviews with children and young people with disabilities to establish:

What are the views of children and young people with disabilities on resilience and what does resilience mean to them?

Overarching Synthesis of findings to answer each review question and aim:

1. To what extent do children and young people's views and meanings of resilience collected in primary research map onto current concepts and definitions in the literature?
2. What are the views of children and young people with disabilities on current resilience promoting interventions, and do their views and experiences match with the programme theory and logic of interventions reported in the literature?
3. If designing a new resilience promoting intervention for children and young people with disabilities, what do children and young people think would work and what would the intervention look like?