National Institute for Health and Care Excellence

Draft for consultation

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

[D] Evidence review for supporting families and carers

NICE guideline TBC

Evidence reviews

August 2021

Draft for consultation

These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists

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Supporting families and carers

Recommendations supported by this evidence review

This evidence review supports recommendations 1.6.1, 1.6.2, 1.6.5 - 1.6.12, 1.15.24, 1.17.14 and the research recommendation on short break services.

Review question

What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Introduction

The review aims to identify the optimal interventions for enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs.

The committee agreed that the review question would encompass service design including the involvement of service users.

At the time of scoping and developing the review protocols, documents referred to health, social care and education in accordance with NICE style. When discussing the evidence and making recommendations, these services will be referred to in the order of education, health and social care for consistency with education, health and care plans.

Summary of the protocol

See Table 1 for a summary of the Population, Intervention, Comparison and Outcome (PICO) characteristics of this review.

Table 1: Summary of the protocol (PICO table)

Population	• Families of disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support • Carers of disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support
Intervention	Intervention(s) involving or supporting families and/or carers. For example: • Combined support across sectors ○ Complex discharge planning ○ Advocacy (third sector) ○ Care pathways • Communication strategies such as parent/carer education (e.g. manualised programs [early bird]) • Short breaks (including specialist and respite breaks) • Key worker • Family centred care • Shared decision making ○ Person centred planning • Best interest meetings • Co-production • Feeding strategies (e.g. enteral feeding) • Parent mediated interventions • Behavioural support approaches (e.g. motivational interviewing, restorative practice and appreciative enquiry) • Family therapy • Parent training and resilience (e.g. insider's guide) • Post adoption support fund (e.g. specialist play therapy) • Psychological input and support at diagnosis • Digital technology (e.g. accessing EHCP online and services) • Signposting and referral systems
Comparison	• Any other intervention(s) specifically involving or supporting families and/or carers • Intervention(s) not specifically involving or supporting families and/or carers
Outcome	**Critical** • Participation and inclusion of families and carers in the design, planning and delivery of care • Satisfaction with services as measured by validated scales • Communication as measured by validated scales **Important** • Quality of life (both health- and social-related quality) as measured by validated scales • Capability and confidence to meet the needs of the child or young person as measured by validated scales • Social capital (range of social contact that provides access to social, emotional or practical support) • Employment (of families and/or carers)

EHCP: education, health and care plan

For further details see the review protocol in appendix A.

Methods and processes

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document (Supplement A).

Declarations of interest were recorded according to NICE's conflicts of interest policy.

Effectiveness evidence

Included studies

Sixteen studies were included for this review, 1 systematic review (Tellegen 2013), 12 randomised controlled trials (Benn 2012, Bilgin 2009, Chacko 2009, Chacko 2018, Giallo 2008, Haakonsen Smith 2018, Hoath 2002, Lange 2018, Plant 2007, Sonuga-Barke 2001, Treacy 2005, Taylor 2017), and 3 non-randomised studies (Costich 2009, Harris 2016, and Truesdale Kennedy 2006).

The included studies are summarised in Table 2.

Eight studies compared parent training to either a waitlist (n=5: Bilgin 2009, Benn 2012, Chacko 2018, Giallo 2008, and Treacy 2005); to standard care (n=2: Haakonsen Smith 2018, and Lange 2018); or to both a waitlist and standard care (n=1: Sonuga-Barke 2001). Three studies compared an enhanced parent training program to either a waitlist (n=1: Hoath 2002); or to standard parent training (n=2: Chacko 2009, Plant 2007). One study compared advocacy training to a waitlist (Taylor 2017), and 1 study compared person centred planning to standard care (Truesdale Kennedy 2006). Three studies compared before and after a parenting program called Stepping Stones Triple P: Positive Parenting Program (n=1: Tellegen 2013); a community health worker service (n=1: Costich 2009); or digital health technology (n=1: Harris 2016).

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix J.

Summary of studies included in effectiveness evidence

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies.

Study	Population	Intervention	Comparison	Outcomes	Comments
Benn 2012 RCT USA	N=25 Parents of children with special needs (primary disability label included ASD, ADHD/ learning disability and cognitive or	Mindfulness training SMART (Stress Management and Relaxation Techniques) in-Education, twice a week over 5-weeks	Waitlist control Intervention given later in the autumn	• Capability and confidence to meet the needs of the CYP	Both parents and educators were included in the study. Results are presented for parents only as this is the population targeted in this review

Study	Population	Intervention	Comparison	Outcomes	Comments
	health impairment)	during the summer			
Bilgin 2009 RCT Turkey	N=90 Mothers of children with an intellectual disability	<u>Educational programme</u> 60-minute interactive lecture given by nurse every weekday morning from 15-30th June	<u>Waitlist control</u> Intervention given after completing the post-test	- Capability and confidence to meet the needs of the CYP	
Chacko 2009 RCT USA	N=120 Single mothers of children with ADHD	<u>Enhanced behavioural parent training program (BPT)</u> The Strategies to Enhance Positive Parenting (STEPP) program: Traditional BPT plus several additional enhancements to the format, delivery, and content	<u>Traditional BPT</u> Manualized, 9-week BPT program held for 2 and a half hours each week	- Satisfaction with services	Waitlist control group included in the study however satisfaction reported for STEPP versus Traditional BPT only
Chacko 2018 RCT Denmark	N=161 Families of children between the ages of 3–9 for whom there was a concern about potential ADHD	<u>Behavioural parent training</u> CiC (Caring in Chaos) Intervention, scheduled with 12 weekly sessions on workday evenings, for small groups of parents	<u>Waitlist control</u> Details NR	- Capability and confidence to meet the needs of the CYP	Population does not completely match inclusion criteria; families of children with parent reported ADHD (69%), or other parent reported conditions which included ASD, intellectual disability but also Behaviour Disorder, Attachment Disorder, Anxiety Disorder, Depression, Tics or Tourette's syndrome, Sleep Disorder, or other diagnoses.

Study	Population	Intervention	Comparison	Outcomes	Comments
Costich 2009 Non RCT USA	N=95 Caregivers of children with special health care needs (CSHCN)	Special Kids Achieving Their Everything (SKATE) Community health worker (CHW) program Home visits, needs assessments, and goal-setting sessions over 3-6 months	No comparison group	- Capability and confidence to meet the needs of the CYP	The conditions/ diagnoses of the children were not reported Non comparative retrospective before and after study
Giallo 2008 RCT Australia	N=24 Siblings (aged 8-16 years) and parents of children with an intellectual, sensory, physical, or developmental disability and/or a chronic illness	Sibstars 6-week family-based psycho-educational intervention	Waitlist control Families were offered the intervention following post-test	- Communication - Social capital	
Haakonsen Smith 2018 RCT USA	N=28 Caregivers of children with ASD	Coping effectiveness training (CET) Two individualized one-on-one sessions (90 and 60-minutes) between the genetic counsellor and the caregiver held 1 month apart	Control Client centred discussion, similar to that facilitated during a traditional genetic counselling session	- Capability and confidence to meet the needs of the CYP	
Harris 2016 Non RCT UK	N=33 Families with children cared for by the hospice	MyQuality online tool Hands-on demonstration and training in MyQuality followed by usage as often or infrequently as desired,	No comparison group	- Capability and confidence to meet the needs of the CYP	Non comparative longitudinal, multisite mixed-method evaluation

Study	Population	Intervention	Comparison	Outcomes	Comments
		and ongoing MyQuality support available from the clinical team			
Hoath 2002 RCT Australia	N=21 Families with a child with clinically diagnosed ADHD aged 5-9 years	Enhanced Group Triple P: Positive Parenting Program Five, 2-hour weekly group sessions with a practitioner and four, 20- to 30-minute individual weekly telephone consultations	Waitlist Control Intervention given after completing the post-test	• Capability and confidence to meet the needs of the CYP	Satisfaction was not reported sufficiently to be included; reported at post intervention only (no baseline) and for intervention group only (no control)
Lange 2018 RCT Denmark	N=164 Parents of children aged 3 to 7 years with a clinical ADHD diagnosis	New Forest Parenting Programme (NFPP) Eight sessions delivered by trained therapists, individually to parents	Treatment as usual Standard package of psychoeducation delivered to groups of individual parents by specialized staff	• Capability and confidence to meet the needs of the CYP	Families and carers were not the randomised group; children were randomised to receive parent training versus control
Plant 2007 RCT Australia	N=74 Families with a preschool-aged child (<6 years) with developmental disability	Stepping Stones Triple P-Enhanced (SSTP-E) SSTP-S plus an additional six sessions	Stepping Stones Triple P-Standard (SSTP-S) 10 sessions of intensive behavioural parent training (60-90 minute individual sessions with a practitioner) on a weekly basis	• Satisfaction with services	Waitlist control group included in the study however satisfaction reported for SSTP-E versus SSTP-S only Capability and confidence to meet the needs of the CYP was reported in Tellegen 2013
Sonuga-Barke 2001 RCT UK	N=78 Parents of children (aged 3 years) displaying a preschool	Parent training (PT) Educated about ADHD and introduced to	Waitlist control No contact with clinical services during the trial	• Capability and confidence to meet the needs of the CYP	Families and carers were not the randomised group; children were randomised to receive parent training or parent counselling and

Study	Population	Intervention	Comparison	Outcomes	Comments
	equivalent of ADHD	behavioural strategies	Parent counselling and support (PC&S) No training in behavioural strategies but had the opportunity to explore issues and discuss their feelings *Both PT and PC&S included a structured 8-week program involving eight 1-hour weekly visits by a health visitor therapist		support, versus control
Taylor 2017 RCT USA	N=41 Parents of youth with ASD who were within two years of high school exit	Volunteer Advocacy Project-Transition (VAP-T) 30-hour advocacy training delivered over 12 weeks in Fall 2015	Waitlist control Could participate in the (VAP-T) program in Spring 2017	- Capability and confidence to meet the needs of the CYP	1 year follow-up data is not published in the paper
Tellegen 2013 SR and Meta-analysis Australia	N=659 Families with a child with a disability or developmental disability	Stepping Stones Triple P-Positive Parenting program (SSTP) Five levels of a behavioural parent training program	Control group NR	- Capability and confidence to meet the needs of the CYP	Analysis assesses change in treatment groups from pre-intervention to post-intervention
Treacy 2005 RCT New Zealand	N=42 Families of children diagnosed with ADHD	Parent stress management program (PSM) Evening sessions (2 hours) for 9	Waitlist control Intervention given after completing the post-test	- Capability and confidence to meet the needs of the CYP - Social capital	Data was analysed separately for mothers and fathers

Study	Population	Intervention	Comparison	Outcomes	Comments
		consecutive weeks			
Truesdale-Kennedy Non RCT Northern Ireland	N=69 Families who had a child with a significant learning disability aged 7-19 years	<u>Family Support Project</u> Home visits by a Project Support Worker and the completion of a person centred plan using PATH or MAPS approach	<u>Contrast group 1</u> Families living in a different area of the same Health and Social Services Trust <u>Contrast group 2</u> Families from a different Health and Social Services Trust.	- Social capital	Evaluation study (service audit)

ASD: autism spectrum disorder; ADHD: attention-deficit hyperactivity disorder; BPT: behavioural parent training; CYP: child or young person; MAPS: making action plans; NR: not reported; PATH: planning alternative tomorrows with hope; RCT: randomised controlled trial; SR: systematic review; USA: United States of America

See the full evidence tables in appendix D and the forest plots in appendix E.

Summary of the effectiveness evidence

Overall, there was evidence of an important benefit of parent training (as opposed to waitlist) in communication and social capital (range of social contact that provides access to social, emotional or practical support). There was also evidence of an important benefit on the capability and confidence to meet the needs of the child or young person when parent training was compared to waitlist, standard care and prior to Stepping Stones Triple P (positive parenting program). There was evidence of an important benefit of enhanced parent training (as opposed to standard parent training) in satisfaction with services and capability and confidence to meet the needs of the child or young person when compared to waitlist. The evidence also suggested an important benefit in advocacy training (compared to waitlist) and digital health technology for capability and confidence to meet the needs of the child or young person, and person centred planning (compared to standard care) for social capital. There was no evidence of an important difference in the capability and confidence to meet the needs of the child or young person after a community health worker intervention.

It is important to note that the benefits seen in parent training and enhanced parent training for satisfaction with services, capability and confidence to meet the needs of the child or young person, and social capital were only apparent in some of the scales used to measure these outcomes. These results indicate a degree of variability and therefore must be interpreted with caution.

Overall 16 studies were identified for inclusion in the review, and evidence was very low to high quality. Concerns were identified about risk of bias, inconsistency, indirectness and imprecision. Studies failed to report on a number of critical and important outcomes including participation and inclusion of families and carers in the design, planning and delivery of care, quality of life, and employment. Studies also failed to report on a number of interventions of interest such as short breaks, key worker, family centred care, best interest meetings, co-production and signposting and referral systems.

See appendix F for full GRADE tables.

Economic evidence

Included studies

Two economic studies were identified which were relevant to this question (NEF Consulting 2009, Copps 2007). A single economic search was undertaken for all topics included in the scope of this guideline. See Supplement B for details.

Excluded studies

Economic studies not included in this review are listed, and reasons for their exclusion are provided in appendix J.

Summary of included economic evidence

The systematic search of the economic literature undertaken for the guideline identified:

- One UK study on the costs of short break service as part of Aiming High for Disabled Children initiative (NEF Consulting 2009);
- On UK study on the costs of short break service and key worker service (Copps 2007).

See the economic evidence tables in appendix H. See

Table 3 and Table 4 for the economic evidence profiles for short-break services and key worker services, respectively.

1 **Table 3: Economic evidence profiles: short break services**

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	Cost-effectiveness	Uncertainty
NEF Consulting 2009 UK	Potentially serious limitations[1]	Partially applicable[2]	Type of economic analysis: Cost-offset analysis Intervention: Short break services, including overnight breaks, family-based/individual day care/sessional provision, group based services, specialist and non-specialist provision Comparator: NA, i.e. cost-offset analysis, non-comparative Time horizon: 1 year Primary measure of outcome: process outcomes valued in monetary terms i.e. financial savings associated with a reduction in residential care; parents', families' and carers' stress; educating siblings with behavioural and emotional difficulties	NA	NA	Annual savings of £19,500 per disabled child	Deterministic sensitivity analyses: not undertaken PSA: not undertaken
Copps 2007 UK	Potentially serious limitations[3]	Partially applicable[4]	Type of economic analysis: Cost-offset analysis Intervention: Short break services that included a number of categories such as family based shared care, residential care, sitting services and befriending	NA	NA	Financial benefits: (£50,847)	Deterministic sensitivity analyses: Varying the success of services (i.e. reducing stress among families) from 100-20% the financial benefits for short break service per participant over 15

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	Cost-effectiveness	Uncertainty
			Comparator: NA, i.e. cost-offset analysis, non-comparative Time horizon: 15 years Primary measure of outcome: financial benefits were expressed in terms of lost earnings, sick days, school costs for siblings with associated emotional behavioural or social disorder; residential and foster care placements; family breakdown				years range from (£12,803) to (£67,828) PSA: not undertaken

Abbreviations: NA: not applicable; PSA: Probabilistic sensitivity analysis

1. Hasn't included costs associated with providing short-break service
2. UK study; unclear if meets the criteria for complex needs
3. Some model inputs based on authors' assumptions; limited sensitivity analysis; hasn't considered non-financial benefits; when estimating the financial benefits associated with preventing sick days due to stress the authors considered only GP visits and haven't included secondary care
4. UK study; unclear how well the definition of severely disabled children (i.e. those eligible for the higher rate for the Care Component of the Disability Living Allowance) aligns with the definition of children and young people with disabilities and severe complex needs in the scope

Table 4: Economic evidence profiles: key worker services

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	Cost-effectiveness	Uncertainty
Copps 2007 UK	Potentially serious limitations[1]	Partially applicable[2]	Type of economic analysis: Cost-offset analysis Intervention: Key worker service, named individuals who act as a single point of contact with multiple services	NA	NA	Financial benefits: (£8,042)	Deterministic sensitivity analyses: Varying the success of services (i.e. reducing stress among families) from 100-20% the financial benefits for key worker services per participant over 15 years

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	Cost-effectiveness	Uncertainty
			Comparator: Comparator: NA, i.e. cost-offset analysis, non-comparative Time horizon: 15 years Primary measure of outcome: financial benefits were expressed in terms of lost earnings, sick days, school costs for siblings with associated emotional behavioural or social disorder; residential and foster care placements; family breakdown				range from £43,758 to (£11,267) PSA: not undertaken

Abbreviations: NA: not applicable; PSA: Probabilistic sensitivity analysis

1. Some model inputs based on authors' assumptions; limited sensitivity analysis; hasn't considered non-financial benefits; when estimating sick days the authors considered only GP visits and haven't included secondary care
2. UK study; unclear how well the definition of severely disabled children (i.e. those eligible for the higher rate for the Care Component of the Disability Living Allowance) aligns with the definition of children and young people with disabilities and severe complex needs in the scope

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

Evidence statements

Economic

- There was mixed evidence from two cost-offset analyses based on modelling. One study showed that a short break service for disabled children and their families resulted in financial benefits. The other study showed that a short break service resulted in a cost increase. Although derived from UK studies, this evidence is partially applicable to the NICE decision-making context as it was unclear from the definitions provided how applicable the populations were. Both studies were characterised by potentially serious limitations. One study has not considered intervention costs. In the other study, some model inputs were based on authors' assumptions, and it has not considering non-financial benefits.
- There was evidence from one cost-offset analysis based on modelling showing that a key worker service resulted in a cost increase in severely disabled children. This evidence, although derived from a UK study, is partially applicable to the NICE decision-making context as it was unclear from the definition provided how applicable the population was, and is characterised by potentially serious limitations, including some model inputs based on authors' assumptions and not considering non-financial benefits.

The committee's discussion and interpretation of the evidence

The outcomes that matter most

Participation and inclusion of families and carers in the design, planning and delivery of care was prioritised by the committee as a critical outcome because it measured the level to which the role of families and carers are supported, which was the objective of this review question. Satisfaction with services was selected as a critical outcome due to the importance of providing person-centred services. Communication was selected as a critical outcome due to the importance of communication in enabling families and carers to interact with the child or young person, and subsequently be involved in the planning and delivery of care.

Quality of life (both health- and social-related quality), capability and confidence to meet the needs of the child or young person, social capital, and employment were agreed as important outcomes. Quality of life was considered an important outcome due to the importance of providing person-centred services. Capability and confidence to meet the needs of the child or young person was considered an important outcome due to the fact that when parents and carers feel capable and confident, they are more likely to be involved in the planning and delivery of care. Social capital was considered an important outcome because of the importance of access to social, emotional or practical support in supporting the role of families and carers. Employment was considered an important outcome due to the fact that many parents will give up employment in order to care for their disabled child or young person with severe complex needs.

No evidence was found for the outcomes of participation and inclusion of families and carers, quality of life and employment.

The quality of the evidence

The quality of the evidence was assessed with GRADE and was rated as very low to high. Concerns about the risk of bias ranged from “no serious” to “very serious”. The most serious concerns for the RCTs was bias arising from randomisation, missing outcome data, measurement of the outcome, and selection of reported results. The most serious concerns for the non-randomised studies were biases arising from confounding and measurement of outcomes. There were no serious concerns arising from the systematic review. Concerns about inconsistency ranged from “no serious” to “serious”. The serious concern related to the outcome capability and confidence to meet the needs of the child or young person when parent training was compared to waitlist, and was due to heterogeneity. Concerns about indirectness ranged from “no serious” to “serious” indirectness”. For all outcomes rated as “serious”, this was due to an indirect aspect of the PICO (population) in 1 study. Concerns about imprecision ranged from “no serious” to “very serious”. This was due to 95% confidence intervals crossing boundaries for minimally important differences.

Benefits and harms

There was evidence of a benefit of parent training in terms of communication, capability, and confidence to meet the needs of the child or young person, and social capital. However, important differences were demonstrated in the evidence when outcomes were measured with some scales, but not for all scales indicating there is some uncertainty in the results. Specifically, whilst a benefit was evident in parent training (compared to waitlist and standard care) for capability and confidence to meet the needs of the child or young person when measured with the Parenting Scale (PS) Overall, PS Verbosity, Parenting Sense of Competence (PSOC) Scale Satisfaction and efficacy subscales, and Everyday Parenting Scale, there was no evidence of a benefit in other measures including the PS Laxness, PS Over reactivity, Personal success subscale of the Duygun version Maslach Burnout Inventory, PSOC Efficacy subscale, coping self-efficacy and Parental Locus of Control Scale Efficacy subscale. Similarly, the benefit in social capital was evident when measured with the Seeking Social Support subscale of the Self-Report Coping Scale, whilst there was no evidence of a benefit in other measures including the Brief Social Support Questionnaire (BSSQ) Size and BSSQ Satisfaction. Given these differences, the committee interpreted the results with caution and used the evidence to recommend general elements of the parent training intervention rather than recommending any specific intervention. Further, the quality of evidence was variable and ranged from very low to high quality, however since the majority of evidence was low quality, the committee agreed that a strong recommendation could not be made. The parent training interventions focussed around psychoeducation and included stress management, coping effectiveness and behavioural strategies aimed at increasing the understanding of the child’s needs, providing tools for parents or carers to effectively support their child’s communication, and positively respond to their child’s behaviours. Therefore, the committee made recommendations that education, health and social care services consider jointly developing training, that is designed to help parents and carers, particularly in these areas [1.6.5]. Further, qualitative evidence reported service providers feeling that families needed more support to provide care for their disabled child or young person with severe complex needs (see evidence report M, sub-theme 3.3), so the committee included in the recommendation that training be designed to help parents and carers understand how services work and what support they can provide. There was also low and moderate quality evidence of a benefit of advocacy training where parents who were educated and enabled to advocate for services increased their capability and confidence to meet the needs of the child or young person. Therefore the committee recommended that training be designed to help parents and carers advocate for their child [1.6.6]. Some of the parent training interventions were conducted in group format and subsequently provided parents and carers the opportunity to engage with, and share experiences with other parents and carers of children and young people with similar disabilities and severe complex needs. The committee agreed that providing such opportunities would have a positive impact on parents and carers by helping them to learn from each other and develop support networks. [1.6.9]

There was evidence of a benefit of enhanced parent training in terms of satisfaction with services, and capability and confidence to meet the needs of the child or young person. However, the benefit of enhanced parent training (compared to waitlist) for capability and confidence to meet the needs of the child or young person was evident when measured with the PS Verbosity, whilst there was no evidence of a benefit in other measures including PS Laxness and PS Over reactivity. Similarly, when compared to standard parent training, the benefit in satisfaction with services was evident when measured with the Therapy Attitude Inventory (TAI) satisfaction with process and TAI satisfaction with outcome, whilst there was no evidence of a benefit in other measures including the Client Satisfaction Questionnaire. The evidence was very low and moderate quality and the intervention consisted of enhancements to the format, delivery and content of traditional parent training including training that was targeted at specific diagnoses. Given these differences, and the quality of the evidence, the committee interpreted the results with caution and used the evidence to recommend general elements of enhanced parent training interventions rather than recommending any specific intervention. The committee discussed that typically training should begin with basics and progress to become more detailed, but that training should be focussed to suit the individual as some parents and carers might require more in-depth training straight away, whilst others will not. Further, the committee agreed that practitioners who lead the training need to have skills that are appropriate for the content of the training so that people are not going beyond their skillsets [1.6.7]. If these things are not done, the committee agreed that the training is likely to be less effective. The same evidence also provided data on the availability of afterhours appointments and home-based sessions to encourage attendance. The committee discussed the difficulty for parents or carers to receive training due to conflicting commitments and/or circumstances, thus the need for training to be more flexibly delivered. There was evidence of a benefit of digital health technology in terms of capability and confidence to meet the needs of the child or young person. Although the evidence was of low quality, the committee agreed on the usefulness of digital technology (for example videoconferencing) as a format to deliver training, particularly in the current climate but they recommended using a variety of formats because not everyone will have access to digital technology. They also recommended considering aligning the timing of training with when the child or young person will be receiving prearranged care so that parents are available to attend [1.6.11]. Based on their experience, the committee felt the inclusion of parents and carers in the training could be facilitated further by considering the application of different teaching styles during the training, such as focus groups, role playing and problem based learning with these being tailored to the understanding and learning styles of those individuals attending. This would be particularly relevant for those where English is not their first language or who have poor literacy [1.6.8]. Based on their experience, the committee discussed that training may not always be offered to parents and carers at the optimal time. Whilst some parents and carers are eager to learn as much possible and as quickly as possible, others may need a period of time to deal with emotions such as grief or denial before embarking on training. Given the central importance of parents and carers receiving training to enable them to support their child, the committee felt strongly that parents and carers who decline training when first offered should not be disadvantaged, and should have the option to attend training at a later time when they are ready [1.6.10].

The committee acknowledged that different learning styles existed amongst parents and carers and it is important to involve parents and carers in the development of awareness training programmes (that are either for them or help practitioners work more effectively with them and their children), particularly in relation to the content, structure and evaluation to ensure that training is targeted and relevant and will result in the best possible outcomes. This was supported by qualitative evidence which reported parents and carers feeling positively when given the opportunity to provide their views, and expressing praise for practitioners that had recognised their expertise as parents and carers of the child or young person, whilst working within the boundaries of responsibility (see evidence report A, sub-themes 9.1 and 9.4). The committee felt that currently the development of training programmes did not always involve parents and carers and therefore a recommendation was needed [1.15.24]. Further, the committee felt strongly that parents and carers should evaluate training against it's objectives to ensure it is effective (otherwise providing it is would not be an efficient use of resources) [1.6.12]. As the objectives of training will all differ the committee did not specify what these were in the recommendation.

There was no evidence on psychological input and support at diagnosis. However, based on their knowledge and experience, the committee discussed that parents or carers may require emotional and practical support to enable them to come to terms with their child's diagnosis and subsequently be effectively involved in the planning and delivery of care. In the committee's experience, families often report a desire to have been signposted to these services earlier [1.6.1].

There was evidence of a benefit of person centred planning in terms of social capital. The committee agreed that a person centred planning approach would be beneficial in helping to include parents and carers in care planning but due to the low and very low quality of the evidence and that it only reported on one outcome they only made a weak recommendation [1.6.2].

No evidence was found on the effectiveness of short breaks to enable families/carers to be involved in the planning and delivery of care. However, the committee agreed, based on their experience, that short breaks were beneficial to involving parents and carers in the planning and delivery of care by providing needed respite. This was supported by qualitative evidence from parents who viewed short breaks as beneficial to the whole family as they allowed them to spend time with, and provide attention to other children in the family, and to address other practical demands such as household chores (see evidence report A, sub-theme 13.1). They noted that the SEND Code of Practice (2015) requires the provision of a range of short break options but noted that in practice services can be constrained by the resources currently available in that area, whereas the most successful short breaks are those done in consultation with the parents or carers and tailored to their specific needs. The committee agreed that parents only want care as good as that which they provide themselves for their child or young person, and it is the bespoke offer rather than the 'off the shelf' offer that provides the most value to them. Therefore more needs to be done to provide short break options for children and young people and, the committee re-emphasised the requirement in the SEND Code of Practice (2015) for local authorities to provide a range of short break options [1.17.14]. Due to a lack of evidence on the effectiveness of short breaks, it remains unclear which aspects of short breaks make them most effective, and why some short breaks are valued over others by disabled children and young people with severe complex needs and their families or carers. Therefore, the committee agreed a research recommendation was needed to determine which components of short break services provide the most effective short breaks for disabled children and young people with severe complex needs, their families and carers.

Cost effectiveness and resource use

The committee discussed the recommendations around general support to parents and carers coming to terms with a child's needs and diagnosis. It was noted that since support services already exist and the recommendations are only about signposting to such services / organisations, not providing new support, this recommendation is not expected to result in a resource impact.

There was conflicting existing economic evidence from two studies on short break services. One study found that short break services result in substantial financial benefits but it did not consider the costs associated with providing a short break service. However, assuming intervention costs are the same as reported in Copps 2007 the financial benefits associated with the short break service would far outweigh the provision costs. Evidence from another study on short break services concluded that financial benefits gained were not sufficient to cover the provision costs. The committee acknowledged that both studies were only partially applicable to the NICE decision making context as it was unclear from the definitions provided how applicable the population was. The committee noted that the provision of short breaks is essential to improving outcomes for parents and supporting them to continue in their caring role. Also, whilst not the focus of this question, short breaks can improve outcomes for children and young people by improving their independence and confidence, which can ultimately mean less pressure on parents and carers to provide care. The existing economic analyses did not capture benefits on the child's/ young person's outcomes and therefore may have underestimated the cost-effectiveness of short break services. Given the uncertainties with the economic evidence and the lack of effectiveness evidence, the committee did not make a recommendation about short break services but re-emphasised the requirement for local authorities to provide a range of short break options as set out in the SEND Code of Practice (2015).

There was economic evidence from one study on key worker services. The analysis showed that key worker services costed more to provide than the value of the financial gains. However, under a certain set of assumptions, key worker services could potentially be cost-saving. It was acknowledged that this study was only partially applicable to the NICE decision making context because it was unclear from the definition provided in the study how applicable the population was. Also, this study was characterised by potentially serious limitations. As a result, and given the lack of effectiveness evidence, the committee could not draw any firm conclusions from this evidence.

The committee explained that person-centred approaches are currently used in planning care and so the recommendation about this was unlikely to result in any significant resource implications. This aligns with the SEND Code of Practice (2015) which specifies that when commissioning training, consideration should be given to meeting the needs of children and young people with SEN or disabilities in a more personalised way.

Similarly, the committee discussed the recommendations around parent / carer training. The committee explained that, at present, services commission such training in isolation or only two services working together (i.e. local authorities with support from health services or health services could lead with the backing from local authorities). Parents and carers could also access such training through children's services, parent / carer forums, and the disabled children's teams. There is no dominant route to this. The committee agreed there is a need for a coordinated approach to training across all three sectors. The committee explained that there might be some costs associated with setting up the framework for such a collaborative approach. However, collaborative working will make the training approach coordinated, cut out duplication of effort and result in efficiencies and cost savings to the organisations involved. Similarly involving parents and carers in the development of such training will result in improved, more relevant content but there is unlikely to be a significant resource impact from doing so. The committee also recommended that the timing of training is aligned with times when the child or young person will be receiving prearranged care, education or familial care so there is unlikely to be a significant resource implication from providing care whilst parents attend training.

The recommendation on information provision is unlikely to have any significant additional resource implications as it is a requirement in the SEND Code of Practice (2015) for local authorities to make arrangements for providing parents with advice and information about matters relating to special educational needs and disability.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.6.1, 1.6.2, 1.6.5 - 1.6.12, 1.15.24, 1.17.14 and the research recommendation on short break services.

References – included studies

Effectiveness

Benn 2012

Benn, Rita, Akiva, Tom, Arel, Sari, Roeser, Robert W., Mindfulness training effects for parents and educators of children with special needs, Developmental Psychology, 48, 1476-1487, 2012

Bilgin 2009

Bilgin, Sonay, Gozum, Sebahat, Reducing burnout in mothers with an intellectually disabled child: an education programme, Journal of advanced nursing, 65, 2552-61, 2009

Chacko 2009

Chacko, Anil, Wymbs, Brian T., Wymbs, Frances A., Pelham, William E., Swanger-Gagne, Michelle S., Girio, Erin, Pirvics, Lauma, Herbst, Laura, Guzzo, Jamie, Phillips, Carlie, O'Connor, Briannon, Enhancing traditional behavioral parent training for single mothers of children with ADHD, Journal of clinical child and adolescent psychology : the official journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53, 38, 206-18, 2009

Chacko 2018

Chacko, A., Scavenius, C., Bending the Curve: a Community-Based Behavioral Parent Training Model to Address ADHD-Related Concerns in the Voluntary Sector in Denmark, Journal of abnormal child psychology, 46, 505-517, 2018

Costich 2019

Costich, M. A., Peretz, P. J., Davis, J. A., Stockwell, M. S., Matiz, L. A., Impact of a Community Health Worker Program to Support Caregivers of Children With Special Health Care Needs and Address Social Determinants of Health, Clinical Pediatrics, 58, 1315-1320, 2019

Giallo 2008

Giallo, Rebecca, Gavidia-Payne, Susana, Barrett, Beresford Breslau Castles Causey Cohen Cohen Dadds Diamond Dunst Ellis Evans Fisman Foster Gamble Giallo Giallo Goodman Gordon Hardy Heiney Hoddap Houtzager Houtzager Houtzager Jacobson Kearney Kliewer Lobato Matthews McCubbin McLinden Phillips Ross Rossiter Sharpe Stein Summers Tarnowski Van Riper Walsh Williams Williams Williams, Evaluation of a family-based intervention for siblings of children with a disability or chronic illness, AeJAMH (Australian e-Journal for the Advancement of Mental Health), 7, 1-13, 2008

Haakonsen Smith

Haakonsen Smith, C., Turbitt, E., Muschelli, J., Leonard, L., Lewis, K. L., Freedman, B., Muratori, M., Biesecker, B. B., Feasibility of Coping Effectiveness Training for Caregivers of Children with Autism Spectrum Disorder: a Genetic Counseling Intervention, Journal of Genetic Counseling, 27, 252-262, 2018

Harris 2016

Harris, Nicola, Beringer, Antonia, Fletcher, Margaret, Families' priorities in life-limiting illness: improving quality with online empowerment, Archives of disease in childhood, 101, 247-52, 2016

Hoath 2002

Hoath, F. E., Sanders, M. R., A feasibility study of Enhanced Group Triple P - Positive parenting program for parents of children with attention-deficit/hyperactivity disorder, Behaviour Change, 19, 191-206, 2002

Lange 2018

Lange, A. M., Daley, D., Frydenberg, M., Houmann, T., Kristensen, L. J., Rask, C., Sonuga-Barke, E., Sondergaard-Baden, S., Udupi, A., Thomsen, P. H., Parent Training for Preschool ADHD in Routine, Specialist Care: A Randomized Controlled Trial, Journal of the American Academy of Child and Adolescent Psychiatry, 57, 593-602, 2018

Plant 2007

Plant, Karen M., Sanders, Matthew R., Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities, Research in Developmental Disabilities, 28, 362-385, 2007

Sonuga-Barke 2001

Sonuga-Barke, E. J., Daley, D., Thompson, M., Laver-Bradbury, C., Weeks, A., Parent-based therapies for preschool attention-deficit/hyperactivity disorder: a randomized, controlled trial with a community sample, Journal of the American Academy of Child and Adolescent Psychiatry, 40, 402-8, 2001

Taylor 2017

Taylor, Julie Lounds, Hodapp, Robert M., Burke, Meghan M., Waitz-kudla, Sydney N., Rabideau, Carol, Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial, Journal of Autism and Developmental Disorders, 47, 846-857, 2017

Tellegen 2013

Tellegen, Cassandra L., Sanders, Matthew R., Stepping Stones Triple P-Positive Parenting Program for children with disability: a systematic review and meta-analysis, Research in developmental disabilities, 34, 1556-71, 2013

Treacy 2005

Treacy, L., Tripp, G., Baird, A., Parent stress management training for attention-deficit/hyperactivity disorder, Behavior therapy, 36, 223-233, 2005

Truesdale-Kennedy 2006

Truesdale-Kennedy, Maria, McConkey, Roy, Ferguson, Pauline, Roberts, Paul, Allen, Carpenter Chan Dale Dempsey Dyson Epstein Friedrich Goldberg Judge Kelly King Law McConkey McConkey McConkey McConkey Polit Robertson Rosenbaum Sanderson Sarason Smyth, An Evaluation of a Family-centred Support Service for Children with a Significant Learning Disability, Child Care in Practice, 12, 377-390, 2006

Economic

Copps

Copps, J., Heady, L., What price an ordinary life? The financial costs and benefits of supporting disabled children and their families, New Philanthropy Capital, 2007

NEF Consulting 2009

1 NEF Consulting., The social and economic value of short breaks, 2009

Appendices

Appendix A – Review protocol

Review protocol for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Table 5: Review protocol

ID	Field	Content
0.	PROSPERO registration number	CRD42019155783)
1.	Review title	What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?
2.	Review question	What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?
3.	Objective	To identify the optimal interventions for enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs. The committee agreed that the review question would encompass service design including the involvement of service users.
4.	Searches	The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • Health Technology Assessment (HTA) • Database of Abstracts of Reviews of Effects (DARE) • British Education Index (BEI) • Educational Information Resources Center (ERIC) • Health Management Information Consortium (HMIC) • Applied Social Science Index and Abstracts (ASSIA) • Social Care Online

ID	Field	Content
		• Social Policy and Practice • Social Science Citation Index • Social Services Abstracts • Sociological Abstracts • PsycINFO • CINAHL • Emcare Searches will be restricted by: • Date: 2000 onwards • Language: English Other searches: • Inclusion lists of systematic reviews • Kings Fund Reports (https://www.kingsfund.org.uk/publications) • National Audit Office • Audit Commission • Open Grey (if insufficient studies are found from other sources) The full search strategies for all databases will be published in the final review.
5.	Condition or domain being studied	Disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support.
6.	Population	Inclusion: • Families of disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support • Carers of disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support Exclusion: • Families of children and young people who do not have needs in all three areas of health, social care and education. • Carers of children and young people who do not have needs in all three areas of health, social care and education.
7.	Intervention/Exposure/Test	Intervention(s) involving or supporting families and/or carers.

ID	Field	Content

		For example:
		• Combined support across sectors
		  ➢ Complex discharge planning
		  ➢ Advocacy (third sector)
		  ➢ Care pathways
		• Communication strategies such as parent/carer education (e.g. manualised programs [early bird])
		• Short breaks (including specialist and respite breaks)
		• Key worker
		• Family centred care
		• Shared decision making
		  ➢ Person centred planning
		• Best interest meetings
		• Co-production
		• Feeding strategies (e.g. enteral feeding)
		• Parent mediated interventions
		• Behavioural support approaches (e.g., motivational interviewing, restorative practice and appreciative enquiry)
		• Family therapy
		• Parent training and resilience (e.g. insider’s guide)
		• Post adoption support fund (e.g. specialist play therapy)
		• Psychological input and support at diagnosis
		• Digital technology (e.g. accessing online services)
		• Signposting and referral systems

8.	Comparator/Reference standard/Confounding factors	• Any other intervention(s) specifically involving or supporting families and/or carers • Intervention(s) not specifically involving or supporting families and/or carers
9.	Types of study to be included	Systematic reviews of RCTs or non-randomised comparative studies (including cohort studies, before and after studies and interrupted time series), and RCTS will be included. Non-randomised studies will be included in the absence of RCTs for a given class of interventions. Service evaluations and audits will be included in the absence of comparative non-randomised studies. Conference abstracts will not be included. Non-randomised studies should adjust for confounders in their analysis such as: dominant provision (e.g. primarily autism, primarily physical disability etc.), definitions of eligibility (e.g. for

ID	Field	Content
		primary SEN), socioeconomic status. Studies will be downgraded for risk of bias if important confounding factors are not adequately adjusted for but will not be excluded for this reason.
10.	Other exclusion criteria	Studies will not be included for the following reasons: • Published prior to 2000 • Not published in the English language • Non Organisation for Economic Co-operation and Development (OCED) country (https://www.oecd.org/about/members-and-partners/) Studies published prior to 2000 will not be considered due to legislative changes, specifically the Children and Families Care Act 2014, and the Aiming High for Disabled Children (AHDC) programme 2007. Studies published in languages other than English will not be considered due to time and resource constraints with translation. Studies published by non OCED countries will not be considered due to differences in health, social care and education services to those implemented in the UK.
11.	Context	All settings will be considered where health, social care and education is provided for disabled children and young people from birth to 25 years with severe complex needs.
12.	Primary outcomes (critical outcomes)	Critical Outcomes: • Participation and inclusion of families and carers in the design, planning and delivery of care • Satisfaction with services as measured by validated scales • Communication as measured by validated scales
13.	Secondary outcomes (important outcomes)	Important Outcomes: • Quality of life (both health- and social-related quality) as measured by validated scales • Capability and confidence to meet the needs of the child or young person as measured by validated scales • Social capital (range of social contact that provides access to social, emotional or practical support) • Employment (of families and/or carers)
14.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion.

ID	Field	Content
		A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), participant characteristics, inclusion and exclusion criteria, details of the interventions, setting and follow-up, relevant outcome data and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
15.	Risk of bias (quality) assessment	Quality assessment of individual studies will be performed using the following checklists: • ROBIS tool for systematic reviews • Cochrane RoB tool v.2 for RCTs and quasi-RCTs • Cochrane ROBINS-I tool for non-randomised (clinical) controlled trials and cohort studies • Effective Practice and Organisation of Care (EPOC) RoB Tool for before and after studies • Effective Practice and Organisation of Care (EPOC) RoB Tool for interrupted time series The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
16.	Strategy for data synthesis	Intervention review: Depending on the availability of the evidence, the findings will be summarised narratively or quantitatively. Where possible, meta-analyses will be conducted using Cochrane Review Manager software. A fixed effect meta-analysis will be conducted and data will be presented as risk ratios or odds ratios for dichotomous outcomes, and mean differences or standardised mean differences for continuous outcomes. Heterogeneity in the effect estimates of the individual studies will be assessed using the I2 statistic. I2 values of greater than 50% and 80% will be considered as significant and very significant heterogeneity, respectively. Heterogeneity will be explored as appropriate using sensitivity analyses and pre-specified subgroup analyses. If heterogeneity cannot be explained through subgroup analysis then a random effects model will be used for meta-analysis, or the data will not be pooled if the I^2 statistic is greater than 80%. The confidence in the findings across all available evidence will be evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group: http://www.gradeworkinggroup.org/ Minimally important differences: • We will check the rehabilitation measures database (www.sralab.org) for published MIDs for scales reported by included studies and use these if available. If not, we will use GRADE default MIDs. • For all remaining continuous outcomes, we will use GRADE default MID of 0.5 times SD of the control groups at baseline (or at follow-up if the SD is not available a baseline). For all remaining dichotomous outcomes (RRs, ORs and HRs), we will use the GRADE default for RRs of 0.8 and 1.25 for consistency.

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• Setting (e.g. co-located vs not)
• Country
• Age group (≥16 years versus <16 years)</td></tr>
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<tr><td>Data analysis</td><td>☐</td><td>☐</td></tr>
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National Guideline Alliance

5b Named contact e-mail</td></tr>
</table>

ID	Field	Content	
		CYPseverecomplexneeds@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and National Guideline Alliance	
25.	Review team members	National Guideline Alliance	
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance which receives funding from NICE.	
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.	
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10113	
29.	Other registration details	None	
30.	Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=155783	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Child, infant, young person, disability, health care, education, social care, service delivery, service organisation	
33.	Details of existing review of same topic by same authors	None	
34.	Current review status	☒	Ongoing

ID	Field	Content	
		☐	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	None	
36.	Details of final publication	www.nice.org.uk	

AHDC: Aiming High for Disabled Children; ASSIA: Applied Social Science Index and Abstracts; BEI: British Education Index; CAF: common assessment framework; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: database of Abstracts of Reviews of Effects; EPOC: Effective Practice and Organisation of Care; ERIC: Educational Information Resources Center; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HMIC: Health Management Information Consortium; HR: hazard ratio; HTA: Health Technology Assessment; MID: minimally important difference; NICE: National Institute for Health and Care Excellence; OECD: Organisation for Economic Co-operation and Development; OR: odds ratio; RCT: randomised controlled trial; RoB: risk of bias; RR: risk ratio; ROBINS-I: risk of bias in non-randomised studies – of interventions; ROBIS: Risk of Bias in Systematic Reviews; SD: standard deviation

Appendix B – Literature search strategies

Literature search strategies for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Databases: Medline; Medline EPub Ahead of Print; and Medline In-Process & Other Non-Indexed Citations

Date of last search: 31/01/2020

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
3	exp CHILD/
4	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric$.ti,ab.
9	YOUNG ADULT/
10	young$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSONS/
13	exp MENTAL DISORDERS/
14	exp COMMUNICATION DISORDERS/
15	exp INTELLECTUAL DISABILITY/
16	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
17	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
18	SHCN.ti,ab.
19	or/12-18
20	11 and 19
21	DISABLED CHILDREN/
22	CSHCN.ti,ab.
23	"Education Health and Care plan?".ti,ab.
24	EHC plan?.ti,ab.
25	EHCP?.ti,ab.
26	or/20-25
27	INTERINSTITUTIONAL RELATIONS/
28	INTERSECTORAL COLLABORATION/
29	"DELIVERY OF HEALTH CARE, INTEGRATED"/
30	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
31	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
32	(intersector$ or multisector$ or jointsector$).ti,ab.
33	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
34	(interprovider? or multiprovider? or jointprovider?).ti,ab.
35	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
36	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
37	((inter or multi$ or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$)).ti,ab.
38	((institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
39	or/27-38
40	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/)
41	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp

#	Searches
	NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
42	(exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
43	or/40-42
44	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social$ adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
45	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
46	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
47	or/44-46
48	STATE MEDICINE/og [Organization & Administration]
49	CHILD HEALTH SERVICES/og [Organization & Administration]
50	ADOLESCENT HEALTH SERVICES/og [Organization & Administration]
51	EDUCATION/og [Organization & Administration]
52	exp EDUCATION, SPECIAL/og [Organization & Administration]
53	exp SOCIAL WORK/og [Organization & Administration]
54	or/48-53
55	*FAMILY/
56	NUCLEAR FAMILY/
57	SINGLE-PARENT FAMILY/
58	PARENTS/
59	*MOTHERS/
60	FATHERS/
61	SINGLE PARENT/
62	SIBLINGS/
63	GRANDPARENTS/
64	*CAREGIVERS/
65	(parent? or parental or mother? or father? or sibling? or brother? or sister? or grandparent? or grandfather? or grandmother? or family or families or caregiver? or carer?).ti.
66	parent?.ab. /freq=4
67	parental.ab. /freq=3
68	mother?.ab. /freq=4
69	father?.ab. /freq=2
70	sibling?.ab. /freq=2
71	brother?.ab. /freq=2
72	sister?.ab. /freq=2
73	grandparent?.ab. /freq=2
74	grandfather?.ab. /freq=2
75	grandmother?.ab. /freq=2
76	family.ab. /freq=4
77	families.ab. /freq=4
78	caregiver?.ab. /freq=3
79	carer?.ab. /freq=2
80	or/55-79
81	intervention?.ti.
82	PROFESSIONAL-FAMILY RELATIONS/
83	"HEALTH SERVICES NEEDS AND DEMAND"/
84	HEALTH SERVICES ACCESSIBILITY/
85	*SOCIAL SUPPORT/
86	(involv$ adj3 care).ti,ab.
87	(professional? adj3 relations$).ti,ab.
88	(service? adj3 need?).ti,ab.
89	(access$ adj5 service?).ti,ab.
90	(access$ adj3 care).ti,ab.
91	(social$ adj5 support$).ti.
92	(social$ adj5 support$).ab. /freq=2

#	Searches
93	(support adj3 need?).ti,ab.
94	(support$ adj3 service?).ti,ab.
95	PATIENT DISCHARGE/
96	(discharg$ adj3 (plan$ or manag$)).ti,ab.
97	CHILD ADVOCACY/
98	PATIENT ADVOCACY/
99	CONSUMER ADVOCACY/
100	(advocacy or advocat$).ti,ab.
101	ORGANIZATIONS, NONPROFIT/
102	((voluntary or civic or third or community or nonprofit or non-profit) adj3 (sector? or organi?ation?)).ti,ab.
103	PATIENT CARE PLANNING/
104	(care adj3 (path? or pathway?)).ti,ab.
105	COMMUNICATION/
106	PATIENT EDUCATION AS TOPIC/
107	INFORMATION SEEKING BEHAVIOR/
108	(communicat$ or information).ti.
109	communicat$.ab. /freq=2
110	information.ab. /freq=2
111	RESPITE CARE/
112	(respite adj3 (care or break?)).ti,ab.
113	short break?.ti,ab.
114	key worker?.ti,ab.
115	((family or families) adj3 center$ adj3 (care or plan$)).ti,ab.
116	DECISION MAKING/
117	((make or making) adj3 decision?).ti,ab.
118	PATIENT-CENTERED CARE/
119	((patient? or person) adj3 center$ adj3 (care or plan$)).ti,ab.
120	(best adj3 interest? adj3 meeting?).ti,ab.
121	(co-production? or coproduction?).ti,ab.
122	FEEDING BEHAVIOR/
123	exp FEEDING METHODS/
124	((feed$ or eat$ or meal$) adj3 (strateg$ or behavio?r? or method?)).ti,ab.
125	exp BEHAVIOR THERAPY/
126	MOTIVATIONAL INTERVIEWING/
127	(behavio?r$ adj3 (support$ or therap$ or intervention?)).ti,ab.
128	motivational interview$.ti,ab.
129	restorative practice?.ti,ab.
130	appreciative enquir$.ti,ab.
131	FAMILY THERAPY/
132	((family or families) adj3 therap$).ti,ab.
133	exp *PARENTS/ed [Education]
134	(parent$ adj3 train$).ti,ab.
135	RESILIENCE, PSYCHOLOGICAL/
136	resilien$.ti,ab.
137	support fund?.ti,ab.
138	PLAY THERAPY/
139	(play adj3 therap$).ti,ab.
140	(diagnos$ adj3 support$).ti,ab.
141	exp COMPUTERS/
142	exp SOFTWARE/
143	exp TELECOMMUNICATION/
144	(website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or phone? or cloud).ti.
145	"REFERRAL AND CONSULTATION"/
146	(signpost$ or sign post$).ti,ab.
147	referr$.ti.
148	(referr$ adj3 system?).ti,ab.
149	or/81-148
150	26 and (39 or 43 or 47 or 54) and 80 and 149
151	limit 150 to english language
152	limit 151 to yr="2000 -Current"
153	LETTER/
154	EDITORIAL/
155	NEWS/
156	exp HISTORICAL ARTICLE/
157	ANECDOTES AS TOPIC/
158	COMMENT/
159	CASE REPORT/
160	(letter or comment*).ti.
161	or/153-160

#	Searches
162	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
163	161 not 162
164	ANIMALS/ not HUMANS/
165	exp ANIMALS, LABORATORY/
166	exp ANIMAL EXPERIMENTATION/
167	exp MODELS, ANIMAL/
168	exp RODENTIA/
169	(rat or rats or mouse or mice).ti.
170	or/163-169
171	152 not 170

Databases: Embase; and Embase Classic

Date of last search: 31/01/2020

#	Searches
1	exp ADOLESCENT/
2	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
3	exp CHILD/
4	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric$.ti,ab.
9	YOUNG ADULT/
10	young$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSON/
13	exp MENTAL DISEASE/
14	INTELLECTUAL IMPAIRMENT/
15	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
16	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/12-17
19	11 and 18
20	HANDICAPPED CHILD/
21	CSHCN.ti,ab.
22	"Education Health and Care plan?".ti,ab.
23	EHC plan?.ti,ab.
24	EHCP?.ti,ab.
25	or/19-24
26	PUBLIC RELATIONS/
27	INTERSECTORAL COLLABORATION/
28	INTEGRATED HEALTH CARE SYSTEM/
29	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
30	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
31	(intersector$ or multisector$ or jointsector$).ti,ab.
32	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
33	(interprovider? or multiprovider? or jointprovider?).ti,ab.
34	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
35	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
36	((inter or multi$ or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$)).ti,ab.
37	((institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
38	or/26-37
39	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/)
40	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
41	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or

#	Searches
	PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
42	or/39-41
43	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social$ adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
44	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
45	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
46	or/43-45
47	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
48	CHILD HEALTH CARE/ and ORGANIZATION/
49	EDUCATION/ and ORGANIZATION/
50	exp SPECIAL EDUCATION/ and ORGANIZATION/
51	SOCIAL WORK/ and ORGANIZATION/
52	or/47-51
53	*FAMILY/
54	*NUCLEAR FAMILY/
55	*SINGLE-PARENT FAMILY/
56	*PARENT/
57	*ADOPTIVE PARENT/
58	*MOTHER/
59	*FATHER/
60	*SINGLE PARENT/
61	exp *SIBLING/
62	exp *GRANDPARENT/
63	*CAREGIVER/
64	(parent? or parental or mother? or father? or sibling? or brother? or sister? or grandparent? or grandfather? or grandmother? or family or families or caregiver? or carer?).ti.
65	parent?.ab. /freq=4
66	parental.ab. /freq=3
67	mother?.ab. /freq=4
68	father?.ab. /freq=2
69	sibling?.ab. /freq=2
70	brother?.ab. /freq=2
71	sister?.ab. /freq=2
72	grandparent?.ab. /freq=2
73	grandfather?.ab. /freq=2
74	grandmother?.ab. /freq=2
75	family.ab. /freq=4
76	families.ab. /freq=4
77	caregiver?.ab. /freq=3
78	carer?.ab. /freq=2
79	or/53-78
80	intervention?.ti.
81	*HEALTH CARE DELIVERY/
82	*SOCIAL SUPPORT/
83	(involv$ adj3 care).ti,ab.
84	(professional? adj3 relations$).ti,ab.
85	(service? adj3 need?).ti,ab.
86	(access$ adj5 service?).ti,ab.
87	(access$ adj3 care).ti,ab.
88	(social$ adj5 support$).ti.
89	(social$ adj5 support$).ab. /freq=2
90	(support adj3 need?).ti,ab.
91	(support$ adj3 service?).ti,ab.
92	*HOSPITAL DISCHARGE/
93	(discharg$ adj3 (plan$ or manag$)).ti,ab.
94	*CHILD ADVOCACY/
95	*PATIENT ADVOCACY/

#	Searches
96	*CONSUMER ADVOCACY/
97	(advocacy or advocat$).ti,ab.
98	*NON PROFIT ORGANIZATION/
99	((voluntary or civic or third or community or nonprofit or non-profit) adj3 (sector? or organi?ation?)).ti,ab.
100	*CLINICAL PATHWAY/
101	*PATIENT CARE PLANNING/
102	(care adj3 (path? or pathway?)).ti,ab.
103	*INTERPERSONAL COMMUNICATION/
104	*PATIENT EDUCATION/
105	*INFORMATION SEEKING/
106	(communicat$ or information).ti.
107	communicat$.ab. /freq=3
108	information.ab. /freq=3
109	*RESPITE CARE/
110	(respite adj3 (care or break?)).ti,ab.
111	short break?.ti,ab.
112	key worker?.ti,ab.
113	*FAMILY CENTERED CARE/
114	((family or families) adj3 center$ adj3 (care or plan$)).ti,ab.
115	*DECISION MAKING/
116	*CLINICAL DECISION MAKING/
117	*MEDICAL DECISION MAKING/
118	*SHARED DECISION MAKING/
119	*FAMILY DECISION MAKING/
120	((make or making) adj3 decision?).ti,ab.
121	((patient? or person) adj3 center$ adj3 (care or plan$)).ti,ab.
122	(best adj3 interest? adj3 meeting?).ti,ab.
123	(co-production? or coproduction?).ti,ab.
124	*FEEDING BEHAVIOR/
125	exp *FOOD INTAKE/
126	((feed$ or eat$ or meal$) adj3 (strateg$ or behavio?r? or method?)).ti,ab.
127	*BEHAVIOR THERAPY/
128	*MOTIVATIONAL INTERVIEWING/
129	(behavio?r$ adj3 (support$ or therap$ or intervention?)).ti,ab.
130	motivational interview$.ti,ab.
131	restorative practice?.ti,ab.
132	appreciative enquir$.ti,ab.
133	*FAMILY THERAPY/
134	((family or families) adj3 therap$).ti,ab.
135	(parent$ adj3 train$).ti,ab.
136	*PSYCHOLOGICAL RESILIENCE/
137	resilien$.ti,ab.
138	support fund?.ti,ab.
139	*PLAY THERAPY/
140	(play adj3 therap$).ti,ab.
141	(diagnos$ adj3 support$).ti,ab.
142	*INFORMATION TECHNOLOGY DEVICE/
143	exp *COMPUTER/
144	*SOFTWARE/
145	*COMMUNICATION SOFTWARE/
146	exp *MOBILE APPLICATION/
147	*WEB BROWSER/
148	*TELECOMMUNICATION/
149	exp *TELEHEALTH/
150	*TELEPHONE/
151	exp *MOBILE PHONE/
152	(website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or phone? or cloud).ti.
153	*PATIENT REFERRAL/
154	(signpost$ or sign post$).ti,ab.
155	referr$.ti.
156	(referr$ adj3 system?).ti,ab.
157	or/80-156
158	25 and (38 or 42 or 46 or 52) and 79 and 157
159	limit 158 to english language
160	limit 159 to yr="2000 -Current"
161	letter.pt. or LETTER/
162	note.pt.
163	editorial.pt.
164	CASE REPORT/ or CASE STUDY/

#	Searches
165	(letter or comment*).ti.
166	or/161-165
167	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
168	166 not 167
169	ANIMAL/ not HUMAN/
170	NONHUMAN/
171	exp ANIMAL EXPERIMENT/
172	exp EXPERIMENTAL ANIMAL/
173	ANIMAL MODEL/
174	exp RODENT/
175	(rat or rats or mouse or mice).ti.
176	or/168-175
177	160 not 176

Database: Health Management Information Consortium (HMIC)

Date of last search: 31/01/2020

#	Searches
1	exp YOUNG PEOPLE/
2	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
3	exp CHILDREN/
4	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
5	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
6	exp PAEDIATRICS/
7	p?ediatric$.ti,ab.
8	YOUNG ADULTS/
9	young$ adult?.ti,ab.
10	or/1-9
11	DISABLED PEOPLE/
12	exp DISABILITIES/
13	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
14	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
15	SHCN.ti,ab.
16	or/11-15
17	10 and 16
18	CSHCN.ti,ab.
19	"Education Health and Care plan?".ti,ab.
20	EHC plan?.ti,ab.
21	EHCP?.ti,ab.
22	or/17-21
23	COLLABORATION/
24	exp INTERAGENCY COLLABORATION/
25	INTERPROFESSIONAL COLLABORATION/
26	COLLABORATIVE CARE/
27	INTEGRATED PROVIDERS/
28	INTEGRATED CARE/
29	INTERDISCIPLINARY SERVICES/
30	JOINT WORKING/
31	HEALTH & SOCIAL SERVICES INTERACTION/
32	COMMUNICATION/
33	HEALTH SERVICE PROVISION/
34	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
35	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
36	(intersector$ or multisector$ or jointsector$).ti,ab.
37	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
38	(interprovider? or multiprovider? or jointprovider?).ti,ab.
39	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
40	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
41	((inter or multi$ or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$)).ti,ab.
42	((institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
43	or/23-42
44	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (exp SOCIAL WORK/ or

#	Searches
	SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SUPPORTIVE SOCIAL WORK/)
45	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
46	(exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SUPPORTIVE SOCIAL WORK/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
47	or/44-46
48	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social$ adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
49	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
50	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
51	or/48-50
52	FAMILIES/
53	NUCLEAR FAMILIES/
54	LONE PARENT FAMILIES/
55	PARENTS/
56	MOTHERS/
57	FATHERS/
58	SIBLINGS/
59	BROTHERS/
60	SISTERS/
61	GRANDPARENTS/
62	GRANDFATHERS/
63	GRANDMOTHERS/
64	CARERS/
65	(parent? or parental or mother? or father? or sibling? or brother? or sister? or grandparent? or grandfather? or grandmother? or family or families or caregiver? or carer?).ti.
66	or/52-65
67	22 and (43 or 47 or 51) and 66
68	limit 67 to yr="2000 -Current"

Database: Social Policy and Practice

Date of last search: 31/01/2020

#	Searches
1	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
2	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
3	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
4	p?ediatric$.ti,ab.
5	young$ adult?.ti,ab.
6	or/1-5
7	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
8	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
9	SHCN.ti,ab.
10	or/7-9

#	Searches
11	6 and 10
12	CSHCN.ti,ab.
13	"Education Health and Care plan?".ti,ab.
14	EHC plan?.ti,ab.
15	EHCP?.ti,ab.
16	or/11-15
17	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
18	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
19	(intersector$ or multisector$ or jointsector$).ti,ab.
20	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
21	(interprovider? or multiprovider? or jointprovider?).ti,ab.
22	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
23	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
24	((inter or multi$ or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$)).ti,ab.
25	((institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
26	or/17-25
27	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social$ adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
28	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
29	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
30	or/27-29
31	(parent? or parental or mother? or father? or sibling? or brother? or sister? or grandparent? or grandfather? or grandmother? or family or families or caregiver? or carer?).ti.
32	parent?.ab. /freq=2
33	parental.ab. /freq=2
34	mother?.ab. /freq=2
35	father?.ab. /freq=2
36	sibling?.ab. /freq=2
37	brother?.ab. /freq=2
38	sister?.ab. /freq=2
39	grandparent?.ab. /freq=2
40	grandfather?.ab. /freq=2
41	grandmother?.ab. /freq=2
42	family.ab. /freq=2
43	families.ab. /freq=2
44	caregiver?.ab. /freq=2
45	carer?.ab. /freq=2
46	or/31-45
47	intervention?.ti.
48	(involv$ adj3 care).ti,ab.
49	(professional? adj3 relations$).ti,ab.
50	(service? adj3 need?).ti,ab.
51	(access$ adj5 service?).ti,ab.
52	(access$ adj3 care).ti,ab.
53	(social$ adj5 support$).ti.
54	(social$ adj5 support$).ab. /freq=2
55	(support adj3 need?).ti,ab.
56	(support$ adj3 service?).ti,ab.
57	(discharg$ adj3 (plan$ or manag$)).ti,ab.
58	(advocacy or advocat$).ti,ab.
59	((voluntary or civic or third or community or nonprofit or non-profit) adj3 (sector? or organi?ation?)).ti,ab.
60	(care adj3 (path? or pathway?)).ti,ab.
61	(communicat$ or information).ti.
62	communicat$.ab. /freq=2
63	information.ab. /freq=2
64	(respite adj3 (care or break?)).ti,ab.

#	Searches
65	short break?.ti,ab.
66	key worker?.ti,ab.
67	((family or families) adj3 center$ adj3 (care or plan$)).ti,ab.
68	((make or making) adj3 decision?).ti,ab.
69	((patient? or person) adj3 center$ adj3 (care or plan$)).ti,ab.
70	(best adj3 interest? adj3 meeting?).ti,ab.
71	(co-production? or coproduction?).ti,ab.
72	((feed$ or eat$ or meal$) adj3 (strateg$ or behavio?r? or method?)).ti,ab.
73	(behavio?r$ adj3 (support$ or therap$ or intervention?)).ti,ab.
74	motivational interview$.ti,ab.
75	restorative practice?.ti,ab.
76	appreciative enquir$.ti,ab.
77	((family or families) adj3 therap$).ti,ab.
78	(parent$ adj3 train$).ti,ab.
79	resilien$.ti,ab.
80	support fund?.ti,ab.
81	(play adj3 therap$).ti,ab.
82	(diagnos$ adj3 support$).ti,ab.
83	(website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or phone? or cloud).ti.
84	(signpost$ or sign post$).ti,ab.
85	referr$.ti.
86	(referr$ adj3 system?).ti,ab.
87	or/47-86
88	16 and (26 or 30) and 46 and 87

1

2 Database: PsycInfo

3 Date of last search: 31/01/2020

#	Searches
1	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
2	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
3	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
4	PEDIATRICS/
5	p?ediatric$.ti,ab.
6	young$ adult?.ti,ab.
7	or/1-6
8	DISORDERS/
9	exp DISABILITIES/
10	PHYSICAL DISORDERS/
11	exp SENSE ORGAN DISORDERS/
12	exp MENTAL DISORDERS/
13	exp COMMUNICATION DISORDERS/
14	SPECIAL NEEDS/
15	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
16	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/8-17
19	7 and 18
20	CSHCN.ti,ab.
21	"Education Health and Care plan?".ti,ab.
22	EHC plan?.ti,ab.
23	EHCP?.ti,ab.
24	or/19-23
25	INTEGRATED SERVICES/
26	INTERDISCIPLINARY TREATMENT APPROACH/
27	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
28	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
29	(intersector$ or multisector$ or jointsector$).ti,ab.
30	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
31	(interprovider? or multiprovider? or jointprovider?).ti,ab.
32	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
33	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
34	((inter or multi$ or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$)).ti,ab.

#	Searches
35	((institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
36	or/25-35
37	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/)
38	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
39	(exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
40	or/37-39
41	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social$ adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
42	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
43	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
44	or/41-43
45	FAMILY/
46	NUCLEAR FAMILY/
47	STEPFAMILY/
48	PARENTS/
49	MOTHERS/
50	FATHERS/
51	SINGLE PARENTS/
52	SIBLINGS/
53	BROTHERS/
54	SISTERS/
55	GRANDPARENTS/
56	CAREGIVERS/
57	(parent? or parental or mother? or father? or sibling? or brother? or sister? or grandparent? or grandfather? or grandmother? or family or families or caregiver? or carer?).ti.
58	parent?.ab. /freq=2
59	parental.ab. /freq=2
60	mother?.ab. /freq=2
61	father?.ab. /freq=2
62	sibling?.ab. /freq=2
63	brother?.ab. /freq=2
64	sister?.ab. /freq=2
65	grandparent?.ab. /freq=2
66	grandfather?.ab. /freq=2
67	grandmother?.ab. /freq=2
68	family.ab. /freq=2
69	families.ab. /freq=2
70	caregiver?.ab. /freq=2
71	carer?.ab. /freq=2
72	or/45-71
73	intervention?.ti.
74	HEALTH SERVICE NEEDS/
75	HEALTH CARE ACCESS/

#	Searches
76	SOCIAL SUPPORT/
77	(involv$ adj3 care).ti,ab.
78	(professional? adj3 relations$).ti,ab.
79	(service? adj3 need?).ti,ab.
80	(access$ adj5 service?).ti,ab.
81	(access$ adj3 care).ti,ab.
82	(social$ adj5 support$).ti.
83	(social$ adj5 support$).ab. /freq=2
84	(support adj3 need?).ti,ab.
85	(support$ adj3 service?).ti,ab.
86	HOSPITAL DISCHARGE/
87	DISCHARGE PLANNING/
88	(discharg$ adj3 (plan$ or manag$)).ti,ab.
89	ADVOCACY/
90	(advocacy or advocat$).ti,ab.
91	NONPROFIT ORGANIZATIONS/
92	((voluntary or civic or third or community or nonprofit or non-profit) adj3 (sector? or organi?ation?)).ti,ab.
93	TREATMENT PLANNING/
94	(care adj3 (path? or pathway?)).ti,ab.
95	COMMUNICATION/
96	INTERPERSONAL COMMUNICATION/
97	CLIENT EDUCATION/
98	INFORMATION SEEKING/
99	(communicat$ or information).ti.
100	communicat$.ab. /freq=2
101	information.ab. /freq=2
102	RESPITE CARE/
103	(respite adj3 (care or break?)).ti,ab.
104	short break?.ti,ab.
105	key worker?.ti,ab.
106	((family or families) adj3 center$ adj3 (care or plan$)).ti,ab.
107	DECISION MAKING/
108	((make or making) adj3 decision?).ti,ab.
109	((patient? or person) adj3 center$ adj3 (care or plan$)).ti,ab.
110	(best adj3 interest? adj3 meeting?).ti,ab.
111	(co-production? or coproduction?).ti,ab.
112	EATING BEHAVIOR/
113	((feed$ or eat$ or meal$) adj3 (strateg$ or behavio?r? or method?)).ti,ab.
114	BEHAVIOR MODIFICATION/
115	BEHAVIOR THERAPY/
116	MOTIVATIONAL INTERVIEWING/
117	(behavio?r$ adj3 (support$ or therap$ or intervention?)).ti,ab.
118	motivational interview$.ti,ab.
119	restorative practice?.ti,ab.
120	appreciative enquir$.ti,ab.
121	FAMILY THERAPY/
122	((family or families) adj3 therap$).ti,ab.
123	PARENT TRAINING/
124	(parent$ adj3 train$).ti,ab.
125	"RESILIENCE (PSYCHOLOGICAL)"/
126	resilien$.ti,ab.
127	support fund?.ti,ab.
128	PLAY THERAPY/
129	(play adj3 therap$).ti,ab.
130	(diagnos$ adj3 support$).ti,ab.
131	exp COMPUTERS/
132	exp DIGITAL TECHNOLOGY/
133	exp COMMUNICATIONS MEDIA/
134	(website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or phone? or cloud).ti.
135	PROFESSIONAL REFERRAL/
136	(signpost$ or sign post$).ti,ab.
137	referr$.ti.
138	(referr$ adj3 system?).ti,ab.
139	or/73-138
140	24 and (36 or 40 or 44) and 72 and 139
141	limit 140 to english language
142	limit 141 to yr="2000 -Current"
143	limit 142 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal")

Database: Emcare

Date of last search: 31/01/2020

#	Searches
1	exp ADOLESCENT/
2	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
3	exp CHILD/
4	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric$.ti,ab.
9	YOUNG ADULT/
10	young$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSON/
13	exp MENTAL DISEASE/
14	INTELLECTUAL IMPAIRMENT/
15	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
16	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/12-17
19	11 and 18
20	HANDICAPPED CHILD/
21	CSHCN.ti,ab.
22	"Education Health and Care plan?".ti,ab.
23	EHC plan?.ti,ab.
24	EHCP?.ti,ab.
25	or/19-24
26	PUBLIC RELATIONS/
27	INTERSECTORAL COLLABORATION/
28	INTEGRATED HEALTH CARE SYSTEM/
29	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
30	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
31	(intersector$ or multisector$ or jointsector$).ti,ab.
32	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
33	(interprovider? or multiprovider? or jointprovider?).ti,ab.
34	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
35	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
36	((inter or multi$ or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$)).ti,ab.
37	((institution$ or organi?ation$ or sector$ or agenc$ or provider? or stakeholder? or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
38	or/26-37
39	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/)
40	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
41	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
42	or/39-41
43	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social$ adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
44	((health$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or

#	Searches
	partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
45	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (care or service? or department? or institution$ or organi?ation$ or sector$ or agenc$ or provider? or policy or policies or collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partnership? or partnering or network$ or inter or multi or joint$ or across or share? or sharing or together or communicat$ or barrier? or facilitat$ or deliver$)).ti,ab.
46	or/43-45
47	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
48	CHILD HEALTH CARE/ and ORGANIZATION/
49	EDUCATION/ and ORGANIZATION/
50	exp SPECIAL EDUCATION/ and ORGANIZATION/
51	SOCIAL WORK/ and ORGANIZATION/
52	or/47-51
53	*FAMILY/
54	*NUCLEAR FAMILY/
55	*SINGLE-PARENT FAMILY/
56	*PARENT/
57	*ADOPTIVE PARENT/
58	*MOTHER/
59	*FATHER/
60	*SINGLE PARENT/
61	exp *SIBLING/
62	exp *GRANDPARENT/
63	*CAREGIVER/
64	(parent? or parental or mother? or father? or sibling? or brother? or sister? or grandparent? or grandfather? or grandmother? or family or families or caregiver? or carer?).ti.
65	parent?.ab. /freq=4
66	parental.ab. /freq=3
67	mother?.ab. /freq=4
68	father?.ab. /freq=2
69	sibling?.ab. /freq=2
70	brother?.ab. /freq=2
71	sister?.ab. /freq=2
72	grandparent?.ab. /freq=2
73	grandfather?.ab. /freq=2
74	grandmother?.ab. /freq=2
75	family.ab. /freq=4
76	families.ab. /freq=4
77	caregiver?.ab. /freq=3
78	carer?.ab. /freq=2
79	or/53-78
80	intervention?.ti.
81	*HEALTH CARE DELIVERY/
82	*SOCIAL SUPPORT/
83	(involv$ adj3 care).ti,ab.
84	(professional? adj3 relations$).ti,ab.
85	(service? adj3 need?).ti,ab.
86	(access$ adj5 service?).ti,ab.
87	(access$ adj3 care).ti,ab.
88	(social$ adj5 support$).ti.
89	(social$ adj5 support$).ab. /freq=2
90	(support adj3 need?).ti,ab.
91	(support$ adj3 service?).ti,ab.
92	*HOSPITAL DISCHARGE/
93	(discharg$ adj3 (plan$ or manag$)).ti,ab.
94	*CHILD ADVOCACY/
95	*PATIENT ADVOCACY/
96	*CONSUMER ADVOCACY/
97	(advocacy or advocat$).ti,ab.
98	*NON PROFIT ORGANIZATION/
99	((voluntary or civic or third or community or nonprofit or non-profit) adj3 (sector? or organi?ation?)).ti,ab.
100	*CLINICAL PATHWAY/
101	*PATIENT CARE PLANNING/
102	(care adj3 (path? or pathway?)).ti,ab.
103	*INTERPERSONAL COMMUNICATION/
104	*PATIENT EDUCATION/
105	*INFORMATION SEEKING/
106	(communicat$ or information).ti.
107	communicat$.ab. /freq=3
108	information.ab. /freq=3

#	Searches
109	*RESPITE CARE/
110	(respite adj3 (care or break?)).ti,ab.
111	short break?.ti,ab.
112	key worker?.ti,ab.
113	*FAMILY CENTERED CARE/
114	((family or families) adj3 center$ adj3 (care or plan$)).ti,ab.
115	*DECISION MAKING/
116	*CLINICAL DECISION MAKING/
117	*MEDICAL DECISION MAKING/
118	*SHARED DECISION MAKING/
119	*FAMILY DECISION MAKING/
120	((make or making) adj3 decision?).ti,ab.
121	((patient? or person) adj3 center$ adj3 (care or plan$)).ti,ab.
122	(best adj3 interest? adj3 meeting?).ti,ab.
123	(co-production? or coproduction?).ti,ab.
124	*FEEDING BEHAVIOR/
125	exp *FOOD INTAKE/
126	((feed$ or eat$ or meal$) adj3 (strateg$ or behavio?r? or method?)).ti,ab.
127	*BEHAVIOR THERAPY/
128	*MOTIVATIONAL INTERVIEWING/
129	(behavio?r$ adj3 (support$ or therap$ or intervention?)).ti,ab.
130	motivational interview$.ti,ab.
131	restorative practice?.ti,ab.
132	appreciative enquir$.ti,ab.
133	*FAMILY THERAPY/
134	((family or families) adj3 therap$).ti,ab.
135	(parent$ adj3 train$).ti,ab.
136	*PSYCHOLOGICAL RESILIENCE/
137	resilien$.ti,ab.
138	support fund?.ti,ab.
139	*PLAY THERAPY/
140	(play adj3 therap$).ti,ab.
141	(diagnos$ adj3 support$).ti,ab.
142	*INFORMATION TECHNOLOGY DEVICE/
143	exp *COMPUTER/
144	*SOFTWARE/
145	*COMMUNICATION SOFTWARE/
146	exp *MOBILE APPLICATION/
147	*WEB BROWSER/
148	*TELECOMMUNICATION/
149	exp *TELEHEALTH/
150	*TELEPHONE/
151	exp *MOBILE PHONE/
152	(website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or phone? or cloud).ti.
153	*PATIENT REFERRAL/
154	(signpost$ or sign post$).ti,ab.
155	referr$.ti.
156	(referr$ adj3 system?).ti,ab.
157	or/80-156
158	25 and (38 or 42 or 46 or 52) and 79 and 157
159	limit 158 to english language
160	limit 159 to yr="2000 -Current"
161	letter.pt. or LETTER/
162	note.pt.
163	editorial.pt.
164	CASE REPORT/ or CASE STUDY/
165	(letter or comment*).ti.
166	or/161-165
167	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
168	166 not 167
169	ANIMAL/ not HUMAN/
170	NONHUMAN/
171	exp ANIMAL EXPERIMENT/
172	exp EXPERIMENTAL ANIMAL/
173	ANIMAL MODEL/
174	exp RODENT/
175	(rat or rats or mouse or mice).ti.
176	or/168-175
177	160 not 176

Databases: Cochrane Central Register of Controlled Trials (CCTR); and Cochrane Database of Systematic Reviews (CDSR)

Date of last search: 31/01/2020

#	Searches
#1	[mh ^"ADOLESCENT"]
#2	[mh ^"MINORS"]
#3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab
#4	[mh "CHILD"]
#5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*):ti,ab
#6	[mh "INFANT"]
#7	(infan* or neonat* or newborn* or baby or babies):ti,ab
#8	[mh "PEDIATRICS"]
#9	(pediatric* or paediatric*):ti,ab
#10	[mh ^"YOUNG ADULT"]
#11	"young$ adult*":ti,ab
#12	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11
#13	[mh "DISABLED PERSONS"]
#14	[mh "MENTAL DISORDERS"]
#15	[mh "COMMUNICATION DISORDERS"]
#16	[mh "INTELLECTUAL DISABILITY"]
#17	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):ti
#18	((sever* or complex* or special or high) near/3 (need or needs)):ti,ab
#19	SHCN:ti,ab
#20	#13 or #14 or #15 or #16 or #17 or #18 or #19
#21	#12 and #20
#22	[mh ^"DISABLED CHILDREN"]
#23	CSHCN:ti,ab
#24	"Education Health and Care plan*":ti,ab
#25	EHC plan*:ti,ab
#26	EHCP*:ti,ab
#27	#21 or #22 or #23 or #24 or #25 or #26
#28	[mh ^"INTERINSTITUTIONAL RELATIONS"]
#29	[mh ^"INTERSECTORAL COLLABORATION"]
#30	[mh ^"DELIVERY OF HEALTH CARE, INTEGRATED"]
#31	(interinstitution* or multiinstitution* or jointinstitution*):ti,ab
#32	(interorganisation* or interorganization* or multiorganisation* or multiorganization* or jointorganisation* or jointorganization*):ti,ab
#33	(intersector* or multisector* or jointsector*):ti,ab
#34	(interagenc* or multiagenc* or jointagenc*):ti,ab
#35	(interprovider* or multiprovider* or jointprovider*):ti,ab
#36	(interstakeholder* or multistakeholder* or jointstakeholder*):ti,ab
#37	(interprofession* or multiprofession* or jointprofession*):ti,ab
#38	((inter or multi or joint) near/3 (institution* or organisation* or organization*or sector* or agenc* or provider? or stakeholder? or profession*)):ti,ab
#39	((institution* or organisation* or organization* or sector* or agenc* or provider? or stakeholder? or profession* or care or service* or department*) near/5 (collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partner*)):ti
#40	#28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39
#41	([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"])
#42	([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh ^EDUCATION] or [mh "EDUCATION, SPECIAL"] or [mh ^SCHOOLS] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^UNIVERSITIES] or [mh ^TEACHING] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#43	([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"]) and ([mh ^EDUCATION] or [mh "EDUCATION, SPECIAL"] or [mh ^SCHOOLS] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^UNIVERSITIES] or [mh ^TEACHING] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#44	#41 or #42 or #43

#	Searches
#45	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 social* near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#46	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#47	(social* near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#48	#45 or #46 or #47
#49	[mh ^"STATE MEDICINE"/og]
#50	[mh ^"CHILD HEALTH SERVICES"/og]
#51	[mh ^"ADOLESCENT HEALTH SERVICES"/og]
#52	[mh ^EDUCATION/og]
#53	[mh "EDUCATION, SPECIAL"/og]
#54	[mh "SOCIAL WORK"/og]
#55	#49 or #50 or #51 or #52 or #53 or #54
#56	[mh ^FAMILY]
#57	[mh ^"NUCLEAR FAMILY"]
#58	[mh ^"SINGLE-PARENT FAMILY"]
#59	[mh ^PARENTS]
#60	[mh ^MOTHERS]
#61	[mh ^FATHERS]
#62	[mh ^"SINGLE PARENT"]
#63	[mh ^SIBLINGS]
#64	[mh ^GRANDPARENTS]
#65	[mh ^CAREGIVERS]
#66	(parent or parents or parental or mother or mothers or father or fathers or sibling* or brother* or sister* or grandparent* or grandfather* or grandmother* or family or families or caregiver or carer or carers).ti.
#67	#56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66
#68	#27 and #40 and #67
#69	#27 and #44 and #67
#70	#27 and #48 and #67
#71	#27 and #55 and #67
#72	#68 or #69 or #70 or #71
#73	#68 or #69 or #70 or #71 with Cochrane Library publication date Between Jan 2000 and Jan 2020, in Cochrane Reviews
#74	#68 or #69 or #70 or #71 with Publication Year from 2000 to 2020, in Trials

Database: Database of Abstracts of Reviews of Effects (DARE)

Date of last search: 31/01/2020

#	Searches
1	MeSH DESCRIPTOR ADOLESCENT IN DARE
2	MeSH DESCRIPTOR MINORS IN DARE
3	((adolescen* or teen* or youth* or young or juvenile* or minors or highschool*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
4	MeSH DESCRIPTOR CHILD EXPLODE ALL TREES IN DARE
5	((child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
6	MeSH DESCRIPTOR INFANT EXPLODE ALL TREES IN DARE
7	((infan* or neonat* or newborn* or baby or babies)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
8	MeSH DESCRIPTOR PEDIATRICS EXPLODE ALL TREES IN DARE
9	((pediatric* or paediatric*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
10	MeSH DESCRIPTOR YOUNG ADULT IN DARE
11	(("young* adult*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))

#	Searches
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
13	MeSH DESCRIPTOR DISABLED PERSONS EXPLODE ALL TREES IN DARE
14	MeSH DESCRIPTOR MENTAL DISORDERS EXPLODE ALL TREES IN DARE
15	MeSH DESCRIPTOR COMMUNICATION DISORDERS EXPLODE ALL TREES IN DARE
16	MeSH DESCRIPTOR INTELLECTUAL DISABILITY EXPLODE ALL TREES IN DARE
17	((disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):TI) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
18	((((sever* or complex* or special or high) adj3 need*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
19	#13 OR #14 OR #15 OR #16 OR #17 OR #18
20	#12 AND #19
21	MeSH DESCRIPTOR DISABLED CHILDREN IN DARE
22	((CSHCN)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
23	((("Education Health" adj2 "Care plan*"))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
24	(("EHC plan*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
25	((EHCP*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
26	#20 OR #21 OR #22 OR #23 OR #24 OR #25
27	MeSH DESCRIPTOR FAMILY IN DARE
28	MeSH DESCRIPTOR NUCLEAR FAMILY IN DARE
29	MeSH DESCRIPTOR SINGLE-PARENT FAMILY IN DARE
30	MeSH DESCRIPTOR PARENTS IN DARE
31	MeSH DESCRIPTOR MOTHERS IN DARE
32	MeSH DESCRIPTOR FATHERS IN DARE
33	MeSH DESCRIPTOR SINGLE PARENT IN DARE
34	MeSH DESCRIPTOR SIBLINGS IN DARE
35	MeSH DESCRIPTOR GRANDPARENTS IN DARE
36	MeSH DESCRIPTOR CAREGIVERS IN DARE
37	((parent or parents or parental or mother* or father* or sibling* or brother* or sister* or grandparent* or grandfather* or grandmother* or family or families or caregiver* or carer*):TI) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
38	#27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37
39	#26 AND #38

Database: Health Technology Abstracts (HTA)

Date of last search: 31/01/2020

#	Searches
1	MeSH DESCRIPTOR ADOLESCENT IN HTA
2	MeSH DESCRIPTOR MINORS IN HTA
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*) IN HTA
4	MeSH DESCRIPTOR CHILD EXPLODE ALL TREES IN HTA
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*) IN HTA
6	MeSH DESCRIPTOR INFANT EXPLODE ALL TREES IN HTA
7	(infan* or neonat* or newborn* or baby or babies) IN HTA
8	MeSH DESCRIPTOR PEDIATRICS EXPLODE ALL TREES IN HTA
9	(pediatric* or paediatric*) IN HTA
10	MeSH DESCRIPTOR YOUNG ADULT IN HTA
11	("young* adult*") IN HTA
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
13	MeSH DESCRIPTOR DISABLED PERSONS EXPLODE ALL TREES IN HTA
14	MeSH DESCRIPTOR MENTAL DISORDERS EXPLODE ALL TREES IN HTA
15	MeSH DESCRIPTOR COMMUNICATION DISORDERS EXPLODE ALL TREES IN HTA
16	MeSH DESCRIPTOR INTELLECTUAL DISABILITY EXPLODE ALL TREES IN HTA
17	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):TI IN HTA
18	(((sever* or complex* or special or high) adj3 need*)) IN HTA
19	#13 OR #14 OR #15 OR #16 OR #17 OR #18
20	#12 AND #19
21	MeSH DESCRIPTOR DISABLED CHILDREN IN HTA
22	(CSHCN) IN HTA
23	(("Education Health" adj2 "Care plan*")) IN HTA
24	("EHC plan*") IN HTA
25	(EHCP*) IN HTA
26	#20 OR #21 OR #22 OR #23 OR #24 OR #25

#	Searches
27	MeSH DESCRIPTOR FAMILY IN HTA
28	MeSH DESCRIPTOR NUCLEAR FAMILY IN HTA
29	MeSH DESCRIPTOR SINGLE-PARENT FAMILY IN HTA
30	MeSH DESCRIPTOR PARENTS IN HTA
31	MeSH DESCRIPTOR MOTHERS IN HTA
32	MeSH DESCRIPTOR FATHERS IN HTA
33	MeSH DESCRIPTOR SINGLE PARENT IN HTA
34	MeSH DESCRIPTOR SIBLINGS IN HTA
35	MeSH DESCRIPTOR GRANDPARENTS IN HTA
36	MeSH DESCRIPTOR CAREGIVERS IN HTA
37	(parent or parents or parental or mother* or father* or sibling* or brother* or sister* or grandparent* or grandfather* or grandmother* or family or families or caregiver* or carer*):TI IN HTA
38	#27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37
39	#26 AND #38

Databases: Applied Social Sciences Index & Abstracts (ASSIA); Social Services Abstracts; Sociological Abstracts; and ERIC (Education Resources Information Centre)

Date of last search: 31/01/2020

#	Searches
1	AB,TI(adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p?ediatric* OR "young* adult?")
2	TI(disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR ((sever* OR complex* OR special OR high) NEAR/3 need?) OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?)
3	AB,TI((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?))
4	TI(interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "coordinat* care" OR partnership? OR partnering OR network*)
5	TI(((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))
6	TI(parent? OR parental OR mother? OR father? OR sibling? OR brother? OR sister? OR grandparent? OR grandfather? OR grandmother? OR family OR families OR caregiver? OR carer?)
7	1 AND 2 AND 3 AND 6 Additional limits - Date: From January 2000 to January 2020
8	1 AND 2 AND 4 AND 6 Additional limits - Date: From January 2000 to January 2020
9	1 AND 2 AND 5 AND 6 Additional limits - Date: From January 2000 to January 2020
10	7 OR 8 OR 9

Database: British Education Index

Date of last search: 31/01/2020

#	Searches
1	TI (parent? OR parental OR mother? OR father? OR sibling? OR brother? OR sister? OR grandparent? OR grandfather? OR grandmother? OR family OR families OR caregiver? OR carer?) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder*

#	Searches
	OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "care co-ordinat*" OR "coordinat* care" OR "coordinat* care" OR partnership? OR partnering OR network*) Limiters - Publication Date: 20000101- 20200131
2	TI (parent? OR parental OR mother? OR father? OR sibling? OR brother? OR sister? OR grandparent? OR grandfather? OR grandmother? OR family OR families OR caregiver? OR carer?) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND AB ((((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))) Limiters - Publication Date: 20000101- 20200131
3	1 or 2

Database: CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature)

Date of last search: 31/01/2020

#	Searches
1	TI (parent? OR parental OR mother? OR father? OR sibling? OR brother? OR sister? OR grandparent? OR grandfather? OR grandmother? OR family OR families OR caregiver? OR carer?) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "care co-ordinat*" OR "coordinat* care" OR "coordinat* care" OR partnership? OR partnering OR network*) Limiters - Publication Date: 2000- 2020
2	TI (parent? OR parental OR mother? OR father? OR sibling? OR brother? OR sister? OR grandparent? OR grandfather? OR grandmother? OR family OR families OR caregiver? OR carer?) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI ((((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))) Limiters - Publication Date: 2000- 2020
3	1 or 2

Database: Social Sciences Citation Index (SSCI)

Date of last search: 31/01/2020

#	Searches
# 1	TOPIC: ((adolescen* or teen* or youth* or young or juvenile$ or minors or highschool*)) Indexes=SSCI Timespan=2000-2020
# 2	TOPIC: ((child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid$ or kindergar* or boy$ or girl$)) Indexes=SSCI Timespan=2000-2020
# 3	TOPIC: ((infan* or neonat* or newborn* or baby or babies)) Indexes=SSCI Timespan=2000-2020
# 4	TOPIC: (p$ediatric*) Indexes=SSCI Timespan=2000-2020
# 5	TOPIC: ("young* adult$") Indexes=SSCI Timespan=2000-2020
# 6	#5 OR #4 OR #3 OR #2 OR #1 Indexes=SSCI Timespan=2000-2020

#	Searches
# 7	TITLE: ((disable$ or disabilit* or handicap* or retard* or disorder$ or impair* or condition$ or difficulty or difficulties or deficit$ or dysfunct*)) Indexes=SSCI Timespan=2000-2020
# 8	TOPIC: (((sever* or complex* or special or high) near/3 need$)) Indexes=SSCI Timespan=2000-2020
# 9	TOPIC: (SHCN) Indexes=SSCI Timespan=2000-2020
# 10	#9 OR #8 OR #7 Indexes=SSCI Timespan=2000-2020
# 11	#10 AND #6 Indexes=SSCI Timespan=2000-2020
# 12	TOPIC: (CSHCN) Indexes=SSCI Timespan=2000-2020
# 13	TOPIC: ("Education Health and Care plan$") Indexes=SSCI Timespan=2000-2020
# 14	TOPIC: ("EHC plan$") Indexes=SSCI Timespan=2000-2020
# 15	TOPIC: (EHCP$) Indexes=SSCI Timespan=2000-2020
# 16	#15 OR #14 OR #13 OR #12 OR #11 Indexes=SSCI Timespan=2000-2020
# 17	TITLE: (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani$ation* OR multiorgani$ation* OR jointorgani$ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession*) Indexes=SSCI Timespan=2000-2020
# 18	TITLE: (((inter or multi* or joint*) near/3 (institution* or organi$ation* or sector* or agenc* or provider* or stakeholder* or profession*))) Indexes=SSCI Timespan=2000-2020
# 19	TITLE: (((institution* or organi$ation* or sector* or agenc* or provider* or stakeholder* or profession* or care or service$ or department*) near/5 (collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partner*))) Indexes=SSCI Timespan=2000-2020
# 20	#19 OR #18 OR #17 Indexes=SSCI Timespan=2000-2020
# 21	TITLE: (((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/5 social)) Indexes=SSCI Timespan=2000-2020
# 22	TITLE: ((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/5 (education or educating or educator or educators or school or schools or teach or teaching or teachers)) Indexes=SSCI Timespan=2000-2020
# 23	TITLE: ((social near/5 (education or educating or educator or educators or school or schools or teach or teaching or teachers))) Indexes=SSCI Timespan=2000-2020
# 24	#23 OR #22 OR #21 Indexes=SSCI Timespan=2000-2020
# 25	TITLE: (parent$ OR parental OR mother$ OR father$ OR sibling$ OR brother$ OR sister$ OR grandparent$ OR grandfather$ OR grandmother$ OR family OR families OR caregiver$ OR carer$) Indexes=SSCI Timespan=2000-2020
# 26	#25 AND #20 AND #16 Indexes=SSCI Timespan=2000-2020
# 27	#25 AND #24 AND #16 Indexes=SSCI Timespan=2000-2020
# 28	#27 OR #26 Indexes=SSCI Timespan=2000-2020

Database: Social Care Online

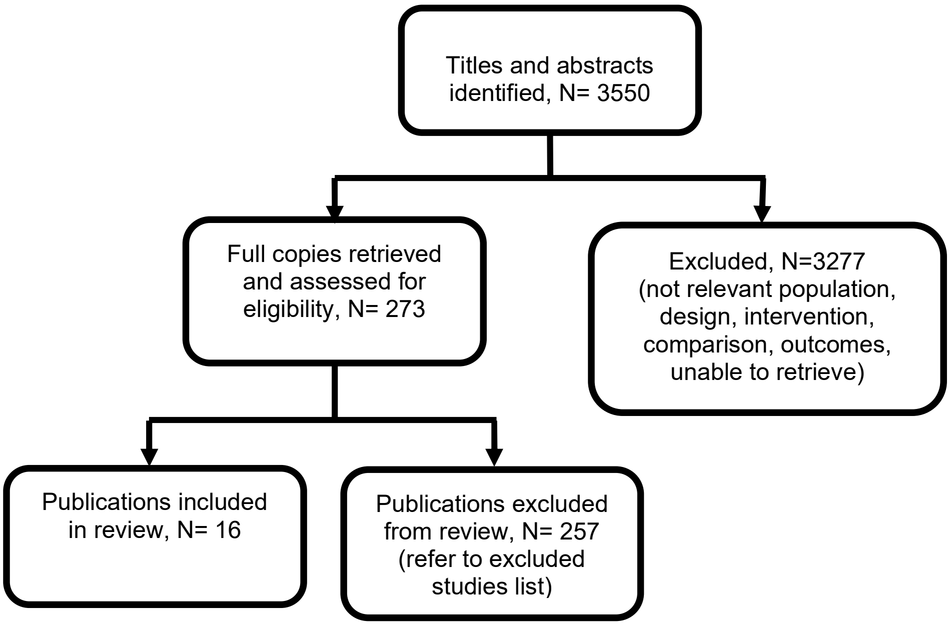
Date of last search: 31/01/2020

#	Searches
	AND Title:'disabled or disability or disabilities or handicap or retard or disorder or impaired or impairment or condition or difficulty or difficulties or deficit or dysfunction or "special need" or "complex need"'
	AND Title:'child or children or schoolchild or schoolchildren or "school age" or "school aged" or preschool or toddler or kid or kindergarden or boy or girl or infant or neonate or newborn or baby or babies or pediatric or paediatric or "young people" or "young adults"'
	AND Title:'interinstitution OR multiinstitution OR jointinstitution OR interorganisation OR multiorganisation OR jointorganisation OR intersector OR multisector OR jointsector OR interagency OR multiagency OR jointagency OR interprovider OR multiprovider OR jointprovider OR interstakeholder OR multistakeholder OR jointstakeholder OR interprofession OR multiprofession OR jointprofession OR service OR collaboration OR coordination OR co-ordination OR partnership OR partnering'
	AND Title: 'parent or parental or mother or father or sibling or brother or sister or grandparent or grandfather or grandmother or family or families or caregiver or carer'
	AND PublicationYear:'2000 2020'

Appendix C – Effectiveness evidence study selection

Study selection for: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Figure 1: Study selection flow chart



Appendix D – Effectiveness evidence

Evidence tables for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Table 5: Evidence tables

Study details	Results and risk of bias assessment
Full citation Benn, Rita, Akiva, Tom, Arel, Sari, Roeser, Robert W., Mindfulness training effects for parents and educators of children with special needs, Developmental Psychology, 48, 1476-1487, 2012 **Ref Id** 1191506 **Country where the study was carried out** USA **Study type** RCT **Study dates** NR **Inclusion criteria** NR (Parents and educators were recruited through the special education services office of a school district in a small Midwestern city, USA. Most participating educators were involved in the district's special education 5-week summer extension program, and many study parents had children enrolled in this program. These children varied in age and disability status. For the educators,	**Results** At randomisation n=32: n=16 treatment, n=16 control At baseline assessment n=25: n=12 treatment, n=13 control Post MT assessment n=24: n=11 treatment, n=13 control Follow-up assessment n=20: n=9 treatment, n=11 control Parenting self-efficacy (confidence) via the Everyday Parenting Scale (Lower scores show better outcomes) Parenting self-efficacy (0–6): Mean (SD) Baseline: treatment=4.08 (0.55), control=3.68 (0.96) Post-MT (5 weeks): treatment=4.20 (0.53), control=3.63 (1.01) Follow-up (2 months): treatment=5.19 (0.60), control=4.54 (0.94) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: Randomisation by computerized random number generator. Treatment and control participants did not significantly differ on any baseline measures. No information on allocation concealment. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: Participants and those delivering the trial were aware of group assignment (blinding was not possible). Outcomes are assessed for those participants who completed intervention.

Study details	Results and risk of bias assessment
study participation fulfilled a district requirement of attending a minimum of 10 hr of professional development.) **Exclusion criteria** NR **Patient characteristics** n=32 Parents (The study also included n=38 educators however the demographics of this population are not included in this systematic review) Sample description demographics, n=25 (parents) Age at study entry (years): 47 (Range: 27–55) Gender: Female=23, Male=2 Education (college degree or higher): 18 (72%) Minority status: 5 (20%) Previous meditation experience: 1 (4%) Family characteristics of children with disabilities: Family composition (n=12 treatment; n=16 control) Married parents: 7=treatment, 13=control Two or more children in family: 11=treatment, 12=control Two children in Special Education(SE): treatment=3, control=2 Age range of children Age in years of child in SE: treatment=5-19, control=9-23 Elementary versus middle/high school: treatment=6:6, control=6:10 Primary disability label Autism spectrum disorder: treatment=4, control=8 Attention-deficit/learning disability: treatment=3, control=5 Cognitive or health impairment: treatment=4, control=2 **Interventions** Mindfulness training (MT) vs Waitlist control	**3. Bias due to missing outcome data (Low/High/Some concerns)** High risk: Outcome data was not available for all, or nearly all randomised participants. Possible that the results were biased by missing outcome data; participants who did not complete the post intervention and follow-up differed from those who completed all assessments. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: Assessment of the outcome could have been influenced by knowledge of the intervention, however unlikely that the measurement or ascertainment of the outcome would have different between groups. **5. Bias in selection of the reported result (Low/High/Some concerns)** Some concerns: No published protocol however outcomes were pre-specified in the methods and results are unlikely to have been selected from multiple analyses of the data. **Overall risk of bias (Low/High/Some concerns)** High risk: The study is judged to be of high risk in one domain, and some concerns in all other domains **Source of funding** Supported in part by the Fetzer Institute, the University of Michigan's Office of Vice President for Research and Institute of Human Adjustment, the Impact Foundation, and the Ann Arbor Public School District. **Other information** Both parents and educators were included in the study. Results are shown for parents only as this is the population targeted in this systematic review.

Study details	Results and risk of bias assessment
Parents participated in MT sessions twice a week over a 5-week period. Parents met for all training sessions during roughly the same time period. Instructors had formal professional training in mindfulness-based stress reduction (MBSR) or mindfulness-based cognitive therapy (a variation of MBSR). In addition, they received 3 days of training in the SMART curriculum by the curriculum developers, with ongoing supervision and consultation as needed. Mindfulness training was the SMART-in-Education (Stress Management and Relaxation Techniques) program, a fully manualized instructional curriculum which involved 36 hours of didactic and group discussion activities, mindfulness practices such as concentration on thoughts or the breath, and homework practices such as assignments of daily sitting practices and monitoring emotional and behavioural responses delivered over nine 2.5 hours' sessions and 2 full days. A typical session consisted of question-and answer periods, didactic lectures and group discussions, modelling of mindfulness practices, and actual group mindfulness practice. **Follow-up** End-point at 5 weeks, and 2-month follow-up	
Full citation Bilgin, Sonay, Gozum, Sebahat, Reducing burnout in mothers with an intellectually disabled child: an education programme, Journal of advanced nursing, 65, 2552-61, 2009 **Ref Id** 914383 **Country where the study was carried out** Turkey **Study type** RCT	**Results** n=90 mothers: intervention=45, control=45 Competence (Personal success) Personal Success subscale of the Maslach Burnout Inventory (MBI) assesses the mother's feelings of competence At baseline (before education): Mean (SD) Intervention=11.62 (4.65), Control=12.60 (5.78) After education: Mean (SD) Intervention=17.64 (5.68), Control=18.55 (4.93) **1. Bias arising from the randomisation process (Low/High/Some concerns)**

Study details	Results and risk of bias assessment
Study dates October 2004 and August 2005 **Inclusion criteria** Mothers of children with an intellectual disability who all attended private education and rehabilitation centres with their children **Exclusion criteria** Mothers who were not able to travel to the study centres on a regular basis due to other familial obligations. **Patient characteristics** Children's mean age in years (SD) Intervention=8.44 (4.85), Control=8.42 (5.05) Mother's mean age in years (SD) Intervention=34.06 (7.08), Control=34.00 (7.72) Gender of disabled child: n (%) Female: Intervention=15 (33.3), control=8 (17.8) Male: intervention=30 (66.7), control=37 (82.2) Mother's education level: n (%) Literate: intervention=4 (8.9), control=10 (22.2) Primary school: intervention=35 (77.8), control=25 (55.6) Secondary school: intervention=6 (13.3), control=10 (22.2) Mother's work status: n (%) Employed: intervention=5 (11.1), control=6 (13.3) Unemployed: intervention=40 (88.9), control=39 (86.7) Financial status: n (%) Income>expenditure: intervention=2 (4.4), control=12 (26.7) income=expenditure: intervention=32 (71.1), control=27 (60.0) income<expenditure: intervention=11 (24.4), control=13 (13.3) **Interventions** Education programme VS waitlist control	Low risk: Participants were randomly allocated to the groups by an independent researcher who was not involved in the study, using a computer-developed random table. Allocation was concealed from the recruiting independent researcher. There were no statistically significant differences between participants in the intervention and control groups at baseline. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: The second author was blinded to group assignment, but the first author was not blinded. Unclear if blinding of participants or deviations from the intervention occurred, however appears all participants received the intervention with those on waitlist control receiving the post-test outcome analysis prior. **3. Bias due to missing outcome data (Low/High/Some concerns)** Low risk: Outcome data was available for all participants. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Low risk: Outcome assessment was not inappropriate and did not differ between groups. The second author, who assessed and analysed the outcomes, was blinded to group assignment **5. Bias in selection of the reported result (Low/High/Some concerns)** Low risk: The protocol does not appear to be published however outcomes and statistical analysis were pre-specified in the methods, and results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data. **Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in at least one domain, but not to be at high risk for any domain. **Source of funding** Funded by the research foundation of Ataturk University.

Study details	Results and risk of bias assessment
Intervention: Interactive 60-minute interactive lecture given by nurse researchers at the education and rehabilitation centres, held every weekday morning from June 15 to June 30, 2005. The programme included information about the characteristics of intellectually disabled children, how to provide the appropriate care for their child, and coping with the stress associated with caring for an intellectually disabled child. It also familiarized them with their child's education, rehabilitation and the support services available for families of intellectually disabled children. In addition, an education booklet was distributed to the mothers and they were asked to read it. It included information on the characteristics of intellectually disabled children, the specific care and education they require, and information about associations, foundations, and governmental organizations that provide support to intellectually disabled children and their families. Additionally, it contained suggestions to help parents, particularly mothers, to cope with the stress associated with taking care of an intellectually disabled child. Waitlist control: Received the same intervention separately after completing the post-test. **Follow-up** 2 months after pre-test (control group) or 2 months after intervention (intervention group)	**Other information**
Full citation Chacko, Anil, Wymbs, Brian T., Wymbs, Frances A., Pelham, William E., Swanger-Gagne, Michelle S., Girio, Erin, Pirvics, Lauma, Herbst, Laura, Guzzo, Jamie, Phillips, Carlie, O'Connor, Briannon, Enhancing traditional behavioral parent training for single mothers of children with ADHD, Journal of clinical child and adolescent psychology: the official journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53, 38, 206-18, 2009 **Ref Id** 1234615	**Results** Total randomised=120; Total complete (post treatment)=118 (98%), and total complete (follow-up)=115 (95%) Consumer Satisfaction measured via the Therapy Attitude Inventory (TAI) No baseline measures reported Treatment Attitude Inventor–Satisfaction with Outcome (TAI-SWO) Mean (SD) STEPP: 24.18 (3.02) Traditional BPT: 20.20 (2.35) Treatment Attitude Inventory–Satisfaction with Process (TAI-SWP) Mean (SD)

Study details	Results and risk of bias assessment
Country where the study was carried out USA **Study type** RCT **Study dates** September 2002 and March 2005 **Inclusion criteria** Single mothers of children (ages 5–12 years) with ADHD Inclusion criteria: Mothers were required to be the primary caregiver and residing without a significant other (e.g., child’s father, boyfriend, fiancé´); however, mothers were included if they resided with other individuals (e.g., parents, siblings, roommates). Children were required to be between 5 to 12 years old at the start of treatment and were required to meet diagnostic criteria for ADHD (any type). Children were included if they were receiving medication for their ADHD symptoms, and parents were asked to maintain the type and dose of medication for the duration of the study and report any changes in medication status to the research study team. For children who were not receiving medication, parents were asked to maintain this medication status for the duration of the study and report any changes in medication status to the research study team **Exclusion criteria** Mothers were not excluded from participation for the presence of any psychiatric conditions. Exclusion criteria: Families were excluded if the child had an IQ of less than 80, if the child was diagnosed with a pervasive developmental disorder, or if there was evidence of psychosis. **Patient characteristics**	STEPP: 16.36 (2.03) Traditional BPT: 14.12 (2.09) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: There is no information on the method of randomisation or allocation concealment, however there were no significant differences between groups on any demographic variables. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants or those delivering the intervention were aware of treatment assignment, nor whether there were any deviations from intended interventions. Appropriate analysis was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Outcome data was available for 98% of participants at post treatment and 95% of participants at follow-up however dropout is not reported by group and there is no evidence that the result was not biased by missing outcome data. Missingness in the outcome could depend on its true value, however this is unlikely. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely. **5. Bias in selection of the reported result (Low/High/Some concerns)** Low risk: The protocol does not appear to be published however outcomes and statistical analysis were pre-specified in the methods, and results being are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data.

Study details	Results and risk of bias assessment
N=120 children with ADHD and their single mothers; n=40 behavioural parent training (BPT), n=40 Strategies to Enhance Positive Parenting (STEPP), n=40 waitlist control. Child Age in Years (M, SD): STEPP=7.36 (1.86), Traditional BPT=8.17 (2.42), Waitlist=8.02 (2.15) Child Sex: STEPP= 77% male, Traditional BPT=66% male, Waitlist=69% male Single Mother Age (Years): STEPP=34.05 (8.27),Traditional BPT=36.77 (8.56), Waitlist=35.25 (8.65) Single Mother Education (Years): STEPP=13.84 (1.66), Traditional BPT=14.28 (1.95), Waitlist=14.22 (1.88) Child Race/Ethnicity: STEPP= 52% Caucasian, 27% African American, 8% Latino, 13% biracial Traditional BPT=56% Caucasian, 18% African American, 13% Latino, 13% biracial Waitlist= 52% Caucasian, 18% African American, 17% Latino, 13% biracial Child ODD/CD Comorbidity Status: STEPP=67.5% ODD, 12.5% CD, Traditional BPT=70% ODD, 10% CD, Waitlist=72.5% ODD, 7.5% CD Percent Medicated: STEPP=40%, Traditional BPT=35%, Waitlist=37.5% **Interventions** Traditional behavioural parent training program (BPT) versus an enhanced behavioural parent training program—the Strategies to Enhance Positive Parenting (STEPP) vs waitlist control group Traditional BPT: Manualized, 9-week BPT program held for 2 and a half hours each week in a collaborative, large-group format to discuss and learn about effective parenting strategies (e.g., positive attending, planned ignoring, incentive systems). Sessions included videotapes of parenting errors whereby single mothers identified these errors and then formulated alternative parenting strategies. Therapists facilitated group discussions, role plays and assigned weekly homework assignments. Children participated in a concurrent traditional, group-based social skills program. STEPP: Manualized, 9-week program held for 2 and a half hours each week which included a collaborative large- group format, identical evidence-based BPT content, identical order of presentation of BPT content, identical videotaped vignettes, therapist-facilitated questions, group discussions, modelling, and role-plays by parents and children participated in a group social skills program.	**Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in most domains, but not to be at high risk of bias for any domain **Source of funding** Support was provided to the first author through a National Institutes of Mental Health, Pre-doctoral National Research Service Award (NRSA; 1 F31 MH071090-01A1), a New York State/Graduate Student Professional Development Award, a Society for a Science of Clinical Psychology Dissertation Award, a Melissa Institute for Violence Prevention and Treatment Dissertation Award, a Society for Clinical Child and Adolescent Psychology Graduate Student Research Award, and a University at Buffalo, College of Arts and Sciences Dissertation Award. **Other information** Satisfaction reported at endpoint only (no baseline or follow-up measures collected) for STEPP versus Traditional BPT

Study details	Results and risk of bias assessment
Plus several enhancements to the format, delivery, and content of traditional BPT including; an enhanced intake procedure, addressing practical barriers (e.g., child care, transportation) to ongoing involvement and developing solutions to these barriers, incorporation of a subgroup, coping-modelling, problem-solving format within the traditional large-group format, incorporation of a systematic, problem-solving treatment method, and incorporation of parent– child interactions within the children's social skills group. Control: 9-week waitlist control group. **Follow-up** Post-treatment at end of treatment at 9 weeks; and 3 month follow-up	
Full citation Chacko, A., Scavenius, C., Bending the Curve: a Community-Based Behavioral Parent Training Model to Address ADHD-Related Concerns in the Voluntary Sector in Denmark, Journal of abnormal child psychology, 46, 505-517, 2018 **Ref Id** 1090656 **Country where the study was carried out** Denmark **Study type** RCT **Study dates** 2013 **Inclusion criteria** Potential participants responded to invitations from the Danish ADHD-organization, ADHD-foreningen via the internet homepage, and in local and national newspapers. Participants had one child in the family between the ages of 3–9 for whom there was a concern about potential ADHD.	**Results** Post-treatment assessment (response rate of 81%) and 4-month follow-up assessments (response rate of 71%). Multiple Imputation (MI) was used to recover survey non responses; 20 complete data sets were imputed, using all outcome and explanatory variables of model, as well as adult and child characteristics. Parenting Behaviour assessed with the Parenting Scale Intervention (CiC): Mean (SD) Baseline=95.90(16.09), Post-treatment=80.76(17.09), Follow-up=84.85(176.0) Control (Waitlist): Mean (SD) Baseline=96.49(16.66), Post-treatment=92.65(18.38), Follow-up=93.94(18.13) Parenting Competence assessed with the Parenting Sense of Competence Scale Total score of PSOC, Satisfaction Intervention (CiC): Mean (SD) Baseline=32.75(6.01), Post-intervention=39.23(6.60), Follow-up=38.38(6.53) Control (Waitlist): Mean (SD)

Study details	Results and risk of bias assessment
Inclusion in the program and this study required availability of another adult to function as an ally during the program to support the primary guardian in implementing the behavioural parent training (BPT) skills (e.g., two biological parents, biological parent and his or her own mother or father, significant-other, sibling). **Exclusion criteria** Children were not pre-screened or excluded based on having a formal ADHD diagnosis. (Children may have ADHD, parental concerns about ADHD, as well as concerns about other mental health issues) **Patient characteristics** total n=161 families of children intervention=80 families (or 160 individual parents/ally), waitlist=81 families (or 162 individual parents/ally) Female Adult Caregiver: intervention=56%, control=56% Biological Parent: intervention= 83%, control=84% Participants live together: intervention=75%, control=75% More than one child in the household intervention: intervention=85%, control=86% Other children with ADHD: intervention=18%, control=9% Parent above clinical cut-off of ADHD: intervention=27%, control=28% Employed (80%): intervention=84%, control=80% Unemployed (4%): intervention=4%, control=7% Other employment status (16%): intervention=2%, control=13% Years of education 9–10 years (19%): intervention=1%, control=8% 10–12 years (42%: intervention=43%, control=45% 13–15 years (24%): intervention=0%, control=35% 15–17 years (10%): intervention=12%, control=8% 18–20 years (1%): intervention=3%, control=1%	Baseline=33.47(7.24), Post-intervention=34.74(7.12), Follow-up=35.18(6.68) Total score of POSC, Efficacy Intervention (CiC): Mean (SD) Baseline=29.87(5.14), Post-intervention=33.40(4.61), Follow-up=33.11(4.27) Control (Waitlist): Mean (SD) Baseline=30.39(4.75), Post-intervention=30.72(4.26), Follow-up=0.56(4.88) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: There is no information on the method of randomisation or allocation concealments, however differences in baseline demographics appear to be compatible with chance **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants or those delivering the intervention were aware of treatment assignment, nor whether there were any deviations from intended interventions. Appropriate analysis was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Outcome data was not available for all, or nearly all participants however no differences were observed in baseline scores on outcomes measures between participants that completed assessments compared to those that did not. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely.

Study details	Results and risk of bias assessment
Male Child: intervention=83%, control=75% Age of child (in years): intervention=7.11(1.5), control=6.96(1.6) Parent reported ADHD diagnosis: intervention=71%, control=68% Age of diagnosis (in years): intervention=6.09(1.46), control=6.16(1.5) Other parent reported diagnosis: intervention=29%, control=28% Intellectual Disability: intervention=1%, control=6% 0.99 Autism Spectrum Disorder: intervention= 6%, control=7% Behaviour Disorder: intervention=9%, control=9% Attachment Disorder: intervention=4%, control=4% Anxiety Disorder: intervention=4%, control=5% Depression: intervention=0%, control=0% Tics or Tourette's syndrome: intervention=5%, control= 1% Sleep Disorder: intervention=4%, control=4% Other diagnosis: intervention=16%, control=12% **Interventions** Behavioural parent training (BPT) vs Waitlist control BPT was the Caring in Chaos (CiC) Intervention, scheduled with 12 weekly sessions on workday evenings, for small groups of parents. Each session lasted 2 ½ hours, except the first and last session, which were one hour longer to allow for greetings and farewells. Three to seven parent/ally pairs (6 to 14 caretakers participated in each group. Parents/allies participated in the CiC group without their children and also received a snack or light meal BPT translated into three core elements: psychoeducation, positive behaviour, and tools for managing disruptive behaviour/conflict. **Follow-up** Post-treatment and 4 months follow-up	**5. Bias in selection of the reported result (Low/High/Some concerns)** Low risk: The protocol does not appear to be published however outcomes and statistical analysis were pre-specified in the methods, and results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data. **Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in at least one domain, but not to be at high risk for any domain. **Source of funding** Funded by TrygFonden (Denmark). **Other information** Population does not completely match inclusion criteria; families of children with parent reported ADHD (69%), or other parent reported conditions which included ASD, intellectual disability but also Behaviour Disorder, Attachment Disorder, Anxiety Disorder, Depression, Tics or Tourette's syndrome, Sleep Disorder, or other diagnoses.
Full citation Costich, M. A., Peretz, P. J., Davis, J. A., Stockwell, M. S., Matiz, L. A., Impact of a Community Health Worker Program to Support Caregivers of Children	**Results** Completion: N=95 patients' caregivers

Study details	Results and risk of bias assessment
With Special Health Care Needs and Address Social Determinants of Health, Clinical Pediatrics, 58, 1315-1320, 2019 **Ref Id** 1191760 **Country where the study was carried out** USA **Study type** Non randomised retrospective before and after study **Study dates** July 2016 and May 2018 **Inclusion criteria** Caregivers of children with special health care needs (CSHCN), who were referred to the Community Health Worker program by their child's paediatrician as part of clinical care. Inclusion criteria: patient must have a chronic medical condition and be either “medically or socially unstable” (i.e., exposure to domestic violence, uncontrolled asthma with frequent hospitalizations) or have the highest level of medical complexity, defined as having 4 or more subspecialists involved in care, or, 2 or more life-sustaining devices (i.e. gastrostomy tube and tracheostomy). **Exclusion criteria** Not reported **Patient characteristics** Caregivers of children with special health care needs (CSHCN) Patient demographics Age, median (SD): 7 (4-12) Female, n (%): 31 (38.8%)	Included in the analysis: N=80; Excluded: N=15 (n=6 absence of documentation of program completion, n=8 referred from the inpatient setting or school-based medical setting for asthma management, n=1 aged older than 18 years of age) Confidence scales 1. I Understand my child’s diagnosis: mean (SD), n=80 Baseline: 3.2 (0.7), Follow-up: 3.5 (0.5) 2. Know how to access care for my child: mean (SD), n=80 Baseline: 3.4 (0.5), Follow-up: 3.5 (0.5) 3. Know what medications my child takes and when to give them: mean (SD), n=62 Baseline: 3.5 (0.5), Follow-up: 3.5 (0.5) 4. Have control over my child’s condition: mean (SD), n=33 Baseline: 3.3 (0.8), Follow-up: 3.5 (0.5) 1. **Risk of bias due to confounding** Serious risk: Baseline and time-varying confounding present; Participants were referred to the program by their paediatricians and chose whether or not to participate in the intervention. The length of time participants underwent the intervention and subsequently time to follow-up varied amongst participants. **2. Bias in selection of participants into the study** Moderate risk: Selection into the study may have been related to intervention and outcome **3. Bias in classification of interventions** Low risk: Intervention status is well defined and based solely on information collected at the time of intervention **4. Bias due to deviations from intended interventions**

Study details	Results and risk of bias assessment
CSHCN level, n (%): Medically or socially unstable 45 (59.2%); >4 subspecialists involved in care or 2 or greater life-sustaining devices 31 (40.8%) Publicly insured, n (%): 63 (90%) Receiving Social Security Insurance, n (%): 34 (46.6%) Self-reported number of specialists, median (IQR): 4 (2-5) Self-reported number of medications, median (IQR): 1 (0-3) Caregiver demographics Age, mean (SD): 37 (10.2) Level of education achieved, n (%): Less than high school 40 (50.6%); High school or GED or above 39 (49.4%) Caregiver not working outside home, n (%): 55 (70.5%) Hispanic, n (%): 70 (87.5%) Spanish only spoken at home, n (%): 50 (62.5%) Social determinants Number of social service referrals requested at intake, mean (%): 2.0 (1.8) Trouble getting medications (%): 15 (20%) **Interventions** Special Kids Achieving Their Everything (SKATE) Community health worker (CHW) program SKATE CHW: Over 3-6 months participants receive home visits, needs assessments, and goal-setting sessions during which caregivers and/or patients have the opportunity to develop their own goals. CHWs are members of the medical home health care team at each of the practices, are based out of local community-based organizations, and are trained in common topics related to the care of children with special health care needs such as the navigation of early intervention services, educational system and medication organization. CHWs attend interdisciplinary medical home meetings at the practices weekly and provide updates to providers, nurse care managers, nursing staff, and social workers. CHWs serve as point of contact for families and assist with navigation of resources available both in the community and in the medical home. **Follow-up**	No information: Deviations from the intended intervention are not reported **5. Bias due to missing data** Moderate risk: Outcome data was not available for all participants (approximately 84% of participants completed the study) and analysis was based on participants who completed the study only. **6. Bias in measurement of outcomes** Serious risk: Outcome measurements were self-reported and vulnerable to influence and knowledge of the intervention received **7. Bias in selection of the reported result** Moderate risk: it appears as though the protocol has not been published, however there is no indication of the selection of the reported analysis from among multiple analyses or the selection of the cohort or subgroups for analysis and reporting on the basis of the results. **Overall risk of bias** Serious risk of bias: The study is judged to be at serious risk of bias in two domains, but not at critical risk of bias in any domain. **Source of funding** Funded in part by New York- Presbyterian Hospital and by the New York Department of Health DSRIP Grant 2015-2020. **Other information** The diagnoses of the children were unclear

Study details	Results and risk of bias assessment
Participants completed the program once provider and/or participant goals are met, therefore program duration was variable. The median period of enrolment was 149.5 days (interquartile range = 108-281.5). Data was collected at follow-up visits and at discharge (time frame not specified)	
Full citation Giallo, Rebecca, Gavidia-Payne, Susana, Barrett, Beresford Breslau Castles Causey Cohen Cohen Dadds Diamond Dunst Ellis Evans Fisman Foster Gamble Giallo Giallo Goodman Gordon Hardy Heiney Hoddap Houtzager Houtzager Houtzager Jacobson Kearney Kliewer Lobato Matthews McCubbin McLinden Phillips Ross Rossiter Sharpe Stein Summers Tarnowski Van Riper Walsh Williams Williams Williams, Evaluation of a family-based intervention for siblings of children with a disability or chronic illness, AeJAMH (Australian e-Journal for the Advancement of Mental Health), 7, 1-13, 2008 **Ref Id** 1234617 **Country where the study was carried out** Australia **Study type** RCT **Study dates** Study dates not reported; conducted over an 18-month period **Inclusion criteria** Not reported; Siblings (aged 8-16 years) and parents of children with an intellectual, sensory, physical, or developmental disability and/or a chronic illness, residing at home. **Exclusion criteria** Not reported	**Results** Randomised, n=24 families Dropout, n=3: n=1 waitlist condition (limited availability), n=2 intervention (failed to return post-intervention surveys) Completed, n=21: intervention, n=12; waitlist, n=9 The Family Problem Solving Communication Index Intervention, n=12: Mean (SD) Baseline=19.67 (4.77), Post intervention=21.58 (5.35) Waitlist control, n=9: Mean (SD) Baseline=18.44 (4.10), Post intervention=18.89 (4.01) The Self-Report Coping Scale - Approach coping, Seeking Social Support (Sibling coping) Intervention, n=12: Mean (SD) Baseline=23.75 (5.05), Post intervention=24.75 (3.39) Waitlist control, n=9: Mean (SD) Baseline=19.22 (5.93), Post intervention=20.33 (5.43) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: There is no information on the allocation concealment, however randomisation was computer generated. Analyses revealed no demographic differences between the groups. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants or those delivering the intervention were aware of treatment assignment, nor whether there were any deviations from intended interventions. Per protocol (completer) analysis was used.

Study details	Results and risk of bias assessment
Patient characteristics 21 siblings (aged 8-16 years) and their parents intervention n=12, waitlist control n=9 Siblings demographics Age of siblings in years (M, SD): intervention=11.75 (2.86), control=11.00 (2.29) Age range (years): intervention=9-16, control=8-16 Sex n (%) Female: intervention=6 (50.0%), control=6 (66.7%) Male: intervention=6 (50.0%), control=3 (33.3%) Age in relation to child with disability Older: intervention=7 (58.3%), control=8 (88.9%) Young: intervention=5 (41.7%), control=1 (11.1%) Attended sibling group in past: intervention=7 (58.3%), control=5 (55.6%) Parent demographics Respondent’s age (M, SD): intervention=43.83 (6.63), control=41.78 (3.99) Relationship to child n (%) Biological mother: intervention=12 (100%), control=9 (100%) Family structure Couple family: intervention=11 (91.7%), control=9 (100%) Single parent family: intervention=1 (8.3%)control=0 Respondent’s country of origin Australia: intervention=9 (75.0%), control=8 (88.9%) Overseas-born: intervention=3 (25.0%), control=1 (11.1%) Language spoken at home English: intervention=12 (100%), control=9 (100%) Respondent’s employment Full-time: intervention=1 (8.3%), control=2 (22.2%) Part-time: intervention=6 (50.0%), control=4 (44.4%) Not working: intervention=5 (41.7%), control=3 (33.3%) SES Index (M, SD): intervention= 1036.68(51.85), control=1062.28(68.43) n children in family (M, SD): intervention=2.75 (.62), control=2.56 (0.53) Child with disability or illness demographics Age of child in years (M, SD): intervention=10.92 (4.21), control=10.07 (4.67) Age range (years): intervention=3-16, control=6-21	**3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Outcome data were not available for all, or nearly all randomised participations (completion rate of 87%). There is no evidence that the result was not biased by outcome data, and missingness in the outcome could depend on its true value, although this is unlikely. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely. **5. Bias in selection of the reported result (Low/High/Some concerns)** Some concerns: There is no information on whether the data has been analysed according to a pre-specified plan. The results may have been selected on the basis of multiple eligible outcome measurements within the outcome domain, however this is unlikely. **Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in all domains, but not to be at high risk of bias for any domain. **Source of funding** Not reported **Other information**

Study details	Results and risk of bias assessment
Sex n (%) Male: intervention=7 (58.3%), control=5 (55.6%) Female: intervention=5 (41.7%), control=4 (44.4%) Type of disability Down Syndrome: intervention= 1 (8.3%), control=3 (33.3%) Autism: intervention=3 (25.0%) , control=2 (22.2%) ADHD: intervention=1 (8.3%), control=0 Polymicrogyria: intervention=1 (8.3%), control=0 Multiple disabilities: intervention=2 (16.7%), control=1 (11.1%) Cystic Fibrosis: intervention=0, control=1 (11.1%) Congenital Heart Disorder: intervention= 2 (16.7%), , control=0 Multiple illnesses: intervention= 0, control=1 (11.1%) Williams Syndrome: intervention=1 (8.3%), control=1 (11.1%) Severity of disability (parent rated) Mild: intervention=3 (25.0%), control=5 (55.6%) Moderate: intervention=8 (66.7%), control=1 (11.1%) Severe: intervention=1 (8.3%), control=3 (33.3%) **Interventions** Sibstars versus waitlist control Sibstars: 6-week family-based psycho-educational intervention for siblings and parents delivered to individual families using written information and telephone support. The sibling program consisted of an introduction, coping with things that stress you out, getting along with other and dealing with problems. The parent program consisted of an introduction, stress in the family, dealing with children's behaviour, managing family time and routines, communication in the family, and dealing with problems in the family. After the first face-to-face session, each week families were required to read an information booklet and complete the practice activities provided. Telephone support was provided weekly by a clinician with postgraduate psychology training to discuss progress through the information booklet and practice activities. Sessions were 20-30 minutes in duration. Waitlist Control: All waitlist families were offered the intervention following post-test. **Follow-up**	

Study details	Results and risk of bias assessment
Post-test questionnaires completed 2 weeks after the intervention, 8 weeks after no contact for waitlist control group	
Full citation Haakonsen Smith, C., Turbitt, E., Muschelli, J., Leonard, L., Lewis, K. L., Freedman, B., Muratori, M., Biesecker, B. B., Feasibility of Coping Effectiveness Training for Caregivers of Children with Autism Spectrum Disorder: a Genetic Counseling Intervention, Journal of Genetic Counseling, 27, 252-262, 2018 **Ref Id** 1192044 **Country where the study was carried out** USA **Study type** RCT **Study dates** Recruitment began early July of 2010 and continued for 12 weeks. **Inclusion criteria** Caregivers of children with ASD. Inclusion criteria: primary caregiver of a child with ASD (established by caregiver report); at least 18 years of age; child has no known syndromic disorder that included co-morbid features that could influence parental responses (including but not limited to Rett Syndrome, Tuberous Sclerosis Complex, Fragile X Syndrome, Neurofibromatosis, Prader-Willi Syndrome and Angelman Syndrome); and able to read, write and speak English. Only caregivers whose children lived with them were eligible, and only one caregiver per household was included in the study.	**Results** total randomised n=28: treatment (n=15) or control (n=13) groups completed follow-up n=22: treatment (n=12), or control (n=10) groups Caregivers perceived self-efficacy via The coping self-efficacy (CSE) scale to assess caregivers' perceived self-efficacy for coping with challenges and threats Treatment, n=12; Mean (SD) Baseline: 177.1 (47.7), Post-intervention: 211.7 (41.5), Change: 34.6 Control, n=10; Mean (SD) Baseline: 181.3 (43.7), Post-intervention: 200.6 (51.6), Change: 19.3 **1. Bias arising from the randomisation process (Low/High/Some concerns)** High risk: There is no information on the method of randomisation or allocation concealment, and participants were stratified according to the caregiver's perception of severity of the child's condition. Baseline demographics were not significantly different, with the exception of annual household income with more individuals in the treatment group reporting a household income above $70,000. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants or those delivering the intervention were aware of treatment assignment, nor whether there were any deviations from intended interventions. Appropriate analysis (per protocol, excluding participants who did not receive both sessions) was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Outcome data was not available for all, or nearly all participants and missingness in the outcome could depend on its true

Study details	Results and risk of bias assessment
Exclusion criteria Children with genetic diagnoses were not included to generate a more homogeneous sample. **Patient characteristics** Age of caregiver, mean (SD): total=38.2 (7.4), treatment=37.2 (5.3), control=39.4 (9.6) Age of child, mean (SD): total=5.4 (2.4), treatment=5.3 (2.5), control=5.5 (2.4) Age at child's diagnosis, mean (SD): total=3.03 (1.5), treatment=3.17 (1.67), control=2.87 (1.20) Relation to child, % (n) Biological Mother: total=82 (18), treatment=92 (11), control=70 (7) Biological Father: total=5 (1), treatment=0 (0), control=10 (1) Adoptive Mother: total=9 (2), treatment=0 (0), control=20 (2) Biological Grandmother:total=5 (1), treatment=8 (1), control=0 (0) Marital status, % (n) Married: total=63 (14), treatment=75 (9), control=50 (5) Single/Never Married: total=22 (5), treatment=17 (2), control=30 (3) Separated: total=5 (1), treatment=8 (1), control=0 (0) Widowed: total=5 (1) , treatment=0 (0), control=10 (1) Current Partner: total=5 (1), treatment=0 (0), control=10 (1) Education level of caregiver, % (n) High School: total=9 (2), treatment=8 (1), control=10 (1) Technical School: total=5 (1), treatment=8 (1), control=0 (0) Some College: total=18 (4), treatment=0 (0), control=40 (4) Completed College: total=23 (5), treatment=34 (4), control= 10(1) Post-Graduate: total=45 (10), treatment= 0 (6), control= 40 (4) Racial background, % (n) White: total=68 (15), treatment=75 (9), control=60 (6) Black or African American: total=22 (5), treatment=25 (3), control=20 (2) Other: total=10 (2), treatment=0 (0), control=20 (2) Annual household income, % (n) Under $30,000: total=25 (5), treatment=27 (3), control=22 (2) $30,001–50,000: total=10 (2), treatment=0 (0), control=22 (2) $50,001–70,000: total=15 (3), treatment=0 (0), control=33 (3) Above $70,000: total=50 (10), treatment=73 (8), control=22 (2)	value; a greater percentage of those participants who withdrew had less than a college education, and had more children than those who did not withdraw. However attrition rates did not vary between groups. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely. **5. Bias in selection of the reported result (Low/High/Some concerns)** Low risk: The protocol does not appear to be published however outcomes and statistical analysis were pre-specified in the methods, and results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data. **Overall risk of bias (Low/High/Some concerns)** High risk: The study is judged to be of high risk in one domain, and some concerns in most other domains **Source of funding** Supported by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health. **Other information**

Study details	Results and risk of bias assessment
Number of children with ASD, % (n) One: total=91 (20), treatment=83 (10), control=100 (0) Two: total=9 (2), treatment=17 (2), control=0 (0) Total number of children, % (n) One: total=14 (3), treatment=8 (1), control=20 (2) Two: total=63 (14), treatment=67 (8), control= 60 (6) Three: total=14 (3), treatment=8 (1), control= 20 (2) Four: total=9 (2), treatment=17 (2), control=0 (0) Child's diagnosis,%(n) Autism: total=77 (17), treatment=75 (9), control=80 (8) Pervasive developmental disorder-not otherwise specified: total=18 (4), treatment=25 (3), control=10 (1) Asperger's Syndrome: total=5 (1), treatment=0 (0), control=10 (1) Child's gender, % (n) Male: total=68 (15), treatment=75 (9), control=60 (6) Female: total=32 (7), treatment=25 (3), control=40 (4) **Interventions** Coping effectiveness training (CET) VS Control Intervention: Participants received two individualized sessions, delivered one-on-one between the genetic counsellor and the caregiver. The first session was 90 min and the second was 60 min, held one month apart. In the first session, participants engaged in a 30-min discussion about aspects of their child's condition; the latter 60 min consisted of a psychoeducational discussion about stress, appraisals, coping, and the match between appraisals and coping. Participants were guided through three worksheets to direct their thinking about how they appraise and cope with stressful situations, and were given a homework assignment to complete the same three worksheets in relation to stressors that arose before the second session. During the second session, participants discussed stressful situations that arose during the time since the first session. The psychoeducational discussion was revisited, alongside the worksheets and the homework assignment as they applied to the shared examples.	

Study details	Results and risk of bias assessment
Control: The control sessions were administered by the same interventionist as in the intervention arm. During both sessions, participants were asked to share information about their child's diagnosis and care, similar to a client centred discussion that might be facilitated during a traditional genetic counselling session. Sessions were guided by client issues devoid of components of the CET intervention including the worksheets. **Follow-up** 1 month after the second session	
Full citation Harris, Nicola, Beringer, Antonia, Fletcher, Margaret, Families' priorities in life-limiting illness: improving quality with online empowerment, Archives of disease in childhood, 101, 247-52, 2016 **Ref Id** 914639 **Country/ where the study was carried out** UK **Study type** Non randomised longitudinal, multisite mixed-method evaluation **Study dates** April 2013 to January 2014 **Inclusion criteria** Not reported; Families of children with life limiting illness were invited to participate if they attended the hospice **Exclusion criteria** Families with immediate events making an invitation inappropriate (such as imminent death, social or other personal issues).	**Results** N=33 families consented to participate; N=32 were set up on the MyQuality system N=30 achieved first FES score, N=19 achieved second FES score (3 months) Family Empowerment Scale (FES) Overall Score: Mean scores (SD) n=30; Baseline: 3.45 (0.12), Follow-up: 3.85 (0.11) n=19; Baseline: 3.50 (0.15), Follow-up: 3.85 (0.11) Family dimension: Mean scores (SD) n=30; Baseline: 3.79 (0.12), Follow-up: 4.13 (0.12) n=19; Baseline: 3.90 (0.16), Follow-up: 4.13 (0.12) Services dimension: Mean scores (SD) n=30; Baseline: 3.82 (0.12), Follow-up: 4.31 (0.11) n=19; Baseline: 3.88 (0.15), Follow-up: 4.31 (0.11) Community dimension: Mean scores (SD) n=30; Baseline: 2.76 (0.20), Follow-up: 2.95 (0.20) n=19; Baseline: 2.77 (0.25), Follow-up: 2.95 (0.20) **1. Risk of bias due to confounding**

Study details	Results and risk of bias assessment
Patient characteristics N=33 families with children cared for by the hospice Children ages: Range=3 months and 21 years (mean 9.4 years). Diagnoses included: severe cerebral palsy, intractable epilepsy, metabolic and genetic disorders. Due to either young age or cognitive impairment, no child was able to enter data themselves. Data entry was by parents, predominantly by their mother (n=24), by their father (n=4) and by both parents (n=4). **Interventions** MyQuality online tool Parents were registered on the MyQuality website, given a hands-on demonstration and training in its use, and then invited to use it as often or infrequently as they wished. Ongoing MyQuality support was available to every family from their "local champion" who were members of the clinical team given a 6 h day's face-to-face training programme on study processes and use of the website. "Champions" led on recruitment, patient support and data collection at their hospice, and linked to the project lead. MyQuality enables families to identify, describe, prioritise and monitor the issues that most impact on their quality of life, and to share this information with their health and other professional carers. The tool can be accessed via the internet and is free of charge. The data entered, and access to that data, is controlled by the patient/carer. The child's nominated key professionals can be given access to their graphs, and trigger points can be set up to instigate early review of symptoms that fall outside set limits **Follow-up** 3 months	Serious risk of bias: The important confounding factors (dominant provision, definitions of eligibility and socioeconomic status) are not adequately adjusted for. Baseline confounding present; families were invited to participate if they attended the hospice and had no immediate events such as imminent death, social or other personal issues. **2. Bias in selection of participants into the study** Low risk: All participants who would have been eligible for the target trial appear to be included in the study and start of follow up and start of intervention coincided. 3. **Bias in classification of interventions** Low risk: Intervention status is well defined and intervention definition is based solely on information collected at the time of intervention. **4. Bias due to deviations from intended interventions** No information: Deviations from the intended intervention are not reported **5. Bias due to missing data** Moderate risk: Outcome data was not available for all participants (approximately 63% of participants completed the 3-month follow-up) and analysis was based on participants who completed the study only. **6. Bias in measurement of outcomes** Serious risk: The relevant outcome measurements (FES scores) were self-reported and vulnerable to influence and knowledge of the intervention received **7. Bias in selection of the reported result** Moderate risk: it appears as though the protocol has not been published, however there is no indication of the selection of the reported analysis from among multiple analyses or the selection of the cohort or subgroups for analysis and reporting on the basis of the results. **Overall risk of bias**

Study details	Results and risk of bias assessment
	Serious risk of bias: The study is judged to be at serious risk of bias in two domains, but not at critical risk of bias in any domain. **Source of funding** Financial support for initial development of MyQuality from the Department of Health and Marie Curie Cancer Care. Funding of the study from the Health Foundation. **Other information**
Full citation Hoath, F. E., Sanders, M. R., A feasibility study of Enhanced Group Triple P - Positive parenting program for parents of children with attention-deficit/hyperactivity disorder, Behaviour Change, 19, 191-206, 2002 **Ref Id** 1234618 **Country where the study was carried out** Australia **Study type** RCT **Study dates** Not reported **Inclusion criteria** Inclusion criteria: the target child was aged between 60 and 119 months; parents reported that they were concerned about their child's behaviour; the child showed no sign of developmental disorder, intellectual impairment or significant health impairment; the child was not currently having regular contact with another professional or agency for behavioural problems; and the parents were not currently having regular contact with another professional agency for parenting support and were not intellectually disabled.	**Results** Randomised, n=21 families: n=10 EGTP, n=11 WL The Parenting Scale (PS) Completed post-intervention, n=20: n=9 EGTP (90%), n=11 WL (100%) Laxness*, Mean (SD) EGTP: Baseline=2.67 (1.05), Post-intervention=2.56 (0.96) Waitlist control: Baseline=3.09 (1.00), Post-intervention=2.93 (1.03) Over-reactivity, Mean (SD) EGTP: Baseline=3.76 (1.03), Post-intervention=3.13 (1.09) Waitlist control: Baseline=3.80 (1.12), Post-intervention=3.60 (1.05) Verbosity**, Mean (SD) EGTP: Baseline=4.16 (1.28), Post-intervention=3.17 (0.98) Waitlist control: Baseline=3.78 (1.15), Post-intervention=3.97 (1.11) Completed follow-up, n=12: n=8 EGTP (88%), n=4 WL (66%) Parents Report on Parenting Styles at 3 months Laxness*, Mean (SD) EGTP: Baseline=2.59 (1.10), Post-intervention=2.38 (NR), Follow-up=2.23 (1.18) Over-reactivity, Mean (SD) EGTP: Baseline=3.88 (1.13), Post-intervention=3.13 (NR), Follow-up=2.35 (1.05) Verbosity**, Mean (SD)

Study details	Results and risk of bias assessment
Exclusion criteria Not reported **Patient characteristics** Twenty families with a child with clinically diagnosed ADHD aged between 5 and 9 years participated **Interventions** Enhanced intervention group (Enhanced Group Triple P; EGTP) versus wait list (WL) condition EGTP: An enhanced version of "Standard Group Triple P" targeting specific ADHD characteristics, which included five, 2-hour weekly group sessions with a practitioner at one of two local state primary schools, and four, 20- to 30-minute individual weekly telephone consultations starting the week of the fifth group session. After hours' sessions were available to encourage both parents (where applicable) to attend. The program taught parents 17 core child management strategies designed to promote children's competence and development and to help parents manage behaviour. In addition, parents were taught a six-step planned activities routine to enhance generalisation and maintenance of parenting skills and received active skills training and support from a trained practitioner which included modelling, role-plays, feedback and the use of specific homework tasks. Waitlist control: No treatment and no contact with the researcher for 12 weeks. Patients completed the pre-test and post-test and then participated in the EGTP program. **Follow-up** Post-intervention (12 weeks), and 3 months' follow-up	EGTP: Baseline=4.13 (1.46), Post-intervention=3.13 (NR), Follow-up=3.18 (1.02) The Client Satisfaction Questionnaire (CSQ) No baseline measures Parents, n=9: Mean (SD) Quality of service received: 6.67 (0.71) Type of program: 6.62 (1.20) Program met child's needs: 5.78 (1.39) Program met parent's needs: 5.56 (1.67) Amount of help received: 6.56 (0.73) Effectiveness in dealing with child behaviour: 6.56 (1.01) Effectiveness in dealing with family issues: 6.33 (1.00) Improvement in relationship with partner: 5.80 (1.64), n=5 Overall satisfaction with program: 6.44 (1.01) Would you come back to Triple P: 5.89 (1.36) Learnt skills applicable to other family members: 6.11 (0.93) Child's behaviour at this point: 6.00 (0.87) Feelings about the child's behaviour: 6.22 (0.83) Overall mean satisfaction: 6.14 (0.73) * Defined as giving in, not enforcing rules or providing positive consequences in response to negative behaviour ** Defined as using lengthy verbal responses and relying on talking even when this is ineffective **1. Bias arising from the randomisation process (Low/High/Some concerns)** High risk: No information on randomisation or allocation concealment. Appropriate statistical analyses were not performed on baseline demographics and observation suggests some differences may be present between groups. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)**

Study details	Results and risk of bias assessment
	Some concerns: There is no information on whether participants were aware of treatment assignment, nor whether there were any deviations from intended interventions. The practitioner was not aware of the intervention groups prior to the completion of pre-intervention questionnaires. Per protocol (completer) analysis was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Data was available for nearly all participants randomised at post-intervention (95%), however not at follow-up (57%). There is no evidence that the result was not biased by missing outcome data, and missingness in the outcome could depend on its true value, although this is unlikely. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely. **5. Bias in selection of the reported result (Low/High/Some concerns)** Some concerns: There is no information on whether the data has been analysed according to a pre-specified plan. The results may have been selected on the basis of multiple eligible outcome measurements within the outcome domain, however this is unlikely. **Overall risk of bias (Low/High/Some concerns)** High risk: The study is judged to be of high risk of bias in one domain, and raised some concerns in all other domains **Source of funding** Not reported **Other information** Satisfaction reported at post intervention only (no baseline) and for intervention group only (no control)

Study details	Results and risk of bias assessment
Full citation Lange, A. M., Daley, D., Frydenberg, M., Houmann, T., Kristensen, L. J., Rask, C., Sonuga-Barke, E., Sondergaard-Baden, S., Udupi, A., Thomsen, P. H., Parent Training for Preschool ADHD in Routine, Specialist Care: A Randomized Controlled Trial, Journal of the American Academy of Child and Adolescent Psychiatry, 57, 593-602, 2018 **Ref Id** 1192320 **Country where the study was carried out** Denmark **Study type** RCT **Study dates** Children and their parents were recruited from May 2012 to November 2015 **Inclusion criteria** Children aged 3 to 7 years; clinical ADHD diagnosis supported by the Development and Well-Being Assessment (DAWBA); and Danish as a first language spoken at home. **Exclusion criteria** Intellectual disabilities (IQ < 70); autism spectrum disorder diagnosis; in receipt of pharmacologic or psychosocial treatment for ADHD; severe parental psychiatric disorder (i.e., untreated psychosis, bipolar or severe depressive disorder); and severe social adversity in the home (i.e., active child protection involvement). **Patient characteristics** N=164 randomised participants; N=88 intervention (NFPP) group, N=76 control (TAU)	**Results** Parental self-efficacy and satisfaction measured via the Parenting Sense of Competence Scale (PSOC) PSOC Efficacy: Treatment (NFPP) group; Mean (SD) Baseline: n=86, 30.54 (5.46); Endpoint T2: n=81, 32.21 (5.67); Follow-up T3: n=81, 32.54 (4.71) Control (TAU) group; Mean (SD) Baseline: n=75, 30.19 (6.03); Endpoint T2: n=64, 29.52 (6.05); Follow-up T3: n=64, 30.83 (5.96) PSOC Satisfaction: Treatment (NFPP) group; Mean (SD) Baseline: n=86, 38.06 (7.01); Endpoint T2: n=81, 39.59 (6.06); Follow-up T3: n=81, 39.45 (6.63) Control (TAU) group; Mean (SD) Baseline: n=75, 37.20 (7.11); Endpoint T2: n=64, 36.81 (7.00); Follow-up T3: n=64, 30.05 (7.91) **1. Bias arising from the randomisation process (Low/High/Some concerns**) Low risk: Allocation sequence was adequately concealed and the allocation sequence was random. Demographic tables display treatment and control data combined and compared with a comparison group of children who received an ADHS diagnosis in the same period; supplementary data and text confirm background and clinical baseline characteristics were well balanced across arms. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Low risk: Research assistants were masked to treatment allocation and located separately to avoid contamination. Trial participants could not be masked but parents were asked not to reveal the treatment status of their children to teachers. An appropriate analysis was used.

Study details	Results and risk of bias assessment
Treatment and control data has been combined in the study, and presented for all randomised participants (n=164 Children with ADHD) Year of diagnosis 2012: 16% 2013: 35% 2014: 49% Age group 3-5 years: 57% 6-7 years: 43% Sex Girls: 27% Boys: 73% Living arrangement Single parent: 32% Both parents: 65% Foster or unknown: 4% Registered mother (for parents living with the child) Biological mother: 99% 99% Registered father(for parents living with the child) Biological father: 100% Mother’s highest education level (for parents living with the child) Elementary school: 15% High school level: 51% Bachelor and above: 33% Father’s highest education level (for parents living with the child) Elementary school: 15% High school level: 56% Bachelor and above: 26% Mother employed (for parents living with the child) Yes: 79% Father employed (for parents living with the child) Yes: 68% Family gross income (1,000 euros) (of the child’s family) less than 50: 20% 50-75: 12% 75-100: 34% > 100: 25%	**3. Bias due to missing outcome data (Low/High/Some concerns)** Low risk: Outcome data were available for all, or nearly all, randomised participants **4. Bias in measurement of the outcome (Low/High/Some concerns)** Low risk: The method of measuring the outcome was not inappropriate and measurement did not differ between intervention groups. Outcome assessors were unaware of the intervention received by study participants. **5. Bias in selection of the reported result (Low/High/Some concerns)** Low risk: The protocol has been published and outcomes and statistical analysis were pre-specified in the methods. The results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data. **Overall risk of bias (Low/High/Some concerns)** Low risk: The study is judged to be at low risk of bias for all domains **Source of funding** Supported by research grants from TrygFonden and Helsefonden, Denmark, and supported by the Central and Capital Regions of Denmark. **Other information** Families and carers were not the randomised group; Children were randomised to receive parent training versus control

Study details	Results and risk of bias assessment
Mother ever received psychiatric diagnosis (for parents living with the child) Yes: 23% Father ever received psychiatric diagnosis (for parents living with the child) Yes:16% Mother’s age (y), mean (SD) (for parents living with the child): 35.4 (5.4) Father’s age (y), mean (SD) (for parents living with the child): 38.5 (5.6) **Interventions** The New Forest Parenting Programme (NFPP) versus treatment as usual NFPP: 8 sessions delivered by trained therapists, individually to parents (including 6 sessions delivered in the clinic and 2 in the child’s home) with the child present during 3 sessions. Therapists had had different professional backgrounds which included clinical psychologists, nurse specialist, and nursery teacher, and had extensive clinical experience of preschool ADHD (5–15 years) but no experience of delivering manual-based treatments or of practicing behavioural methods NFPP included 5 elements: psychoeducation about the nature of preschool ADHD to enhance parents’ understanding of their child’s behaviour; scaffolding to help parents work from the child’s level of development; promoting proactive parenting and enhancing parent-child interaction to support child development and decrease parental stress; relieving the child’s ADHD symptoms and related neuropsychological deficits through play and games that target attention, impulsivity, and self-regulation; and guiding parents in the use of behavioural strategies to improve behaviour and ADHD symptoms. Treatment as usual: typically consisted of a standard package of psychoeducation delivered to groups of individual parents by specialized staff. Most parents were offered 3 to 4 group sessions, with each lasting 2 to 3 hours, and some were offered individual sessions in addition to or instead of group intervention. TAU included information about ADHD as a developmental disorder; how ADHD symptoms obstruct normal play and the development of preschool skills, and how ADHD and executive dysfunctions interrupt daily routines. Parents were also offered practical advice on how to support young children through psychosocial management (e.g., visual aids and daily structure).	

Study details	Results and risk of bias assessment
Follow-up First follow-up, endpoint (T2), 12 weeks after baseline assessments Second follow-up (T3); 36 weeks after T2 (48 weeks after baseline assessment, 11 months)	
Full citation Plant, Karen M., Sanders, Matthew R., Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities, Research in Developmental Disabilities, 28, 362-385, 2007 **Ref Id** 707904 **Country where the study was carried out** Australia **Study type** RCT **Study dates** Not reported **Inclusion criteria** Families with a preschool-aged child (<6 years) with developmental disability from the geographical catchment area of South East Queensland, Australia. Inclusion criteria: The child was receiving early intervention services due to identified developmental disability; the child presented with developmental disability or was 'at risk' due to a diagnosed condition; the child had not yet commenced primary school education, and; mothers rated their child's behaviour as being in the elevated range on the Eyberg Child Behavior Inventory (ECBI; intensity score ≥131 or problem score ≥15; Eyberg & Pincus, 1999). **Exclusion criteria** Not reported	**Results** Parenting skills and ability measured via the Parenting Scale (PS) and Parenting Sense of Competence Scale (PSOC) At endpoint (100% completion): n=74 families; n=24 SSTP-E, n=26 SSTP-S, n=24 waitlist Parenting Scale (PS) total: Mean (SD) SSTP-E group: At baseline=3.00 (0.58), Post intervention=2.72 (0.71) SSTP-S group: At baseline=2.93 (1.04), Post intervention=2.41 (0.72) Waitlist control group: At baseline=2.87 (0.87), Post intervention=2.96 (0.65) Parenting Sense of Competence Scale (PSOC) total: Mean (SD) SSTP-E group: At baseline=54.54 (6.25), Post intervention=68.25 (8.87) SSTP-S group: At baseline=56.73 (8.36), Post intervention=65.85 (10.91) Waitlist control group: At baseline=57.13 (15.41), Post intervention=58.46 (11.56) At follow-up (90% completion and no waitlist group): total n=45 families; n=23 SSTP-E, n=22 SSTP-S Parenting Scale (PS) total: Mean (SD) SSTP-E group: At baseline=3.02 (0.58), Post intervention=2.70 (0.72), follow-up=2.53 (0.57) SSTP-S group: At baseline=2.86 (0.80), Post intervention=2.22 (0.64), follow-up=2.38 (0.67) Parenting Sense of Competence Scale (PSOC) total: Mean (SD) SSTP-E group: At baseline=57.87 (6.17), Post intervention=67.87 (8.86), follow-up=64.78 (8.50) SSTP-S group: At baseline=58.42 (8.43), Post intervention=66.73 (11.60), follow-up=65.21 (15.29)

Study details	Results and risk of bias assessment
Patient characteristics n=74 families; n=24 SSTP-E, n=26 SSTP-S, n=24 waitlist Child's age (months): SSTP-E=56.63 (12.36), SSTP-S=54.62 (15.25), waitlist=54.04 (13.16) Mother's age (years): SSTP-E=36.38 (3.91), SSTP-S=36.27 (5.60), waitlist=37.83 (8.82) Father's age (years): SSTP-E=40.91 (5.50), SSTP-S=39.53 (5.51), waitlist=39.18 (6.07) Number of children in the family: SSTP-E=2.42(1.02), SSTP-S=2.81 (1.81), waitlist=2.13 (0.80) Child's gender: % (n) Male: SSTP-E=70.8 (17), SSTP-S=69.2 (18), waitlist=83.3 (20) Child's disability: % (n) Down syndrome: SSTP-E=4.2 (1), SSTP-S=19.2 (5), waitlist=8.3 (2) Other chromosomal abnormality: SSTP-E=16.7 (4), SSTP-S=7.7 (2), waitlist=4.2 (1) Cerebral Palsy: SSTP-E=12.5 (3), SSTP-S=7.7 (2), waitlist=0.0 (0) Autism Spectrum Disorder: SSTP-E=25 (6), SSTP-S=26.9 (7), waitlist=45.8 (11) Global development delay: SSTP-E=16.7 (4), SSTP-S=19.2 (5), waitlist=16.7 (4) Other: SSTP-E=25 (6), SSTP-S=19.2 (5), waitlist=25.0 (6) Level of disability: % (n) Borderline/at risk: SSTP-E=4.2 (1), SSTP-S=0.0 (0), waitlist=16.7 (4) Mild: SSTP-E=33.3 (8), SSTP-S=38.5 (10), waitlist=16.7 (4) Moderate: SSTP-E=45.8 (11), SSTP-S=50.0 (13), waitlist=45.8 (11) Severe: SSTP-E=16.7 (4), SSTP-S=11.5 (3), waitlist=20.8 (5) **Interventions** Stepping Stones Triple P-Enhanced (SSTP-E), versus, Stepping Stones Triple P-Standard (SSTP-S), versus waitlist (WL) control group SSTP-E and SSTP-S included 60–90 min individual sessions with a practitioner on a weekly basis. After-hours appointments were available to encourage both parents to attend and some home-based intervention was provided due to transport limitations.	Parental satisfaction via the Client Satisfaction Questionnaire (CSQ) Total score: Mean (SD) SSTP-E=75.50 (9.18) SSTP-S=73.75 (9.89) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: There is no information about concealment of the allocation sequence, however there were no significant differences across the three groups at baseline. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: No information on whether participants or those delivering the intervention were aware of groups, nor whether there were deviations from the intended interventions. Per protocol (completer) analysis was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: All participants completed the post-intervention, while approximately 90% completed the follow-up and there were no significant differences in the rate of completion versus non-completion across the two conditions. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely. **5. Bias in selection of the reported result (Low/High/Some concerns)** Some concerns: Data were not analysed according to a pre-specified plan, however statistical analysis and results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data.

Study details	Results and risk of bias assessment
SSTP-S: 10 sessions of the standard version of Stepping Stones Triple P (SSTP) intervention program; an adaptation of the Triple P-Positive Parenting Program specifically designed for parents who have a child with a disability. Parents are taught 25 core child management strategies; Fourteen designed to promote children's competence and development (i.e. quality time, talking with children, physical affection, praise, attention, tangible rewards, engaging activities, activity schedules, setting a good example, physical guidance, incidental teaching, Ask–Say–Do, teaching backwards, and behavior charts); and 11 focus on helping parents manage misbehavior (i.e. diversion, setting rules, directed discussion, planned ignoring, clear and direct instructions, communication, logical consequences, blocking, brief interruption, quiet time, and time-out). Parents were also taught a six-step planned activities routine to enhance generalization and maintenance of parenting skills (i.e. plan ahead, set rules, select engaging activities, identify rewards and consequences, and provide feedback to child) which allowed parents to apply parenting skills to a broad range of target behaviors in both home and community settings. Parents were provided with a workbook which enabled them to set and monitor their own goals for behavior change, and received active skills training and support from their trained practitioner including training methods such as modelling, role plays, feedback, and the use of specific homework tasks. SSTP-E: The same 10 session intensive behavioral parent training as families in the SSTP-S condition, plus an additional six sessions which focused on assisting parents to cope with caring for a child with a developmental disability. Control group: Completed pre-assessment and post-assessment 16 weeks later. Following post-assessment, they participated in the program of their choice, and did not take any further part in the study. **Follow-up** Post-intervention (16 weeks for control and SSTP-E, and 10 weeks for SSTP-S), and 1 year follow-up	**Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in all domains, but not to be at high risk of bias for any domain. **Source of funding** Funding support from the Australian Research Council and Apex Foundation and project support from the government services **Other information** No follow-up data is available for families in the waitlist condition and it was considered unethical to allow preschool aged children with problem behaviour to remain without intervention through to 1-year follow-up.
Full citation Sonuga-Barke, E. J., Daley, D., Thompson, M., Laver-Bradbury, C., Weeks, A., Parent-based therapies for preschool attention-deficit/hyperactivity disorder: a randomized, controlled trial with a community sample, Journal of the American Academy of Child and Adolescent Psychiatry, 40, 402-8, 2001	**Results** n=78 were randomised: parent training (PT; n=30), parent counselling and support (PC&S; n=28) or a waiting-list control (n=20). The Parental Sense of Competence Scale (PSOC)

Study details	Results and risk of bias assessment
Ref Id 1234619 **Country where the study was carried out** UK **Study type** RCT **Study dates** Not reported **Inclusion criteria** Male or Female 3-year-old children identified at their 3-year developmental check of children born between January 1992 and September 1993. Inclusion criteria: Children who scored more than 20 on the Werry-Weiss-Peters Activity Scale; children who met clinically validated cut-offs on the Parental Account of Childhood Symptoms (PACS) ADHD/Hyperkinesis scale and whose parents reported that their condition was associated with impairment significant enough to warrant clinical intervention. **Exclusion criteria** Children whose parents had a serious mental illness, they had a serious learning disability, or they had a previous diagnosis for an unrelated mental health condition. **Patient characteristics** Three-year-old children displaying a preschool equivalent of ADHD (n=78); Gender: n=48 male 29% of children in the study met the criteria for PACS conduct problems 42% of the sample were from social classes 1 or 2 (professional) 40% were from classes 3 or 4 (skilled) 18% were from classes 5 or 6 (unskilled)	PSOC Efficacy PT: Baseline=21.96 (5.38), Post-intervention=24.88 (4.52), Follow-up=23.74 (4.75) PC&S: Baseline=21.07 (5.08), Post-intervention=22.33 (4.30), Follow-up=22.68 (4.94) WLC: Baseline=25.01 (3.30), Post-intervention=24.29 (2.57), Follow-up=21.85 (6.39) PSOC Satisfaction PT: Baseline=24.00 (6.60), Post-intervention=30.80 (5.18), Follow-up=27.10 (5.13) PC&S: Baseline=25.64 (3.87), Post-intervention=26.99 (3.81), Follow-up=26.55 (5.26) WLC: Baseline=25.71 (4.01), Post-intervention=24.44 (4.32), Follow-up=24.40 (6.12) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: There is no information on the method of randomisation or allocation concealment. There is no comparison of baseline demographics between intervention and control groups; baseline measurements for the relevant outcomes are compared with a group of non-ADHD controls. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants were aware of treatment assignment, nor whether there were any deviations from intended interventions. A coder was blind to the status of the sessions and appropriate analysis (intention to treat) was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Low risk: Outcome data were available for all participants; missing data was imputed and numbers lost to attrition were low (9%).

Study details	Results and risk of bias assessment
Interventions Parent training (PT), versus parent counselling and support (PC&S), versus waiting-list control Both treatments consisted of a structured 8-week program for parents involving eight 1-hour weekly visits by one of two specially trained health visitor therapists, carried out on a one-to-one basis in the client's home. PT: Parents were educated about ADHD and introduced to behavioural strategies for increasing attention and behavioural organization and reducing defiant and difficult behaviour. In most sessions therapists worked with both mother and child. Parents completed a behaviour diary and progress was monitored on a weekly basis. PC&S: Parents received no training in behavioural strategies but were given the opportunity to explore issues of concern to them and to discuss their feelings about their child and the impact that the child had on the family in a nondirective, nonthreatening environment. The behaviour diary was used to structure discussions. Waitlist control: children received no contact with clinical services during the 23 weeks of the trial **Follow-up** Post-intervention at week 8, and follow-up during week 23 (15 weeks post-intervention)	**4. Bias in measurement of the outcome (Low/High/Some concerns)** Low risk: The method of measuring the outcome was not inappropriate and measurement did not differ between intervention groups. Outcome assessors were unaware of the intervention received by study participants. **5. Bias in selection of the reported result (Low/High/Some concerns)** Low risk: The protocol does not appear to be published however outcomes and statistical analysis were pre-specified in the methods, and results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data. **Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in two domains, but not to be at high risk of bias for any domain. **Source of funding** Supported by a grant from the NHS R&D Committee. **Other information** Families and carers were not the randomised group; children were randomised to receive parent training or parent counselling and support, versus control
Full citation Taylor, Julie Lounds, Hodapp, Robert M., Burke, Meghan M., Waitz-kudla, Sydney N., Rabideau, Carol, Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial, Journal of Autism and Developmental Disorders, 47, 846-857, 2017 **Ref Id** 1171885 **Country where the study was carried out** USA	**Results** Randomised n=45: treatment (N = 22) versus wait-list control (N = 23) Completed treatment n=41 (4 discontinued, 2 from each group): treatment (N = 20) versus wait-list control (N = 21) Advocacy skills and comfort (the degree to which parents felt comfortable and skilled in advocating for their son/daughter with ASD) Treatment (N = 20): Mean (SD) Baseline: 3.54 (0.46), Post-intervention: 4.10 (0.67) Wait-list control (N = 21): Mean (SD)

Study details	Results and risk of bias assessment
Study type RCT **Study dates** Fall of 2015 to Spring of 2017 **Inclusion criteria** Parents of youth with ASD within two years of high school exit Inclusion criteria: Youth with ASD had to be in the "transition years," defined as within two years before or after high school exit; youth must have received a previous medical or educational diagnosis of an ASD, which was confirmed during a clinical evaluation; families must have lived in one of the metropolitan areas in which the program was being delivered (in-person in BLINDED or by webcast in BLINDED or BLINDED), and the primary respondent from each family was willing/able to travel to the specific project site to participate in the intervention sessions on Monday evenings for 12 consecutive weeks and families were required to live within the state for which the program was developed; participants needed to be willing to be randomized to either the intervention group (taking the program in the fall of 2015) or control group (taking the program in the spring of 2017). ASD diagnoses were confirmed using the Autism Diagnostic Observation Schedule-2 administered by research-reliable clinicians to the son/daughter with ASD. **Exclusion criteria** Not reported **Patient characteristics** N=41 parents; treatment (N = 20) or wait-list control (N = 21) Parent demographics Sex: %(n) Male: Overall=2.4% (1), intervention=0, control=4.8% (1) Female: Overall=97.6% (40), intervention=100% (20), control=95.2% (20) Age, Mean (SD): Overall=49.99 (5.89), intervention=49.38 (7.08),	Baseline: 3.45 (0.61), Post-intervention: 3.31 (0.64) Parental empowerment via the Family Empowerment Scale Treatment (N = 20): Mean (SD) Baseline: 122.30 (19.81), Post-intervention: 135.66 (16.86) Wait-list control (N = 21): Mean (SD) Baseline: 121.58 (17.59), Post-intervention: 119.66 (16.82) **1. Bias arising from the randomisation process (Low/High/Some concerns)** Some concerns: Groups were assigned using a random number generator, however there is no information about concealments of the allocation sequence. No statistical differences in baseline demographics. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants or those delivering the intervention were aware of treatment assignment, nor whether there were any deviations from intended interventions. Per protocol ("as-treated"/completer) analysis was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Outcome data was available for 91% of participants, and participants who dropped out were more likely to be racial/ethnic minorities and to have incomes less than $40,000. However the number of participants lost was similar across groups. **4. Bias in measurement of the outcome (Low/High/Some concerns)** Some concerns: The method of measuring outcomes was not inappropriate and did not differ by group. No information on the blinding of outcome; assessment could have been influenced by knowledge of the intervention however this is unlikely. **5. Bias in selection of the reported result (Low/High/Some concerns)**

Study details	Results and risk of bias assessment
control=50.57 (4.58) Income, Mean (SD): Overall=4.80 (2.41), intervention=4.85 (2.39), control=4.76 (2.49) Education: %(n) High school or less: Overall=4.9% (2), intervention=10.0% (2), control=0 Some college: Overall=24.4% (10), intervention=10.0% (2), control=38.1% (8) Bachelor's degree: Overall=39.0% (16), intervention=40.0% (8), control=38.1% (8) Post Bachelor's: Overall=31.7% (13), intervention=40.0% (8), control=23.8% (5) Race: %(n) White: Overall=87.8% (36), intervention=90.0% (18), control=85.7% (18) African-American: Overall=7.3% (3), intervention=5.0% (1), control=9.5% (2) Other: Overall=4.8% (2), intervention=5.0% (1), control=4.8% (1) Youth demographics Sex: % (n) Male: Overall=82.9% (34), intervention=85.0% (17), control=81.0% (17) Female: Overall=17.1% (7), intervention=15.0% (3), control=19.0% (4) Age, Mean (SD): Overall=18.24 (1.87), intervention=18.14 (1.74), control=18.34 (2.02) Intellectual disability: % (n) Yes: Overall=31.7% (13), intervention=35.0% (7), control=28.6% (6) No: Overall=68.3% (28), intervention=65.0% (13), control=71.4% (15) Abbreviated IQ, Mean (SD): Overall=80.10 (24.75), intervention=78.74 (26.27), control=81.40 (23.83) Adaptive behaviour, Mean (SD): Overall=58.00 (13.20), intervention=55.40 (15.51), control=60.48 (10.32) Autism symptoms, Mean (SD): Overall=80.66 (8.97), intervention=81.85 (8.37), control=79.52 (9.57) Comorbid psychiatric diagnosis: % (n) Yes: Overall=41.5% (17), intervention=30.0% (6), control=52.4% (11) No: Overall=58.5% (24), intervention=70.0% (14), control=47.6% (10) Number of services: Mean (SD): Overall=3.02 (2.20), intervention=2.85 (2.46), control=3.19 (1.97)	Low risk: The protocol does not appear to be published however outcomes and statistical analysis were pre-specified in the methods, and results are unlikely to have been selected from multiple eligible outcome measurements or analyses of the data. **Overall risk of bias (Low/High/Some concerns)** Some concerns: The study is judged to raise some concerns in most domains, but not to be at high risk of bias for any domain. **Source of funding** Funded by the National Institute of Mental Health (R34 MH104428), with core support from the National Institute of Child Health and Human Development (U54 HD083211) and the National Center for Advancing Translational Sciences (CTSA UL1 TR000445) **Other information** Follow-up data not reported in this paper

Study details	Results and risk of bias assessment
Interventions Volunteer Advocacy Project-Transition (VAP-T) versus Waitlist Control VAP-T program: 30-hour advocacy training to educate parents of youth with ASD about the adult service delivery system and to enable parents to advocate for services. Conducted on Monday evenings for 12 consecutive weeks in the fall of 2015. VAP-T was comprised of didactic instruction, family-sharing activities, case studies, and group discussions directed by a licensed clinical social worker who had been trained in Person-Cantered Planning with two decades of experience working both individually and in groups with individuals with disabilities and their families. The curriculum reflected multiple domains: person centred thinking (i.e., how to incorporate the desires and dreams of the person with ASD into post-secondary plans), secondary education, post-secondary education, financial support, employment, Medicaid, future planning, medical services, and advocacy. Within each domain, there were 1–3 topics. Control group: Waitlist group who could participate in the VAP-T program in Spring 2017 The control group received a list of local disability resources, as well as publicly-available toolkits pertaining to the transition to adulthood and employment for people with disabilities. Other than periodic emails about local transition-related seminars or workshops (sent to both groups), research staff did not provide other resources to the control group during the intervention sessions, nor throughout the 12-month follow-up period. **Follow-up** Post intervention (12 weeks) and 1 year follow-up	
Full citation Tellegen, Cassandra L., Sanders, Matthew R., Stepping Stones Triple P-Positive Parenting Program for children with disability: a systematic review and meta-analysis, Research in developmental disabilities, 34, 1556-71, 2013 **Ref Id** 914359	**Results** Parenting style, measured with the Parenting Scale All levels combined (n studies=11) d effect size=0.725, Lower 95% CI=0.553, Upper 95% CI=0.896 Level 2 (n studies=2) d effect size=0.352, Lower 95% CI=0.254, Upper 95% CI=0.957

Study details	Results and risk of bias assessment
Country where the study was carried out Australia (Included studies were carried out in Australia, Germany and Canada) **Study type** Systematic review and meta-analysis **Study dates** Included studies were published between 2001 and 2013. (Databases were searched for studies published between 1970 to 30 June 2012) **Inclusion criteria** Included studies needed to meet the following criteria: The study reported outcomes from an evaluation of an intervention recognized by the authors of the paper as form of Stepping Stones Triple P. (No limitations were set regarding trial design for including studies); The study was available in English or German; The study reports mean, standard deviations and sample sizes either within the publication or upon author contact; the study contributed original data not contained in other studies. (When two or more reports contained the same data from the same sample, the report containing the most comprehensive dataset was included in the review) **Exclusion criteria** Exclusion criteria for the selection of studies: If there was no outcome data for parents or families; if the study only reported on acceptability data, practitioner outcomes or consumer satisfaction data; If means, standard deviations and sample sizes were not obtainable; If the study only contained data included in another study and contributed no original data **Patient characteristics** Parents of children with disabilities including: Developmental disability alone or in combination with behavioural problem indicated by interview and Developmental Behaviour Checklist pretest score or comorbid behavioural problems, Autism Spectrum Disorder, Down Syndrome, Cerebral Palsy or other intellectual disability, or Autism/Asperger's Syndrome.	Level 3 (n studies=1) d effect size=0.707, Lower 95% CI=0.270, Upper 95% CI=1.143 Level 4 (n studies=6) d effect size=0.855, Lower 95% CI=0.609, Upper 95% CI=1.101 Level 5 (n studies=2) d effect size=0.623, Lower 95% CI=0.210, Upper 95% CI=1.036 Parenting satisfaction and efficacy, measured with the Parenting Sense of Competence Scale (PSOC) or the Parenting Tasks Checklist (PTC) All levels combined (n studies=9) d effect size=0.523, Lower 95% CI=0.315, Upper 95% CI=0.730 Level 2 (n studies=2) d effect size=0.350, Lower 95% CI=0.077, Upper 95% CI= 0.777 Level 3 (n studies=1) d effect size=0.821, Lower 95% CI=0.378, Upper 95% CI=1.264 Level 4 (n studies=5) d effect size=0.411, Lower 95% CI= 0.106, Upper 95% CI=0.715 Level 5 (n studies=1) d effect size=0.785, Lower 95% CI=0.276, Upper 95% CI=1.293 **1. Study eligibility criteria** Low concern: Considerable effort has been made to clearly specify the review question and objectives, and to pre-specify and justify appropriate and detailed eligibility criteria that have been adhered to during the review **2. Identification and selection of studies**

Study details	Results and risk of bias assessment
Child mean age (range): 3.5 - 6.15 years Child age (range): Up to 17 years Percent boys (range): 57.1-85 % **Interventions** Stepping Stones Triple P-Positive Parenting program (SSTP) SSTP programs are designed for parents of children with a disability and include five levels of intervention: Level 1: A media and communication strategy Level 2: A brief selective intervention, such as one or two larger-group seminars Level 3: A narrow focus-training where brief, tailored interventions are delivered individually to parents Level 4: Broad focus training of 10 sessions delivered through individual, group of self-directed formats Level 5: Intensive additional modules for families experiencing extra problems Included studies reported the following interventions: STTP Seminars, Self-directed (reading SSTP booklet and tip sheets), Primary Care SSTP, Group SSTP, Individual SSTP, Standard SSTP, Enhanced SSTP **Follow-up** Not reported	Low concern: Substantial effort has been made to identify as many relevant studies as possible through a variety of search methods using a sensitive and appropriate search strategy and steps were taken to minimise bias and errors when selecting studies for inclusion **3. Data collection and study appraisal** Unclear concern: Risk of bias was assessed using appropriate criteria, data extraction involved one reviewer however this was checked by a second reviewer. Unclear if the risk of bias assessment involved two reviewers. Relevant study characteristics and results were extracted. **4. Synthesis and findings** Low concern: The synthesis is unlikely to produce biased results; appears that any limitations in the data were overcome. **Judging risk of bias** Low concern: The findings of the review are likely to be reliable. Phase 2 did not raise any concerns with the review process or concerns were appropriately considered in the review conclusions. The conclusions were supported by the evidence and included consideration of the relevance of included studies. **Source of funding** Not reported **Other information** Study assesses change in treatment groups from pre-intervention and post-intervention
Full citation Treacy, L., Tripp, G., Baird, A., Parent stress management training for attention-deficit/hyperactivity disorder, Behavior therapy, 36, 223-233, 2005 **Ref Id** 1234621	**Results** n=42 families randomised (n=63 parents) Percentage of parents who completed at baseline=(98.4%), Post treatment (84.1%), Post treatment for waitlist group only (83.3%), 6-month follow-up (69.8%), and 12-month follow-up (57.1%). Parenting Scale to assess parenting styles/discipline practices.

Study details	Results and risk of bias assessment
Country where the study was carried out New Zealand **Study type** RCT **Study dates** Not reported **Inclusion criteria** Parents of children diagnosed with DSM-IV ADHD **Exclusion criteria** The presence of severe relationship difficulties between parents who both wished to participate and/or a major psychiatric disorder. **Patient characteristics** n=42 families n=63 parents: n=40 (63.5%) mothers (including 3 stepmothers and 1 foster mother); n=23 (36.5%) fathers (including 2 stepfathers) n=27 (64.3%) of the families were 2-parent families (not all fathers from 2-parent families participated) Age range of the participating mothers: 28 to 49 years (M = 36 years, 3 months; SD = 5 years, 6 months) Age range of the participating fathers: 26 to 53 years (M = 38 years, 9 months; SD = 6 years, 7 months). Family socioeconomic status: ranged from 1 to 6 (M = 4.2, SD = 1.7) lower scores reflecting higher SES. Children age range: 6 to 15 years (M = 9 years, 5 months; SD = 2 years, 1 month), all but 2 of the children were less than 13 years n=37 (88.1%) of the children were male. The majority of the children (88.1%) were prescribed medication (methylphenidate) for the management of their ADHD symptoms. Parent reports indicated: n=18 (47.4%) had delinquent behaviour, n=20 (56.1%) of the children had aggressive behaviour problems	Parenting Scale - Laxness* Treatment Group, M (SD) Mother's: Baseline (n=20): 2.9 (1.1), Post intervention (n=17): 2.6 (1.1) Father's: Baseline (n=13): 3.0 (0.7), Post intervention (n=10): 2.8 (0.6) Waitlist Group, M (SD) Mother's: Baseline (n=20): 2.8 (0.9), Post intervention (n=16): 3.2 (1.2), Post-program WL (n=17): 2.4 (0.8) Father's: Baseline (n=9): 3.3 (0.8), Post intervention (n=8): 2.9 (0.6), Post-program WL (n=7): 3.0 (0.6) Parenting Scale - Over reactivity Treatment Group, M (SD) Mother's: Baseline (n=20): 3.5 (0.9), Post intervention (n=16): 3.2 (0.9) Father's: Baseline (n=13): 3.7 (0.8), Post intervention (n=10): 3.5 (1.1) Waitlist Group, M (SD) Mother's: Baseline (n=20): 3.7 (1.0), Post intervention (n=16): 4.0 (0.9), Post-program WL (n=17): 3.1 (0.9) Father's: Baseline (n=9): 3.3 (0.7), Post intervention (n=8): 3.2 (0.7), Post-program WL (n=7): 3.1 (0.8) Parenting Scale - Verbosity** Treatment Group, M (SD) Mother's: Baseline (n=20): 3.7 (0.9), Post intervention (n=17): 3.3 (0.9) Father's: Baseline (n=13): 4.1 (0.4), Post intervention (n=10): 3.6 (0.6) Waitlist Group, M (SD) Mother's: Baseline (n=20): 3.6 (1.0), Post intervention (n=16): 3.8 (0.7), Post-program WL (n=17): 3.2 (0.9) Father's: Baseline (n=9): 4.0 (0.6), Post intervention (n=8): 4.0 (0.5), Post-program WL (n=7): 3.6 (0.6) Parental Locus of Control Scale (PLOC) to measure parents' perceived locus of control in childrearing situations PLOC, Parental Efficacy subscale Treatment Group, M (SD)

Study details	Results and risk of bias assessment
Interventions Parent stress management program (PSM) versus wait-list control PSM: Evening sessions (2 hours in duration including a short refreshment break.) for 9 consecutive weeks at the ADHD Research Clinic. Financial assistance ($30 per session) was provided to cover the cost of child care and travel. If unable to attend their weekly group session, parents were required to attend an individual catch-up session to remain eligible to continue with the PSM program. Catch-up sessions, run by one of the two group leaders, were approximately 1 hour in duration and took place before the next group session. Group sessions generally were structured with a review of the previous session, including homework, followed by a presentation by the group leaders and a group discussion. Following this, parents broke into smaller groups to complete exercises designed to demonstrate and reinforce the material presented. Homework exercises were presented and discussed and on conclusion of the session parents were provided with a handout of the material covered. Session content included; Orientation to the program and understanding stress, Education about ADHD, Rights and resources, Problem-solving skills, Cognitive restructuring, Communication skills, Self-care skills, Parenting skills, and Wrap-up session. Waitlist control group: Parents began the PSM program after post-treatment assessment. They were asked to complete the measures a third time after completing the program. **Follow-up** Post-treatment at 11 weeks, and 6 and 12 months Consumer satisfaction questionnaires were anonymously completed and returned within 2 weeks of completing the PSM program.	Mother's: Baseline (n=20): 22.5 (5.8), Post intervention (n=17): 21.5 (7.4) Father's: Baseline (n=12): 22.8 (3.8), Post intervention (n=11): 22.1 (4.2) Waitlist Group, M (SD) Mother's: Baseline (n=19): 22.8 (5.2), Post intervention (n=17): 22.7 (6.0), Post-program WL (n=17): 20.4 (5.7) Father's: Baseline (n=8): 21.3 (3.0), Post intervention (n=8): 21.5 (2.9), Post-program WL (n=8): 23.4 (4.7) Brief Social Support Questionnaire (BSSQ) to measure Perceived levels of social support BSSQ Size Treatment Group, M (SD) Mother's: Baseline (n=20): 3.2 (1.9), Post intervention (n=17): 3.5 (2.1) Father's: Baseline (n=11): 2.2 (1.7), Post intervention (n=10): 2.4 (2.1) Waitlist Group, M (SD) Mother's: Baseline (n=20): 2.9 (1.3), Post intervention (n=17): 3.2 (1.5), Post-program WL (n=17): 3.4 (1.3) Father's: Baseline (n=9): 2.1 (1.2), Post intervention (n=7): 1.9 (0.8), Post-program WL (n=7): 2.2 (1.0) BSSQ Satisfaction Treatment Group, M (SD) Mother's: Baseline (n=17): 4.9 (1.0), Post intervention (n=17): 4.8 (0.8) Father's: Baseline (n=12): 4.6 (0.9), Post intervention (n=9): 4.6 (0.8) Waitlist Group, M (SD) Mother's: Baseline (n=20): 5.2 (0.6), Post intervention (n=17): 5.3 (0.6), Post-program WL (n=17): 5.3 (0.5) Father's: Baseline (n=9): 4.3 (1.5), Post intervention (n=7): 4.3 (1.1), Post-program WL (n=7): 4.5 (1.3) * Defined as giving in, not enforcing rules or providing positive consequences in response to negative behaviour ** Defined as using lengthy verbal responses and relying on talking even when this is ineffective

Study details	Results and risk of bias assessment
	1. Bias arising from the randomisation process (Low/High/Some concerns) Some concerns: There is no information on allocation concealment, nor whether there were any baseline differences between groups; participant's demographics are presented for the included participations as a whole. **2. Bias arising due to deviations from intended interventions (Low/High/Some concerns)** Some concerns: There is no information on whether participants or those delivering the intervention were aware of treatment assignment, nor whether there were any deviations from intended interventions. Per protocol (completer) analysis was used. **3. Bias due to missing outcome data (Low/High/Some concerns)** Some concerns: Outcome data was not available for all, or nearly all randomised participants and there is no evidence that the result was not biased by missing outcome data. Missingness in the outcome could depend on its true value, however this is unlikely. **4. Bias in measurement of the outcome (Low/High/Some concerns)** High risk: The method of measuring outcomes was not inappropriate and did not differ by group. Outcomes were participant-reported and typically completed at home; therefore, could have been influenced by knowledge of the intervention. **5. Bias in selection of the reported result (Low/High/Some concerns)** High risk: The protocol does not appear to be published, and data was subsequently analysed separately for mothers and fathers when marked changes were observed in mother's scores compared to no change in fathers' scores. **Overall risk of bias (Low/High/Some concerns)** High risk: The study is judged to be of high risk of bias in at two domains **Source of funding**

Study details	Results and risk of bias assessment
	Supported by grants from the Health Research Council of New Zealand and the Child Protection Trust Otago. **Other information** Insufficient presentation of results on the outcome consumer satisfaction (CSQ) for data extraction. Data was subsequently analysed separately for mothers and fathers when marked changes were observed in mother's scores compared to no change in fathers' scores. 6 and 12-month follow-up data is not presented in the paper.
Full citation Truesdale-Kennedy, Maria, McConkey, Roy, Ferguson, Pauline, Roberts, Paul, Allen, Carpenter Chan Dale Dempsey Dyson Epstein Friedrich Goldberg Judge Kelly King Law McConkey McConkey McConkey McConkey Polit Robertson Rosenbaum Sanderson Sarason Smyth, An Evaluation of a Family-centred Support Service for Children with a Significant Learning Disability, Child Care in Practice, 12, 377-390, 2006 **Ref Id** 1101516 **Country where the study was carried out** Northern Ireland **Study type** Non randomised evaluation (service audit) **Study dates** Not reported **Inclusion criteria** Families who had a child with a significant learning disability aged 7-19 years living in a defined location within one of the Health and Social Services Trusts in Northern Ireland. All children, no matter how severely disabled were eligible **Exclusion criteria**	**Results** N=40 families involved with the Families Project; N=27 agreed to take part in the evaluation (Lost; n=6 families due to sensitive issues such as child protection concerns, stress in the family, and marital disharmony, n=2 families were unavailable) At 12 months (n=69 total): Families participating in the Families project (n=19/27); (Lost n=8: n=6 families due to sensitive issues such as child protection concerns, stress in the family, and marital disharmony, n=2 families were unavailable) Comparison group of parents recruited from the same Health and Social Services Trust (n=25) Comparison group of parents from an area served by a different Health and Social Services Trust (n=25). Social Support Questionnaire (SSQ) Families Project: (n=19): Mean (SD) Baseline: 17.33 (5.16), Follow-up: 17.20 (2.81) Contrast Group 1 (n=25): Mean (SD) Baseline: 15.96 (3.08), Follow-up:12.96 (2.49) Contrast Group 2 (n=25): Mean (SD) Baseline: 17.20 (3.01), Follow-up:14.04 (4.11)

Study details	Results and risk of bias assessment
Not reported **Patient characteristics** Carers demographics Mothers: 72% Married: 80% Aged under 40 years of age: 52% Had two or more children: 95% Had completed third-level education: Around one third Owner-occupiers: 77% No wage-earner in the household: 26% Children demographics n=69 in the study Male: 67% Female: 33% female Age range: 5 to 18 years (mean of 11 years) All had a statement of special educational needs that named learning difficulties 15% of children had an additional physical disability 30% of the children had a diagnosis of autism spectrum conditions (reported by carers) 12% had Down syndrome 10% had cerebral palsy 3% had Attention Deficit Disorders Nearly all children attended a special school: (95%). **Interventions** Family Support Project versus two contrast groups Family support project: Each family was visited at home on a number of occasions and arrangements were made to complete a person-centred plan using a Planning Alternative Tomorrows with Hope (PATH) or Making Action Plans (MAPS) approach which identified the aspirations and needs of the young person and of the family, and was used as the basis for activity	**1. Risk of bias due to confounding** Serious risk: The important confounding factors (dominant provision, definitions of eligibility and socioeconomic status) are not adequately adjusted for. Baseline confounding present; families approached by a project worker or their social worker and given information about the evaluation. **2. Bias in selection of participants into the study** Moderate risk: Selection into the study may have been related to intervention and outcome **3. Bias in classification of interventions** Low risk: Intervention status is well defined and based solely on information collected at the time of intervention **4. Bias due to deviations from intended interventions** No information: Deviations from the intended intervention are not reported **5. Bias due to missing data** Moderate risk of bias: Outcome data was not available for all participants (approximately 70% of intervention group were available for follow-up) and analysis was based on participants who completed the study only. **5. Bias in measurement of outcomes** Serious risk: Outcome measurements were self-reported and vulnerable to influence and knowledge of the intervention received **6. Bias in selection of the reported result** Moderate risk: it appears as though the protocol has not been published, however there is no indication of the selection of the reported analysis from among multiple analyses or the selection of the cohort or subgroups for analysis and reporting on the basis of the results. **Overall risk of bias**

Study details	Results and risk of bias assessment
planning and for referrals to specialist agencies or professional. The project support worker visited each family on a monthly basis as a minimum to review progress and to deal with any concerns. Volunteer helpers were matched with individual families and usually accompanied the young person to chosen activities. Arrangements were made to use a range of community facilities such as swimming pools, leisure and sports facilities, and drama groups. Work experience placements were also sought for older teenagers. Meetings were held at the service base for groups of young people to engage in specific activities, such as Arts and Crafts. A siblings group was also formed that met monthly for organised activities. Parents were also offered the opportunity to attend occasional meetings that dealt with specific topics of their choosing. Aims of the family support project were the following: To provide a designated project support worker to each family so that they have one contact person for information and advice, and someone who would also liaise with other agencies and professionals on their behalf; To use person-centred planning approaches to identify the support needs of families, especially with respect to out-of-home activities for their child at evenings, weekends and school holidays; To use community development strategies to gain access to local leisure amenities; to develop the capacity of youth and community groups to include children with a learning disability, to recruit volunteer helpers and become involved in strategic planning groups covering the locality; To provide opportunities for siblings of the affected child to share experiences through meetings and leisure activities; To offer parents opportunities to become involved in support and education groups. Contrast groups: Likely to be availing of a range of services provided to families who have a child with a disability, such as special schools, therapies, and social work support. Contrast group 1: Families living in a different area of the same Health and Social Services Trust Contrast group 2: Families from a different Health and Social Services Trust. **Follow-up** Start of evaluation period, and 12 months later	Serious risk of bias: The study is judged to be at serious risk of bias in two domains, but not at critical risk of bias in any domain. **Source of funding** The Families project was 75% granted aided by the DHSSPS, with additional funding from Positive Futures. **Other information**

ADHD: attention deficit hyperactivity disorder; ASD: autistic spectrum disorder; CAMHS: child and adolescent mental health services; CYP: child or young person; DSM-IV: Diagnostic and Statistical Manual of Mental Disorders-version 4; EHC: education, health and care; LD: learning disabilities; M: mean; N: number of participants; RCT: randomised controlled trial; SD: standard deviation ; SR: systematic review; WL: waitlist

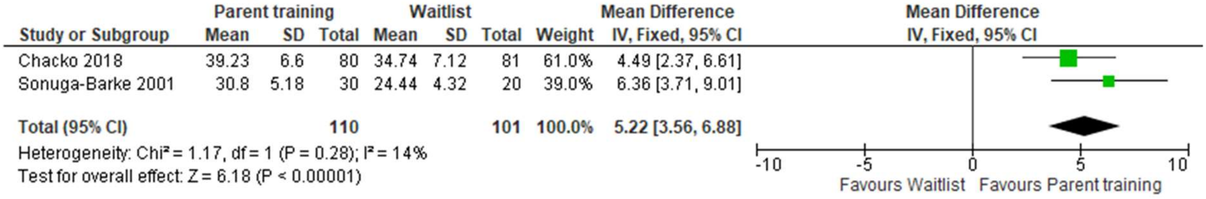
Appendix E – Forest plots

Forest plots for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

This section includes forest plots only for outcomes that are meta-analysed. Outcomes from single studies are not presented here; the quality assessment for such outcomes is provided in the GRADE profiles in appendix F.

Comparison 1: Parent training versus waitlist control

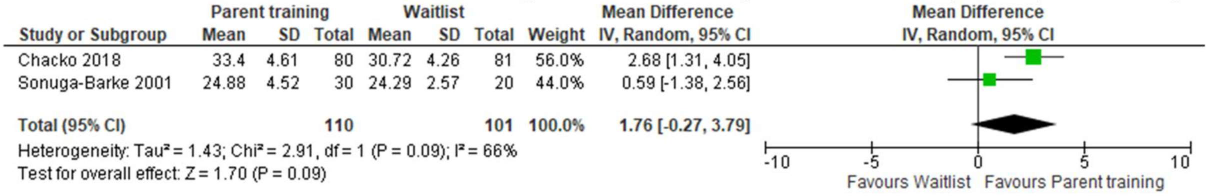
Figure 2: Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Satisfaction



	Parent training			Waitlist				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI
Chacko 2018	39.23	6.6	80	34.74	7.12	81	61.0%	4.49 [2.37, 6.61]
Sonuga-Barke 2001	30.8	5.18	30	24.44	4.32	20	39.0%	6.36 [3.71, 9.01]
Total (95% CI)			**110**			**101**	**100.0%**	**5.22 [3.56, 6.88]**

Heterogeneity: $Chi^2 = 1.17$, $df = 1$ ($P = 0.28$); $I^2 = 14\%$
Test for overall effect: $Z = 6.18$ ($P < 0.00001$)

Figure 3: Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Efficacy

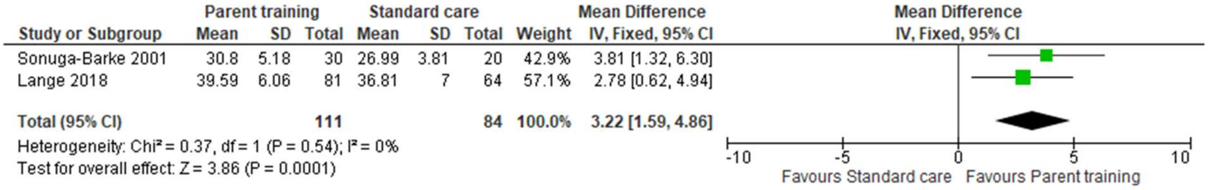


	Parent training			Waitlist				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Chacko 2018	33.4	4.61	80	30.72	4.26	81	56.0%	2.68 [1.31, 4.05]
Sonuga-Barke 2001	24.88	4.52	30	24.29	2.57	20	44.0%	0.59 [-1.38, 2.56]
Total (95% CI)			**110**			**101**	**100.0%**	**1.76 [-0.27, 3.79]**

Heterogeneity: $Tau^2 = 1.43$; $Chi^2 = 2.91$, $df = 1$ ($P = 0.09$); $I^2 = 66\%$
Test for overall effect: $Z = 1.70$ ($P = 0.09$)

Comparison 2: Parent training versus standard care

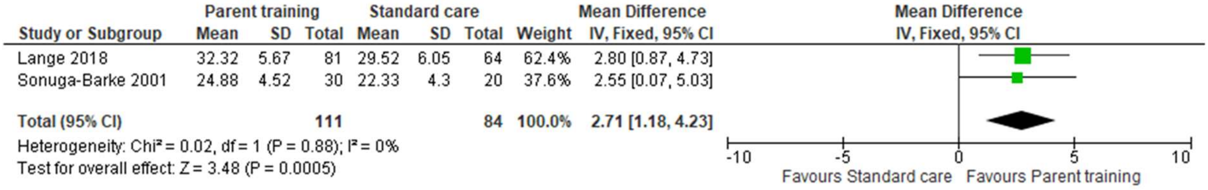
Figure 2: Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Satisfaction



	Parent training			Standard care				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI
Sonuga-Barke 2001	30.8	5.18	30	26.99	3.81	20	42.9%	3.81 [1.32, 6.30]
Lange 2018	39.59	6.06	81	36.81	7	64	57.1%	2.78 [0.62, 4.94]
Total (95% CI)			**111**			**84**	**100.0%**	**3.22 [1.59, 4.86]**

Heterogeneity: $Chi^2 = 0.37$, $df = 1$ ($P = 0.54$); $I^2 = 0\%$
Test for overall effect: $Z = 3.86$ ($P = 0.0001$)

Figure 3: Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Efficacy



	Parent training			Standard care				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI
Lange 2018	32.32	5.67	81	29.52	6.05	64	62.4%	2.80 [0.87, 4.73]
Sonuga-Barke 2001	24.88	4.52	30	22.33	4.3	20	37.6%	2.55 [0.07, 5.03]
Total (95% CI)			**111**			**84**	**100.0%**	**2.71 [1.18, 4.23]**

Heterogeneity: Chi² = 0.02, df = 1 (P = 0.88); I² = 0%
Test for overall effect: Z = 3.48 (P = 0.0005)

Appendix F – GRADE tables

GRADE tables for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Table 6: Evidence profile for comparison 1: Parent training versus waitlist

Quality assessment							No of patients		Effect			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Parent training**	**Waitlist control**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Communication, measured with the Family Problem Solving Communication Index (FPSC) at endpoint (8 weeks) (range of scores: 0-30; Better indicated by higher values)												
1 (Giallo 2008)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[2]	none	12	9	-	MD 2.69 higher (1.31 lower to 6.69 higher)	LOW	CRITICAL
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Laxness (range of scores: 1-7; Better indicated by lower values)												
1 (Treacy 2005)	randomised trials	very serious[3]	no serious inconsistency	no serious indirectness	serious[4]	none	27	24	-	MD 0.27 lower (0.72 lower to 0.19 higher)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Over reactivity (range of scores: 1-7; Better indicated by lower values)												
1 (Treacy 2005)	randomised trials	very serious[3]	no serious inconsistency	no serious indirectness	serious[4]	none	26	24	-	MD 0.41 lower (0.91 lower to 0.09 higher)	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect			
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Parent training	Waitlist control	Relative (95% CI)	Absolute	Quality	Importance
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Verbosity (range of scores: 1-7; Better indicated by lower values)												
1 (Treacy 2005)	randomised trials	very serious[3]	no serious inconsistency	no serious indirectness	serious[5]	none	27	24	-	MD 0.45 lower (0.82 to 0.07 lower)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Overall (range of scores: 1-7; Better indicated by lower values)												
1 (Chacko 2009)	randomised trials	serious[6]	no serious inconsistency	no serious indirectness	serious[7]	none	80	81	-	MD 0.40 lower (0.58 to 0.21 lower)	LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the personal success subscale of the Duygun version Maslach Burnout Inventory (MBI) at endpoint (2 months) (range of scores: 0-32; Better indicated by lower values)												
1 (Bilgin 2009)	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[9]	none	45	45	-	MD 0.91 lower (3.11 lower to 1.29 higher)	LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Satisfaction subscale (range of scores: 6-54; Better indicated by higher values)												
2 (Chacko 2018, Sonuga-Barke 2001)	randomised trials	serious[10]	no serious inconsistency	serious[11]	no serious imprecision	none	110	101	-	MD 5.22 higher (3.56 to 6.88 higher)	LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Efficacy subscale (range of scores: 6-36;Better indicated by higher values)												
2 (Chacko 2018,	randomised trials	serious[10]	serious[12]	serious[11]	serious[13]	none	110	101	-	MD 1.76 higher (0.27	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Parent training	Waitlist control	Relative (95% CI)	Absolute		
Sonuga-Barke 2001)										lower to 3.79 higher)		
Capability and Confidence to meet the needs of the child or young person, measured with the Parental Locus of Control Scale (PLOC) - Efficacy subscale at endpoint (11 weeks) (range of scores: 10-50; Better indicated by higher values)												
1 (Treacy 2005)	randomised trials	very serious[3]	no serious inconsistency	no serious indirectness	very serious[14]	none	28	25	-	MD 0 higher (2.61 lower to 2.61 higher)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Everyday Parenting Scale at endpoint (5 weeks) (range of scores: 0-6; Better indicated by higher values)												
1 (Benn 20120	randomised trials	very serious[15]	no serious inconsistency	no serious indirectness	serious[16]	none	11	13	-	MD 0.57 higher (0.06 lower to 1.2 higher)	VERY LOW	IMPORTANT
Social capital, measured with the Brief Social Support Questionnaire (BSSQ) – Size at endpoint 11 weeks (range of scores: 1-6; Better indicated by higher values)												
1 (Treacy 2005)	randomised trials	very serious[3]	no serious inconsistency	no serious indirectness	serious[17]	none	27	24	-	MD 0.38 higher (0.55 lower to 1.32 higher)	VERY LOW	IMPORTANT
Social capital, measured with the Brief Social Support Questionnaire (BSSQ) – Satisfaction at endpoint 11 weeks (range of scores: 1-6; Better indicated by higher values)												
1 (Treacy 2005)	randomised trials	very serious[3]	no serious inconsistency	no serious indirectness	serious[18]	none	26	24	-	MD 0.34 lower (0.77 lower to 0.08 higher)	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Parent training**	**Waitlist control**	**Relative (95% CI)**	**Absolute**		
Social capital, measured with the Seeking Social Support subscale of the Self-Report Coping Scale (SCS) at endpoint 8 weeks (range of scores: 8-40; Better indicated by higher values)												
1 (Giallo 2008)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[19]	none	12	9	-	MD 4.42 higher (0.39 to 8.45 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; ROB 2: Cochrane risk of bias tool version 2; SD: standard deviation

[1] Evidence downgraded by 1 due to some concerns in all domains, but not at high risk of bias for any domain as per RoB 2

[2] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group= 2.05)

[3] Evidence downgraded by 2 due to high risk of bias in two domains (selection of reported results and measurement of the outcome) as per RoB 2

[4] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = -0.42)

[5] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 0.40)

[6] Evidence downgraded by 1 due to some concerns in four domains (randomisation, deviations from intended interventions, missing outcome data and measurement of the outcome) as per RoB 2

[7] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x control group SD=0.28)

[8] Evidence downgraded by 1 due to some concerns in 1 domain (deviations from intended interventions) as per RoB 2

[9] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group =1.39)

[10] Evidence downgraded by 1 due to some concerns in two domains (randomisation and deviations from intended interventions)

[11] Evidence downgraded by 1 due to indirect aspect of PICO (population)

[12] Evidence downgraded by 1 due to serious heterogeneity (I-squared inconsistency statistic of 50-75%)

[13] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 2.01)

[14] Evidence downgraded by 2 due to 95% CI crossed 2 MID (0.5x SD of the control group = 2.05)

[15] Evidence downgraded by 2 due to high risk of bias in 1 domain (missing outcome data) as per RoB 2

[16] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 0.48)

[17] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 0.62)

[18] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 0.52)

[19] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 2.96)

Table 7: Evidence profile for comparison 2: Parent training versus standard care

Quality assessment							**No of patients**		**Effect**			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Parent training**	**Standard care**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Satisfaction (range of scores: 6-54; Better indicated by higher values)												
2 (Lange 2018, Sonuga-Barke 2001)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[2]	none	111	84	-	MD 3.22 higher (1.59 to 4.86 higher)	LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence Scale (PSOC) - Efficacy (range of scores: 6-36; Better indicated by higher values)												
2 (Lange 2018, Sonuga-Barke 2001)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[3]	none	111	84	-	MD 2.71 higher (1.18 to 4.23 higher)	LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the coping self-efficacy (CSE) at 1 month (range of scores: 0-286; Better indicated by higher values)												
1 (Haakonsen Smith 2018)	randomised trials	very serious[4]	no serious inconsistency	no serious indirectness	very serious[5]	none	12	10	-	MD 11.1 higher (28.58 lower to 50.78 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; ROB 2: Cochrane risk of bias tool version 2; SD: standard deviation

[1] Evidence downgraded by 1 due to some concerns in two domains (randomisation and deviations from intended interventions) but not at high risk of bias for any domain as per RoB 2

[2] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 2.78)

[3] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 2.33)

[4] Evidence downgraded by 2 due to high risk of bias in one domain (randomisation) as per RoB 2

[5] Evidence downgraded by 2 due to 95% CI crossed 2 MID (0.5x SD of the control group = 21.85)

Table 8: Evidence profile for comparison 3: Enhanced parent training program versus waitlist

Quality assessment							No of patients		Effect			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Enhanced parenting program**	**Waitlist control**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Laxness (range of scores: 1-7; Better indicated by lower values)												
1 (Hoath 2002)	randomised trials	very serious[1]	no serious inconsistency	no serious indirectness	very serious[2]	none	9	11	-	MD 0.37 lower (1.24 lower to 0.50 higher)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Over reactivity (range of scores: 1-7; Better indicated by lower values)												
1 (Hoath 2002)	randomised trials	very serious[1]	no serious inconsistency	no serious indirectness	serious[3]	none	9	11	-	MD 0.47 lower (1.41 lower to 0.47 higher)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) - Verbosity (range of scores: 1-7; Better indicated by lower values)												
1 (Hoath 2002)	randomised trials	very serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	9	11	-	MD 0.80 lower (1.72 lower to 0.12 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; ROB 2: Cochrane risk of bias tool version 2; SD: standard deviation

[1] Evidence downgraded by 2 due to high risk of bias in 1 domain (randomisation) as per RoB 2

[2] Evidence downgraded by 2 due to 95% CI crossed 2 MID (0.5x SD of the control group at baseline = 0.5)

[3] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 0.56)

[4] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 0.57)

Table 9: Evidence profile for comparison 4: Enhanced parent training program versus standard parent training

Quality assessment							**No of patients**		**Effect**		**Quality**	**Importance**
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Enhanced parent training program**	**standard parent training**	**Relative (95% CI)**	**Absolute**		
Satisfaction with services, measured with the Therapy Attitude Inventory (TAI) - Satisfaction with process at endpoint (9 weeks) (range of scores: 10-50; Better indicated by higher values)												
1 (Chacko 2009)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	40	40	-	MD 2.24 higher (1.34 to 3.14 higher)	MODERATE	CRITICAL
Satisfaction with services, measured with the Therapy Attitude Inventory (TAI) - Satisfaction with outcome at endpoint (9 weeks) (range of scores: 10-50; Better indicated by higher values)												
1 (Chacko 2009)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	40	40	-	MD 3.98 higher (2.79 to 5.17 higher)	MODERATE	CRITICAL
Satisfaction with services, measured with the Client Satisfaction Questionnaire (CSQ) at endpoint (16 weeks) (range of scores: 13-91; Better indicated by higher values)												
1 (Plant 2007)	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	24	26	-	MD 1.75 higher (3.54 lower to 7.04 higher)	LOW	CRITICAL

CI: confidence interval; MD: mean difference; MID: minimal important difference; ROB 2: Cochrane risk of bias tool version 2; SD: standard deviation

[1] Evidence downgraded by 1 due to some concerns in 4 domains (randomisation, deviations from intended interventions, missing outcome data and measurement of the outcome) as per RoB 2

[2] Evidence downgraded by 1 due to some concerns in all domains, but not at high risk of bias in any domain as per RoB 2

[3] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group at follow-up = 4.94)

Table 10: Evidence profile for comparison 5: Advocacy training versus waitlist

Quality assessment							**No of patients**		**Effect**			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Advocacy training**	**Waitlist**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Capability and Confidence to meet the needs of the child or young person, measured with Advocacy skills and comfort at endpoint (12 weeks) (range of scores: 1-5; Better indicated by higher values)												
1 (Taylor 2017)	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	20	21	-	MD 0.79 higher (0.39 to 1.19 higher)	MODERATE	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Family Empowerment Scale (FES) at endpoint (12 weeks) (range of scores: 34-170; Better indicated by higher values)												
1 (Taylor 2017)	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	20	21	-	MD 16 higher (5.69 to 26.31 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; ROB 2: Cochrane risk of bias tool version 2; SD: standard deviation

[1] Evidence downgraded by 1 due to some concerns in 4 domains (randomisation, deviations from intended interventions, missing outcome data and measurement of the outcome) as per RoB 2

[2] Evidence downgraded by 1 due to some concerns in four domains (randomisation, deviations from intended interventions, missing outcome data and measurement of the outcome) as per RoB 2

[3] Evidence downgraded by 1 due to 95% CI crossed 1 MID (0.5x SD of the control group = 8.79)

Table 11: Evidence profile for comparison 6: Person centred planning versus standard care

Quality assessment							**No of patients**		**Effect**			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Person centred planning**	**Standard care**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Social capital, measured with the Social Support Questionnaire (SSQ) at endpoint (12 months) - Standard from the same area (range of scores not reported; Better indicated by higher values)												
1 (Truesdale Kennedy 2006)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	19	25	-	MD 4.24 higher (2.64 to 5.84 higher)	LOW	IMPORTANT

Quality assessment							No of patients		Effect			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Person centred planning**	**Standard care**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Social capital, measured with the Social Support Questionnaire (SSQ) at endpoint (12 months) - Standard from a different area (range of scores not reported; Better indicated by higher values)												
1 (Truesdale Kennedy 2006)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	serious[2]	none	19	25	-	MD 3.16 higher (1.11 to 5.21 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; ROB 2: Cochrane risk of bias tool version 2; SD: standard deviation

[1] Very serious risk of bias (confounding and measurement of outcomes) as per ROBINS-I

[2] 95% CI crosses 1 MID (0.5x SD of the control group at baseline = 1.54)

Table 12: Evidence profile for comparison 7: Before and after Stepping Stones Triple P (positive parenting program)

Quality assessment							No of patients		Effect			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Stepping Stones Triple P**	**Control**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Capability and confidence to meet the needs of the child or young person, measured with the Parenting Sense of Competence (PSOC) and Parenting Tasks Checklist (PTC) (Better indicated by higher values)												
1 (Tellegen 2013)	Systematic review and meta-analysis	no serious risk of bias	no serious inconsistency	no serious indirectness	serious [1]	none	303	157	-	SMD 0.52 higher (0.31 to 0.73 higher)	MODERATE	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with the Parenting Scale (PS) (Better indicated by lower values)												
1 (Tellegen 2013)	Systematic review and meta-analysis	no serious risk of bias	no serious inconsistency	no serious indirectness	no serious imprecision	none	340	194	-	SMD 0.72 higher (0.55 to 0.90 higher)	HIGH	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; SD: standard deviation

[1] 95% CI crosses 1 MID (Default MID for continuous outcomes = 0.50)

Table 13: Evidence profile for comparison 8: Before and after community health worker

Quality assessment							**No of patients**		**Effect**			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Before Community health worker**	**After Community health worker**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Capability and Confidence to meet the needs of the child or young person, measured with Caregiver Confidence - I understand my child's diagnosis (range of scores: 1-4; Better indicated by higher values)												
1 (Costich 2009)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	serious[2]	none	80	80	-	MD 0.30 higher (0.11 to 0.49 higher)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with Caregiver Confidence - I know how to access care for my child (range of scores: 1-4; Better indicated by higher values)												
1 (Costich 2009)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	serious[3]	none	80	80	-	MD 0.10 higher (0.05 lower to 0.25 higher)	VERY LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with Caregiver confidence - I know what medications my child takes and when to give them (range of scores: 1-4; Better indicated by higher values)												
1 (Costich 2009)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	62	62	-	MD 0.00 higher (0.18 lower to 0.18 higher)	LOW	IMPORTANT
Capability and Confidence to meet the needs of the child or young person, measured with Caregiver confidence - I have control over my child’s condition (range of scores: 1-4; Better indicated by higher values)												
1 (Costich 2009)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	33	33	-	MD 0.20 higher (0.12 lower to 0.52 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference; MID: minimal important difference; SD: standard deviation

[1] Very serious risk of bias (confounding and measurement of outcomes) as per ROBINS-I
[2] 95% CI crosses 1 MID (0.5x intervention group at baseline SD=0.35)
[3] 95% CI crosses 1 MID (0.5x intervention group at baseline SD=0.25)
[4] 95% CI crosses 1 MID (0.5x intervention group at baseline SD=0.40)

Table 14: Evidence profile for comparison 9: Before and after digital health technology

Quality assessment							**No of patients**		**Effect**			
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Before Digital health technology**	**After Digital health technology**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Capability and Confidence to meet the needs of the child or young person, measured with the Family Empowerment Scale (FES) (range of scores: 1-5; Better indicated by higher values)												
1 (Harris 2016)	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	19	30	-	MD 0.40 higher (0.33 to 0.47 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference
[1] Very serious risk of bias (confounding and measurement of outcomes) as per ROBINS-I

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

One global search was undertaken – please see Supplement B for details on study selection.

Appendix H – Economic evidence tables

Economic evidence tables for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Table 15: Economic evidence tables for short break and key worker services

Study **Country** **Study type**	**Intervention details**	**Study population** **Study design** **Data sources**	**Costs: description and values** **Outcomes: description and values**	**Results: Cost-effectiveness**	**Comments**
NEF Consulting 2009 UK Cost-offset analysis Conflict of interest: not reported Funding: Action for Children and the Every Disabled Child Matters Campaign	Short break services including overnight breaks, family-based/individual day care/sessional provision, group based services, specialist and non-specialist provision Comparator: NA, i.e. cost-offset analysis, non-comparative	Disabled children and their families Economic modelling Source of effectiveness data: various published sources Source of resource use data: various published sources Source of unit costs: unclear (various published sources)	Costs: residential care, costs to health services due to parents', families' and carers stress (GP visits, sickness absence), costs to schools of educating siblings with behavioural and emotional difficulties Intervention costs have not been considered in the analysis Primary outcome measure: Financial savings associated with reduction in: residential care; parents', families' and carers' stress; educating siblings with behavioural and emotional difficulties The value of annual benefits (current provision of short breaks, n=1,871):	The provision of short break service results in annual financial benefits of £19,500 per disabled child. However, this does not include the costs associated with providing the short break service. Sensitivity analyses: none undertaken	Perspective: public sector including health, social care and education Currency: UK£ Cost year: likely 2008 Time horizon: 1 year Discounting: NA Applicability: partially applicable Quality: potentially serious limitations

Study Country Study type	Intervention details	Study population Study design Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
			Residential care placements: £28,351,693 Health service (parents', families' and carers' stress): £2,446,069 Health service (sickness and absence): £1,252,054 Schools (educating siblings with behavioural and emotional difficulties): £4,487,757 The value of annual benefits (optimal provision of short breaks, n=8,911 disabled children): Residential care placements: £135,008,061 Health service (parents', families' and carers' stress): £11,647,947 Health service (sickness and absence): £5,962,161 Schools (educating siblings with behavioural and emotional difficulties): £21,370,271		
Copps 2007 UK Cost-offset analysis	Short break service that included a number of categories such as family based shared care, residential care, sitting services and befriending	Severely disabled children (workable definition as those eligible for the higher rate for the Care Component of the	Costs: intervention costs for short breaks (carer overheads, carer time) and key worker (management, administration, overheads and travel); lost earnings, sick days, GP visits, school	Short break service and key worker service results in the financial benefits of (£50,847) and	Perspective: public sector (health, social care, and education) plus indirect costs Currency: UK£

Study Country Study type	Intervention details	Study population Study design Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
Conflict of interest: not reported. Funding: The True Colours Trust.	Key worker service, named individuals who act as a single point of contact with multiple services Comparator: NA, i.e. cost-offset analysis, non-comparative	Disability Living Allowance) Economic modelling Source of effectiveness data: various published studies and assumptions Source of resource use data: various published sources including academic studies, government statistics, charity surveys and local authority evaluations Source of unit costs: unclear (various published studies)	costs for siblings with emotional, behavioural or social disorder (EBSD); residential care; foster care; family breakdown Mean cost of short break service per child over 15 years: £81,584 Mean cost of key worker service per child over 15 years: £25,023 Financial benefits of short break service per child over 15 years: Conservative estimate: £30,737 Optimistic estimate: £44,494 Conservative (optimistic) estimate assumes that: 40% (60%) of primary carers that do not work return to work part-time; 60% (80%) of extra sick days taken by parents are prevented; 60% (80%) of GP appointments made by parents are prevented;	(£8,042) over 15 years, respectively Sensitivity analyses: Varying the success of services (i.e. reducing stress among families) from 100-20% the financial benefits for short break service per participant over 15 years range from (£12,803) to (£67,828) and for key worker service £43,758 to (£11,267)	Cost year: 2005/2006 prices Time horizon: 15 years Discounting: 3% Applicability: Partially applicable Quality: Potentially serious limitations

Study Country Study type	Intervention details	Study population Study design Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
			20% (40%) of siblings that would otherwise develop ESBD do not; 60% (80%) of children that would have gone into residential care do not; 20% (40%) of families that would otherwise separate do not. Financial benefits of key worker services per child over 15 years: Conservative estimate: £16,981 Optimistic estimate: £30,737 Conservative (optimistic) estimate assumes that: 20% (40%) of primary carers that do not work return to work part-time; 40% (60%) of extra sick days taken by parents are prevented; 40% (60%) of GP appointments made parents are prevented; 0% (20%) of siblings that would otherwise develop ESBD do not;		

Study Country Study type	Intervention details	Study population Study design Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
			40% (60%) of children that would have gone into residential care do not; 0% (20%) of families that would otherwise separate do not.		

1 *Abbreviations: EBSD: Behavioural or social disorder; GP: General practitioner; NA: not applicable; PSA: Probabilistic sensitivity analysis*

Appendix I – Economic model

Economic model for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

No economic analysis was conducted for this review question.

Appendix J – Excluded studies

Excluded studies for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Effectiveness studies

Table 16: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Family to Family Network extends support to families raising children with a disability, Prairie Rose, 70, 19-19, 2001	Full text unavailable
A Collection of Early Intervention Articles: Family-Centered Service Delivery, Play of Children with Disabilities, Assistive Technology for Young Children. Birth through Two. Let's Play! Project, 1-264, 2000	Study design: A collection of articles, all published pre 2000
Developing a new service model that supports the health and wellbeing of children with a disability and their families: what do parents want?, Developmental Medicine & Child Neurology, 58, 87-88, 2016	Publication type: Conference abstract
aMAZE : support for parents of children with special needs, Community Health UK Action, 5, 2004	Publication type: Review article
Abbott, D., Watson, D., Townsley, R., The proof of the pudding: What difference does multi-agency working make to families with disabled children with complex health care needs?, CHILD AND FAMILY SOCIAL WORK, 10, 229-238, 2005	Study design: Qualitative
Abbott, David, Agencies united, Community Care, 2004	Publication type: Review article
Acar, Cimen, Tekin-Iftar, Elif, Yikmis, Ahmet, Effects of Mother-Delivered Social Stories and Video Modeling in Teaching Social Skills to Children With Autism Spectrum Disorders, The Journal of Special Education, 50, 215-226, 2017	Outcomes: No relevant outcomes reported
Acheson-Silver, M. J., Brandt, K., The development and implementation of a multidisciplinary perinatal/neonatal palliative care program, Pediatrics, 144, 2019	Publication type: Conference abstract
Adams, Richard C., Tapia, Carl, Council on children with, disabilities, Murphy Na, Norwood K. W. Jr Adams R. C. Burke R. T. Friedman S. L. Houtrow A. J. Kalichman M. A. Kuo D. Z. Levy S. E. Turchi R. M. Wiley S. E. Bridgemohan C. Peacock G. Strickland B. Wells N. Wiznitzer M. Mucha S., Early intervention, IDEA Part C services, and the medical home: collaboration for best practice and best outcomes, Pediatrics, 132, e1073-88, 2013	Publication type: Overview of model and recommendations for practice. No effectiveness data

Study	Reason for Exclusion
Aitken, M. E., Korehbandi, P., Parnell, D., Parker, J. G., Stefans, V., Tompkins, E., Schulz, E. G., Experiences from the development of a comprehensive family support program for pediatric trauma and rehabilitation patients, Archives of Physical Medicine and Rehabilitation, 86, 175-179, 2005	Publication type: Overview of programme development and implementation. No data on effectiveness
An, Mihee, Effects of a Collaborative Intervention Process for Children with Disabilities on Parent-Therapist Interaction, Parent Empowerment, and Child Performance, Effects of a Collaborative Intervention Process for Children with Disabilities on Parent-Therapist Interaction, Parent Empowerment & Child Performance, 1-1, 2016	Outcomes: Relevant information not reported in sufficient detail for analysis
Arango, Polly, Family-centered care, Academic Pediatrics, 11, 97-9, 2011	Publication type: Commentary
Ashori, Mohammad, Norouzi, Ghasem, Jalil-Abkenar, Seyyedeh Somayyeh, James, Neil, The effect of positive parenting program on mental health in mothers of children with intellectual disability, Journal of Intellectual Disabilities, 23, 385-396, 2019	Non-OECD country: Iran
Baker, T., Haines, S., Yost, J., DiClaudio, S., Braun, C., Holt, S., The role of family-centered therapy when used with physical or occupational therapy in children with congenital or acquired disorders, Physical Therapy Reviews, 17, 29-36, 2012	Outcomes: No relevant outcomes reported. Checked for any relevant primary studies
Bastida-Pozuelo, M. F., Sanchez-Ortuno, M. M., Meltzer, L. J., Nurse-led brief sleep education intervention aimed at parents of school-aged children with neurodevelopmental and mental health disorders: Results from a pilot study, Journal for specialists in pediatric nursing : JSPN, 23, e12228, 2018	Outcomes: No relevant outcomes reported
Baum, L. S., Internet parent support groups for primary caregivers of a child with special health care needs, Pediatric nursing, 30, 381-401, 2004	Study design: Survey with no comparative data
Bearss, Karen, Johnson, Cynthia, Smith, Tristram, Lecavalier, Luc, Swiezy, Naomi, Aman, Michael, McAdam, David B., Butter, Eric, Stillitano, Charmaine, Minshawi, Noha, Sukhodolsky, Denis G., Mruzek, Daniel W., Turner, Kylan, Neal, Tiffany, Hallett, Victoria, Mulick, James A., Green, Bryson, Handen, Benjamin, Deng, Yanhong, Dziura, James, Effect of parent training vs parent education on behavioral problems in children with autism spectrum disorder: a randomized clinical trial, JAMA: Journal of the American Medical Association, 313, 1524-1533, 2015	Outcomes: No relevant outcomes reported
Bekhet, A. K., Online Positive Thinking Training Intervention for Caregivers of Individuals with ASD: Necessity, Acceptability and Feasibility,	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
Issues in Mental Health Nursing, 38, 443-448, 2017	
Bendixen, R. M., Elder, J. H., Donaldson, S., Kairalla, J. A., Valcante, G., Ferdig, R. E., Effects of a father-based in-home intervention on perceived stress and family dynamics in parents of children with autism, American Journal of Occupational Therapy, 65, 679-687, 2011	Outcomes: No relevant outcomes reported
Beresford Bryony, et al.,, Managing behaviour and sleep problems in disabled children: an investigation into the effectiveness and costs of parent-training interventions: summary report, 39p., 2010	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Blacher, J., Baker, B. L., 'They can't always get what they want': Service delivery and well-being in Latina mothers of young adults with intellectual disability, Journal of Intellectual Disability Research, 48, 368, 2004	Publication type: Conference abstract
Bloch, Judith S., The Home/School Collaborative Model, Children and Schools, 30, 189-191, 2008	Publication type: Model overview. No effectiveness data
Bourke-Taylor, Helen M., Jane, Fiona M., Mothersâ ™ Experiences of a Womenâ ™s Health and Empowerment Program for Mothers of a Child with a Disability, Journal of Autism and Developmental Disorders, 48, 2174-2186, 2018	Study design: Qualitative
Bowen, Keith, The Children's National Service Framework, Llais, 3-5, 2005	Full text unavailable
Brian, Jessica, Bernardi, Kate, Dowds, Erin, Easterbrook, Rachel, MacWilliam, Stacey, Bryson, Susan, Feasibility of Training Early Childhood Educators in a Community Child Care Setting Using a Caregiver-Mediated Intervention for Toddlers with Autism Spectrum Disorder, Journal of Education and Training Studies, 5, 93-102, 2017	Intervention and outcomes: Change in knowledge and skills following training of early childhood educators. Intervention does not aim to increase involvement of families
Bristow, Sally, Jackson, Debra, Shields, Linda, Usher, Kim, The rural mother's experience of caring for a child with a chronic health condition: An integrative review, Journal of clinical nursing, 27, 2558-2568, 2018	Study design: Review of qualitative evidence
Buelow, J. M., Johnson, C. S., Dunn, D. W., Perkins, S. M., Satisfaction with "creating avenues for parent partnership;" an intervention for parent's of children with epilepsy, Epilepsia, 50, 4, 2009	Publication type: Conference abstract
Buelow, Janice M., Austin, Austin Austin Balcazar Buelow Buelow Carlton-Ford Dunst Dyson Feldman Ford-Gilboe Glueckhauf Hastings Hoare Hoare Itzhaky Lewis Ozer Patton Pelchat Rutter Sabaz Shore Singer Singh Steffenburg, An intervention for parents of children with epilepsy and significant learning problems: Lessons learned from a feasibility	Publication type and outcomes: Feasibility study with no effectiveness data

Study	Reason for Exclusion
study, Journal of the American Psychiatric Nurses Association, 13, 146-152, 2007	
Buono, Serafino, Citta, Santina, Bennett, Buono Manchanda, Tele-assistance in intellectual disability, Journal of Telemedicine and Telecare, 13, 241-245, 2007	Outcomes: No relevant outcomes reported
Burke, M. M., Lee, C. E., Rios, K., A pilot evaluation of an advocacy programme on knowledge, empowerment, family-school partnership and parent well-being, Journal of Intellectual Disability Research, 63, 969-980, 2019	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Burton-Smith, R., McVilly, K. R., Yazbeck, M., Parmenter, T. R., Tsutsui, T., Service and support needs of Australian carers supporting a family member with disability at home, Journal of Intellectual & Developmental Disability, 34, 239-247, 2009	Study design: Mixed methods self reported survey. No comparative data
Butz, A. M., Pulsifer, M., Marano, N., Belcher, H., Lears, M. K., Royall, R., Effectiveness of a home intervention for perceived child behavioral problems and parenting stress in children with in utero drug exposure, Archives of Pediatrics and Adolescent Medicine, 155, 1029-1037, 2001	Population: Unlikely to have severe complex needs, only 23% had clinically significant emotional/behavioural problems; other needs not reported
Calculator, S. N., Description and evaluation of a home-based, parent-administered program for teaching enhanced natural gestures to individuals with angelman syndrome, American Journal of Speech-Language Pathology, 25, 1-13, 2016	Outcomes: No relevant reported data for extraction
Caples, M., Sweeney, J., Quality of life: A survey of parents of children/adults with an intellectual disability who are availing of respite care, British Journal of Learning Disabilities, 39, 64-72, 2011	Study design: Qualitative
Cardon, Teresa A., Ayres, Bandura Bellini Buggey Cardon Cardon Cardon Carpenter Carpenter Charlop Charlop-Christy Cihak Corbett Corbett D'Ateno Dawson Dawson Dowrick Dunham Gast Ingersoll Ingersoll Ingersoll Ingersoll Koegel Kratochwill Kromrey Libby Lord Lord Lord Lovaas Lovaas Nally Nikopoulos Palechka Perry Reagon Rellini Rogers Rogers Rosenberg Schopler Sennet Shane Sparrow Stone Taylor Tereshko Yoder Zimmerman, Teaching caregivers to implement video modeling imitation training via iPad for their children with autism, Research in Autism Spectrum Disorders, 6, 1389-1400, 2012	Outcomes: No relevant outcomes reported
Cavkaytar, A., Pollard, E., Effectiveness of Parent and Therapist Collaboration Program (PTCP) for Teaching Self-Care and Domestic Skills to Individuals with Autism, Education and Training in Developmental Disabilities, 44, 381-395, 2009	Outcomes: No relevant outcomes reported
Chadwick, Oliver, MomÄ iloviÄ‡, NataÅ¡a, Rossiter, Rowena, Stumbles, Elise, Taylor, Eric, A randomized trial of brief individual versus	Outcomes: Insufficient presentation of results for extraction

Study	Reason for Exclusion
group parent training for behaviour problems in children with severe learning disabilities, Behavioural and cognitive psychotherapy, 29, 151-167, 2001	
Challenging Behaviour, Foundation, Paving the way: how to develop effective local services for children with learning disabilities whose behaviours challenge, 23, 2015	Study design: Resource guide exampling different elements of positive behavioural support
Chan, P., Chow, V., Fung, C., Yuen, C. K., Leung, K., A three-year review of parent management training programme for attention-deficit hyperactivity disorder children, East Asian Archives of Psychiatry, 20, 42, 2010	Publication type: Conference abstract
Chandran, H., Jayanthi, K., Prabavathy, S., Renuka, K., Bhargavan, R., Effectiveness of video assisted teaching on knowledge, attitude and practice among primary caregivers of children with Autism Spectrum Disorder, Advances in Autism, 5, 231-242, 2019	Non-OECD county: India
Ciccone, Natalie, Hennessey, Neville, Stokes, Stephanie F., Community-based early intervention for language delay: a preliminary investigation, International Journal of Language & Communication Disorders, 47, 467-70, 2012	Population: Parents of children with delayed language development
Coates, J., Taylor, J. A., Sayal, K., Parenting interventions for ADHD: a systematic literature review and meta-analysis, Journal of Attention Disorders, epub, 2014	Study design: Systematic review including non-relevant primary studies. Relevant primary studies retrieved for inclusion.
Corcoran, J., Dattalo, P., Parent involvement in treatment for ADHD: a meta-analysis of the published studies, Research on Social Work Practice, 16, 561-570, 2006	Outcomes: No relevant outcomes reported
Dang, K., Bent, S., Lawton, B., Warren, T., Widjaja, F., McDonald, M. G., Breard, M., O'Keefe, W., Hendren, R. L., Integrating autism care through a school-based intervention model: A pilot study, Journal of Clinical Medicine, 6 (10) (no pagination), 2017	Interventions: Interventions are not targeted at involving or supporting the families and/or carers
D'Arcy, Fiona, Flynn, Jacinta, McCarthy, Yvonne, O'Connor, Catherine, Tierney, Edel, Sibshops: an evaluation of an interagency model, Journal of intellectual disabilities : JOID, 9, 43-57, 2005	Outcomes: No relevant outcomes reported
de Bruin, Esther I., Blom, René, Smit, Franka M. A., van Steensel, Francisca J. A., Bögels, Susan M., MYmind: Mindfulness training for Youngsters with autism spectrum disorders and their parents, Autism: The International Journal of Research & Practice, 19, 906-914, 2015	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
DeHoff, B. A., Staten, L. K., Rodgers, R. C., Denne, S. C., The Role of Online Social Support in Supporting and Educating Parents of Young Children With Special Health Care Needs in the United States: A Scoping Review, Journal of Medical Internet ResearchJ Med Internet Res, 18, 2016	Study design: Scoping review. No relevant data for extraction

Study	Reason for Exclusion
Dempsey, Ian, Keen, Deb, A Review of Processes and Outcomes in Family-Centered Services for Children with a Disability, Topics in Early Childhood Special Education, 28, 42-52, 2008	Publication type: Narrative review on family centred practice
Dickinson, Helen, et, al, Whose outcomes are they anyway? Report of the pilot evaluation of a joint service, Journal of Integrated Care, 17, 37-44, 2009	Outcomes: No relevant outcomes reported
Dikow, Nicola, Moog, Ute, Karch, Stephanie, Sander, Anja, Kilian, Samuel, Blank, Rainer, Reuner, Gitta, What do parents expect from a genetic diagnosis of their child with intellectual disability?, Journal of Applied Research in Intellectual Disabilities, 32, 1129-1137, 2019	Study design and intervention: Survey with no interventions involving or supporting families and/or carers.
Dunst, Carl J., Trivette, Carol M., Hamby, Deborah W., Meta-analysis of family-centered helpgiving practices research, Mental retardation and developmental disabilities research reviews, 13, 370-8, 2007	Study design: Meta analysis with no relevant data for extraction. Checked for any relevant primary studies
Duvdevany, I., Abboud, S., Stress, social support and well-being of Arab mothers of children with intellectual disability who are served by welfare services in northern Israel, Journal of Intellectual Disability Research, 47, 264-272, 2003	Intervention: Interventions are not targeted at involving or supporting the families and/or carers
Edelstein, H., Schippke, J., Sheffe, S., Kingsnorth, S., Children with medical complexity: a scoping review of interventions to support caregiver stress, Child: Care, Health & DevelopmentChild Care Health Dev, 43, 323-333, 2017	Outcomes: Scoping review with no relevant data for extraction. Checked for any relevant primary studies
Ely, Mindy S., Gullifor, Kateri, Hollinshead, Tara, Family-Centered Early Intervention Visual Impairment Services through Matrix Session Planning, Journal of Visual Impairment & Blindness, 111, 169-174, 2017	Publication type: Narrative review
Evans, Steven W., Axelrod, Jennifer, Langberg, Joshua M., Adelman, Barkley Barkley Barkley Barkley Barkley Cohen Conners DuPaul Dupper Ervin Evans Evans Evans Evans Evans Evans Jacobson Jensen Mannuzza Pelham Pelham Pelham Pelham Reynolds Robin Rones Safer Safer Shaffer Smith Smith Smith Stewart Wechsler Weiss Weist, Efficacy of a School-Based Treatment Program for Middle School Youth With ADHD: Pilot Data, Special Issue: Expanded School Mental Health: Exploring Program Details and Developing the Research Base, 28, 528-547, 2004	Outcomes: No relevant outcomes reported
Fareo, Dorcas Oluremi, Counselling Intervention and Support Programmes for Families of Children with Special Educational Needs, Journal of Education and Practice, 6, 103-109, 2015	Publication type: Narrative review
Fields, Scott A., Psychoeducational groups for youth attention-deficit hyperactivity disorder: a	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
family medicine pilot project, Mental Health in Family Medicine, 8, 2011	
Foundation For People With Learning, Disabilities, Recognising fathers: ideas for practitioners in education, health, social care and family support settings to involve fathers in meetings and appointments about their children with learning disabilities, 3p., 2009	Study design: Survey with no comparative data
Franck, L. S., O'Brien, K., The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care, Birth Defects Research, 111, 1044-1059, 2019	Publication type and population: Narrative review on family integrated care for low birthweight and preterm infants.
Gallego, G., Dew, A., Lincoln, M., Bundy, A., Bulkeley, K., Brentnall, J., Veitch, C., Carers' preferences for the delivery of therapy services for people with disability in rural Australia: evidence from a discrete choice experiment, Journal of Intellectual Disability Research, 62, 371-381, 2018	Study design and outcomes: Survey and qualitative interviews with no relevant outcomes reported
Gardiner, E., Iarocci, G., Examining Family Quality of Life Within the Context of a Participant-Directed ASD Funding Program in British Columbia, Canada, Journal of Policy and Practice in Intellectual Disabilities, 15, 110-123, 2018	Study design: Survey with no comparative data
Gauntlett-Gilbert, J., Clinch, J., Connell, H., Rogers, V., Increasing parent resilience in chronic paediatric conditions: The case of chronic pain, Archives of Disease in Childhood, 100, A121, 2015	Publication type: Conference abstract
Gentles, S. J., Lokker, C., McKibbon, K. A., Health information technology to facilitate communication involving health care providers, caregivers, and pediatric patients: a scoping review, Journal of Medical Internet Research, 12, e22, 2010	Population: Scoping review of paediatric patients with health conditions, including asthma, diabetes, special needs and mental health etc.
Gettings, Sheryl, Franco, Fabia, Santosh, Paramala J., Facilitating support groups for siblings of children with neurodevelopmental disorders using audio-conferencing: a longitudinal feasibility study, Child and adolescent psychiatry and mental health, 9, 8, 2015	Study design: Qualitative
Giarelli, E., Souders, M., Pinto-Martin, J., Bloch, J., Levy, S. E., Intervention pilot for parents of children with autistic spectrum disorder, Pediatric nursing, 31, 389-399, 2005	Outcomes: No relevant outcomes reported
Gobrial, Ereny, Raghavan, Raghu, Calm child programme: Parental programme for anxiety in children and young people with autism spectrum disorder and intellectual disabilities, Journal of Intellectual Disabilities, 22, 315-327, 2018	Outcomes: No relevant outcomes reported
Gomez, D., Bridges, A. J., Andrews, A. R., Cavell, T. A., Pastrana, F. A., Gregus, S. J., Ojeda, C. A., Delivering parent management training in an integrated primary care setting:	Population: Youth with externalizing behaviour issues

Study	Reason for Exclusion
Description and preliminary outcome data, Cognitive and Behavioral Practice, 21, 296-309, 2014	
Gormez, V., Forbes, F., Self-image profile in children and adolescents with attention deficit hyperactivity disorder and the quality of life of their parents, Klinik Psikofarmakoloji Bulteni, 25, S84, 2015	Publication type: Conference abstract
Gouin, Jean-Philippe, Estrela, Chelsea, Desmarais, Kim, Barker, Erin T., Aggarwal, Allik Bailey Bailey Barker Barker Baron Bernberg Bower Russa Boyd Bronfrenbrenner Cadman Christian Costanzo Coussons-Read Cowen Dantzer Dykens Dykens Ershler Feinberg Fillenbaum Fonareva Ford Franceschi Friedman Friedman Gallagher Gallagher Glaser Glaser Gouin Gouin Gouin Hafner Harper Hayes Holt-Lunstad House Idler Karst Khanna Kiecolt-Glaser Kiecolt-Glaser Kiecolt-Glaser Kiecolt-Glaser Kiecolt-Glaser Kiecolt-Glaser Kiecolt-Glaser Lach Lekander Libby Lindo Lord Loucks Lovell Lovell Lutgendorf Lutgendorf Maggio Marshall Mavranezouli McDade McDade McEwen Mezuk Michaud Miller Miodrag O'Connor Pearson Pennebaker Pickard Pottie Ridker Rimmerman Rohleder Sargent-Cox Sbarra Seltzer Seltzer Singer Singh Smith Smith Spruijt-Metz Steptoe Tehee Tellegen Unden Vedhara von Kanel von Kanel Warfield Weijerman White Zhang Zimet, The impact of formal and informal support on health in the context of caregiving stress, Special Issue: Biosocial Models of Family Science, 65, 191-206, 2016	Outcomes: No relevant outcomes reported
Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., Le Couteur, A., Leadbitter, K., Hudry, K., Byford, S., Barrett, B., Temple, K., Macdonald, W., Pickles, A., Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial, The Lancet, 375, 2152-2160, 2010	Outcomes: No relevant outcomes reported
Gulmans, Jitske, Vollenbroek-Hutten, M. M., Visser, J. J., A web-based communication system for integrated care in cerebral palsy : design features, technical feasibility and usability, Journal of Telemedicine and Telecare, 16, 389-393, 2010	Study design: Qualitative
Haack, Lauren M., Villodas, Miguel, McBurnett, Keith, Hinshaw, Stephen, Pfiffner, Linda J., Parenting as a Mechanism of Change in Psychosocial Treatment for Youth with ADHD, Predominantly Inattentive Presentation, Journal of Abnormal Child Psychology, 45, 841-855, 2017	Comparison: Parenting component of intervention is the same in both arms
Halpin, Julia, Pitt, Sally, Dodd, Emma, EarlyBird in South Staffordshire: reflections on an innovative model of interagency working to	Publication type: Narrative review

Study	Reason for Exclusion
deliver an intervention for families of preschool children with autistic spectrum disorder, BRITISH JOURNAL OF SPECIAL EDUCATION, 2011	
Hamad, C. D., Serna, R. W., Morrison, L., Fleming, R., Extending the reach of early intervention training for practitioners: A preliminary investigation of an online curriculum for teaching behavioral intervention knowledge in autism to families and service providers, Infants and Young Children, 23, 195-208, 2010	Interventions: Interventions are not targeted at involving or supporting the families and/or carers
Hamilton, Leslie J., Lerner, Carlos F., Presson, Angela P., Klitzner, Thomas S., Effects of a medical home program for children with special health care needs on parental perceptions of care in an ethnically diverse patient population, Maternal and Child Health Journal, 17, 463-9, 2013	Outcomes: No relevant outcomes reported
Hand, Ailish, Raghallaigh, Ciara Ni, Cuppage, Jennifer, Coyle, Sadhbh, Sharry, John, A controlled clinical evaluation of the Parents Plus Children's Programme for parents of children aged 6-12 with mild intellectual disability in a school setting, Clinical Child Psychology and Psychiatry, 18, 536-555, 2013	Outcomes: No relevant outcomes reported for extraction.
Hartling, L., Milne, A., Tjosvold, L., Wrightson, D., Gallivan, J., Newton, A. S., A systematic review of interventions to support siblings of children with chronic illness or disability, Journal of Paediatrics and Child Health, 50, E26-E38, 2014	Population: Systematic review of children with chronic illness or disability including cancer, diabetes, etc. Checked for any relevant primary studies
Hassan, Mahfuz, Simpson, Andrea, Danaher, Katey, Haesen, James, Makela, Tanya, Thomson, Kendra, An Evaluation of Behavioral Skills Training for Teaching Caregivers How to Support Social Skill Development in Their Child with Autism Spectrum Disorder, Journal of Autism and Developmental Disorders, 48, 1957-1970, 2018	Study design and outcomes: Evaluation with insufficient presentation of results for extraction
Hautmann, C., Greimel, L., Imort, S., Katzmann, J., Pinior, J., Scholz, K., Dopfner, M., Efficacy of guided self-help for parents of children with externalizing behaviour problems-a randomized controlled trial with an active control group, European Child and Adolescent Psychiatry, 22, S173, 2013	Publication type: Conference abstract
Hayashi, Reiko, Frost, Caren J., Being, belonging, and becoming: examining rehabilitation service delivery to children with disabilities and their families, Journal of Social Work in Disability and Rehabilitation, 4, 39-56, 2005	Outcomes: No relevant outcomes reported
Hernandez-Ruiz, Eugenia, Aksan, Allgood Baron-Cohen Benavides Braddock Bradshaw Chiang Constantino Cooper Davis Dawson Dawson Estes Estes Estevanovic Geretsegger Gilmore Gordon Juhnke Kalas Kessler Kim Kirby Koegel Lequia Lord Oono Ozonoff Pasiali Paul	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs

Study	Reason for Exclusion
Powell Prochaska Rogers Rogers Rogers Rogers Rogers Schwartzberg Strauss Thompson Thompson Vivanti Vivanti Walworth Williams Zwaigenbaum, Music therapy and Early Start Denver Model to teach social communication strategies to parents of preschoolers with ASD: A feasibility study, Music Therapy Perspectives, 36, 26-39, 2018	
Hodgetts, S., McConnell, D., Zwaigenbaum, L., Nicholas, D., The impact of autism services on mothers' psychological wellbeing, Child: Care, Health and Development, 43, 18-30, 2017	Study design and outcomes: Survey with no relevant outcomes for extraction
Hodgetts, Sandra, Nicholas, David, Zwaigenbaum, Lonnie, McConnell, David, Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors, Social science & medicine (1982), 96, 138-46, 2013	Study design and outcomes: Mostly qualitative evidence and limited quantitative evidence does not report any relevant outcomes
Hodgetts, Sandra, Zwaigenbaum, Lonnie, Nicholas, David, Profile and Predictors of Service Needs for Families of Children with Autism Spectrum Disorders, Autism: The International Journal of Research and Practice, 19, 673-683, 2015	Intervention: No intervention targeted at involving or supporting the families and/or carers
Hodonj, Andrej, SCHOOL-PARENT COLLABORATIONS IN INDIGENOUS COMMUNITIES: PROVIDING SERVICES FOR CHILDREN WITH DISABILITIES, Drustvena Istrazivanja, 24, 310-313, 2015	Language: Review in Croatian
Hogan, Dennis P., Park, Jennifer M., Goldscheider, Frances K., The Health Consequences of a Disabled Sibling for School-Age Children, Research in Social Science and Disability, 3, 185-205, 2003	Study design: Survey with no relevant intervention
Hong, E. R., Neely, L., Gerow, S., Gann, C., The effect of caregiver-delivered social-communication interventions on skill generalization and maintenance in ASD, Research in Developmental Disabilities, 74, 57-71, 2018	Outcomes: No relevant outcomes reported
Hopgood, Miles, Shaw, John, Development of integrated children's services in Exeter: a case study, MCC Building Knowledge for Integrated Care, 10, 29-34, 2002	Study design: Narrative review of a case study
Hotham, S., Hamilton-West, K. E., Hutton, E., King, A., Abbott, N., A study into the effectiveness of a postural care training programme aimed at improving knowledge, understanding and confidence in parents and school staff, Child Care Health and Development, 43, 743-751, 2017	Interventions: Interventions are not targeted at involving or supporting the families and/or carers. Educational professionals including teachers and teaching assistants were also targeted and made up the majority of participants (73%)
Hu, Jung, Lin, Jin-Ding, Yen, Chia-Feng, Loh, Ching-Hui, Hsu, Shang-Wei, Lin, Lan-Ping, Wu, Sheng-Ru, Effectiveness of a stress-relief initiative for primary caregivers of adolescents with intellectual disability, Journal of Intellectual & Developmental Disability, 35, 29-35, 2010	Non OECD Country: Taiwan

Study	Reason for Exclusion
Hudson, A. M., Matthews, J. M., Gavidia-Payne, S. T., Cameron, C. A., Mildon, R. L., Radler, G. A., Nankervis, K. L., Evaluation of an intervention system for parents of children with intellectual disability and challenging behaviour, Journal of intellectual disability research : JIDR, 47, 238-49, 2003	Outcomes: Insufficient presentation of results for extraction
Hueckel, R. M., Mericle, J. M., Frush, K., Martin, P. L., Champagne, M. T., Implementation of condition help: Family teaching and evaluation of family understanding, Journal of Nursing Care Quality, 27, 176-181, 2012	Population: Families of hospitalised children requiring a rapid response team (patients with acute care needs including intensive care, pediatric bone marrow transplant and ambulatory care)
Huskens, Bibi, Palmen, Annemiek, Van der Werff, Marije, Lourens, Tino, Barakova, Emilia, Improving Collaborative Play between Children with Autism Spectrum Disorders and Their Siblings: The Effectiveness of a Robot-Mediated Intervention Based on Lego® Therapy, Journal of Autism and Developmental Disorders, 45, 3746-3755, 2015	Outcomes: No relevant outcomes reported
Ingersoll, Brooke PhD, Shannon, Katherine PhD, Berger, Natalie M. A., Pickard, Katherine M. A., Holtz, Bree PhD, Self-Directed Telehealth Parent-Mediated Intervention for Children With Autism Spectrum Disorder: Examination of the Potential Reach and Utilization in Community Settings, Journal of Medical Internet Research, 19, 2017	Outcomes: No relevant outcomes reported
Ingersoll, Brooke R., Wainer, Allison L., Pilot study of a school-based parent training program for preschoolers with ASD, Autism : the international journal of research and practice, 17, 434-48, 2013	Population: Children with an education diagnosis of ASD including those without official evaluation who were receiving services for early childhood developmental delay, speech-language impairment or health impairment.
Jacko, Virginia A., Mayros, Roxann, Brady-Simmons, Carol, Chica, Isabel, Moore, J. Elton, Anderson, Crocker Denham Ihsen Madray Martlew Skellenger Troster, Blind Babies Play Program: A model for affordable, sustainable early childhood literacy intervention through play and socialization, Journal of Visual Impairment & Blindness, 107, 238-242, 2013	Publication type: Review article
Jackson, Alun C., Liang, Rachel P. T., Frydenberg, Erica, Higgins, Rosemary O., Murphy, Barbara M., Parent education programmes for special health care needs children: a systematic review, Journal of clinical nursing, 25, 1528-47, 2016	Population: Systematic review of families with children with special health care needs, such as severe congenital heart disease, diabetes etc.
Jansen, S. L. G., van der Putten, A. A. J., Vlaskamp, C., What parents find important in the support of a child with profound intellectual and multiple disabilities, Child: Care, Health and Development, 39, 432-41, 2013	Study design: Exploratory study with no relevant data reported
Jennings, S., Khanlou, N., Su, C., Public health policy and social support for immigrant mothers raising disabled children in Canada, Disability and Society, 29, 1645-1657, 2014	Publication type: Narrative review

Study	Reason for Exclusion
Join-Lambert, Hélène, Parental Involvement and Multi-Agency Support Services for High-Need Families in France, Social Policy and Society, 15, 317-329, 2016	Study design: Narrative review of qualitative evidence
Kahriman, I., Polat, S., Daar, G., Measurement of level of social support and burnout perceived by mothers with mentally disabled children, Archives of Disease in Childhood, 99, A557, 2014	Publication type: Conference abstract
Kaiser, Ann P., Hancock, Terry B., Nietfeld, Jennifer P., The effects of parent-implemented Enhanced Milieu Teaching on the social communication of children who have autism, Early Education and Development, 11, 423-446, 2000	Outcomes: No relevant outcomes reported for extraction
Kaiser, Ann P., Roberts, Megan Y., Parent-implemented enhanced milieu teaching with preschool children who have intellectual disabilities, Journal of speech, language, and hearing research : JSLHR, 56, 295-309, 2013	Outcomes: No relevant outcomes
Kamiyama, T., Ueno, A., Noro, F., Parenting interventions for parents of children with developmental disabilities: a review and future directions, Japanese Journal of Special Education, 49, 361-375, 2011	Language: Japanese
Keenan Mickey, et al.,, Meeting the needs of families living with children diagnosed with autism spectrum disorder, 180p., bibliog., 2007	Study design: Survey with no comparative data
Kelly, P., Family support for children with ADHD. An essential part of daily management, Advance for nurse practitioners, 11, 53-56, 2003	Full text unavailable
Kendall-Raynor, Petra, It's a family affair, Nursing Standard, 22, 2007	Publication type: Review
Kendle, J., Campanale, R., A pediatric learning experience: respite care for families with children with special needs, Nurse educator, 26, 95-98, 2001	Publication type: Narrative review
Khanlou, Nazilla, Mustafa, Nida, Vazquez, Luz Maria, Haque, Nasim, Yoshida, Karen, Stressors and Barriers to Services for Immigrant Fathers Raising Children with Developmental Disabilities, International journal of mental health and addiction, 13, 659-674, 2015	Publication type: Narrative review of qualitative evidence
Kleve, L., Crimlisk, S., Shoebridge, P., Greenwood, R., Baker, B., Mead, B., Is the Incredible Years programme effective for children with neuro-developmental disorders and for families with Social Services involvement in the "real world" of community CAMHS?, Clinical child psychology and psychiatry, 16, 253-264, 2011	Outcomes: No relevant outcomes are reported
Knapp, Caprice, Madden, Vanessa, Marcu, Mircea, Sloyer, Phyllis, Shenkman, Elizabeth, Parents' experiences in choosing a health plan for their children with special health care needs,	Study design: Survey with no relevant data reported

Study	Reason for Exclusion
Maternal and child health journal, 15, 217-24, 2011	
Koegel, Robert L., Symon, Jennifer B., Kern Koegel, Lynn, Albin, Bryson Choutka Clark Cohen Connell Dawson Dunlap Dunlap Fombonne Forehand Gething Gething Gillberg Hart Helge Koegel Koegel Koegel Koegel Koegel Koegel Koegel Koegel Koegel Koegel Koegel Koegel Koegel Laski Loschen Lovaas Matson McClannahan McGee Minnes Moes Pierce Prizant Sanders Santelli Schreibman Schreibman Singer Singer Slater Stahmer Stiebel Strain Thorpe Vaughn Watson, Parent education for families of children with autism living in geographically distant areas, Journal of Positive Behavior Interventions, 4, 88-103, 2002	Outcomes: No relevant outcomes reported
Kothari, J., Morgan, S., Multi-agency training programmes for professionals and parents of children with ADHD, Archives of disease in childhood, 1), A97, 2010	Publication type: Conference abstract
Kramer, J., Hwang, I., Helfrich, C., Samuel, P., Carrellas, A., Youth and parent perspectives of a problem solving intervention to increase participation of transition-age youth with developmental disabilities, Developmental Medicine and Child Neurology, 58, 96-97, 2016	Publication type: Conference abstract
Kratochwill, T. R., McDonald, L., Levin, J. R., Scalia, P. A., Coover, G., Families and Schools Together: an experimental study of multi-family support groups for children at risk, Journal of School Psychology, 47, 245â 265, 2009	Population: Not limited to disabled CYP with severe complex needs; less than half were considered at risk based on behavioural problems and only 5 were identified as having serious emotional disturbance
Kratz, Lyn, Uding, Nancy, Trahms, Cristine M., Villareale, Nanci, Kieckhefer, Gail M., Managing childhood chronic illness: parent perspectives and implications for parent-provider relationships, Families, systems & health : the journal of collaborative family healthcare, 27, 303-13, 2009	Study design: Qualitative
Kube, D. A., Bishop, E. A., Roth, J. M., Palmer, F. B., Evaluation of a parent led curriculum in developmental disabilities for pediatric and medicine/pediatric residents, Maternal and Child Health Journal, 17, 1304-1308, 2013	Population: Paediatric and medicine/paediatric residents
LaBarbera, Robin, A Comparison of Teacher and Caregiver Perspectives of Collaboration in the Education of Students with Autism Spectrum Disorders, Teacher Education Quarterly, 44, 35-56, 2017	Study design: Mixed methods web based questionnaire on perspectives of collaborative education
Lang, R., Machalicek, W., Rispoli, M., Regester, A., Training parents to implement communication interventions for children with autism spectrum disorders (ASD): a systematic review, Evidence-Based Communication Assessment and Intervention, 3, 174-190, 2009	Study design: Systematic review with no relevant data for extraction. Checked for any relevant primary studies
Langberg, Joshua M., Vaughn, Aaron J., Williamson, Pamela, Epstein, Jeffery N., Girio-Herrera, Erin, Becker, Stephen P., Abikoff,	Interventions: Interventions are not targeted at involving or supporting the families and/or carers

Study	Reason for Exclusion
Abikoff Anesko Chorpita DuPaul Evans Evans Evans Evans Evans Evans Frazier Froehlich Hatch Hoagwood Langberg Langberg Langberg Langberg Langberg Langberg Langberg Molina Pfiffner Power Shaffer Weisz Weisz Weisz Weisz Wolraich Wolraich Wolraich, Refinement of an organizational skills intervention for adolescents with ADHD for implementation by school mental health providers, School Mental Health: A Multidisciplinary Research and Practice Journal, 3, 143-155, 2011	
Law, E. F., Fisher, E., Fales, J., Noel, M., Eccleston, C., Systematic review and meta-analysis of parent and family-based interventions for children and adolescents with chronic medical conditions, Journal of Pediatric Psychology, 39, 866-886, 2014	Intervention and population: Systematic review of parent and family based psychological therapies for children and adolescents with chronic medical conditions such as asthma, cancer, etc.
Law, J., Plunkett, C., Taylor, J., Gunning, M., Developing policy in the provision of parenting programmes: Integrating a review of reviews with the perspectives of both parents and professionals, Child: Care, Health and Development, 35, 302-312, 2009	Publication type: Review article
Lee, P. C., Niew, W. I., Yang, H. J., Chen, V. C., Lin, K. C., A meta-analysis of behavioral parent training for children with attention deficit hyperactivity disorder, Research in Developmental Disabilities, 33, 2040-2049, 2012	Study design: Meta analysis with no relevant data for extraction. Checked for any relevant primary studies
Leiter, V., Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities, Social Science & Medicine, 58, 837-849, 2004	Study design: Qualitative
Lennox, Nicholas, Ware, Robert, Carrington, Suzanne, O'Callaghan, Michael, Williams, Gail, McPherson, Lyn, Bain, Chris, Ask: a health advocacy program for adolescents with an intellectual disability: a cluster randomised controlled trial, BMC public health, 12, 750, 2012	Outcomes: No relevant outcomes reported
Levitz, B., Employing the parents of children with disabilities as service coordinators for other families: A programme evaluation, Journal of Intellectual Disability Research, 44, 363-364, 2000	Publication type: Abstract only
Liabo Kirstin, et al.,, A review of key worker systems for disabled children and the development of information guides for parents, children and professionals: a report for the Wales Office of Research and Development, 50p., 2001	Full text unavailable
Liabo Kristin, et al.,, A review of key worker systems for children with disabilities and development of information guide for parents, children and professionals: summary, 3p., 2001	Full text unavailable
Looman, Wendy S., Hullsiek, Robyn L., Pryor, Lyndsay, Mathiason, Michelle A., Finkelstein, Stanley M., Adams, Arauz Boudreau Berman Berry Berry Bethell Bramlett Bryant-Lukosius	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
Cady Caicedo Casey Cohen Cohen Collaco Dillman Eiser Farmer Farmer Feudtner Finkelstein Gordon Houtrow Johaningsmeir Klitzner Kuo Kuo Kuo Kuo Looman Looman Looman McKissick Medrano Mosquera Mugno Palfrey Peter Schultz Seid Stein Varni Varni Varni Varni Wood, Health-related quality of life outcomes of a telehealth care coordination intervention for children with medical complexity: A randomized controlled trial, Journal of Pediatric Health Care, 32, 63-75, 2018	
Lundahl, B., Risser, H. J., Lovejoy, M. C., A meta-analysis of parent training: moderators and follow-up effects, Clinical Psychology Review, 26, 86-104, 2006	Study design: Meta analysis with no relevant data for extraction. Checked for any relevant primary studies
Mackey, Sandra, Goddard, Linda D., Promoting the Health of Families of Children with Disabilities: Acceptability and Utility of a Health-Mentoring Project, Diversity in Health and Social Care, 3, 141-149, 2006	Outcomes: No relevant outcomes reported
Magaña, S., Li, H., Miranda, E., Paradiso de Sayu, R., Improving health behaviours of Latina mothers of youths and adults with intellectual and developmental disabilities, Journal of Intellectual Disability Research, 59, 397-410, 2015	Outcomes: No relevant outcomes reported
Malow, B. A., Reynolds, A. M., Weiss, S., Adkins, K., Artibee, K. J., Clemons, T., Frank, K., Goldman, S. E., Katz, T., Loh, A., Parent-based sleep education program for children with autism, Sleep, 35, A371, 2012	Meeting abstract
Mc Nicholas, F., Sharkey, L. M., MacEvilly, D., Begley, M., Group psycho-education and training programme for parents of children with selective mutism, European Child and Adolescent Psychiatry, 20, S16, 2011	Publication type: Conference abstract
McAleese, Aisling, Lavery, Christine, Dyer, Kevin F. W., Baird, Baker-Ericzon Baron-Cohen Boyd Brabender Braun Cullen Cullen Drew Duarte Foxx Francis Hartley Hastings Hastings Heiman Howlin Ingersoll Jones Krantz Leekam Levy Mandell McConachie McConachie McDougle Newschaffer Nicholas Ozonoff Panerai Pillay Rogers Rogers Rutter Schreibman Siegel Simonoff Sofronoff Weiss Wright, Evaluating a psychoeducational, therapeutic group for parents of children with autism spectrum disorder, Child Care in Practice, 20, 162-181, 2014	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
McAllister, Jeanne W., McNally Keehn, Rebecca, Rodgers, Rylin, Mpofu, Philani Brian, Monahan, Patrick O., Lock, Thomas M., Effects of a Care Coordination Intervention with Children with Neurodevelopmental Disabilities and Their Families, Journal of developmental and behavioral pediatrics : JDBP, 39, 471-480, 2018	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
McConachie, H., Diggle, T., Parent implemented early intervention for young children with autism spectrum disorder: a systematic review, Journal of Evaluation in Clinical Practice, 13, 120-129, 2007	Interventions: Interventions are not targeted at involving or supporting the families and/or carers
McConkey, Roy, Truesdale, Maria, Conliffe, Chris, The features of short break residential services valued by families who have children with multiple disabilities, Journal of Social Work, 4, 61-75, 2004	Study design and outcomes: Mixed method study with no relevant outcomes reported
McConnaughy, R. P., Wilson, S. P., InfoAble Portal: developing a disability information portal for a support network for families, Journal of Consumer Health on the Internet, 14, 1-11, 2010	Publication type: Review article
McCullough, K., Simon, S. R., Feeling heard: A support group for siblings of children with developmental disabilities, Social Work with Groups, 34, 320-329, 2011	Publication type: Review article
McDermid, Samantha, et, al, Evaluation of the impact of Action for Children short break services on outcomes for children: final report, 115p., 2011	Outcomes: No relevant outcomes reported for extraction
McDuffie, Andrea, Oakes, Ashley, Machalicek, Wendy, Ma, Monica, Bullard, Lauren, Nelson, Sarah, Abbeduto, Leonard, Early Language Intervention Using Distance Video-Teleconferencing: A Pilot Study of Young Boys With Fragile X Syndrome and Their Mothers, American Journal of Speech-Language Pathology, 25, 46-66, 2016	Population: Boys with Fragile X Syndrome
McNeilly, P., Macdonald, G., Kelly, B., The participation of parents of disabled children and young people in health and social care decisions, Child: care, health and development, 43, 839-846, 2017	Study design: Survey reporting qualitative outcomes
McPherson, K. M., McNaughton, H., Pentland, B., Information needs of families when one member has a severe brain injury, International Journal of Rehabilitation Research, 23, 295-301, 2000	Population: Adults with brain injury
Meadan, H., Ostrosky, M. M., Zaghlawan, H. Y., Yu, S. Y., Promoting the social and communicative behavior of young children with autism spectrum disorders: a review of parent-implemented intervention studies, Topics in Early Childhood Special Education, 29, 90-104, 2009	Study design: Review with no relevant data for extraction. Checked for any relevant primary studies
Meadan, Hedda, Daczewitz, Marcus E., Internet-Based Intervention Training for Parents of Young Children with Disabilities: A Promising Service-Delivery Model, Early Child Development and Care, 185, 155-169, 2015	Intervention: Systematic review examining internet based training compared to home training
Menting, A. T., Orobio de Castro, B., Matthys, W., Effectiveness of the Incredible Years parent training to modify disruptive and prosocial child behavior: a meta-analytic review, Clinical Psychology Review, 33, 901-913, 2013	Outcomes: No relevant outcomes reported for extraction

Study	Reason for Exclusion
Mereoiu, Mariana, Abercrombie, Sara, Murray, Mary M., Angell, Carter Coleman Diliberto Fitzgerald Friend Hammond Hartmann Hess Konrad Kretlow Lo Lynch McNulty Mezirow Mezirow Mezirow Mezirow More More Mueller Patti Pizur-Barnekow Ruble Ryan Shelden Tisdell Tucker Turnbull Van Haren Westling Williams-Diehm, Structured intervention as a tool to shift views of parent-professional partnerships: Impact on attitudes toward the IEP, Exceptionality Education International, 26, 36-52, 2016	Intervention and outcomes: Interventions are not aimed at involving or supporting families and/or carers. No relevant outcomes are reported
Miller, L. C., Perouse de Montclos, M. O., Sorge, F., Special needs adoption in France and USA 2016: How can we best prepare and support families?, Neuropsychiatrie de l'Enfance et de l'Adolescence, 64, 308-316, 2016	Study design: Narrative review
Miller-Kuhaneck, Heather, Watling, Renee, Parental or Teacher Education and Coaching to Support Function and Participation of Children and Youth With Sensory Processing and Sensory Integration Challenges: A Systematic Review, The American journal of occupational therapy : official publication of the American Occupational Therapy Association, 72, 7201190030p1-7201190030p11, 2018	Study design: Systematic review with no relevant data for extraction. Checked for any relevant primary studies
Mirza, M., Krischer, A., Stolley, M., Magana, S., Martin, M., Review of parental activation interventions for parents of children with special health care needs, Child: Care, Health and Development, 44, 401-426, 2018	Population: Children with special health care needs.
Mitchell, Wendy, Mitchell, Wendy, Better for the Break? Short Break Services for Children and Teenagers with Autistic Spectrum Disorders and Their Families, Child and Family Social Work, 9, 125-126, 2004	Publication type: Review article
Moghimi, M., Esmaeilpour, N., Karimi, Z., Zoladl, M., Moghimi, M. A., Effectiveness of resilience teaching via short message service on stress of mothers of educable mentally retarded children, Iranian Journal of Psychiatry and Behavioral Sciences, 12, e59966, 2018	Non-OECD country: Iran
Muldoon, Deirdre, Cosbey, Joanna, A Family-Centered Feeding Intervention to Promote Food Acceptance and Decrease Challenging Behaviors in Children With ASD: Report of Follow-Up Data on a Train-the-Trainer Model Using EAT-UP, American Journal of Speech-Language Pathology, 27, 278-287, 2018	Outcomes: No relevant outcomes reported
Mulligan, Bethany, et, al, Developing outcome measures for a family intensive support service for children presenting with challenging behaviours, British Journal of Learning Disabilities, 43, 161-167, 2015	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Mulqueen, J. M., Bartley, C. A., Bloch, M. H., Meta-analysis: parental interventions for	Interventions: Interventions are not targeted at involving or supporting the families and/or carers

Study	Reason for Exclusion
preschool ADHD, Journal of Attention Disorders, epub, 2013	
Myers, Scott M., Johnson, Chris Plauche, Council on Children With Disabilities, U. S., Afzal, Aman Aman Aman Anderson Arnold Arnold Bailaban-Gil Baranek Birnbrauer Black Bondy Bondy Bosch Bostic Bowers Bregman Brereton Bruinsma Buchsbaum Buitelaar Campbell Canitano Cheng-Shannon Chez Chrisiodulu Cohen Connor Cooley Croen Dawson Dawson DeLong DeMyer Dosreis Eikeseth Eldevik Erickson Fankhauser Fombonne Fombonne Giannotti Goldstein Gray Greenspan Gutstein Handen Handleman Hardan Harris Hollander Hollander Hollander Hollander Horner Horvath Horvath Howard Howlin Howlin Hrdlicka Ingrassia Jan Jaselskis Johnson Jou Kagan-Kushnir Kasari Kerbeshian Klin Koegel Konstantareas Kowatch Krasny Kuddo Kulman La Camera Langworthy-Lam Layton Lee Leyfer Lightdale Liptak Lord Lorimer Lovaas Lovaas Mahoney Mahoney Malow Malow Mandell Marans Marcus Mastergeorge Matson McConnell McCracken McDougle McDougle McEachin Mehta Melmed Meltzer Mesibov Mesibov Millar Molloy Moore Murphy Murphy Myers Myers Namerow Lord O'Neill Olley Owens Owley Oyane Ozonoff Paavonen Patzold Paul Pavone Perry Phillips Pickett Polimeni Posey Posey Posey Posey Posey Quintana Ratey Reed Reynhout Rogers Rogers Rogers Rogers Rogers Rogers Rogers Rugino Sallows Sankar Scahill Schaaf Schepis Schopler Schreck Schreibman Seltzer Shannon Shavelle Shea Short Smith Smith Smits Steingard Steingard Stigler Sugie Syzmanski Taylor Taylor Taylor Tordjman Torrente Towbin Troost Tsakanikos Tuchman Tuchman Tuchman Turk Valicenti-McDermott Venter Vittello Volkmar Volkmar Weiskop Weiss Weiss Whalen Wieder Wiggs Williams Witwer, Management of children with autism spectrum disorders, Pediatrics, 120, 1162-1182, 2007	Publication type: Review article
Newson, Kirstie, PARENT PARTICIPATION: IMPROVING SERVICES FOR DISABLED CHILDREN, Community Care, 43, 2005	Publication type: Advertisement
Noterdaeme, M., A controlled pilot study of the effect of group training of parents of pre-schoolers with autism on social communication and parenting stress, Developmental Medicine and Child Neurology, 55, 7, 2013	Publication type: Conference abstract
Nowell, Sallie W., Watson, Linda R., Boyd, Brian, Klinger, Laura G., Efficacy Study of a Social Communication and Self-Regulation Intervention for School-Age Children With Autism Spectrum Disorder: A Randomized Controlled Trial, Language, Speech, and Hearing Services in Schools, 50, 416-433, 2019	Outcomes: No relevant outcomes reported for extraction

Study	Reason for Exclusion
Ogg, Julia A., Carlson, John S., Albers, Anastopoulos Chorpita Chronis DuPaul DuPaul Eyberg Eyberg Gresham Hartman Hoagwood Kamphaus Kazdin Kelley Kiresuk Kratochwill Lees LeFever Parker Pelham Pelham Rapport Smith Webster-Stratton Webster-Stratton Webster-Stratton Webster-Stratton Webster-Stratton Webster-Stratton Webster-Stratton, The self-administered Incredible Years Parent Training Program: Perceived effectiveness, acceptability, and integrity with children exhibiting symptoms of attention-deficit/hyperactivity disorder, Journal of Evidence-Based Practices for Schools, 10, 143-166, 2009	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Ogourtsova, T., Majnemer, A., O'Donnell, M., Promoting evidence-based practice in the provision of health-coaching interventions for parents of children with developmental disabilities: Systematic literature review, Developmental Medicine and Child Neurology, 60, 112, 2018	Publication type: Abstract
Olivos, Edward M., Gallagher, R. J., Aguilar, Jill, Fostering Collaboration with Culturally and Linguistically Diverse Families of Children with Moderate to Severe Disabilities, Journal of Educational & Psychological Consultation, 20, 28-40, 2010	Publication type: Review article
Olson, Heather Carmichael, Jirikowic, Tracy, Kartin, Deborah, Astley, Susan, Adnams, Arendt Astley Astley Astley Autti-Ramo Barr Bertrand Burden Butz Butz Chandler Chudley Church Coggins Coggins Coles Coles Connor Dolk Eyler Fried Fryer Goldschmidt Grant Greene Guralnick Gurwitch Howell Jacobson Jacobson Jacobson Janzen Jirikowic Klintsova Larrouque Larrouque Mattson Mattson Mattson Mattson Miura Morse Murray Nair O'Connor O'Connor Olson Olson Olson Olson Olson Olson Osborn Richardson Roebuck Schuler Singer Steinhausen Stratum Streissguth Streissguth Streissguth Streissguth Streissguth Streissguth Streissguth Streissguth Thomas Whaley, Responding to the challenge of early intervention for fetal alcohol spectrum disorders, Infants & Young Children, 20, 172-189, 2007	Publication type: Review article
Olswang, Lesley B., Pinder, Gay Lloyd, Hanson, Rebecca A., Communication in young children with motor impairments: teaching caregivers to teach, Seminars in Speech and Language, 27, 199-214, 2006	Outcomes: No relevant outcomes reported
Onrust, Simone A., Romijn, Geke, de Beer, Yvette, Family Group Conferences within the integrated care system for young people with ID: a controlled study of effects and costs, BMC Health Services Research, 15, 392, 2015	Outcomes: No relevant outcomes reported
Oono, I. P., Honey, E. J., McConachie, H., Parent-mediated early intervention for young	Interventions: Interventions are not targeted at involving or supporting the families and/or carers

Study	Reason for Exclusion
children with autism spectrum disorders (ASD), Evidence-Based Child Health, 8, 2380-2479, 2013	
Oulton, K., Sell, D., Gibson, F., Parents of children and young people with intellectual disabilities: What it means for them to be partners in their child's hospital care, Journal of Applied Research in Intellectual Disabilities, 31, 540-540, 2018	Publication type: Conference abstract
Owen, Carrie, Ziebell, Laura, Lessard, Chantal, Churcher, Elisabeth, Bourget, Virginia, Villenueve, Helene, Interprofessional Group Intervention for Parents of Children Age 3 and Younger With Feeding Difficulties: Pilot Program Evaluation, Nutrition in Clinical Practice, 27, 129-135, 2012	Population: Parents of children referred to occupational therapy for feeding problems
Owens, Julie Sarno, Richerson, Lauren, Beilstein, Elizabeth A., Crane, Anna, Murphy, Caroline E., Vancouver, Jeffrey B., School-based mental health programming for children with inattentive and disruptive behavior problems: first-year treatment outcome, Journal of Attention Disorders, 9, 261-74, 2005	Intervention: Interventions are not targeted at involving or supporting the families and/or carers
Oxford Brookes University Institute of Public Care, Evaluation of the Integrated Family Support Service in Newport: summary findings, 6, 2016	Publication type: Report
Oxford Brookes University Institute of Public Care, The Right Help at the Right Time for Children with Disabilities in Newport: findings from an evaluation of the Children with Additional Needs Service, 6, 2016	Publication type: Report
Ozen, A., Effectiveness of Siblings-Delivered iPad Game Activities in Teaching Social Interaction Skills to Children with Autism Spectrum Disorders, Educational Sciences-Theory & Practice, 15, 1287-1303, 2015	Outcomes: No relevant outcomes reported
Parada-Toro, Irene, Gomez-Quiroz, Rosa M., Trevino-Siller, Sandra, Aguinaga-Auerra, Cameron Coffey Fernandez Finnegan Garcia Sanchez Jimenez Martiniello Nelson Perez-Pedraza Ramos Schmid Tamis-LeMonda Vazquez-Briseno Ygual-Fernandez, Development and pilot testing of an educational intervention for parents, caregivers and teachers of children with verbal communication disabilities in Mexico, Health & Social Care in the Community, 25, 790-798, 2017	Population: Children with verbal communication disabilities
Parladé, Meaghan V., Weinstein, Allison, Garcia, Dainelys, Rowley, Amelia M., Ginn, Nicole C., Jent, Jason F., Parentâ "Child Interaction Therapy for children with autism spectrum disorder and a matched case-control sample, Autism: The International Journal of Research & Practice, 24, 160-176, 2020	Outcomes: No relevant outcomes reported for data extraction
Pattison, Kay, University Of, York, Support for families caring for children with disabilities in an	Full text unavailable

Study	Reason for Exclusion
area of high deprevation: who will help me cope, who will help me care?, 2008	
Pearl, E. S., Parent management training for reducing oppositional and aggressive behavior in preschoolers, Aggression and Violent Behavior, 14, 295-305, 2009	Publication type: Review article
Pennington, L., Goldbart, J., Marshall, J., Interaction training for conversational partners of children with cerebral palsy: a systematic review, International Journal of Language & Communication Disorders, 39, 151-70, 2004	Publication type: Systematic Review with no relevant data for extraction. Included studies list checked for any relevant papers.
Peredo, Tatiana Nogueira, Zelaya, Maria Isabel, Kaiser, Ann P., Agazzi, Bedore Bedore Brady Brannon Calzada Carle Chernoff Domenech Rodriguez Duran Francis Gast Goodrich Gutierrez-Clellan Hammer Hampton Hoff Ijalba Jackson-Maldonado Jackson-Maldonado Kaiser Kaiser Kohnert Kohnert Lonigan Lugo-Neris Mancilla-Martinez Miller Miller Moore Morgan Paradis Paradis Pratt Paez Rathmann Restrepo Roberts Roberts Roberts Roid Saracho Sheng Snow Tsybina Winsler Zimmerman, Teaching low-income Spanish-speaking caregivers to implement EMT en Espanol with their young children with language impairment: A pilot study, American Journal of Speech-Language Pathology, 27, 136-153, 2018	Population: Young children with language impairment
Pighini, Maria J., Goelman, Hillel, Buchanan, Marla, Schonert-Reichl, Kimberly, Brynelsen, Dana, Learning from parents' stories about what works in early intervention, International journal of psychology : Journal international de psychologie, 49, 263-70, 2014	Study design: Qualitative
Pilnick, Alison, James, Deborah, "I'm thrilled that you see that": guiding parents to see success in interactions with children with deafness and autistic spectrum disorder, Social science & medicine (1982), 99, 89-101, 2013	Study design: Case study
Power, Thomas J., Mautone, Jennifer A., Marshall, Stephen A., Jones, Heather A., Cacia, Jaclyn, Tresco, Katy, Cassano, Michael C., Jawad, Abbas F., Guevara, James P., Blum, Nathan J., Ambrosini, Bagner Bagner Barkley Bradley-Klug Braveman Bryant-Stephens Bussing Cohen Dishion Eiraldi Epstein Evans Eyberg Fabiano Fabiano Fiks Foy Guevara Hollingshead Kataoka Kazdin Kelley Kohl Krain Leslie Loney McKay McKay Nock Pelham Power Power Power Power Power Power Power Shonkoff Toomey Yeh, Feasibility and potential effectiveness of integrated services for children with ADHD in urban primary care practices, Clinical Practice in Pediatric Psychology, 2, 412-426, 2014	Outcomes: No relevant outcomes reported
Prelock, Patricia A., Beatson, Jean, Bitner, Brooke, Broder, Carri, Ducker, Amy, Baron-Cohen, Beatson Compton Dunn Dunst Fadiman Filer Filipek Friend Garnett Gilliam Gilliam	Publication type: Review article

Study	Reason for Exclusion
Goldrick Goodluck Hartman Hartman Kalyanpur Kisthardt Koegel Koegel Krug Linder Lord Mount Myles Prizant Prizant Rainforth Robins Saleebey Saleebey Schopler Shelton Smith Strain Westby Westby Wetherby Wolfberg Wolfberg, Interdisciplinary assessment of young children with autism spectrum disorder, Language, Speech, and Hearing Services in Schools, 34, 194-202, 2003	
Pretis, Manfred, Meeting the needs of parents in early childhood intervention: the educational partnership with parents-good practice and challenges, Journal of Policy and Practice in Intellectual Disabilities, 8, 73-76, 2011	Publication type: Review article
Quinn, Mark, Carr, Alan, Carroll, Louise, O'Sullivan, David, Parents Plus Programme 1: Evaluation of Its Effectiveness for Pre-School Children with Developmental Disabilities and Behavioural Problems, Journal of Applied Research in Intellectual Disabilities, 20, 345-359, 2007	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Rahi, J. S., Manaras, I., Tuomainen, H., Lewando Hundt, G., Health services experiences of parents of recently diagnosed visually impaired children, British Journal of Ophthalmology, 89, 213-218, 2005	Study design: Qualitative
Rebollo, M. F., Iturriaga, G. S., Saez, C. D., Gonzalez, E. S., Enhanced family-centered care coordination for children with special needs in the Basque Region, International Journal of Integrated Care, 16, 2016	Publication type: Conference abstract
Redmond, Bairbre, Richardson, Victoria, Bairbre, Redmond, Victoria, Richardson, Just getting on with it: exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability, 16, 205-218, 2003	Study design: Qualitative
Reynolds, Shawn, Lynch, Shane L., Litman, Sandy, Training care teams of children with autism spectrum disorders in positive behaviour support: an innovative approach, Healthcare quarterly (Toronto, Ont.), 14 Spec No 3, 95-9, 2011	Full text unavailable
Rickard, Eóin D., Brosnan, Eileen, Oâ ™Laoide, Aoife, Wynne, Ciara, Keane, Mary, McCormack, Margaret, Sharry, John, A first-level evaluation of a school-based family programme for adolescent social, emotional and behavioural difficulties, Clinical Child Psychology & Psychiatry, 21, 603-617, 2016	Population: Children with social, emotional and behavioural difficulties with no mention of complexity or comorbidities
Rickards, Anne L., Walstab, Janet E., Wright-Rossi, Roslyn A., Simpson, Jacquie, Reddihough, Dinah S., A randomized, controlled trial of a home-based intervention program for children with autism and developmental delay, Journal of Developmental and Behavioral Pediatrics, 28, 308-316, 2007	Outcomes: No relevant outcomes reported for data extraction

Study	Reason for Exclusion
Roberts, M. Y., Kaiser, A. P., The effectiveness of parent-implemented language interventions: a meta-analysis, American Journal of Speech-Language Pathology, 20, 180-199, 2011	Population: Children aged 18-60 months with primary and secondary language impairments; 39% classified with intellectual disability.
Rogers, Helen, Cameron, Daisy, Cann, Warren, Littlefield, Lyn, Lagioia, Vince, Evaluation of the Family Intervention Service for Children Presenting with Characteristics Associated with Attention Deficit Hyperactivity Disorder, Australian e-Journal for the Advancement of Mental Health, 2, 2003	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Rogers, Ruth, et al.,, Evaluation of the special educational needs parent partnership services in England (Research Report RR719), 2006	Study design and outcomes: Evaluation including a literature review with no relevant data for extraction
Ronis, S. D., Baldwin, C. D., Blumkin, A., Kuhlthau, K., Szilagyi, P. G., Patient-Centered Medical Home and Family Burden in Attention-Deficit Hyperactivity Disorder, Journal of Developmental & Behavioral Pediatrics, 36, 417-25, 2015	Study design: Survey with no relevant data for extraction
Rosenberg, S. A., Robinson, C., Fryer, G. E., Evaluation of paraprofessional home visiting services for children with special needs and their families, Topics in Early Childhood Special Education, 22, 158-168, 2002	Population: Not limited to disabled CYP. Includes children at risk due to environmental or caregiving factors
Roulstone, Alan, Hudson, Val, Carer participation in England, Wales and Northern Ireland: A challenge for interprofessional working, Journal of Interprofessional Care, 21, 303-317, 2007	Study design: Qualitative
Ruble, Lisa A., McGrew, John H., Community Services Outcomes for Families and Children with Autism Spectrum Disorders, Research in Autism Spectrum Disorders, 1, 360-372, 2007	Outcomes: No relevant outcomes reported
Sanders, M. R., Kirby, J. N., Tellegen, C. L., Day, J. J., The Triple P-Positive Parenting Program: a systematic review and meta-analysis of a multi-level system of parenting support, Clinical Psychology Review, 34, 337-357, 2014	Population and intervention: Systematic review and meta-analysis of a parenting and family support system designed to prevent and treat behavioural and emotional problems in children with and without developmental disabilities
Sarkar, Madhurima, Sanders, Lee M., Kelleher, Kelly J., Chisolm, Deena J., Psychosocial Health, e-Health Literacy, and Perceptions of e-Health as Predictors and Moderators of e-Health Use Among Caregivers of Children with Special Healthcare Needs, Telemedicine journal and e-health : the official journal of the American Telemedicine Association, 22, 123-131, 2016	Intervention: Interventions are not aimed at involving or supporting families and/or carers.
Sawyer, Brook E., Campbell, Philippa H., Brown, Campbell Campbell Campbell Campbell Campbell Campbell Colyvas Dunst Fleming Friedman Graham Harrison Hebbeler Klein McBride McWilliam McWilliam Pawl Peterson Peterson Pretti-Frontczak Ridgley Rosenthal Rush Salisbury Salisbury Sawyer Sawyer Unger Valvano, Teaching caregivers in early intervention, Infants & Young Children, 30, 175-189, 2017	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
SBU â “ Swedish Agency for Health Technology Assessment and Assessment of Social Services, Scientific evidence and evidence gaps in social care regarding assessment routines and interventions for individuals with disabilities or their families, 2016	Full text unavailable
Scharer, K., Internet social support for parents: the state of science, Journal of child and adolescent psychiatric nursing : official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc, 18, 26-35, 2005	Publication type: Review article
Scharer, K., Colon, E., Moneyham, L., Hussey, J., Tavakoli, A., Shugart, M., A comparison of two types of social support for mothers of mentally ill children, Journal of Child and Adolescent Psychiatric Nursing, 22, 86â 98, 2009	Outcomes: Qualitative data only
Seliner, B., Latal, B., Spirig, R., When children with profound multiple disabilities are hospitalized: A cross-sectional survey of parental burden of care, quality of life of parents and their hospitalized children, and satisfaction with family-centered care, Journal for Specialists in Pediatric Nursing, 21, 147-157, 2016	Study design: A cross-sectional survey
Sharabi, Adi, Marom-Golan, Dafna, Social Support, Education Levels, and Parents' Involvement: A Comparison between Mothers and Fathers of Young Children with Autism Spectrum Disorder, Topics in Early Childhood Special Education, 38, 54-64, 2018	Study design: Retrospective questionnaire comparing parental levels of involvement
Sharieff, G. Q., Hostetter, S., Silva, P. D., Foster parents of medically fragile children can improve their BLS scores: Results of a demonstration project, Pediatric Emergency Care, 17, 93-95, 2001	Outcomes: No relevant outcomes reported
Shields, J., The NAS EarlyBird Programme: autism-specific early intervention for parents, Professional care of mother and child, 10, 53-4, 2000	Publication type: Review article
Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., Logan, S., Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies, Developmental Medicine and Child Neurology, 55, 602-609, 2013	Study design: Systematic review with no relevant data for extraction.
Siller, Michael, Reyes, Nuri, Hotez, Emily, Hutman, Ted, Sigman, Marian, Longitudinal change in the use of services in autism spectrum disorder: Understanding the role of child characteristics, family demographics, and parent cognitions, Autism: The International Journal of Research & Practice, 18, 433-446, 2014	Study design and intervention: Longitudinal study and interventions are not targeted at involving or supporting the families and/or carers

Study	Reason for Exclusion
Singer, G. H., Ethridge, B. L., Aldana, S. I., Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: a meta-analysis, Mental Retardation and Developmental Disabilities Research Reviews, 13, 357-369, 2007	Outcomes: No relevant outcomes reported for data extraction. Checked for any relevant primary studies
Sloper, P., Greco, V., Beecham, J., Webb, R., Key worker services for disabled children: What characteristics of services lead to better outcomes for children and families?, Child: care, health and development, 32, 147-157, 2006	Outcomes: Insufficient presentation of results for extraction
Smith, J., Fenton, G., Coyne, I., Swallow, V., Implementing and evaluating models of family centred care or children with long term conditions-where next?, Archives of Disease in Childhood, 100, A94, 2015	Publication type: Conference abstract
Social Policy Research, Unit, Care coordination and key worker services for disabled children in the UK, 4p., 2004	Study design: Survey with no comparative data
Solomon, R., Necheles, J., Ferch, C., Bruckman, D., Pilot study of a parent training program for young children with autism: The PLAY Project Home Consultation program, Autism, 11, 205-224, 2007	Outcomes: No relevant outcomes reported
Solomon, R., Van Egeren, L. A., Mahoney, G., Quon Huber, M. S., Zimmerman, P., PLAY Project Home Consultation intervention program for young children with autism spectrum disorders: a randomized controlled trial, Journal of developmental and behavioral pediatrics : JDBP, 35, 475-485, 2014	Outcome: No relevant outcomes reported
Sonuga-Barke, Edmund J. S., Thompson, Margaret, Daley, David, Laver-Bradbury, Cathy, Parent training for Attention Deficit/Hyperactivity Disorder: is it as effective when delivered as routine rather than as specialist care?, The british journal of clinical psychology, 43, 449-57, 2004	Outcomes and population: Outcome measures are the same as those reported in Sonuga-Barke 2001 and the waitlist population have already been included
Statham June, Holtermann Sally, Families on the brink: the effectiveness of family support services, CHILD AND FAMILY SOCIAL WORK, 9, 153-166, 2004	Population: Families offered services in response to a crisis or new need.
Statham, June, Outcomes and effectiveness of family support services: a research review, 24p.,bibliog., 2000	Publication type: Narrative review
Stewart, Janeen, Galvin, Jane, Froude, Elspeth H., Lentin, Primrose, Evaluation of the Australian adaptation of the Keeping It Together (KIT-Australia) information package with carers of children with special needs, Australian occupational therapy journal, 57, 268-75, 2010	Study design: Survey with no relevant data for extraction
Stewart, M. J., Reutter, L., Fostering partnerships between peers and professionals, The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres, 33, 97-116, 2001	Study design: Qualitative

Study	Reason for Exclusion
Stille, Christopher J., Communication, comanagement, and collaborative care for children and youth with special healthcare needs, Pediatric annals, 38, 498-504, 2009	Publication type: Review article
Stubbe, Dorothy E., Weiss, Gabrielle, Anastopoulos, Anastopoulos Arnold Barkely Barkley Barkley Barkley Barkley Carlson Cousins Cunningham Dulcan Edwards Firestone Firestone Forehand Forehand Gittelman Goldfried Greenfield Greenhill Hinshaw Horn Horn Kazdin Kazdin Lonigan Pelham Pelham Pelham Pelham Pelham Pfiffner Pisterman Pisterman Spencer Szatmari Weiss, Psychosocial interventions: Individual psychotherapy with the child, and family interventions, Child and Adolescent Psychiatric Clinics of North America, 9, 663-670, 2000	Publication type: Review article
Summers, N., Jenkins, C., Enabling practice: An investigation into the support of families with children with learning disabilities, Journal of Learning Disabilities, 5, 57-67, 2001	Outcomes: No relevant outcomes reported
Swallow, V., Carolan, I., Smith, T., Webb, N. J., Knafl, K., Santacroce, S., Campbell, M., Harper-Jones, M., Hanif, N., Hall, A., A novel Interactive Health Communication Application (IHCA) for parents of children with long-term conditions: Development, implementation and feasibility assessment, Informatics for health & social care, 41, 20-46, 2016	Population: Chronic kidney disease - unlikely to have needs in all three areas
TadiÄ‡, Valerija, Pring, Linda, Dale, Naomi, Story discourse and use of mental state language between mothers and school-aged children with and without visual impairment, International Journal of Language & Communication Disorders, 48, 679-688, 2013	Outcomes: No relevant outcomes reported
Taylor, April, Lizzi, Michele, Marx, Alison, Chilkatowsky, Maryann, Trachtenberg, Symme W., Ogle, Sue, Implementing a care coordination program for children with special healthcare needs: partnering with families and providers, Journal for healthcare quality : official publication of the National Association for Healthcare Quality, 35, 70-7, 2013	Outcomes: No relevant outcomes reported
Thomas, Cecilia, Corcoran, Jacqueline, Family Approaches to Attention Deficit Hyperactivity Disorder: A Review to Guide School Social Work Practice, Children and Schools, 25, 19-34, 2003	Publication type: Narrative review
Thomas, S., Does integration make a difference to the lives of children with a disability?, Archives of disease in childhood, 3), A96, 2015	Publication type: Conference abstract
Tosh, R., Arnott, W., Scarinci, N., Parent-implemented home therapy programmes for speech and language: a systematic review, International Journal of Language & Communication Disorders, 52, 253-269, 2017	Outcomes: No relevant outcomes reported
Trute, B., Hiebert-Murphy, D., Wright, A., Family-centred service coordination in childhood	Intervention: Interventions are not targeted at involving or supporting the families and/or carers

Study	Reason for Exclusion
health and disability services: The search for meaningful service outcome measures, Child: Care, Health and Development, 34, 367-372, 2008	
Tudor, M. E., Lerner, M. D., Intervention and support for siblings of youth with developmental disabilities: a systematic review, Clinical Child and Family Psychology Review, epub, 2014	Study design: Systematic review with no relevant data for extraction
Ufer, Lisa Gorman, Moore, Julie A., Hawkins, Kristen, Gembel, Gina, Entwistle, David N., Hoffman, David, Care Coordination: Empowering Families, a Promising Practice to Facilitate Medical Home Use Among Children and Youth with Special Health Care Needs, Maternal and Child Health Journal, 22, 648-659, 2018	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Ungar, Michael, Liebenberg, Linda, Landry, Nicole, Ikeda, Janice, Caregivers, young people with complex needs, and multiple service providers: A study of triangulated relationships, Family Process, 51, 193-206, 2012	Study design: Qualitative
van der Westhuizen, D., Family-centred interventions to improve communication between psychiatric disordered children, their families and the multi-professional team, South African Journal of Psychiatry, 13, 117-117, 2007	Publication type: Abstract only
Vostanis, Panos, Anderson, Lisa, Window, Suzanne, Evaluation of a family support service: short-term outcome, Clinical Child Psychology and Psychiatry, 11, 513-28, 2006	Population: Children with behavioural problems
Waid, J., Kelly, M., Supporting family engagement with child and adolescent mental health services: A scoping review, Health & Social Care in the Community, 2020	Interventions: Scoping review. Interventions are not targeted at involving or supporting the families and/or carers
Wang, M., Kim, J., Family quality of life of Korean families of children with intellectual and developmental disabilities and relationship to family and professional partnerships and service quality, Journal of Intellectual Disability Research, 60, 759-759, 2016	Publication type: Scientific oral presentation
Webb, R., Beecham, J., Sloper, P., Department for, Education, Skills,, Greco, V., An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs, 2005	Study design and outcomes: Survey with no relevant outcomes reported
Wei, Y. S., Chu, H., Chen, C. H., Hsueh, Y. J., Chang, Y. S., Chang, L. I., Chou, K. R., Support groups for caregivers of intellectually disabled family members: effects on physical-psychological health and social support, Journal of Clinical Nursing, 21, 1666-77, 2012	Population: Caregivers of intellectually disabled adults (not children/young people)
Weiss, A. L., Theadore, G., Involving parents in teaching social communication skills to young children, Topics in Language Disorders, 31, 195-209, 2011	Publication type: Review article
Welch, V., Hatton, C., Emerson, E., Collins, M., Robertson, J., Langer, S., Wells, E., Using direct	Study design: Survey with no comparative data

Study	Reason for Exclusion
payments to fund short breaks for families with a disabled child, Child: Care, Health & Development, 38, 900-9, 2012	
Welsh, J. A., Viana, A. G., Petrill, S. A., Mathias, M. D., Interventions for internationally adopted children and families: A review of the literature, Child and Adolescent Social Work Journal, 24, 285-311, 2007	Interventions: Interventions are not targeted at involving or supporting the families and/or carers
Whitton, C., Williams, C., Wright, B., Jardine, J., Hunt, A., The role of evaluation in the development of a service for children with life-limiting conditions in the community, Child: Care, Health & Development, 34, 576-83, 2008	Study type: Survey with no comparative data
Wienke, W., Wienke, C., Wienke, S., Using community partnerships to support families with young children with disabilities, Journal of Intellectual Disability Research, 48, 386, 2004	Publication type: Meeting abstract
Williams, Kate E., Berthelsen, Donna, Nicholson, Jan M., Walker, Sue, Abad, Vicky, The effectiveness of a short-term group music therapy intervention for parents who have a child with a disability, Journal of music therapy, 49, 23-44, 2012	Study design and intervention: Non randomised controlled trial and class of intervention is covered by RCTs
Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., Liebergen, A., Leuenberg, K., Setter, R. K., Ridder, L., Curry, H., Barnard, M., Sanders, S., A community-based intervention for siblings and parents of children with chronic illness or disability: The ISEE study, Journal of Pediatrics, 143, 386-393, 2003	Outcomes: Insufficient presentations of results for extraction
Wolraich, M. L., Bickman, L., Lambert, E. W., Simmons, T., Doffing, M. A., Intervening to improve communication between parents, teachers, and primary care providers of children with ADHD or at high risk for ADHD, Journal of Attention Disorders, 9, 354-368, 2005	Outcomes: Insufficient presentation of results for extraction
Wood, David L., McCaskill, Quimby E., Winterbauer, Nancy, Jobli, Edessa, Hou, Tao, Wludyka, Peter, Stowers, Kristi, Livingood, William, Ammentorp, Anderson Aragon Auslander Baker Bromley Chomicki Cooley Cooley Darby Davidson Fan Farmer Flynn Gupta Halfon Ireys King Krauss Krauss Law Lawoko Liptak Mah McPherson Moore Mulvihill Narayan Nelson Newacheck Ngui Patrick Ross Ruiz-Moral Seid Shonkoff Stevens Stile Strickland Tippy Warfield Weisman Ziring, A multi-method assessment of satisfaction with services in the Medical Home by parents of children and youth with special health care needs (CYSHCN), Maternal and Child Health Journal, 13, 5-17, 2009	Study design: Survey with no comparative data
Wynne, Ciara, Doyle, Caoimhe, Kenny, Rachel, Brosnan, Eileen, Sharry, John, A first-level evaluation of a family intervention for adolescent social, emotional and behavioural difficulties in Child and Adolescent Mental Health Services,	Population: Adolescents with social, emotional and behavioural difficulties attending Child and Adolescent Mental Health Services

Study	Reason for Exclusion
Journal of Child & Adolescent Mental Health, 28, 33-46, 2016	
Yates, T. C., Lero, D., The mirror has two faces-exploring the needs of family/friend caregivers of people living with HIV and other episodic disabilities in Ontario, Canadian Journal of Infectious Diseases and Medical Microbiology, 26, 133B, 2015	Publication type: Meeting abstract
Yildirim, A., Hacihasanoglu Asilar, R., Karakurt, P., Effects of a nursing intervention program on the depression and perception of family functioning of mothers with intellectually disabled children, Journal of Clinical Nursing, 22, 251-261, 2013	Outcomes: No relevant outcomes reported
Ziviani, J., Feeney, R., Cuskelly, M., Meredith, P., Hunt, K., Effectiveness of support services for children and young people with challenging behaviours related to or secondary to disability, who are in out-of-home care: A systematic review, Children and Youth Services Review, 34, 758-770, 2012	Population: Children and young people with, or at risk for emotional and behavioural disorders, challenging behaviour, or externalising behaviour problems
Ziviani, Jenny, Feeney, Rachel, Khan, Asad, Early Intervention Services for Children With Physical Disability: Parents' Perceptions of Family-Centeredness and Service Satisfaction, Infants & Young Children: An Interdisciplinary Journal of Early Childhood Intervention, 24, 364-382, 2011	Study design: Cross sectional study
Zuna, Nina, Gràcia, Marta, Haring, Samuel H., Aguilar, Jeannie M., Parental perceptions and satisfaction with family services in families of children with autism spectrum disorder and other developmental disabilities, Journal of Intellectual & Developmental Disability, 41, 233, 2016	Study design: Survey with no comparative data
Zurynski, Y., Altman, L., Breen, C., Woolfenden, S., Care coordination for children with chronic and complex conditions in Australia: significant benefits for patients and their families, International Journal of Integrated Care, 18, 2018	Exclude: Poster abstract
Zwi, Morris, Jones, Hannah, Thorgaard, Camilla, York, Ann, Dennis, Jane A., Parent Training Interventions for Attention Deficity Hyperactivity Disorder (ADHD) in Children Aged 5 to 18 Years. Campbell Systematic Reviews. 2012:2, 1-100, 2011	Study design and outcomes: Systematic review with no relevant data for extraction. Parental confidence reported in 1 study (book)

Economic studies

See Supplement B for the list of excluded studies across all reviews.

Appendix K – Research recommendations – in full

Research recommendations for review question: What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

Research recommendation

What components of short break services are most effective for disabled children and young people with severe complex needs and their families and carers?

Why this is important

Short breaks provide respite for families with disabled children and young people with severe complex needs, allowing families to spend time with other children and each other may allow the child or young person to have experiences that the family is unable to provide. As a result, short breaks have the potential to prevent family breakdown and subsequently protect the child or young person with disabilities and complex needs. Although it is a statutory duty for local authorities to provide short breaks, it is unclear which aspects of short breaks make them most effective, for example the duration of break, the inclusion of a sleep over, and whether it is tailored to the individual needs of the child or young person. It is also unclear why young people and their families value certain short breaks more than others.

Rational for research recommendation

Table 17: Research recommendation rationale

Importance to the population	This research will help to understand the most effective components of short breaks for disabled children and young people with severe complex needs, and if this changes across age ranges and types of provisions.
Relevance to NICE guidance	This evidence would be essential to inform future updates of recommendations in the current guideline to enable evidence-based recommendations about what constitutes an effective short break.
Relevance to the NHS	The Short Breaks Regulations 2011 places a statutory duty on Local Authorities to provide a range of short breaks for disabled children and young people. Short breaks may reduce crisis admissions and keep families together. A child or young person with an intact family is likely to be less vulnerable and there is a potential impact on the child or young person's mental health and physical health.
National priorities	The NHS Long Plan includes a number of areas that are applicable to children and young people with severe complex needs and special educational needs and disabilities, including personalised care. Short breaks align with personalised care.
Current evidence base	There is currently no published evidence about the effectiveness of the components of short breaks interventions.

Equality considerations	There are health inequalities for disabled children and young people with severe complex needs who are eligible to access short breaks and this population are in a protected characteristic covered by the Equality Act (2010). This research may help redress imbalances of resources in disadvantaged families.

NHS: national health service.

Modified PICO table

Table 18: Research recommendation modified PICO table

Population	Disabled children and young people (from birth to 25 years) with severe complex needs who require health, social care, and education support. • Birth to Primary school age (0-5 years) • Primary education (5-11 years) • Secondary education (11–16 years) • Further education (16-25 years) and: Families and carers of disabled children and young people (from birth to 25 years) with severe complex needs who require health, social care, and education support
Intervention	Components of short break services such as: • Giving a set amount of funding for families to use to access any group they wish (e.g., they may have £500 pa to access any mainstream group) • Providing 2 or 3 specific groups for families which provide a set amount or short breaks activities • Provision of a resource allocation and amount of activities based upon assessed need • Sleepover experiences • Extended time including social activities (e.g., tea and evening activities). • Setting (e.g., residential or individual PAs home) • Arrangement and booking of the short break service
Comparator	Any other components of short break services
Outcomes	Disabled children and young people with severe complex needs: • Safety (e.g. CQC inspection measures) • Self-efficacy (e.g., as measured by validated scales or assisted communication aids such as talking mats or ‘it’s all about me’) • Trust (e.g. attendance at short break services) • Resilience (measured by validated scales) • Health and wellbeing (both maintenance and improvement, measured by validated scales)

	- Developmental progress including social and emotional development (measured by validated scales) - Foster care placement stability - Entering the care system - Access to short breaks - Quality of life (both health- and social-related quality as measured by validated scales) - Satisfaction with services (as measured by validated scales) Families and carers of disabled children and young people with severe complex needs: - Capability and confidence to meet the needs of the child or young person (as measured by validated scales) - Quality of life (both health- and social-related quality as measured by validated scales) - Satisfaction with services (as measured by validated scales) - Trust (e.g. attendance at short break services)
Study design	Non-randomised comparative studies (including cohort studies, before and after studies and interrupted time series), service evaluations and audits
Timeframe	None
Additional information	NA

CQC: care quality commission; NA: not applicable; PA: personal assistant.,