

**RESILIENCE-BUILDING WITH DISABLED CHILDREN AND YOUNG PEOPLE:
A REVIEW AND CRITIQUE OF THE ACADEMIC EVIDENCE BASE**

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Abstract: The aim of this paper was to review published accounts of resilience-based approaches with and for disabled children and young people aged up to 25 years. The review is part of a broader study looking more generally at resilience-based interventions with and for young people. The authors attempt to summarise the approaches and techniques that might best support those children and young people who need them the most. However, when compared to the number of evaluated resilience-based approaches to working with typically-developing children and young people, those including children and young people with complex needs are disappointingly lacking. Of 830 retrieved references, 46 were relevant and 23 met the inclusion criteria and form the body of this review. They covered a variety of intervention content, setting, and delivery, and diverse children and young people, making comparative evaluation prohibitive. The difficulties in identifying suitable resilience-based interventions are discussed, together with the authors' iterative approach, which was informed by realist review methodology for complex social interventions. The review is set into a context of exclusion, an ableist mindset and the political economy of research. It also provides recommendations for future research and practice development in this field.

Keywords: resilience, intervention, disability, young people, review

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Resilience may be usefully viewed as positive development despite adversity (see Hart, Blincow, & Thomas, 2007; Masten, 2011; Rutter, 2006; Ungar, 2012). Hart et al. (2007) suggest that “resilience is evident where people with persistently few assets and resources, and major vulnerabilities ... have better outcomes than we might expect given their circumstances, and in comparison to ... other children in their contexts” (p. 10).

There is a vast academic literature on resilience-building with children and young people, and the benefits and outcomes of interventions or programs designed to enhance specific or general aspects of their resilience. These include concrete progress, such as improved confidence, coping and self-esteem, and less measureable outcomes, such as doing better than expected, or simply maintaining the status quo (Hart et al., 2007). These benefits are of particular importance to children and young people with disabilities, who face additional adversity, disadvantage, and challenges to their development. The purpose of the review is to summarise which resilience interventions were effective in enhancing resilience, and with what populations, with a focus on whether and how children and young people with disabilities were included in academic studies of explicit resilience-building approaches. Prior to interrogating the evidence base, this article sets out why it focuses on children and young people with disabilities and the enhancement of resilience, how we define disability, and the approach used to conduct the review.

There is a strong link between disability, exclusion, and socioeconomic inequality (Hosseinpoor et al., 2013), and the implications for children and young people with disabilities depend on the nature of their disability, where they live, their culture, socioeconomic status, and gender (United Nations Children’s Emergency Fund [UNICEF], 2013b; van Campen & van Santvoort, 2013). Figures show that in particular, education, training, and employment opportunities for girls with disabilities are fewer than for girls without disabilities, and even boys with disabilities (Groce, 2004). Children with long-term illnesses or disabilities have been shown to underperform in educational attainment, maths, verbal and non-verbal skills, at age seven, compared to their non-disabled peers (Jones, Gutman, & Platt, 2013). Contact a Family (2013) recently reported that children with disabilities experience illegal exclusions from school on a regular basis in England and Wales.

Young people with neurodevelopmental conditions, learning or mental health difficulties, in the United Kingdom, United States, and Canada, are more likely to go to prison than other young people because the youth justice system is failing to recognise their needs (Doob & Cesaroni, 2004; Hughes, Williams, Chitsabesan, Davies, & Mounce, 2012; Odgers, Burnette, Chauhan, Moretti, & Reppucci, 2005; Talbot, 2010). Swedish adolescents with disabilities are more likely to experience psychological symptoms (Brunnberg, Lindén Boström, & Berglund, 2007) and abuse, such as force at sexual debut, than adolescents without disabilities (Brunnberg, Lindén Boström, & Berglund, 2012). A study from Switzerland compared the prevalence and intensity of victimisation from bullying and found higher rates of teasing, physical aggression, and social exclusion for adolescents with chronic conditions compared to young people without chronic conditions (Pittet, Berchtols, Akre, Michaud, & Suris, 2010). Young people with a learning difficulty may also be at increased risk of substance misuse, which Cosden (2001) suggests may be a negative coping strategy related to the developmental need for family support over a longer period of time, increased difficulty in making friendships with peers, and a lack of understanding of the effects of their own disability. The general pressures of living in an ableist society are also likely to contribute.

The World Health Association (WHO) considers participation in age-appropriate activities to be *essential* for understanding functioning of children with disabilities (WHO, 2007). It also improves children's social relationships, academic performance, mental health, physical health, and skills and competencies (Forsyth & Jarvis, 2002; Janssen & Leblanc, 2010; Mâsse, Miller, Shen, Schiariti, & Roxborough, 2013). However, it is clear that children and young people with disabilities are often excluded from activities others take for granted, many of which can help to build resilience. For example, Mâsse et al. (2013) found that in Canadian schools, children with a range of disabilities were restricted from participating in educational, physical, and social/recreational activities such as art/music lessons or summer camp, particularly if they were from poorer families or had more severe disabilities.

Perusing the resilience literature, it seems to us that most academic research is conducted from a psychological or medical view of disability (e.g., Lee et al., 2009; Storch et al., 2012), instead of a social model of disability (e.g., Evans & Plumridge, 2007; Runswick-Cole & Goodley, 2013). Some have even critiqued the concept of resilience itself, for making implicitly ableist assumptions and being conflated with normative perspectives on health (Hutcheon & Wolbring, 2013). This is clearly a contested area, hence an important question to consider is what is meant by *disability*, and how it will be defined and measured relative to this review, in order to answer the question: whether and how children and young people with disabilities are included in academic studies of explicit resilience-building approaches.

In writing this paper our interest in resilience from a disability perspective, as researchers, parents, and practitioners, arises in part from our personal circumstances. Our group of seven includes adults who identify as having disabilities, parents of children with complex needs, and practitioners who work day-to-day with disabled children and young people. Exploration within our team revealed 25 conditions or differences perceived by society as disabilities, including physical disabilities, neurodiversity, sensory impairment, chronic medical conditions, learning difficulties, and mental health difficulties.

Method

According to the WHO (2012):

'Disabilities' is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.

Whilst this is the definition of disability we are using, we cannot do it justice because it rendered our search unfeasibly large. The issue of defining "disability" is itself subjective, multifarious, and incredibly nuanced. It has implications for those who do or do not fit a particular definition, and corresponds to a vast and growing disability studies literature from a variety of theoretical perspectives (e.g., Salvador-Carulla & Gasca, 2010; Schalock & Luckasson, 2013). Understandably, the way that disability is defined can affect the research findings (Grönvik, 2009), but including a wide range of disability-related search terms made the search broad and non-specific. Therefore we took a pragmatic approach. Disability in this review was conceived to include children and young people fitting the WHO (2012) definition of disability, but in particular those with physical disability, severe or chronic physical or psychiatric illness, and learning difficulty, mostly referred to in the research base

as learning, cognitive, or intellectual disability, despite preference of the term “learning difficulties” by self-advocates who have them (Goodley, 2005).

Limited time and resources made a wider search impractical. Therefore we did not specifically include mental health/illness search terms, which themselves return a vast number of results. This is in part due to the popularity of “well-being” programs and the perceived preventative nature of resilience interventions aimed at preventing depression, anxiety and stress, and increasing socio-emotional competence in typically-developing children and young people with average levels of need. The aim of our review was not to look at broad interventions aimed at the mental health of the general population, but those focused specifically on children and young people with the most long-term and complex needs.

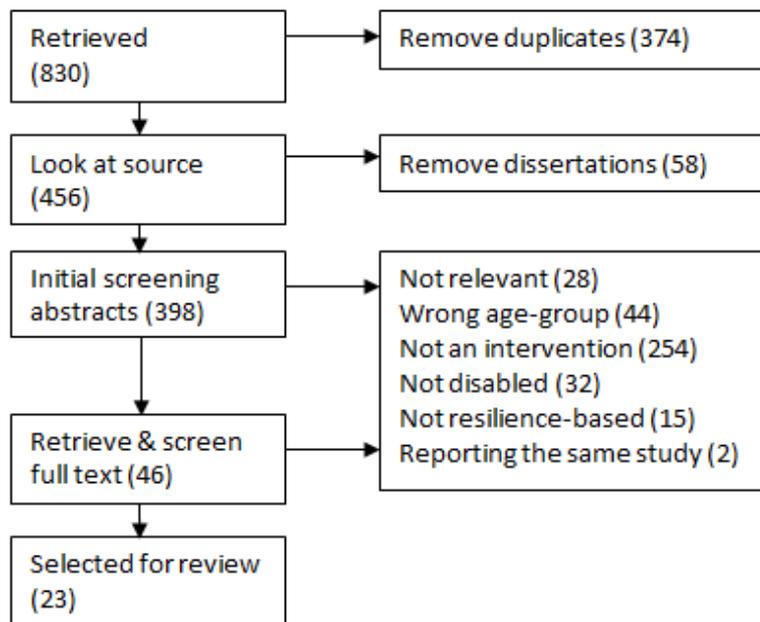
Our review methodology grew out of the “realist” review approach for complex social interventions (Pawson, Greenhalgh, Harvey, & Walshe, 2005), which aims to identify what works for whom, in what circumstances, in what respects and how. Resilience-enhancing interventions generally do not suit a traditional review approach due to a lack of comparable elements. We formulated some broad aims in consultation with the parents and practitioners with whom we regularly work, and incorporated these into an iterative, flexible approach outlined below (as per Hart & Heaver, 2013).

A parsimonious search was made using disability search terms (disabl* OR disabilit* OR autis* OR chronic OR EBD OR severe) in conjunction with resilien* AND (youth OR young OR child* OR adolescen*). Additional search terms (e.g., “complex”, or terms relating to specific acquired and congenital conditions and disabilities, sensory impairment, psychiatric illness, neurodiversity or learning difficulties) *did not* increase the number of (relevant) results; therefore it was concluded that these concise terms were sufficient, and would be included in most papers concerning children and young people with a disability. Children and young people with what is generally termed “severe” mental health or behavioural problems were captured by inclusion of the search terms “severe” or (psychiatric) “disability”. The authors assessed whether or not papers included evaluated interventions on the basis of the abstract, rather than through search terms, as many unsuitable articles include the word “intervention” in the abstract referring to future directions.

Articles were initially retrieved from the literature by searching EBSCO databases (AMED, British Nursing Index, CINAHL, Criminal Justice Abstracts, eBook Collection, E-Journals, PsycARTICLES, PsycINFO, SPORTDiscus), Expanded Academic ASAP, AEI, BEI, ERIC, IBSS, PubMed, Web of Science (incl. Medline), ScienceDirect, and Swedish databases Artikelsök and SwePub, for articles between 2000 and 2013, which included resilience keywords in the title, and keywords related to disability and age group in the abstract. The search for articles emanating from the Nordic countries produced no results. Articles originated from countries including U.S.A., Canada, Hong Kong, South Africa, Taiwan, Mexico, Wales, Japan, Germany, and France, and were mostly written in English. Additional publications were identified in an iterative process via Google Scholar, hand searching reference lists, and discussion with colleagues.

The authors screened 398 of the 830 retrieved references, and identified 46 documents as relevant on the basis of their title and abstract. In groups of 2 to 3 we reviewed each full text collaboratively, initially agreeing on 96% of the articles, and reaching 100% consensus on all papers after brief discussion. We considered 23 of the 46 articles to have met the inclusion criteria for the review (see Figure 1).

Figure 1: *The review process.*



Initial inclusion criteria for the search were: At least some of the participants were children or young people aged 0 to 25 years, or were parents/carers/families/teachers of children or young people; at least some of the participants had a disability as defined previously; the intervention was resilience-based; the intervention was evaluated. Interventions were considered to be resilience-based if the following criteria were met: The authors had engaged with the resilience evidence base and attempted to link their program, or components of their program, with specific resilience-enhancing capacities (see, for example, Mental Health Foundation of Australia, 2005); articles included a definition or explanation of resilience that indicated the authors' orientation with respect to the locus and nature of resilience (e.g., individual asset, dynamic transaction between individual/environment). In an iterative process, we expanded two of the inclusion criteria (that the intervention was resilience-based, and that the intervention was evaluated) in a second search, to increase the number of articles, and therefore the usefulness of the review. Some articles were also included that were not strictly interventions, but were excellent practice examples of resilience-building activities with children and young people with complex needs.

The authors chose the age range because our work focuses on children and young people and the parents and practitioners supporting them. Furthermore, interventions with children and young people is where interventions potentially may make the larger difference. As the age group was so broad, and in line with realist approaches that document the ecological context of the interventions, programs were not required to target predefined developmental or resilience aspects which would be context- and age-specific. However, it was considered essential that discussion of underlying models or theories provided a conceptual basis for why the intervention would be effective in enhancing resilience in that age group (e.g., increased self-esteem).

Consistent with our own practice, experience, and research interests, and because of the connection between inequalities, disability, and adversity, we wanted to capture any information regarding inequalities faced by the children and young people in the studies. Inequality, by and in itself, directly impacts on psychological and physical health, to a degree

that cannot simply be ameliorated by psychological interventions (Prilleltensky & Prilleltensky, 2005). An inequalities perspective is imperative when considering children and young people with disabilities and their families, who face additional financial hardship, lack of opportunities, more intense and longer-term caring responsibility, multiple bureaucratic procedures, access barriers, stigma and discrimination, and often have to negotiate with and manage multiple ineffective, unresponsive, and underfunded professionals and services, often reported to work in a disjointed fashion. Resilience scholars, and those writing about resilience interventions, often define “resilience” as residing solely within individuals, rather than as a dynamic interplay between persons and their environments (Hart et al., 2007). Making resilient moves with and/or on behalf of children and young people may be seen as a response to inequalities; therefore, resilience-based interventions might well include an inequalities dimension. The parents and practitioners with whom we are working support children and young people in contexts they would define as complex inequality or disadvantage, those who are “denied access to the tools needed for self-sufficiency” (Mayer, 2003, p. 2). These parents and practitioners were eager to find out more about what best supports these children and young people’s resilience.

Detailed information about each intervention was collated to gain an understanding of what worked, for whom and in what context: participant characteristics, method and intensity of delivery, setting and circumstances. To identify whether an intervention satisfied all or most of the inclusion criteria, aspects such as resilience definition, program-theory links, capacities, and measures and outcomes were also recorded. Additional headings collected evaluation design and methodology, program costs, funding and implementation history (where available), and strengths and weaknesses of the program and the evaluation.

Results and Discussion

When it came to identifying comparable resilience-based, well-evaluated interventions, the reality was bleak. In previous work (Hart & Heaver, 2013), we had to exclude some useful and innovative articles as they did not meet the inclusion criteria, the most common reasons being that they did not properly relate their study to resilience conceptually, despite using the term in the abstract or keywords. However, when looking for approaches to building resilience with disabled children and young people, had we applied the same strict criteria, just seven of the original 830 papers would have been suitable (Bloemhoff, 2006; Buckner et al., 2005; Leve, Fisher, & Chamberlain, 2009; Macpherson, Hart, & Heaver, in press; Mears & Stevenson, 2006; Theron, 2006; Woodier, 2011).

After the first iteration of our search, we decided to expand our inclusion criteria – papers still had to address the population of interest (i.e., children and young people, with some of the sample having a disability), but they were also considered if they were resilience-based but not evaluated (e.g., Alvord & Grados, 2005; Burka, 2007; Ellis, Braff, & Hutchinson, 2001), if their link to the resilience literature was not explicitly stated in the introduction, despite reporting a program that clearly could be conceptualised as increasing resilience (e.g., Ferreyra, 2001; Morison, Bromfield, & Cameron, 2003; Pelchat, 2010), and in some cases if they were not strictly “interventions”, for example describing the benefit of individual resilience-building activities that were not part of an intervention (Jessup, Cornell, & Bundy, 2010), or existing service provision that was not part of a research project (Evans & Plumridge, 2007; Morison et al., 2003). With a redefined set of inclusion criteria, the second iteration identified 23 of the papers as suitable for inclusion in this review.

Originally it was our intention to structure the results section according to the commonly asked questions of our own parent and practitioner collaborators, and attempt to identify what works for whom, in what circumstances, in what respects and how (e.g., Pawson et al., 2005; Hart & Heaver, 2013). However, there was so little actual data, that this has not been possible. Details that would satisfy these questions, such as cost, are often missing from published evaluations of resilience-based interventions involving participants who do not have disabilities; there is even less information available about interventions for the disabled children and young people who are the focus of this review. Therefore we have taken a slightly different approach, focusing more on what has been done and how, and who has been left out and why, rather than making evaluative comparisons of effectiveness.

Participants

Approximately 800 children and young people from nine countries participated in the 23 studies, in samples sizes ranging from 2 to 213; Alvord and Grados (2005), Ferreyra (2001), Leve et al. (2009), and Mears and Stevenson (2006) did not provide sample sizes. Despite being key to interpreting the generalisability of their results, a large proportion of the studies omitted to report major demographic characteristics of their samples. Half the studies did not supply information about gender (Alvord & Grados, 2005; Burka, 2007; Ellis et al., 2001; Evans & Plumridge, 2007; Ferreyra, 2001; Gauvin-Lepage & Lefebvre, 2012; Leve et al., 2009; Mears & Stevenson, 2006; Morison et al., 2003; Pelchat, 2010; Stallard et al., 2005); of the studies that did, around 32% of participants were female (see Figure 2). The participants were aged 0 to 25 years, with the most commonly included age group being 13, and those aged between 9 and 18 years were most commonly included (in at least nine studies; see Figure 3).

Figure 2: *Gender breakdown of participants.*

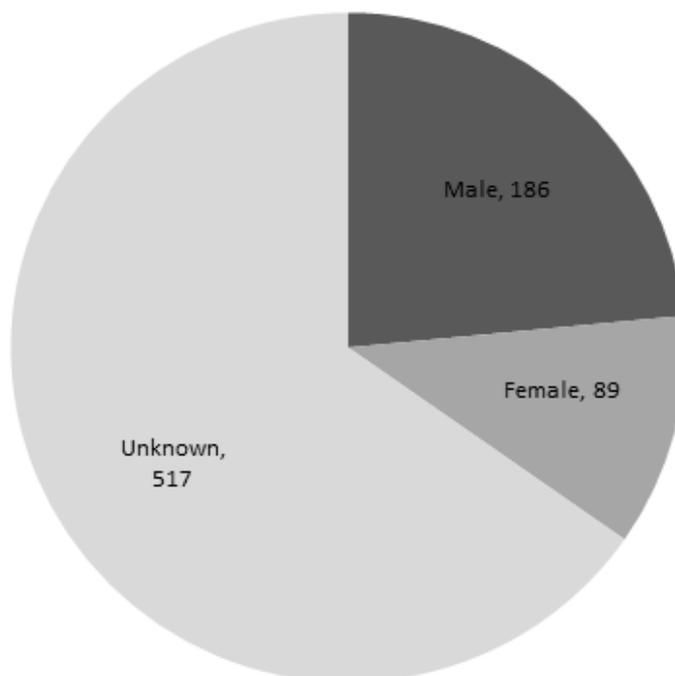
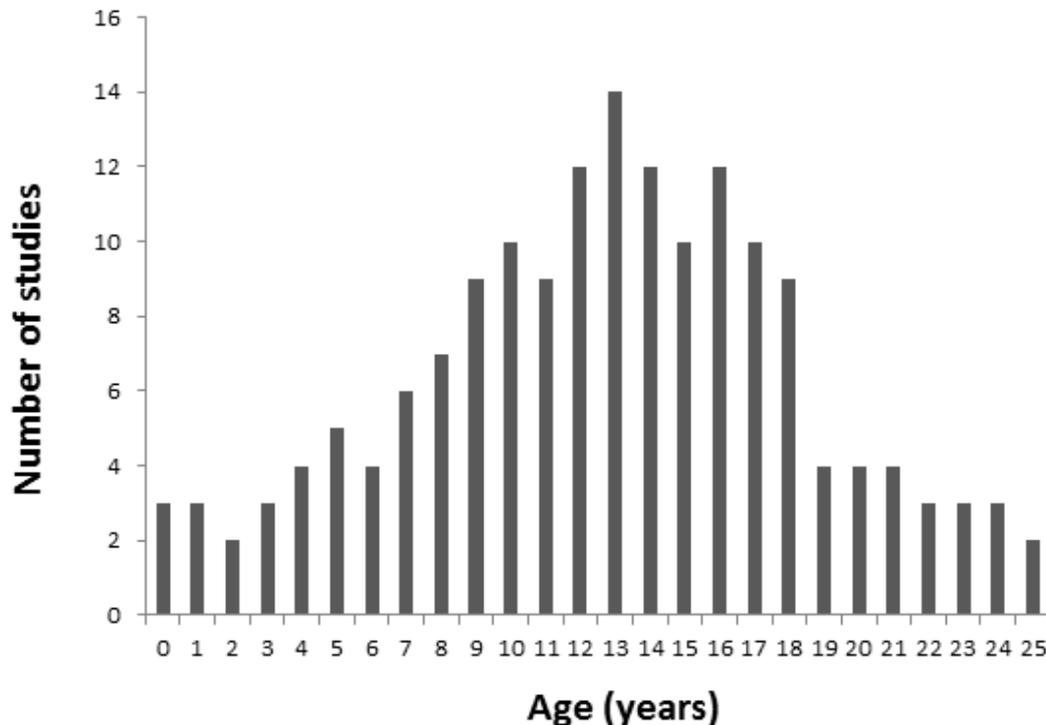


Figure 3: *Frequency of age groups in the studies.*



Twenty of the 23 studies included solely disabled children and young people (some with multiple disabilities and complex needs), with the remaining three studies (Ellis et al., 2001; Firth, Frydenberg, Steeg, & Bond, 2013; Stallard et al., 2005) also including typically-developing peers (see Table 1). Only 6 studies gave any indication of participants’ socioeconomic status (Ellis et al., 2001; Ferreyra, 2001; Firth et al., 2013; Irie & Tsumura, 2011; Lee et al., 2009; Stallard et al., 2005), with five studies reporting race/ethnicity (Buckner et al., 2005; Ferreyra, 2001; Firth et al., 2013; Lee et al., 2009; Storch et al., 2012), and none recording sexual orientation.

What did the studies do exactly, for how long, and with what intensity?

This review has confirmed our observations from many years of research and practice, that to be effective as practitioners, parents, and researchers in the resilience field, one has to be contextually focused. Perhaps understandably, one of the capacities specific to resilience-building interventions for disabled children and young people that was not mentioned in interventions for typically-developing (or where no specific details of the sample were given, at least assumed to be typically-developing) peers, was “accurate understanding of the illness and its medical and psychosocial consequences” on the individual and the family (Shapiro, 2002, p. 1376). Therefore some interventions included psychoeducation, information, and advice on helping the children and young people/families to cope with their specific condition or disability (e.g., Buckner et al., 2005; Evans & Plumridge, 2007; Ferreyra, 2001; Firth et al. 2013; Mu & Chang, 2010; Shapiro, 2002; Storch et al., 2012). However, only two studies

included identity formation (see Gwernan-Jones, 2008) as a disabled young person (Ferreya, 2001) or as the family of a disabled child (Mu & Chang, 2010).

Several interventions had a specific focus for enhancing resilience including: prevention elements such as mental health (Firth et al., 2013; Stallard et al., 2005; Storch et al., 2012) and substance use (Ferreya, 2001); learning new skills such as problem-solving, social and life skills (Alvord & Grados, 2005; Ellis et al., 2001; Ferreya, 2001; Macpherson et al., in press; Mears & Stevenson, 2006; Theron, 2006); leisure, outdoor activities, and hobbies (Bloemhoff, 2006; Buckner et al., 2005; Burka, 2007; Ellis et al., 2001; Evans & Plumridge, 2007; Jessup et al., 2010); creative therapies including art/music (Macpherson et al., in press; Theron, 2006); and work experience (Woodier, 2011). Length and intensity was very wide-ranging – from one-off sessions of 1 to 4 hours (Bloemhoff, 2006; Mu & Chang, 2010) to weekly sessions over 2 to 3 years (Ferreya, 2001; Woodier, 2011; see Table 1).

Several interventions worked with the wider family system rather than just the individual child (Alvord & Grados, 2005; Burka, 2007; Evans & Plumridge, 2007; Ferreya, 2001; Gauvin-Lepage & Lefebvre, 2012; Lee et al., 2009; Morison et al., 2003; Mu & Chang, 2010; Shapiro, 2002), and in some cases included significant others involved with the child, such as teachers (Ferreya, 2001; Mears & Stevenson, 2006) and health-care practitioners (Lee et al., 2009; Gauvin-Lepage & Lefebvre, 2012).

Given the individual nature of disability and chronic illness, it is perhaps not surprising that compared to interventions for typically-developing youth, articles in this review included a highly customised approach to meet individual levels of need (e.g., Ellis et al., 2001; Evans & Plumridge, 2007; Ferreya, 2001; Gauvin-Lepage & Lefebvre, 2012; Leve et al., 2009; Macpherson et al., in press; Morison et al., 2003; Mu & Chang, 2010; Pelchat, 2010; Shapiro, 2002; Theron, 2006; Woodier, 2011), often informed by a focus group or collaboration with the children, young people and their families (e.g., Ellis et al., 2001; Ferreya, 2001; Gauvin-Lepage & Lefebvre, 2012; Macpherson et al., in press; Pelchat, 2010; Storch et al., 2012). By contrast, only two interventions used a universal approach at the level of the classroom and/or school (Firth et al., 2013; Stallard et al., 2005). One program featured an inclusive model of teacher training to change the whole school culture, and a coping program for students with dyslexia, nested within a whole-class coping program aimed at all students in that year (Firth et al., 2013). Whilst they excluded pupils with other types of reading difficulties (from lack of opportunity, learning difficulties, Asperger syndrome, sensory impairment, or emotional difficulties), those pupils (assuming they were present) still received the general whole-class coping skills intervention. Unfortunately the results of this well-intentioned, sustainable intervention were weak, with minimal improvement, lack of difference between dyslexic/non-dyslexic students at the start or end of the study, and observed benefits that could have been the result of the passage of time.

Table 1: *Summary of contexts, interventions and delivery (where given). (SES=SocioEconomic Status; M=Male; F=Female).*

<i>Study</i>	<i>Children & young people</i>	<i>Age</i>	<i>No.</i>	<i>Delivery</i>	<i>Other info</i>
Alvord & Grados, 2005; USA	ADHD, anxiety, limited number with "mild" Asperger's, learning disabilities, fine-motor/gross-motor skills deficits (all) Details: Facilitated, single-sex, goal-oriented social skills group to learn new skills; included free play, relaxation training, active parental involvement, reward system and homework. Outcome: Empirical data collected but not included.	4-14 yrs	-	24-28 sessions over 2 semesters; clinician facilitator	not < average IQ or aggression/ antisocial
Bloemhoff, 2006; South Africa	Behavioural and/or emotional problems (e.g., depression, anti-social behaviour) (all); at-risk, referred under Child Care Act 1983 Details: Ropes course in environment of 'safe' risk-taking and competition; followed by facilitated processing and reflection to apply learning to real life. Outcome: Significant increase in protective factors after course compared to before.	16 yrs	47 (M)	One-off 4hr session; researcher facilitator	
Buckner et al., 2005; USA	Asthma (all); Caucasian & African American; low & moderate-high SES Details: Residential camp including outdoor physical/leisure activities, such as canoeing and country dancing, combined with asthma education. Outcome: Increased resilience after camp compared to before, improvement still present at 6 months.	12-14 yrs	12 (8F 4M)	3 day camp; nurses, camp staff	
Burka, 2007; USA	Learning challenges (e.g., learning disability, ADHD) or medical problems (e.g., diabetes, cerebral palsy) (all) Details: Summer program of challenging but fun activities; included individual work, arts and crafts, coping and problem-solving skills, earning non-competitive awards for reaching goals. Outcome: Not reported.	8-13 yrs	49	3hrs a day, 5 days a week for 3 weeks; program staff	
Ellis et al., 2001; USA	Learning, emotional, attention hyperactivity disorders (some); at-risk, referred from judicial/mental health services; low SES	12-18 yrs	72	2-5 evenings; program staff, therapeutic recreation specialists	Participatory

<i>Study</i>	<i>Children & young people</i>	<i>Age</i>	<i>No.</i>	<i>Delivery</i>	<i>Other info</i>
	Details: Leisure and skills activities, individualised for youth unable to participate independently; included academic, life and stress management skills, opportunity for personally meaningful pursuits, community service and represent peers at youth-directed planning and strategy meetings. Outcome: Reported greater sense of self-efficacy, voice and self-confidence.				
Evans & Plumridge, 2007;	Autism spectrum, learning difficulties, hearing impairments, physical impairments & complex needs (all)	5-13 yrs	47	-	Social model of disability; awareness raising
England	Details: Wide-ranging inclusive, integrated and specialist play and leisure provision, such as after-school clubs, holiday play-schemes; included specialist information and advice, respite, advocacy and peer support for families. Outcome: Reported increased confidence and self-esteem, reduced isolation.				
Ferreira, 2001;	Specific learning difficulties (e.g., dyscalculia, dyslexia, dysgraphia, dysphasia, ADHD, motor/social perceptual learning disability) and/or physical disability (cerebral palsy, spina bifida, spinal cord injury, amputee, speech disabilities) (all); African American, Latina, Asian American, Native American, Caucasian; from economically challenged/diverse neighbourhoods	14-21 yrs	- F	1-3hrs a week during school year for 2 yrs; program staff with disabilities	Addresses basics; participatory
USA	Details: Facilitated group and one-to-one counselling; focus group developed content and responsive curriculum including life-skills, substance use prevention, disability awareness/rights and identity formation; provided adult female disabled role models and help with basic living support, food, clothing and shelter. Outcome: Increased academic resilience, confidence and social capital, decreased substance use.				
Firth et al., 2013;	Dyslexia (some); Anglo-European; 1/3 receiving maintenance allowance	10-11 yrs	23 (8F, 15M)	10 x 50mins weekly; teachers	
Australia	Details: Dyslexia-specific coping skills program in addition to whole-class CBT program for all students, whole-school changes in practice (e.g., teacher training, student screening) and dyslexia-friendly environment (e.g., nonprint-based access to curriculum and means of expression). Outcome: Inconclusive – authors suggest measured				

<i>Study</i>	<i>Children & young people</i>	<i>Age</i>	<i>No.</i>	<i>Delivery</i>	<i>Other info</i>
	improvements in locus of control and non-productive coping due to age/development.				
Gauvin-Lepage & Lefebvre, 2012; Canada	Moderate-severe traumatic brain injury (all) Details: Focus on recognising the knowledge and expertise of families, helping them feel better supported and understood; intervention designed and tested with the family. Outcome: On-going research, results not yet available.	Adolesc-ent	8	Nurses	Collaborative with parents
Irie & Tsumura, 2011; Japan	Learning difficulties/developmental disability (all); moderate-high SES Details: Family coping intervention through interviews with researcher. Outcome: Over time parents learned to verbalise feelings and take joint ownership of their children's condition.	3-5 yrs	4 (1F 3M)	~90mins, ~monthly for 1 year; researcher	
Jessup et al., 2010; Australia	Blind & visually impaired (all); had met educational & developmental milestones Details: Participants' own pre-existing leisure pursuits, hobbies and activities, including sports, volunteering, music, tutoring others and being a mentor. Outcome: Activities provided acceptance, supportive relationships, desirable identity, experiences of power, control and social justice, enabling them to thrive despite adversity.	16-24 yrs	8 (4F 4M)	At least once a week	
Lee et al., 2009; USA	Mental health issues (ADHD, adjustment disorder, mood disorder, depression, oppositional defiant, bipolar, disruptive, impulse-control, dysthymia, PTSD, anxiety, Trichotillomania) (all); Caucasian, African American, multiracial; mostly low income; at-risk, referred by judicial/children's/mental health services Details: Family intervention utilising behavioural prescriptions, solution building and crisis plans, disrupting problem-maintaining behaviours within family and between family and services. Outcome: Significant improvements in child functioning, parental competency, family cohesion and adaptability, maintained at 6 months.	4-17	77 (27F 50M)	Up to 6 weeks; mental health workers	
Leve et al., 2009;	Severe emotional & behavioural difficulties (all); in foster care	9-18 yrs	-	6-9 months; foster parents &	

<i>Study</i>	<i>Children & young people</i>	<i>Age</i>	<i>No.</i>	<i>Delivery</i>	<i>Other info</i>
USA				multi-disciplinary team	
	Details: Community home foster parents intensively trained, supervised and supported to provide positive adult support, mentoring, close supervision and consistent limit setting; individualised strength-building, positive interventions (e.g., social skills training, academic support, reward charts) coordinated in the home, with peers, in educational settings, with birth and/or adoptive family. Outcome: Improved social behaviour, placement stability and supportive attachment and peer relationships.				
Macpherson et al., in press; England	Mental health complexities and/or learning difficulties (all)	16-25 yrs	9 (5F 4M)	10 x 4hr weekly; inclusive art therapist, researcher, play therapist	Participatory, food provided
	Details: Visual arts workshops building toward end of course exhibition; included learning new arts skills, connecting communities, expressing and processing emotions, following a resilience curriculum; participants co-developed a practitioner resource. Outcome: Increased sense of belonging, confidence and coping with difficult feelings.				
Mears & Stevenson, 2006; New Zealand	Special educational needs (all)	13-14 yrs	1 class	3 weeks; researcher, school staff	Action research
	Details: In class curriculum including role playing, problem-solving, discussion around videos showing “risky” scenarios. Outcome: Increase in resilience after intervention compared to beforehand; reported increase in self-confidence, self-esteem and ability to identify and handle risky situations.				
Morison et al., 2003; Australia	Chronic moderate-severe physical illness or disability (metabolic/endocrine disorders, epilepsy, chronic bowel disorders, malignancies, central nervous system disorders, asthma, cystic fibrosis, cardiac disease) (all)	0-25 yrs	82	counsellors	Builds capacity
	Details: Flexible, customised interventions to accommodate needs of all family members; wide variety of activities, type, length and location; included peer mentoring, community education and social events; no time constraint or limits to participation. Outcome: Anecdotal, positive feedback from clients and professionals.				
Mu & Chang, 2010; Taiwan	Epilepsy (all), 63% also having learning difficulties	0-18 yrs	78 (31F 47M)	1-2 x 60-90mins; researchers	Identity formation

<i>Study</i>	<i>Children & young people</i>	<i>Age</i>	<i>No.</i>	<i>Delivery</i>	<i>Other info</i>
	Details: Nursing intervention with family to define roles and responsibilities of family members and foster family resilience; included parental needs checklist, psycho-education, enhancing mastery and coping, and reconstructing identity. Outcome: Significant reductions in family boundary ambiguity and maternal depression.				
Pelchat, 2010; Canada	Down Syndrome or cleft lip/palate (all)	0-18 mths	46	Researcher, perinatal care nurses	Co-created with parents
	Details: Therapeutic intervention with family addressing needs at level of individual, parental, conjugal and familial/extra-familial; included forging reciprocal partnership between family and professionals, sharing reciprocal resources, coping skills. Outcome: Positive impacts reported by family and professionals, including increased confidence in their knowledge and skills.				
Shapiro, 2002; USA	Complex, chronic health problems & developmental disabilities (hypotonic cerebral palsy, anaemia; learning, social and behavioural disabilities, memory problems, mental health problems) (all)	13 yrs	1 (F)	1 year; clinical psychologist	Collaborative with parent; negotiating for resources
	Details: Psychotherapy with child, parent and family to make better use of existing and new resources in multiple systems and form coherent illness narrative. Outcome: Improved health efficacy, communication and shared problem-solving.				
Stallard et al., 2005; England	Severe emotional problems (e.g., anxiety) (some); from area of social & economic deprivation, at-risk	9-10 yrs	213	10 sessions over 1 term; school nurses	
	Details: Universal CBT approach using in-class workbooks to teach relaxation, problem-solving and coping skills. Outcome: Significant improvements in anxiety and self-esteem, reported positive classroom culture.				
Storch et al., 2012; USA	Tic disorder (Tourette's or chronic tic disorder) with associated psychosocial impairment (all); Caucasian, Hispanic	8-16 yrs	8 (2F 6M)	10 x 50mins weekly; clinical psychology doctoral students	Focus group contributed to content
	Details: Individual CBT psychotherapy sessions; focuses on psycho-education and coping/living with tics and managing associated distress, anxiety and impairment, rather than trying to reduce frequency/severity or suppress. Outcome: Improvements in self-concept, anxiety and quality of life.				
Theron, 2006;	Specific learning difficulties (e.g., spoken or written language, listening,	secondary	6 (4F 8M)	12 x 1hr sessions over 5.5	

<i>Study</i>	<i>Children & young people</i>	<i>Age</i>	<i>No.</i>	<i>Delivery</i>	<i>Other info</i>
South Africa	speaking, reading, writing, spelling or doing maths) (all); at-risk	school		months; researcher facilitator	
<p>Details: School-based individualised program and group therapy; included art, music, CBT, resilience curriculum, visualisation and role-play. Outcome: Increased resilience attributes, particularly positive future orientation, compared to before intervention.</p>					
Woodier, 2011 ; Scotland	Emotional & behavioural difficulties (e.g., ADHD, prenatal alcohol/drug exposure) (all); looked after, school exclusion	11-15 yrs	2 (M)	3hrs/week for 1-3 yrs; teacher, input from multi-disciplinary team	
<p>Details: One-to-one asset-building curriculum to identify strengths, plus individual, structured voluntary work experience placement in community for academic credit. Outcome: Increased inclusion with school and peers, positive future orientation and responsibility for self.</p>					

Some of the interventions built capacity, for example the Paediatric and Adolescent Support Service included a parent peer mentoring scheme where parents who had “been there, done that” received training as volunteer mentors for other parents, acting as role models and gaining “recognition for their value as experienced people with much to offer others” (Morison et al., 2003, pp. 127–128). Having parents or young people developing and/or delivering training, for example in the manner of the Amaze charity in Brighton, U.K. (Hart, Virgo, & Aumann, 2006), and the Experience in Mind community group, also in Brighton, (Taylor, & Hart, 2011), enables interventions to involve the most excluded parents and young people, potentially makes groups more sustainable, and builds training capacity and the wider social capital of parents and young people.

Noticeably, despite the important resilience-building benefits of encouraging hobbies, talents, and interests (e.g., Gilligan, 1999; Jessup et al., 2010), these dimensions appear to have been left out of most resilience-based interventions for children and young people, as we have found in earlier work (Hart & Heaver, 2013). Arguably, their inclusion in resilience programs is even more important for disabled children and young people, as they are already being given fewer opportunities and resources than their typically-developing peers. Funded programs usually come with significant resources. Using some of these to develop hobbies and interests could result in an impressive return on investment, laying the foundations for meaningful activities and job opportunities in adulthood.

Other papers in the search that did not include an intervention but were worth mentioning for their strategies and models addressing specific resilience capacities in special education include Jones (2011), Hartley (2010), and Kourkoutas and Xavier (2010).

Exclusion through disability-blindness and an ableist mindset

Analysis of this data set leads us to suggest that children and young people with complex needs are unjustly under-represented in study samples. Our view prior to undertaking this review, that resilience-focused interventions seemed to exclude the very people who might need them the most, has been confirmed. These marginalised children and young people already have fewer chances and a greater need for intervention, yet some of the most generously funded studies continue to deliberately exclude children and young people with complex needs. Some studies such as repetitions of the Penn Resiliency Program (PRP) often target what are termed “sub-clinical” samples, with a preventative focus on “teaching skills for promoting positive experiences or coping with everyday problems, rather than addressing clinical levels of symptoms that might require advanced clinical training to address” (Kranzler, Parks, & Gillham, 2011, p. 486). A social-skills group therapy model excluded children and young people with “below average intellectual capability or severe aggression”, rather than providing additional support to sessions, on the basis that these youth would be antisocial, and that “placing antisocial youth together results in interventions that are often ineffective and may even increase the likelihood of delinquency” (Alvord, & Grados, 2005, p. 242). Somewhat in opposition to the research ethos the authors are advocating, one study took Functional Analysis, an approach designed for students with severe disabilities, behavioural problems, or emotional disorders, and applied it preventatively to children who had no identified disabilities, but who showed “mild behavioural challenges in regular education classrooms” (Stoiber & Gettinger, 2011, p. 689), described as *talking in class when they shouldn't, or not staying in their seat*.

For most studies, exclusion was more subtle, reducing the likelihood of their cohort including any children and young people with complex needs by: (a) using written or

computer-administered program materials that may be inaccessible to students with learning, reading, or communication difficulties (we know from experience that the concepts included in commonly-used resilience scales can be difficult to convey to participants with moderate learning difficulties, and to students in chronic pain who may not be able to concentrate or process much information at one time); (b) taking opportunity samples from low-risk mainstream schools, where disabled pupils who do attend mainstream school may still be absent on the day that the intervention takes place through ill-health, illegal exclusion, or lack of inclusive provision (e.g., Grunstein & Nutbeam, 2006); (c) using university undergraduate populations where students are less likely to have a moderate to severe learning difficulty (e.g., Stallman, 2011); (d) conducting program activities that are inaccessible or non-adapted, or which take place in a location inaccessible to students with physical disabilities (e.g., Ewert & Yoshino, 2011); or (e) conducting an intervention in a workplace (e.g., Bennett, Aden, Broome, Mitchell, & Rigdon, 2010) when young people with disabilities aged 16 to 25 have a rate of unemployment two to four times higher than those without disabilities (Burchardt, 2005).

Standardised Cognitive Behavioural Therapy (CBT) programs may not be accessible for children and young people with learning difficulties. They might struggle with aspects such as identifying thoughts, separating thoughts from feelings, and learning and applying new information and concepts (Mirow, 2008). These children and young people require creative individual adaptation to meet their needs, such as using simple language, including parents/carers, and actually having a less collaborative, more directive, approach (Willner, 2009).

We do not mean to imply that all these studies necessarily set out to exclude children and young people with disabilities and complex needs, but their prevalence in the research evidence base suggests a level of disability blindness and an “ableist mindset” (e.g., Butler, & Parr, 1999; Chouinard, Hall, & Wilton, 2010), along with an absence of an “inequalities imagination” (Hall & Hart, 2004; Hart, Hall, & Henwood, 2003). Even when researchers are aware of inequality and inclusion issues, they may be guided by different definitions of an “inclusive” program. For example, inclusion may be achieved through additional separate “specialist provision” giving disabled children and young people similar opportunities to their non-disabled peers; additional “integrated activities” that disabled and non-disabled children and young people both participate in together; or supporting disabled children and young people to be safely integrated into mainstream provision by providing equal access to existing play and leisure activities (Evans, & Plumridge, 2007).

Evans and Plumridge (2007) reported that some services actually “rais[ed] awareness of the needs of disabled children and attempted to change the practice of mainstream providers” (p. 235) through providing deaf awareness and British Sign Language training for mainstream services, and “tackl[ing] disabling barriers within all the spheres of children’s lives” (p. 231). However, overall, few interventions addressed consciousness-raising, or the basics, such as giving participants a decent breakfast. These arenas would be included in resilience interventions that took inequalities seriously. For future resilience-based interventions we consider that an “inequalities imagination” (Hart et al., 2003) is needed on the part of the designers and deliverers, to ensure that resilience-based approaches act as political moves against the structural and power inequality manifest in some children and young people’s lives, through poverty, marginalisation, unemployment, and constellated disadvantage (Hart et al., 2007; Hart et al., 2003; Prilleltensky & Prilleltensky, 2005). Addressing basic inequalities and lack of access to developmentally-appropriate resources has been authoritatively described as the single most important step in improving mental health

outcomes (Friedli, 2009; Layard, 2005), yet is rarely explicitly considered and worked with beyond citing contextual issues relating to the child's social ecology, even when interventions target disadvantaged populations. This may partly be due to difficulty in defining what constitutes disadvantage, and how it is located and measured (Hart et al., 2007; Mayer, 2003; Prilleltensky & Prilleltensky, 2005).

There are also other, more subtle political issues of disability rights to be considered. Children and young people with disabilities have been regarded as a small group that is difficult to visualize. But this viewpoint does not reflect reality. In Sweden about 14 to 18% of young people in secondary and upper-secondary school report that they have one or more disabilities (Brunnberg, Lindén Boström, & Persson, 2009), with 3% reporting multiple disabilities (Brunnberg & Olsson, 2013). The political goal for disabled children and young people in many countries has been "equality", but this has in many contexts centred on equality in attending, for example, the same school as their non-disabled peers. Equality has not been a concept of quality, for example, in education or communication. Children and young people with disabilities have the equal right to be heard and listened to, and to be treated in the best way (UNICEF, 2013a). This should apply to their meaningful participation in research studies, both as participants and, ideally, as collaborators in the research process and intervention design. More than 20 years ago, Oliver (1992) made the point that disability research "has had little influence on policy and made no contribution to improving the lives of disabled people" (p. 101), and could even be described as "alienating" (p. 101) rather than emancipatory. It feels as though little has changed.

In terms of balancing the cost efficiency of time and resources against helping those most in need, more debate needs to occur amongst researchers regarding where it is realistic and ethical to draw the line. Sometimes it is clear how the balance has been reached; for example, Storch et al.'s (2012) CBT program for young people with tic disorders was contextual and participatory – focusing on coping skills specific to living with tics, and conducting focus groups with the youths themselves to inform the content of the course. It was delivered via one-to-one psychotherapy sessions, making it resource-intensive. Costs were reduced by having doctoral students deliver the sessions, rather than more qualified therapists, and by keeping the program to ten weekly sessions of 50 minutes each. A consequence of using less experienced practitioners conducting a short program was that young people with more complex needs (e.g., having a "comorbid" diagnosis), who therefore might require a greater level of support, were excluded from participating. Providing intensive, contextualised, and customised interventions via experienced practitioners is expensive; the higher the cost, the fewer children and young people having the opportunity to benefit; the greater the level of customisation, the less generalisable it may be, with a reduced economy of scale. Funders may be more willing to award money to a marketable prevention program that states it will help 50 children now and could be rolled out to 500 in the future, than to an intervention that costs the same and will help five children with complex needs in the here and now.

The political economy and market orientation of research, or "academic capitalism" (Barry, 2011), promotes the use of "tame" populations and means that money is usually spent on typically-developing children and young people with average levels of need. Research often focuses on those who will sit quietly and complete the measures that the researchers are interested in, with minimal supervision and in the fastest time. The children and young people who are most in need of resilience-based interventions are left out because they may need support to participate in the study; those support needs will need to be assessed; suitably qualified and experienced researchers/practitioners will need to be part of the team, or training

will need to be provided in order to sensitively and appropriately support participants; scales/measures will need to be adapted, not only in terms of presentation in a suitably accessible format (e.g., short sentences, easy read, or pictorial), but also in terms of concepts that are meaningful and relevant to the participants (e.g., not asking about activities that participants are unable to do), and not making assumptions (e.g., that having lots of friendships is necessarily beneficial or desirable to someone with autism); extra time will need to be built into the research project to allow for supported participation, which may also need co-operation and co-ordination of parent, carer or trusted adult attendance at sessions, or arrangement of appropriate transport and travel expenses.

Children and young people with complex needs are less likely to form a convenient opportunity sample, in contrast to pupils in a large mainstream school. The authors know that it is immensely difficult to keep participants with learning difficulties involved in research, but it is politically, morally, and ethically very important. Other researchers could learn from, for example, the Swedish study “Life and Health” (Brunnberg & Olsson, 2013) in which students with different types of disabilities could read and answer the survey in sign language, talked language, spelling with big letters, as well as in a traditional format as text. While the survey was still not presented in easy-to-read text, it did however have a high response rate and was more inclusive than most.

In studies where researchers do not specify the participant demographics, it is easy to work out that they have not included children and young people with disabilities, based on the description of the work, the questionnaires they used to evaluate the program, the level of staffing, and the lack of tailoring for individuals. Some programs are implicitly ableist, for example developing an exercise or physical activity-based resilience-building intervention, which has not, or cannot, be adapted for different needs. We are advocating a more transparent and reflective approach to the inclusion of disabled children and young people, with the hope that some balance can be achieved. One way to address exclusion might be to acknowledge the tensions between factors – including finances, time constraints, and funding body agendas – from an informed viewpoint, admitting that there are excluded populations and stating reasons for decisions about participants. This in itself might encourage more attention to be paid to what should be done differently to make research more inclusive.

Limitations of the methodology

This review used the WHO (2012) definition of disability, and the researchers have translated their interpretation of the definition into the search terms and search strategies that were applied. The definition, and its interpretation, will therefore both influence the results of the literature search (e.g., Grönvik, 2009). Iterative evolution of the inclusion criteria introduces a researcher bias to the choice of which studies to include, albeit informed by years of research and practice in this area, but this should be acknowledged reflexively. Such subjective influences make a literature search less replicable and more contextualised. However, given the area of interest, this may be appropriate, and we have tried to make explicit all decisional processes in our strategy.

The articles that were included varied in the degree to which authors had engaged with the resilience evidence base and definitional debates. Therefore the programs included are diverse in their theoretical underpinnings and adherence to resilience principles, and it is unlikely that there was a great deal of overlap in perspectives. However this may reflect broader disagreements over the definition of the terms resilience and disability. Where possible, the authors have tried to highlight studies that take a more socio-

ecological/inequalities view of resilience (e.g., Hart et al., 2007; Masten, 2011; Rutter, 2006; Ungar, 2012), rather than those focusing on individual traits or characteristics in isolation from contextual issues, and those with a more participatory approach, incorporating the input of the young people with disabilities themselves into the research process.

Additional difficulty in finding comparable studies lies partly in the specific and distinct effects, restrictions, and life-courses of different types of chronic illness and disability (e.g., as per Shapiro (2002), steady, fluctuating, or progressive; impacting predominantly physical, cognitive, or sensory functioning; invoking sympathy or stigma; visible or hidden), which may result in different types of intervention or therapeutic approaches being selected for their benefits and potential fit with the individual. Categories were complex and diverse, and the only “population” where there was any overlap in terms of labels was “behavioural and emotional problems”, which is itself a broad umbrella for a range of conditions and severities. Imagining the interplay of the unique effects that a young person’s disability has on them, the context of their individual environment, their family and the available resources, leads to an appreciation of the enormous amount of individual difference *within* a group of children or young people participating in one specific study, let alone *between* studies. Trying to compare groups from different studies, with the massive variation in resilience-building approaches and activities taken, makes a review of comparable studies with comparable populations and programs almost impossible. It also highlights the even greater need for contextualised understanding of and response to the individual child’s situation, rather than standardised, manualised interventions aimed at large groups of typically-developing children and young people in mainstream settings.

Conclusion

Of the papers identified, only 23 met (at least in part) the inclusion criteria, including a robust resilience concept and basis to the intervention, and a way of measuring changes in the children and young people’s resilience. The 23 studies covered a variety of program content, setting, delivery, and children and young people. Due to the lack of evaluated, theoretically-sound programs designed for the needs of children and young people with disabilities, the inclusion criteria were applied more flexibly if the intervention demonstrated solid links to resilience but was not evaluated, or if the intervention lacked a specific definition of resilience but was clearly linked to resilience capacities (e.g., self-esteem). Overall, it was difficult to summarise such sparse and disparate studies in a meaningful way, particularly when small sample sizes and analyses of varying type and quality made it challenging to draw conclusive or comparative results. The authors would like to encourage better research “practice”, that will lead to the conducting of rich, informative, and detailed research that is inclusive, participatory, and sustainable in its approach, and suitable to inform a realist review. Whilst this is a very complex goal to realise, our review has provided some evidence for the notion that resilience-based programs hold promise, despite design flaws, small samples, poor definitions, and inconsistent measurement.

The academic publishing landscape has been dramatically changed by recent research council open access policies that hold grant recipients accountable to wider stakeholders and the general public. This may yet provide opportunities for positive developments in relation to the inclusion of disabled children and young people in research. Some journals suggest major demographic characteristics of study samples should be included in the methodology section of new submissions, to “provide a more complete understanding of the sample and of the generalisability of the findings” (American Psychological Association, 2013). The authors suggest that such disclosure should become mainstream within the social sciences: A

demographics statement that describes which disadvantaged or marginalised groups are included in the sample, including people who identify as having disabilities, should be required as part of project outputs. If no participants are described as experiencing these types of inequality, then a rationale should be provided by the researchers that explains why a non-representative sample has been chosen. In addition to making this information explicit and publicly available, this would increase awareness and shift focus onto inequalities issues. Goodhart's Law identifies that the measurement of a system usually disturbs it (McIntyre, 2000), and the use of non-representative opportunity samples in large-scale, publicly-funded studies is a system most in need of some disturbance.

The overall flavour of the resilience and disability research evidence base is of measuring how things are, and identifying fairly fixed characteristics of individuals which are associated with better outcomes. Practitioners wishing to know what they can do right now to help disabled children and young people make resilient moves within the context of their own lives, can experience the literature as frustrating, difficult to digest, and hard to learn from. There is often a huge gap between what research reports, and what people want to know and learn about when working in the messy, complexity of situated practice. The research world must do more to answer the questions of parents and practitioners who support children and young people with disabilities and complex needs. Researchers also need to think of ways to capture the views, needs and experiences of children and young people with disabilities to ensure the relevance of their interventions. Children and young people with highly complex needs were of specific interest to the parents and practitioners we consulted, and we can infer from the papers in our review that, perhaps unsurprisingly, these children and young people responded to high intensity, individually-customised interventions.

Given the high level of illegal school exclusions experienced by disabled children and young people in England and Wales (Contact a Family, 2013), with devastating effects on their basic education, coupled with the well-documented disadvantages they face throughout their lives, more effort should be made to focus resilience-based interventions on supporting children, young people, their families and schools, to undo this damaging practice. Young people beyond the age of 18 were rarely included in studies, therefore research and practice developments could target older populations who may be as, or even more, socially-excluded than their younger peers. Finally, it is a great irony that third-sector organisations, which are far less resourced than universities, are doing the most research with disabled children and young people (e.g., Burchardt, 2005; Contact a Family, 2013). Academics based in universities could, as a start, team up with these organisations to lend support in taking this much-needed dimension of resilience research and practice development forward.

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