National Institute for Health and Care Excellence and Care

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

[K] Evidence review of barriers and facilitators of joined-up care

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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The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

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ISBN:

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Barriers and facilitators of joined-up care

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.8 - 1.1.10, 1.1.14, 1.1.15, 1.1.17, 1.1.29, 1.1.31, 1.1.32, 1.1.36, 1.1.46, 1.1.47, 1.2.7, 1.3.1, 1.3.2, 1.3.4, 1.3.7, 1.3.8, 1.3.11, 1.3.12, 1.4.1, 1.4.3, 1.4.4, 1.4.9 - 1.4.13, 1.4.18, 1.4.22 - 1.4.24, 1.5.1 – 1.5.3, 1.6.3, 1.7.6, 1.8.4, 1.8.11, 1.14.1, 1.15.1, 1.15.3, 1.15.9 – 1.15.14, 1.15.16 - 1.15.19, 1.15.22, 1.15.23, 1.15.27, 1.15.28, 1.15.30 – 1.15.32, 1.16.4, 1.17.1, 1.17.3, 1.17.5, 1.17.9 - 1.17.13, 1.17.15, 1.17.16. Other evidence supporting these recommendations can be found in the evidence reviews on Views and experiences of service users (evidence report A), Supporting participation in education and social activities (evidence report F), Views and experiences of service providers (evidence report M), Commissioning, practice and service delivery models (evidence report N).

Review question

What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

Introduction

The views and experiences of service users, providers and practitioners are integral to improving the quality and performance of joined-up care between health, social care and education services. The aim of this review is to identify the barriers and facilitators to joined-up care between health, social care and education services for disabled children and young people with severe complex needs as perceived or experienced by the service users themselves, service providers and practitioners.

The qualitative evidence from this review will be combined with quantitative evidence from other systematic reviews on effective joint commissioning, integration and joint working between practitioners across health, social care and education services to identify the optimal delivery of joined-up care.

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, phenomenon of interest and context characteristics of this review.

Table 1: Summary of the protocol

Population	• Disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support. • 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. • People who provide, or work in, health care, social care or educational services for disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support.

Phenomenon of Interest	The views and experiences of service users, service providers and practitioners, specifically on the barriers and facilitators relating to joined-up care between health, social care and education services for disabled children and young people with severe complex needs. • Service users: People using or eligible to use all three services; health, social care and education. • Service providers: People providing one or more of the three services; health, social care and education. • Practitioners: People working in one or more of the three services; health, social care and education Potential themes include: • Budgets (boundaries / combined) • Thresholds and eligibility criteria including diagnosis • Disjointed commissioning & provision, cultures • Information governance/protection, • IT systems/data management and technology • Long term planning • Education & staff training (joint training) • Policy and legislation • Location (co-location, separate locations) • Transports • Adjustments, facilities and communication • Disruption to everyday life • Keyworkers and facilitators • Home-schooling • Age related transitions (e.g. children to adult services, primary to secondary school)
Context	All settings will be covered in which health, social care and education is provided for disabled children and young people from birth to 25 years with severe complex needs. Studies sought will be those published in the English language from the UK, from 2013 until the date the searches are run.

For further details see the review protocol in appendix A.

Methods and process

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.

Qualitative evidence

Included studies

A systematic review of the literature was conducted using a combined search. Thirty-three qualitative studies were included in this review (Adams 2017; Adams 2018; Boesley 2018; Boyce 2015; Brooks 2013; Children's Commissioner for Wales 2018; Cohen 2017; Council for Disabled Children 2018; Dillenburger 2016; Fox 2017; Griffith 2013; Hurt 2019; Hutton 2018; Kaehne 2013; Karim 2014; Kiernan 2019; Kirk 2014; McCartney 2017; McConkey 2013; McKean 2017; Molteni 2013; National Autistic Society 2015; Palikara 2019; RIP STARS 2018; Rodriguez 2014; Sales 2018; Skipp 2016; Smith 2014; Spivack 2014; Taylor 2014; Thom 2014; Thom 2015; Young 2018).

The date of publication ranged from 2013 to 2019. All included studies were conducted in the UK and provided data on the views and experiences of barriers and facilitators to joined-up care between education, health and social care services. Data collection methods included: surveys (Cohen 2017), semi-structured surveys (Palikara 2019), surveys with open ended or free text questions (Adams 2017; National Autistic Society 2015), interviews (Adams 2018; Kaehne 2013; Kirk 2014; Smith 2014; Taylor 2014; Thom 2014; Thom 2015), semi-structured interviews (Boesley 2018; Boyce 2015; Council for Disabled Children 2018; Fox 2017; Griffith 2013; Karim 2014; Kiernan 2019; McCartney 2017; McConkey 2013; McKean 2017; Sales 2018; Spivack 2014), focus groups (Hurt 2019), interviews and group discussions (RIP STARS 2018), semi-structured interviews and focus groups (Brooks 2013; Rodriguez 2014; Skipp 2016; Young 2018), focus groups and interviews (Hutton 2018), focus groups and online questionnaires (Children's Commissioner for Wales 2018), semi-structured interviews, questionnaire with free text questions and focus groups (Dillenburger 2016), and focus groups, semi-structured interviews and a questionnaire with an open-ended question (Molteni 2013).

Study populations included disabled children and young people with severe complex needs, their families and carers, and professionals from education, health and social care services.

The included studies are summarised in Table 2.

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 the qualitative evidence

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

Table 2: Summary of included studies

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
Adams 2017 Education, Health and Social Care Services	Service users: N=722 Young people (aged 16 years and above) identified from the National Pupil Database and Individualised Learner Record as having an EHC plan in place in 2015 N=12,921 Parents/carers of children and young people identified from the National Pupil Database and Individualised Learner Record as having an EHC plan in place in	**Needs or conditions:** Autistic spectrum disorder, speech, language and communication needs, social, emotional & mental health, moderate, severe or profound and multiple learning difficulty, physical disability, difficulty,	**Setting:** NR **Data collection:** Survey with free text questions	• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Professional and staff knowledge and training • Service users' involvement and relationships with service providers

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
	2015	hearing impairment, visual impairment, multi-sensory impairment **Age Range (Mean):** 0 to 25 years (NR)		
Adams 2018 Education, Health and Social Care Services	Service users: N=25 Young people (aged 16 years and above) or parents/carers of children and young people identified from the National Pupil Database and Individualised Learner Record as having an EHC plan in place in 2015* *Follow-up from Adams 2017	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** NR (face-to-face) **Data collection:** Interviews	• Importance of key worker/lead professional • Relationships between service providers • Diagnosis and identification of needs first • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Long waiting times for support
Boesley 2018 Education, Health and Social Care Services	Service providers: N=16 SENCOs based in England and had undertaken an application for an EHC plan, or transferred a statement of SEN into an EHC plan.	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Primary and secondary schools across England (telephone) **Data collection:** Semi-structured interviews	• Relationships between service providers • Introduction of EHC plans • Joined-up care requires a substantial amount of time, organisation and commitment • Professional and staff knowledge and training • Service users' involvement and relationships with service providers • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Organisation of services

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
				• Funding and resources • An imbalanced distribution in the amount of support provided to children/young people • Long waiting times for support • Attitudes and social stigma about service provisions
Boyce 2015 Education, Health and Social Care Services	Service users: N=26 Parents of children who are certified as severely sight impaired or sight impaired Service providers: N=35 Health, education and social care professionals involved in certifying and supporting infants and children with vision impairment	**Needs or conditions:** Severely sight impaired or sight impaired (including infants and children with complex needs) **Age Range (Mean):** NR	**Setting:** Hospital **Data collection:** Semi-structured interviews	• Information sharing • Organisation of services • Relationships between service providers • Diagnosis and identification of needs first • Professional and staff knowledge and training
Brooks 2013 Health and Social Care Services	Service users: N=2 Children with complex needs (aged 6 and 10 years) N=7 Parents with children who have continuing complex care needs Service providers: N=18 Stakeholders and professionals who have significant input into children's and families' care within the study locality (community paediatricians, nurses, therapists and teachers)	**Needs or conditions:** Cystic fibrosis, spina bifida, microcephaly, biliary atresia, tuberous sclerosis **Age Range (Mean):** 1 to 16 years (NR)	**Setting:** Service users: Family home, parents place of work Service providers: Professionals place of work, telephone **Data collection:** Semi-structured interviews and focus groups	• Relationships between service providers • Importance of key worker/lead professional • Information sharing • Communication and support • Joined-up care requires a substantial amount of time, organisation and commitment • An imbalanced distribution in the amount of support provided to children/young people
Children's	Service users:	**Needs or**	**Setting:**	• Organisation of

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
Commissioner for Wales 2018 Education, Health and Social Care Services	N=99 Young people (aged 14 to 26) with learning disabilities N=187 Parents of children and young people with learning disabilities Service providers: N=43 Professionals from education, health, social care and voluntary services who work with young people with learning disabilities	**conditions:** Learning disabilities **Age Range (Mean):** 14 to 26 years (NR)	NR **Data collection:** Focus groups (young people and service providers) and online questionnaires (parents)	services • Transition • Funding and resources • An imbalanced distribution in the amount of support provided to children/young people • Joined-up care requires a substantial amount of time, organisation and commitment • Relationships between service providers • Communication and support • Information sharing • Long waiting times for support • Service users' involvement and relationships with service providers • Importance of key worker/lead professional
Cohen 2017 Education and Health Services	Service users: N=1 Young person (aged 16 years) with a confirmed genetic diagnosis of 22q11DS N=33 Parents/carers of individuals of any age with a confirmed genetic diagnosis of 22q11DS	**Needs or conditions:** 22q11DS **Age Range (Mean):** NR	**Setting:** URL link via websites and social media **Data collection:** Survey	• Joined-up care requires a substantial amount of time, organisation and commitment • Professional and staff knowledge and training • Diagnosis and identification of needs first • Information sharing
Council for Disabled Children 2018 Education, Health and Social Care Services	Service users: N=6 Parents of adopted children with disabilities that became apparent during or after adoption Service providers:	**Needs or conditions:** ADHD, attachment difficulties/disorder, ASD, complex health needs,	**Setting:** Primarily telephone **Data collection:** Semi-structured	• Relationships between service providers • Organisation of services • Long waiting times for support • Diagnosis and

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
	N=13 Professionals with experience of supporting adopted children with disabilities that became apparent during or after adoption	developmental delay or trauma, dyspraxia, FASD/FAS, genetic condition, hearing loss, learning difficulties, sensory processing issues	interviews	identification of needs first - Funding and resources - Information sharing - Communication and support - Importance of key worker/lead professional
Dillenburger 2016 Health and Social Care Services	Service users: N=14 Caregivers and parents of individuals with ASD	**Needs or conditions:** Learning disabilities, attention deficit hyperactivity disorder, dyslexia, dyspraxia, sleep disorders, anxiety, tourette's syndrome, asthma, eczema. (N=12 had one or more co-occurring conditions) **Age Range (Mean):** 3 to 27 years (NR)	**Setting:** Participants home or office (face-to-face or self-completion) whichever was preferred **Data collection:** Semi structured interviews, questionnaire with free text questions and focus groups **Analysis:** NR	- An imbalanced distribution in the amount of support provided to children/young people - Long waiting times for support
Fox 2017 Education, Health and Social Care Services	Service users: N=15 Parents to a child under 16 years of age who has a diagnosis of autism and who identified as a member of the Bristol Somali migrant community	**Needs or conditions:** Autism **Age Range (Mean):** 4 to 13 years (7 years)	**Setting:** Community centre or participants' own homes (according to preference) **Data collection:** Semi structured interviews	- Communication and support - Diagnosis and identification of needs first - Service users' involvement and relationships with service providers - Long waiting times for support - Attitudes and social stigma about service

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
				provisions
Griffith 2013 Education, Health and Social Care Services	Service users: N=10 Parents Service providers: N=8 Assessment service providers (social and communication team, and child and adolescent mental health services)	**Needs or conditions:** Autism, Asperger syndrome, and no diagnosis **Age Range (Mean):** 2 to 12 years (6.6 years)	**Setting:** Local clinic (face-to-face) **Data collection:** Semi-structured interviews	- Working across multiple services
Hurt 2019 Education and Health Services	Service users: N=7 Parent of primary school children with ASD Service providers: N=16 Health and education professionals working within an NHS multidisciplinary neurodevelopmental team and a mainstream primary school	**Needs or conditions:** ASD **Age Range (Mean):** NR	**Setting:** One health board and one primary school in South Wales **Data collection:** Focus groups	- Communication and support - Information sharing - Organisation of services - Diagnosis and identification of needs first - Working across multiple services
Hutton 2018 Education, Health and Social Care Services	Service users: N=9 Parents/carers of disabled children (aged 18 years or younger) who accessed at least two paediatric rehabilitation therapy services (e.g. physiotherapy, occupational therapy, and speech and language therapy)	**Needs or conditions:** NR **Age Range (Mean):** 2 to 16 years (8.7 years)	**Setting:** One region in the South of England (face-to-face) **Data collection:** Focus groups and interviews	- Joined-up care requires a substantial amount of time, organisation and commitment - Funding and resources
Kaehne 2013 Health and Social Care Services	Service users: N=3 Parent representatives involved in planning new co-located services for children with significant disabilities	**Needs or conditions:** Significant disabilities. **Age Range (Mean):** 0 to 19 years (NR)	**Setting:** NR **Data collection:** Interviews	- Joined-up care requires a substantial amount of time, organisation and commitment - Relationships between service providers - Service users' involvement and

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
				relationships with service providers - Attitudes and social stigma about service provisions - An imbalanced distribution in the amount of support provided to children/young people - Organisation of services - Communication and support
Karim 2014 Education and Health Services	Service providers: N=21 Professionals from the NHS and two local education authorities working with children with ASD	**Needs or conditions:** ASD **Age Range (Mean):** NR	**Setting:** NR **Data collection:** Semi-structured interviews	- Diagnosis and identification of needs first - Relationships between service providers - Organisation of services - Funding and resources
Kiernan 2019 Education, Health and Social Care Services	Service users: N=10 Mothers of children whose behaviours had been described as challenging, based on parental disclosure of their child/children's diagnoses of intellectual disability, behavioural needs and special educational needs	**Needs or conditions:** (moderate, severe or profound and multiple) learning difficulties, ASD, cerebral palsy, ADHD, ODD **Age Range (Mean):** 7 to 18 years (13.6 years)	**Setting:** Preferred location **Data collection:** Semi-structured interviews	- Communication and support - Joined-up care requires a substantial amount of time, organisation and commitment - Organisation of services
Kirk 2014 Health and Social Care Services	Service users: N=16 Young people (aged over 16 years) not at an end-of life stage, from one children's hospice N=16 Parents of young people	**Needs or conditions:** Cerebral palsy, pervasive developmental disorder, duchenne muscular dystrophy,	**Setting:** Preferred location **Data collection:** Interview	- Communication and support - Organisation of services

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
	not at an end-of life stage, from one children's hospice	spinal muscular atrophy, down's syndrome, congenital condition, metabolic condition, other nervous system conditions **Age Range (Mean):** 16 to 31 years* (20.5 years) *The percentage of participants aged 28-31 years was 12.5% for YP and 8.3% for parents		
McCartney 2017 Education and Health Care Services	Service providers: N=7 Speech and language therapists involved in transition between child and adult services	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Workplaces and universities in one Scottish health board **Data collection:** Semi-structured interviews	• Information sharing • Transition • Joined-up care requires a substantial amount of time, organisation and commitment • Professional and staff knowledge and training • Communication and support
McConkey 2013 Health and Social Care Services	Service users: N=14 Family members of children currently receiving services from Action for Children, or had received services in the past 2 years Service providers: N=34 Key workers and	**Needs or conditions:** Developmental disabilities and severely challenging behaviours **Age Range (Mean):** Up to 19 years (NR)	**Setting:** In a private room in the short break service/family homes (face-to-face), and telephone **Data collection:** Semi-	• Information sharing • Professional and staff knowledge and training • Organisation of services • An imbalanced distribution in the amount of support provided to children/young people

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
	Referrers of children currently receiving services from Action for Children, or had received services in the past 2 years		structured interviews	• Attitudes and social stigma about service provisions • Long waiting times for support • Service users' involvement and relationships with service providers • Relationships between service providers • Working across multiple services
McKean 2017 Health and Social Care Services	Service providers: N=33 Key professionals working with children with speech, language and communication needs	**Needs or conditions:** Speech, language and communication needs **Age Range (Mean):** NR	**Setting:** One local authority and NHS trust in England **Data collection:** Semi-structured interviews	• Joined-up care requires a substantial amount of time, organisation and commitment • Relationships between service providers • Organisation of services • Professional and staff knowledge and training • Funding and resources • Long waiting times for support • Diagnosis and identification of needs first • Communication and support
Molteni 2013 Education and Health Services	Service providers: N=22 Teams of professionals involved in implementing the Social Communication, Emotional Regulation, Transactional Support (SCERTS) model	**Needs or conditions:** Severe learning difficulties **Age Range (Mean):** NR	**Setting:** NR **Data collection:** Focus groups, semi-structured interviews and one open-ended question on a questionnaire	• Relationships between service providers • Joined-up care requires a substantial amount of time, organisation and commitment • Attitudes and social stigma about service provisions • Information sharing
National Autistic	Service users:	**Needs or**	**Setting:**	• Long waiting times

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
Society 2015 Education, Health and Social Care Services	N=231 Children and young people (aged under 25 years) with autism N=1,431 Parent or carer of children or young people with autism	**conditions:** Autism **Age Range (Mean):** NR	NR **Data collection:** Survey including open-ended questions	for support • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Communication and support
Palikara 2019 Education, Health and Social Care Services	Service providers: N=374 Professionals working in special education	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Survey distributed through research network **Data collection:** Semi-structured survey	• Funding and resources • Introduction of EHC plans • Organisation of services • Relationships between service providers • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Long waiting times for support • Joined-up care requires a substantial amount of time, organisation and commitment • Professional and staff knowledge and training
RIP STARS 2018 Education, Health and Social Care Services	Service users: N=15 Children and young people with disabilities N=10 Parent/carers of children and young people with disabilities Service providers: N=17	**Needs or conditions:** NR **Age Range (Mean):** 13 to 25	**Setting:** NR **Data collection:** Interviews and group discussions	• Introduction of EHC plans • Attitudes and social stigma about service provisions • Transition • Organisation of services • Relationships between service providers • Funding and resources • Information sharing • Difficulty in obtaining an EHC plan (or replacing a

Study	**Population**	**Description of child/young person**	**Methods**	**Themes applied after thematic synthesis**
				statement of SEN with an EHC plan) • Joined-up care requires a substantial amount of time, organisation and commitment
Rodriguez 2014 Unclear what services were involved	Service users: N=20 Parents of children with life limiting conditions Service providers: N=21 Professionals working in paediatric care	**Needs or conditions:** Cancer, cerebral palsy, muscular dystrophy, congenital disorder, neurological disorder, genetic disorder **Age Range (Mean):** NR	**Setting:** One UK county, including both urban and rural areas **Data collection:** Semi-structured interviews (service users) and focus groups (service providers)	• Communication and support • Importance of key worker/lead professional • An imbalanced distribution in the amount of support provided to children/young • Service users' involvement and relationships with service providers
Sales 2018 Education, Health and Social Care Services	Service users: N=4 Children and young people (aged 10 to 17) N=7 Parents Service providers: N=9	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Work or home (face-to-face) **Data collection:** Semi-structured interviews	• Introduction of EHC plans • An imbalanced distribution in the amount of support provided to children/young people • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Joined-up care requires a substantial amount of time, organisation and commitment • Funding and resources • Relationships between service providers • Organisation of services • Attitudes and social stigma about service

Study	**Population**	**Description of child/young person**	**Methods**	**Themes applied after thematic synthesis**
				provisions
Skipp 2016 Education, Health and Social Care Services	Service users: N=15 Young people with experience of the EHC process N=77 Parents with experience of the EHC process	**Needs or conditions:** Behavioural/social/emotional, cognition and learning, communication and interaction, physical or sensory **Age Range (Mean):** NR	**Setting:** Telephone interviews. Location for focus groups NR **Data collection:** Semi-structured interviews and focus groups	• Relationships between service providers • Joined-up care requires a substantial amount of time, organisation and commitment • Service users' involvement and relationships with service providers • Long waiting times for support • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) • Diagnosis and identification of needs first • An imbalanced distribution in the amount of support provided to children/young people • Funding and resources • Introduction of EHC plans • Importance of key worker/lead professional • Attitudes and social stigma about service provisions • Organisation of services
Smith 2014 Education, Health and Social Care Services	Service users: N=31 Families participating in the new EHC planning pathway that received an EHC plan	**Needs or conditions:** Autism, learning disability, physical disability, learning and physical disabilities,	**Setting:** Family home (face-to-face) and telephone **Data collection:** Interviews	• Funding and resources • An imbalanced distribution in the amount of support provided to children/young people • Joined-up care requires a

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		autism and learning disability, autism and learning and physical disabilities **Age Range (Mean):** 0 to 25 years (NR)		substantial amount of time, organisation and commitment - Long waiting times for support - Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) - Professional and staff knowledge and training - Communication and support - Relationships between service providers - Organisation of services - Importance of key worker/lead professional
Spivack 2014 Education, Health and Social Care Services	Service providers: N=NR Lead professionals involved in collaborative working with social care.	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** NR (face-to-face) and telephone **Data collection:** Semi-structured interviews	- Introduction of EHC plans - Relationships between service providers - Professional and staff knowledge and training - Funding and resources
Taylor 2014 Education, Health and Social Care Services	Service providers: N=61 Professionals with experience of responding to at least two child protection cases involving a disabled child.	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Telephone **Data collection:** Interviews	- Relationships between service providers - Professional and staff knowledge and training - Importance of key worker/lead professional - Information sharing - Service users' involvement and relationships with service providers
Thom 2014 Education, Health	Service providers: N=26 Professionals	**Needs or conditions:** SEND	**Setting:** NR	- Information sharing - Funding and resources

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
and Social Care Services	responsible for engaging with post-16 providers and young people, and/or with experience of post-16 transitions for children and young people with SEND.	**Age Range (Mean):** NR	**Data collection:** Interviews	• Relationships between service providers • Introduction of EHC plans • Attitudes and social stigma about service provisions • Organisation of services
Thom 2015 Education, Health and Social Care Services	Service users: N=9 Children and young people from pathfinder families who had just completed EHC plans N=83 Parents/carers from pathfinder families who had just completed EHC plans	**Needs or conditions:** Autism, learning disabilities, physical disabilities **Age Range (Mean):** 0 to 25 (NR)	**Setting:** Family home or telephone **Data collection:** Interviews	• Importance of key worker/lead professional • Service users' involvement and relationships with service providers • Communication and support
Young 2018 Health and Social Care Services	Service users: N=2 Young people (aged 19 and 23 years) registered with a pilot short-break service for young adults aged 18–24 years with life-limiting conditions N=4 Mothers of young adults registered with the pilot service Service providers: N=15 Health or Social Care staff working the pilot service	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Pilot short-break service for young adults aged 18–24 years with life-limiting conditions **Data collection:** Semi-structured interviews or focus groups	• Organisation of services • Funding and resources • Relationships between service providers

ADHD: attention deficit hyperactivity disorder; ASD: autistic spectrum disorder; EHC: education health care; FAS: fetal alcohol syndrome; FASD: fetal alcohol spectrum disorders; NR: not reported; ODD: oppositional defiance disorder; SCERTS: social communication, emotional regulation, transactional support; SEN: special educational needs; SENCO: special educational needs coordinator; SEND: special educational needs and disability; YP: young people

See the full evidence tables in appendix D. No meta-analysis was conducted (and so there are no forest plots in appendix E).

The following themes were identified through analysis of the included studies:

- Relationships between service providers

- Communication and support
- Service users’ involvement and relationships with service providers
- Attitudes and social stigma about service provisions
- Funding and resources
- Organisation of services
- Information sharing
- Long waiting times for support
- Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)
- An imbalanced distribution in the amount of support provided to children/young people
- Professional and staff knowledge and training
- Joined-up care requires a substantial amount of time, organisation and commitment
- Working across multiple services
- Diagnosis and identification of needs first
- Introduction of EHC plans
- Importance of key worker or lead professional
- Transition

The data from the included studies were synthesised and explored in a number of central themes and sub-themes (central themes shown in **Error! Reference source not found.**; see appendix L for sub-theme maps).

Figure 1: Theme map

Summary of the qualitative evidence

The evidence generated 17 main themes. Twenty studies provided evidence relating to relationships between service providers. Fourteen studies provided evidence relating to communication and support. Ten studies provided evidence relating to the involvement of disabled children and young people and their families and carers, and their relationships with service providers. Nine studies provided evidence relating to attitudes and social stigma about service provisions. Fourteen studies provided evidence relating to funding and resources. Eighteen studies provided evidence relating to organisation of services. Twelve studies provided evidence relating to information sharing. Twelve studies provided evidence relating to long waiting times for support. Nine studies provided evidence relating to difficulty in obtaining an education, health and care (EHC) plan (or replacing a statement of special educational need with an EHC plan). Ten studies provided evidence relating to an imbalanced distribution in the amount of support provided to children and young people. Eleven studies provided evidence relating to professional and staff knowledge and training. Fifteen studies provided evidence relating to joined-up care requiring a substantial amount of time, organisation and commitment. Three studies provided evidence relating to working across multiple services. Nine studies provided evidence relating to diagnosis and identification of needs first. Seven studies provided evidence relating to the introduction of EHC plans. Nine studies provided evidence relating to the importance of a key worker or lead professional. Three studies provided evidence relating to transition. The quality of the evidence ranged from very low to high.

See appendix F for full GRADE-CERQual tables.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no economic studies were identified which were applicable to this review question. A single economic search was undertaken for all topics included in the scope of this guideline. See Supplement B for details.

Excluded studies

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

Summary of included economic evidence

No economic studies were identified which were applicable to this review question.

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

No economic studies were identified which were applicable to this review question.

The committee’s discussion and interpretation of the evidence

The outcomes that matter most

The committee agreed that the views of children and young people, their families and carers and commissioners, providers and practitioners should be considered to capture a broad range of perspectives. Both general views and perceived barriers and facilitators of joined-up care across education, health, social care, and other services for disabled children and young people with severe complex needs were considered. The committee did not pre-specify themes as they did not want to constrain the evidence, however they identified a number of potential themes as illustrative of the main themes to guide the review. The potential themes were not exhaustive and an emergent approach was taken to the thematic analysis. The committee focused their discussion only on themes that emerged from the evidence; the potential themes were not discussed by the committee when developing recommendations. This question presents the barriers and facilitators of joined-up care. The general experiences of children and young people, their families and carers, commissioners, providers and practitioners are considered in other review questions (see evidence reports A and M).

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall quality ranged from very low to high. Concerns about the methodological limitations of the primary studies were assessed with the CASP checklist and ranged from “major” to “none or very minor”. The most common issues were lack of consideration of the relationship between researcher and participants, somewhat limited detail provided on data analysis, no justification for the data collection methods and setting, an absence of a clear statement of findings, lack of information about recruitment and potential for recruitment bias and a lack of information about, or justification for, study design. Concerns about coherence ranged from “minor” to “none or very minor”. For the majority of the review findings, concerns were “none or very minor”, as there was no ambiguous data nor data that contradicted the findings. For the remaining findings, some of the evidence was contradictory. Concerns about relevance were “none or very minor” for all of the review findings. This is because no evidence from a substantially different context as the review question was included in the review. Concerns about adequacy ranged from “major” to “none or very minor”. There were major concerns where the evidence did not offer rich data moderate concerns where the evidence offered some rich data; and minor concerns where the evidence offered moderately rich data.

The quality of the review findings is summarised here according to the over-arching themes and sub-themes:

Main theme 1: Relationships between service providers

- Sub-theme 1.1: Negative professional relationships and disagreements inhibit joint working. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.2: Service providers failing to take responsibility and be effectively involved in collaborative working. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.3: Importance of understanding the roles, responsibilities and expectations of other professionals/staff. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.4: Putting aside professional differences for the good of the child or young person. The overall quality of this sub-theme was judged to be very moderate.
- Sub-theme 1.5: Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.6: Mutual respect between professionals which allows equal opportunity to have opinions voiced and challenged. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.7: Shared values and priorities promote joint working. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.8: Clear targets improved accountability and the distribution of responsibility across services. The overall quality of this sub-theme was judged to be moderate.

Main theme 2: Communication and support

- Sub-theme 2.1: Lack of communication (verbal and written) between services. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 2.2: Lack of communication and support that address language and cultural barriers. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 2.3: More information and support for service users to understand and access the available services. The overall quality of this sub-theme was judged to be moderate.

Main theme 3: Service users' involvement and relationships with service providers

- Sub-theme 3.1: Co-working improved when professionals worked closely with parents and kept them informed. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 3.2: Families vary in their ability and willingness to make decisions and be involved in care planning. The overall quality of this sub-theme was judged to be moderate.

Main theme 4: Attitudes and social stigmas about service provisions

- Sub-theme 4.1: Fear of, and stigma associated with, social services. The overall quality of this sub-theme was judged to be low.
- Sub-theme 4.2: Need to work at shifting attitudes to look holistically at meeting the needs of children/young people. The overall quality of this sub-theme was judged to be low.
- Sub-theme 4.3: Service providers not 'buying in' to approach. The overall quality of this sub-theme was judged to be low.
- Sub-theme 4.4: Low expectations of the ambitions and capability of children and young people. The overall quality of this sub-theme was judged to be moderate.

Main theme 5: Funding and resources

- Sub-theme 5.1: Joint funding and strategic planning as a method of supporting collaborative working. The overall quality of this sub-theme was judged to be very low.
- Sub-theme 5.2: Lack of funding and resources is a barrier to providing services and person-centred, joined-up care The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.3: Not enough funding or resources to support change from statements to EHC plans. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.4: Funding is driven by special educational needs. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.5: Fighting against financial pressures. The overall quality of this sub-theme was judged to be low.
- Sub-theme 5.6: Competing priorities can impact the allocation of limited resources. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.7: Staffing of services impacts the quality of the service. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.8: Personalised budgets and direct payments increase flexibility but also burden on the family to make decisions and arrange care. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.9: Service providers have a lack of control over allocation of resources and there is a lack of transparency about decision making. The overall quality of this sub-theme was judged to be moderate.

Main theme 6: Organisation of services

- Sub-theme 6.1: Rigid definition of, and criteria for, services leads to gaps in service provision. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 6.2: Specialist services provide benefit but there is a lack of provisions to make these services available. The overall quality of this sub-theme was judged to be low.
- Sub-theme 6.3: Mainstream services provide benefit but more effort and support is needed to integrate children and young people. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 6.4: Lack of appropriate services. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 6.5: Inconsistency across paperwork and procedures used in different services, regions and local authorities. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 6.6: Importance of clear pathways for referrals between services. The overall quality of this sub-theme was judged to be low.
- Sub-theme 6.7: Having the right people involved and collaborating can overcome gaps in service provision. The overall quality of this sub-theme was judged to be very low.
- Sub-theme 6.8: Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial. The overall quality of this sub-theme was judged to be moderate.

Main theme 7: Information sharing

- Sub-theme 7.1: Information is not always shared nor sufficient to meet the needs of other services. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 7.2: Sharing information to streamline processes and transition. The overall quality of this sub-theme was judged to be low.
- Sub-theme 7.3: Sharing information increases understanding of the child or young person and their needs. The overall quality of this sub-theme was judged to be low.
- Sub-theme 7.4: Inconsistent information provided to parents. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 7.5: Accessing electronic patient records through an online portal to improve working. The overall quality of this sub-theme was judged to be high.
- Sub-theme 7.6: Development and sharing of a behaviour management plan provided benefit. The overall quality of this sub-theme was judged to be moderate.

Main theme 8: Long waiting times for support

- Sub-theme 8.1: Lack of urgency to provide support until the child/young person reaches crisis point. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 8.2: Replacements of statements with EHC plans resulted in delays to support provisions. The overall quality of this sub-theme was judged to be moderate.

- Sub-theme 8.3: Unavailability of staff able to complete the necessary paperwork/assessments. The overall quality of this sub-theme was judged to be high.
- Sub-theme 8.4: Additional assessments cause delays in implementing EHC plans. The overall quality of this sub-theme was judged to be high.
- Sub-theme 8.5: Delays from one service can impact access to other services. The overall quality of this sub-theme was judged to be low.

Main theme 9: Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)

- Sub-theme 9.1: An over emphasis on academic progress overshadowed other areas of need and impacted on the child/young person's ability to access an EHC plan. The overall quality of this sub-theme was judged to be high.
- Sub-theme 9.2: Lack of understanding of, and difficulty providing evidence for, SEMH needs is a barrier to accessing EHC plans. The overall quality of this sub-theme was judged to be high.
- Sub-theme 9.3: Not all children/young people who need support meet the criteria for an EHC plan. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.4: The process of getting an EHC plan takes too long and requires a lot of work. The overall quality of this sub-theme was judged to be low.
- Sub-theme 9.5: Children/young people need to reach a crisis point to access EHC plans. The overall quality of this sub-theme was judged to be low.
- Sub-theme 9.6: Professionals, staff and families lack understanding of the EHC plan process. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.7: Professionals and staff lack the expertise and knowledge needed to complete the EHC plan. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.8: There is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.9: A lack of available services is increasing demands for EHC plans. The overall quality of this sub-theme was judged to be high.
- Sub-theme 9.10: Time taken for EHC plans to be refined and embedded in practice. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.11: Revisions to EHC plan paperwork and processes made without consultation or notice. The overall quality of this sub-theme was judged to be high.

Main theme 10: An imbalanced distribution in the amount of support provided to children/young people

- Sub-theme 10.1: Individuals who shout the loudest are more likely to receive the desired support. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 10.2: Looked after children are more likely to receive an EHC plan. The overall quality of this sub-theme was judged to be low.
- Sub-theme 10.3: Families vary in their ability and willingness to fight for services. The overall quality of this sub-theme was judged to be low.

- Sub-theme 10.4: Regional disparity in the availability of services. The overall quality of this sub-theme was judged to be low.

Main theme 11: Professional and staff knowledge and training

- Sub-theme 11.1: Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 11.2: Misconceptions and lack of understanding from professionals lead to incorrect, or a lack of, advice and referrals. The overall quality of this sub-theme was judged to be high.
- Sub-theme 11.3: Multi-agency training is important to bridge the gaps between professionals and get everyone on the same page. The overall quality of this sub-theme was judged to be very low.
- Sub-theme 11.4: Opportunities to learn from, observe and model other services. The overall quality of this sub-theme was judged to be high.
- Sub-theme 11.5: Service providers having knowledge of the EHC plan process. The overall quality of this sub-theme was judged to be moderate.

Main theme 12: Joined-up care requires a substantial amount of time, organisation and commitment

- Sub-theme 12.1: Large time investment is needed by parents to coordinate services and manage appointments. The overall quality of this sub-theme was judged to be low.
- Sub-theme 12.2: Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 12.3: Lack of ongoing involvement from external agencies. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 12.4: Responsibility and resources are required to ensure plans are implemented and reviewed to accurately reflect changing needs. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 12.5: Workloads are negatively impacted by the cumbersome and onerous nature of paperwork and interprofessional working. The overall quality of this sub-theme was judged to be moderate.

Main theme 13: Working across multiple services

- Sub-theme 13.1: Sharing staff across multiple settings improved knowledge of the child. The overall quality of this sub-theme was judged to be low.
- Sub-theme 13.2: Assigned consistent one point of contact or agency would be beneficial to joint working. The overall quality of this sub-theme was judged to be moderate.

Main theme 14: Diagnosis and identification of needs first

- Sub-theme 14.1: Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support. The overall quality of this sub-theme was judged to be moderate.

- Sub-theme 14.2: Professionals were more committed to achieving multi-disciplinary working for complex diagnoses and had to rationalise making an independent diagnosis. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 14.3: Early identification of needs and making referrals before a diagnosis has been reached promotes early access to support. The overall quality of this sub-theme was judged to be low.
- Sub-theme 14.4: Service providers having knowledge of the child or young person's needs at the start of the process. The overall quality of this sub-theme was judged to be high.
- Sub-theme 14.5: Parents identifying concerns and proactively seeking help. The overall quality of this sub-theme was judged to be moderate.

Main theme 15: Introduction of EHC plans

- Sub-theme 15.1: Lack of SMART outcomes in EHC plans makes it unclear what support will be needed and who is responsible for providing it. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 15.2: Recognising the child or young persons' strengths can lead to loss of service provision. The overall quality of this sub-theme was judged to be low.
- Sub-theme 15.3: EHC plans are primarily concentrated around education and place less emphasis on health and social care. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 15.4: EHC plans have increased joint working and integration. The overall quality of this sub-theme was judged to be moderate.

Main theme 16: Importance of key worker or lead professional

- Sub-theme 16.1: Continuity of key worker/lead professional is important for consistency and relationships. The overall quality of this sub-theme was judged to be moderate.
- Sub0theme 16.2: Key worker/lead professional is important for having a holistic view and coordinating services. The overall quality of this sub-theme was judged to be moderate.

Main theme 17: Transition

- Sub-theme 17.1: Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 17.2: Differences in thresholds for accessing adult services compared with child services. The overall quality of this sub-theme was judged to be low.

Benefits and harms

Where the qualitative evidence integrates with quantitative evidence, links are discussed in the associated quantitative reviews. This discussion covers qualitative evidence only.

There was moderate quality evidence from sub-theme 2.3 that families are not given enough information about available services and their roles, and that more support is needed to help families understand their options to empower them to make decisions and help them to access services. The committee were aware that the SEND Code of Practice (2015) specifies that local authorities must provide information and advice on the range of services available and that the Local Offer should include information about all available services. Therefore, they recommended that the local authority should include this information, as well as explaining the roles of different services, in their Local Offer [1.17.15]. The committee also agreed the importance of highlighting that SEND Information, Advice and Support services should help children, young people and their families and carers to understand the relevance of this information to their specific needs [1.1.17]. There was also moderate quality evidence from sub-theme 2.2 that language barriers made it difficult for parents to find out about available services and that more support was needed to help them understand and access what was available. The committee were aware, based on their experience, that parents and carers may also have disabilities or communication difficulties that can create a barrier to communication and understanding available information, in addition to any language barriers. Therefore, they recommended that the most effective way of communication with parents and carers is established, which may include, but is not limited to, providing information in different languages or using an interpreter [1.1.14]. The committee acknowledged that there are variations in the use of interpreters across services, with health services requiring independent translation services compared with extended family and friends often being used as translators in education services. However, the committee did not make a recommendation about this as it should be covered by local policies and service level agreements.

Moderate quality evidence from sub-theme 5.2 showed that some practitioners reported that there has been a decrease in funding and that this has impacted the availability of services and acts as a barrier to providing person-centred, joined-up care. The committee were aware that the SEND Code of Practice (2015) specifies that sufficient funding must be provided to cover all support listed in EHC plans, and made a recommendation to highlight this [1.4.23]. There was moderate quality evidence from sub-theme 5.9 that practitioners' requests for additional funding to support a child or young person can be refused without a reason being provided. This causes frustration, creates an obstacle to providing transparent information to children, young people and their families, and can make it difficult to construct an appeal. Therefore, the committee made a strong recommendation that those making the decisions explain the reasons for any refusals to practitioners, the child or young person and their family and explain how to make an appeal [1.4.24]. Further, low quality evidence from sub-theme 5.5 highlighted that some practitioners felt financial pressure to not apply for EHC plans. This was somewhat consistent with views from parents that there is pressure to accept services that are less costly than others. The committee noted that the SEND Code of Practice (2015) requires EHC needs assessment to be based on a recognised threshold of special educational need and not on other factors such as potential availability of funding and, therefore, recommended that local authorities explain that EHC needs assessment should be requested based solely on a child or young person's needs [1.3.2]. The committee also agreed to highlight the importance of including this information in the Local Offer [1.17.15].

There was moderate quality evidence in sub-theme 6.1 from both families and practitioners that narrow entry criteria for services, such as requiring a specific diagnosis or having different age thresholds based on diagnosis, created gaps in service provision. Further, parents reported that some services had entry criteria that depended on previous use of services, such as being ineligible for adult mental health services if their child had attended mainstream school. The committee discussed that it may be appropriate to limit some specialised services to a specific diagnosis but that it is important to consider whether a child's or young person's needs are consistent with those services' aims and if, therefore, they are likely to derive benefit from the service. Therefore, the committee agreed that access should not be based on diagnosis (unless there is a medical reason for this) and/or previous use of services alone and that needs and potential contraindications should also be considered [1.17.3].

There was moderate quality evidence from sub-theme 6.8 that parents, carers and practitioners thought that services were inflexible and that children were required to fit within existing services rather than asking families what they need from services. The committee were aware that the SEND Code of Practice (2015) states that local authorities must involve children, young people and their parents in planning and reviewing the Local Offer, which gives families the opportunity to say what services they think are needed and to raise if they are not happy with the available services. However, in the committee's experience, feedback is rarely given, which could indicate that people do not know how to do this, and some parents reported that they do not know what the Local Offer is. Therefore, the committee made a recommendation to support children, young people and their families to provide this feedback [1.17.16].

Moderate quality evidence from sub-theme 6.3 highlighted that practitioners and parents reported that mainstream services, including education, provided a benefit but more effort, support and training was needed for education providers in order to integrate disabled children and young people into mainstream education. There was also evidence that specialist services provide a benefit, but this was very low quality evidence and not specific to education. Therefore, the committee agreed they could not make a recommendation about whether disabled children and young people with severe complex needs should attend mainstream or specialist schools, but made a recommendation in support of training for education practitioners to support integration where appropriate [1.15.18].

There was some moderate quality evidence from sub-themes 1.1 and 1.4 that there can be negative relationships between professionals and that there can be professional differences and disagreements due to this and competing roles. However, evidence from sub-theme 1.4 reported that practitioners agreed it was important to put aside differences to work together for the good of the child. Conversely, there was moderate quality evidence from sub-theme 1.6 that mutual respect and viewing other practitioners as equal partners increased the opportunity to raise opinions and challenge those of others, which was seen to improve joint working. There was also moderate quality evidence from sub-theme 1.5 that working relationships improved when practitioners worked together frequently or for an extended period of time, and had the opportunity to meet face-to-face. The committee agreed that if practitioners collaborated to develop a positive working culture and take the time to develop positive relationships with each other this would improve joint working [1.14.1]. The committee acknowledged that there needs to be the opportunity to air and resolve disputes to improve working relationships. The committee agreed that most services have procedures and policies in place for how to deal with disagreement within their service, but in their experience there would be a benefit to establishing policies and procedures for resolving interagency disagreements [1.15.3; 1.16.4]. Without such policies and procedures in place, disagreements between different services may not be resolved which would be likely to negatively affect the quality of support provided to children and young people.

There was evidence that closer joint working improved knowledge and understanding of others roles, responsibilities and expectations, which in turn made it easier to have discussions with colleagues and focus on meeting the needs of the child or young person. Based on their experience, the committee agreed that training practitioners to understand the roles of other people and services involved in the care of children and young people would improve joint working. However as they did not have evidence of the effectiveness of training to do this, they made a weak recommendation [1.15.17]. There was also moderate quality evidence from sub-theme 1.7 that joint working improved when practitioners had shared values, particularly regarding commitment to working collaboratively and using a child or young person-centred approach. The committee agreed that this was important but did not make a specific recommendation in response, as following the recommendations made in this guideline should help to align these values across services and individual practitioners. The committee agreed that service managers should make sure there is dedicated time for team and relationship building to enable the above recommendations as, based on their experience, it would be difficult for practitioners to find the time to develop relationships without dedicated time for this and support from managers [1.15.1]. The committee acknowledged that time and resources are stretched but agreed that dedicated time didn’t necessarily mean additional time and that this is often built into training and away days. There was also moderate quality evidence from sub-theme 1.5 that working relationships improved with co-location of services, but the evidence was not of sufficient quality to recommend this due to the significant impact it would have on the organisation of services.

There was moderate quality evidence from sub-theme 1.2 that practitioners were failing to take responsibility to be effectively involved in collaborative working, including that they did not attend interagency meetings, or that they failed to prepare for meetings in advance. The committee agreed that it was crucial practitioners make all reasonable efforts to attend meetings to enable effective joint planning to meet the needs of disabled children and young people with severe complex needs (as required by the SEND Code of practice (2015)) but acknowledged that it may not always be possible to attend. In these instances, the committee agreed that the person who arranged the meeting should be informed, that ideally a briefed delegate, or alternatively a written update or report, should be sent in the practitioner’s place and that it is important the practitioner requests details of any actions relevant to them from the meeting where they were absent, that these are followed up and that minutes and action logs from the meeting are reviewed when available [1.1.32]. The committee agreed that taking these steps would help to ensure that meeting time is used effectively and that non-attendance at meetings would not introduce delays in decision-making and provision of support. In the committee’s experience, having someone the child or young person and their family is unfamiliar, or uncomfortable with, at meetings may cause them discomfort or distress and limit the productivity of meetings. Therefore, they acknowledged that sometimes it may be in the best interest to reschedule meetings, if this does not pose a risk to meeting statutory timescales. However, the committee agreed that it was also important to consider the impact of rescheduling on the family as, for example, parents or carers may need to take time off work to attend meetings which could result in a loss of income [1.1.31].

There was moderate quality evidence from sub-theme 1.8 that having actions that were agreed in front of other practitioners and parents improved accountability and made it more likely that practitioners would follow through on agreed actions. The committee discussed whether this should just apply to actions arising from formal interagency meetings but agreed it should apply to all interagency interactions. They acknowledged that it will not always be possible to agree actions in front of practitioners, children and young people and their parent and carers, but agreed that actions that will directly affect the child or young person should be recorded in an action log and shared with everyone. They also agreed that the actions need to be recorded in a format that can be understood, as it would be unlikely that the same benefits of improved follow through would be seen if they are not in a format that can be understood by everyone, as there would be less accountability (particularly if the child or young person has cognitive impairments or communication needs or disorders) [1.1.29]. Finally, the committee agreed that reviewing the action log regularly to ensure the actions are being done would also be likely to increase the likelihood of practitioners following through on actions and reduce delays [1.1.29]. Moderate quality evidence from theme 16 highlighted that key workers are seen as important for having a holistic view of the child or young person and coordinating services. The committee recommended that a practitioner should be assigned to provide key working support for each child and young person [1.15.10]. Also that children, young people and their families are provided with the contact details for the practitioner providing key working support based on moderate quality evidence from sub-theme 13.2 that a single point of contact would simplify processes and be beneficial to joint working [1.15.9]. This also aligns with the main functions of key working support that are specified in the SEND Code of Practice (2015). There was low to moderate quality evidence from sub-themes 12.1 and 12.2 and another qualitative review (evidence report A, sub-theme 4.2) that children, young people and their families spent a considerable amount of time chasing and coordinating services, conducting administrative work and arranging meetings. There was also low to moderate quality evidence from sub-themes 2.1 and 12.1 that there is a lack of communication between services. Therefore, the committee agreed that those undertaking key working support should be responsible for coordinating and communicating with different services so that parents and carers are not expected to carry out all of this work themselves [1.15.11], which aligns with main functions of key working support that are specified in the SEND Code of Practice (2015). There was low quality evidence from sub-theme 12.1 that parents and carers felt a sense of responsibility in driving the necessary care provisions and invested a large amount of time to coordinate services and manage appointments. This reflected the committees' experience and they agreed that parents and carers should not have to carry out all of this work themselves, as doing so took time and energy away from parenting and/or caring for the child or young person. The committee agreed that the recommendations made about providing key working support should help to address these issues. Further, there was moderate quality evidence from sub-theme 2.3 that more information and support is needed for children, young people and their families to understand and access available services so the committee recommended that practitioners providing key working support also help children and young people and their families to navigate services and are available between reviews and meetings if additional support is needed [1.15.11]. This aligns with provision of information and signposting, which is a main function of key working support in the SEND Code of Practice (2015). There was moderate quality evidence from sub-theme 16.1 that the continuity of key workers, particularly during transition to adult services, is important for consistency and that children and young people felt negatively where key worker support ended prematurely. The committee agreed that staff turnover is inevitable so it is not plausible to recommend that there are not any changes in who provides key working support, but that organising a good handover [1.15.12] and having a contingency plan in place to maintain consistency [1.15.14] should help minimise the impact of a change in practitioner on children and young people. They also noted, based on their experience, that there are some families who do not have a permanently fixed location and move frequently. In such instances there can be difficulties with effective coordination of care and support and timely transfer of information resulting in a detriment to the care and support received by the child or young person. The committee agreed this would be a potential equalities issue and so recommended that the practitioner who provides key working support should be responsible for identifying practitioners in the families new area to share relevant information with, to ensure continuity of care and support and that the family and carers should be given a copy of the information [1.15.13].

Low quality evidence in sub-theme 6.6, noted that practitioners reported that there was a lack of clear pathways for referral between services and that joint working only happened on an ad hoc basis. This reflected the experience of the committee. They were confident that making the processes for referral more effective would help practitioners provide effective and co-ordinated care and support to disabled children and young people with severe complex needs. They made recommendations on how to do this. [1.17.5]. There was high quality evidence from sub-theme 7.5 that practitioners reported discrepancies in which services could access online electronic patient records and that they believed being able to access such records would improve joint working and increase information sharing and identification of disabled children and young people. However, whilst electronic patient records are kept within services, there is currently no established inter-agency record system and the development of such a system would have a significant resource impact and require careful consideration around issues of data protection. Therefore, the committee agreed that it was not possible to make a recommendation in support of shared electronic patient records but agreed that information that the child or young person has agreed to share should be made available to all services involved in supporting that child or young person [1.1.46]. There was also moderate quality evidence from sub-theme 7.1 that some practitioners felt they did not have the opportunity to contribute relevant information that they had about a child or young person. Therefore, the committee recommended that people make use of all information available when conducting assessments in order to build a comprehensive picture of the child or young person’s needs [1.3.11]. One specific area of information sharing highlighted by the moderate quality evidence in sub-theme 7.6 was the development and sharing of a behaviour management plan. Families reported that this provided benefit in terms of helping the child or young person to acquire new skills and providing direction for those newly involved with the child or young person. Given the fact that not all children and young people with severe complex needs will require a behaviour management plan, the committee did not think it was appropriate to recommend that specialised care plans should be developed. However, they agreed that when specialised care plans have been agreed, it would be sensible to share these with all practitioners working with that child or young person to improve their knowledge and understanding of their needs and ensure a consistent approach is used across settings, and made a recommendation supporting this [1.1.47]. This was supported by moderate quality evidence from sub-theme 1.2 in evidence report M that using a consistent approach when interacting with children and young people was beneficial, in terms of being more predictable and helping them to generalise across different settings. The committee discussed that some services may have access to shared care records or digital systems where such care plans could be recorded, which would reduce the need for manually sharing plans. However, as discussed above, there is currently no established inter-agency record system so it is important that care plans are also shared outside of these systems.

There was moderate and high quality evidence from sub-themes 3.1 and 8.3 that children, young people and their families reported good working relationships with practitioners when they were in regular contact and kept informed, and that children and young people experienced anxiety when they didn't know what was happening. There was also low to high quality evidence from sub-themes 2.3, 2.4 and 2.5 in another qualitative review (evidence report A) that service users needed more information and advice about people's roles and aspects of the child or young person's care and that information was often outdated. Therefore, the committee agreed it was important that children, young people and their families are provided with up-to-date information about the care and support they are receiving, and informed about the reason for any delays or changes [1.1.15]. This was further supported by moderate evidence from sub-themes 1.6, 4.2 and 6.3 in evidence report A which showed that families felt stressed and frustrated by the lack of information around delays, whilst families that were kept informed felt more positively. There was also moderate quality evidence from sub-theme 3.1 that children and young people and their families valued when practitioners used the same approach that families had been using at home. The committee discussed the importance of consistency, as highlighted by sub-theme 1.2 in evidence report M, if the approaches used have been beneficial, and made a recommendation in support of this [1.1.8]. Evidence from sub-theme 3.1 also showed that children, young people and their families valued when information was provided in a non-directive way. The committee discussed that this is part of good practice and allows people to consider their options based on factual information. However, they acknowledged that there are situations where it will not be possible to offer a choice, for example where there are statutory requirements. Therefore, they focused the recommendation on providing information without being directive, whilst valuing the experience and perspective of families and carers [1.1.10]. This was supported by moderate quality evidence from sub-theme 9.4 in evidence report A that parents praised when practitioners valued their expertise.

In sub-theme 3.2, there was moderate quality evidence that parents did not always think it was appropriate for them to be involved in making decisions about their child's care due to limited knowledge and expertise. The committee discussed that, in their experience, there is variation in how involved parents feel able or are willing to be and, therefore, recommended that this is discussed with parents [1.6.3]. However, the committee acknowledged that this does not give parents the right to give up parental responsibility, and they will have to consent to the final decision even if they decided to be guided by professional advice without having an in depth discussion about all available options. They therefore recommended that information is provided to children, young people and their parents to enable them to contribute to decision making as fully as possible [1.1.36]. Provision of information is a requirement of the SEND Code of Practice (2015).

There was moderate quality evidence from sub-theme 5.8 that personal budgets and direct payments can increase flexibility and give families greater choice about what services they use, but that it also created additional responsibility for the family. Further, some parents reported they were not sure if they were able, or wanted, to take on the responsibility and questioned whether they had sufficient knowledge to make care decisions and if the receipt of personal budgets and direct payments would impact ongoing professional involvement. As the SEND Code of Practice (2015) requires local authorities to provide all parents, children and young people with impartial information, advice and support in relation to special educational needs, which includes personal budgets, the committee made a strong recommendation for local authorities to provide children, young people and their families with information about personal budgets (including personal health budgets) and direct payments to help them decide if they would like to receive these [1.5.1]. In the committee's experience, when services are commissioned through direct payments and families become the commissioners of care, there can be loss of coordination between support purchased through direct payments and statutory support provided directly through health and social care providers. Therefore, the committee recommended that local authorities and health commissioners continue to ensure services coordinate even if they have been commissioned using direct payments [1.5.2]. If this is not done, then this would likely increase the demands on families to coordinate care, which has already been highlighted in the evidence above (sub-themes 12.1 and 12.2 in this report and sub-theme 4.2 in evidence report A) as taking a considerable amount of time. The committee were aware that personal budgets are mandatory for people aged 18 and over who have a care and support plan, but they have a choice about whether they receive this budget as a direct payment and, therefore, have control of the funds or if this remains with the local authority. They agreed it was important to have a recommendation to make people aware of this as, in their experience, the difference between personal budgets and direct payments is not well understood which may lead to families being provided with inaccurate information and unable to make informed decisions [1.5.3].

Moderate quality evidence from sub-theme 3.1 highlighted that families value professionals who had good communication styles, including being non-judgemental and non-directive. In addition, there was evidence from sub-theme 3.1 in evidence report A that families appreciated when practitioners tailored their communication style to suit the topic of conversation. Therefore, the committee made a recommendation in support of using empathetic and supportive language [1.1.9]. The committee agreed that it was important that children, young people and their families and carers are asked for feedback about how well services have worked with them as their perception of practitioner's behaviour and communication may differ from the views of the practitioners themselves [1.15.31]. Similarly, it is valuable to ask children, young people and their families and carers about how well services have worked with each other because of the different perspective they may have on this, compared with practitioners [1.15.30]. Finally, the committee agreed that there needs to be processes in place for addressing the feedback if children, young people and their families and carers are not happy with how services have worked with them or each other, so that improvements can be made [1.15.32].

There was low quality evidence from sub-theme 4.1 that families can be reluctant to engage with social care services, due to either fear that social service involvement could lead to children being removed from the home or because of perceived stigma. The committee discussed that there is confusion between the different aspects of social care services and that some people, including practitioners working in other services, are more aware of child protection social care services that are involved in safeguarding issues, than family support services which are there to provide support for children and young people with social service needs. Therefore, the committee agreed that it was important to find out what families know about social care services at the point that social care involvement is suggested, and that the difference between child protection social services and broader family support services are explained [1.2.7]. The committee were confident that explaining this information would help to alleviate concerns and increase uptake of social care support, resulting in better provision for the child or young person. This would be particularly relevant for those with characteristics associated with vulnerability and stigma (e.g. travellers).

There was moderate quality evidence from sub-theme 4.4 that children, young people and their parents, and practitioners, reported that some practitioners have low expectations of disabled children and young people and are not good at recognising their ambitions or capabilities. This is supported by moderate quality evidence from sub-theme 1.4 in evidence report M, which agreed that disabled children and young people are often underestimated. Further, in the committee's experience, many disabled children and young people with severe complex needs may not have had the opportunity to consider what is possible for them in terms of future aspirations in relation to employment, independence, relationships and community involvement due to a lack of disabled role models. This lack of awareness of what might be possible can lead to restricted goals and ambitions and outcomes in an EHC plan that do not reflect the genuine strengths, abilities and interest of children and young people. Therefore, the committee recommended that children and young people are encouraged to express their goals and ambitions, and explore their strengths, abilities and interests, and that these are focused on when deciding outcomes for the EHC plan [1.4.1]. Further, they highlighted that expectations should be based on the child or young person's goals and ambitions, not on their condition or profile of needs [1.4.4]. This is consistent with the SEND Code of Practice (2015), which places an emphasis on supporting children and young people to realise their ambitions.

Children, young people and their parents reported in sub-theme 5.7 (moderate quality evidence) that sometimes there could be limited opportunities for service users to engage in activities and interact with practitioners when attending respite services. The committee agreed that social inclusion is important for everyone and that some of the best opportunities for social activities for disabled children and young people may come from attendance at short break and respite services as support may be needed to enable the child or young person to engage in activities. Therefore, they agreed that these services should be used for the benefit of the child or young person, which may include running group social activities, for example, and not just for the purpose of providing a break for families [1.7.6]. Provision of short break services is a statutory requirement.

There was moderate quality evidence from sub-theme 8.1 that service providers and service users felt there was a lack of urgency to provide support until the child or young person reached crisis point, but that reaching a crisis point could be avoided if support was provided earlier. The committee noted the evidence aligned with their experience and suggested that a lack of resourcing and prioritising and statutory obligations all impacted on the situation. The committee had also experienced issues with threshold criteria for accessing support meaning that support only became available after a crisis point had been reached. Therefore, the committee felt strong recommendations were needed in support of early interagency involvement to identify, assess and address needs [1.17.1] and to provide support as soon as the need has been identified to avoid children and young people reaching a crisis point. In addition, the committee agreed that the transition from interim support to the EHC plan should be simple as possible to avoid disruption to the support provided [1.3.8]. In further support of these recommendations, they noted that the SEND Code of Practice (2015) specifies that "where particular services are assessed as being needed, their provision should be delivered in line with the relevant statutory guidance and should not be delayed until the EHC plan is complete".

There was high quality evidence from sub-theme 8.4 that additional assessment caused delays when implementing EHC plans, for example schools conducting their own assessments of the child or young person. The committee noted that implementing the EHC plan was key to providing the necessary care, so recommended that this should happen when provisions are in place, without waiting for the results of other assessments or for a final draft to be agreed, so that needs can start being met as soon as possible [1.4.18].

There was high quality evidence from sub-theme 9.2 that service providers reported there is a lack of understanding of social, emotional and mental health needs (SEMH), and difficulty providing evidence of these needs, which subsequently led to barriers in accessing EHC plans for children and young people with SEMH needs. It was agreed that training practitioners to help them recognise SEMH needs and internalising symptoms would help to address this issue, and the committee made a recommendation supporting this [1.15.19]. The committee also noted, based on their experience, that there is a high demand for access to mental health services and that this was also likely to be a barrier. However, they were not able to make any recommendations in this area as it is not an issue exclusive to children and young people with severe complex needs and so is outside the scope of this guideline.

There was low quality evidence from sub-theme 9.4 that service users felt the process of getting an EHC plan took too long, and required a lot of effort on their part. There was also moderate quality evidence from service providers in sub-theme 9.8 that there is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints. The committee were aware that the SEND Code of Practice (2015) specifies time limits for local authorities, services and practitioners in relation to EHC needs assessments and EHC plans. In light of the evidence suggesting that these time limits may not be reached in practice, supported by their own experience, the committee made recommendations to highlight the requirements in the SEND Code of Practice (2015) [1.3.12]. Whilst the evidence was only about the EHC plan process, the committee agreed, based on their experience that having increased transparency about what services do and how they work together would improve the child or young persons' understanding of how to navigate the system. It would also increase their confidence in the care and support they are receiving an empower them to be more assertive about their needs. Therefore, the committee agreed services should consider doing this. They thought the Local Offer could be used to facilitate transparency because there is a requirement for the Local Offer to share the pathways to access support [1.15.16].

There was low quality evidence from sub-theme 9.5 that service users felt the child or young person had to reach a crisis point, such as exclusion from school or the family home, before an EHC plan was considered necessary. The committee agreed that empowering families to make a request for an EHC needs assessment, providing information on how to get help with this process, and how to appeal if the local authority decides an EHC assessment or plan is not needed, may aid in preventing the child or young person from reaching crisis point. Whilst all of this information is already in the SEND Code of Practice (2015), the committee agreed that practitioners being able to provide this information would make it more accessible [1.3.1], based on the moderate quality evidence from sub-theme 2.3 that more information and support was needed to empower families to access services. The committee also agreed that any thresholds or eligibility criteria used by local authorities for their EHC needs assessment process should be included in the Local Offer so families have easy access to this information [1.17.15].

There was moderate quality evidence from sub-theme 9.6 that both service providers and service users lacked understanding of the EHC plan process. Further, moderate quality evidence from sub-theme 12.5 suggested that the workloads of service providers were negatively impacted by the cumbersome and onerous nature of paperwork, and challenges when communicating with, and coordinating between services. A lack of training or knowledge from individuals about writing EHC plans was seen as a concern, which service providers felt led to discrepancies and a lack of consistency. As local authorities hold responsibility for the EHC process, and writing good quality EHC plans is crucial to achieving the aims set out in the SEND Code of Practice (2015), the committee recommended that they provide training for practitioners to help them understand the EHC needs assessment process, how an EHC plan is developed and how to write and EHC plan [1.17.13]. The committee also agreed it was important to discuss expectations with children and young people and their parents and carers and explain the purpose and process of EHC plans, including how they can be involved, possible outcomes and review processes [1.3.4]. This was consistent with high quality evidence from sub-theme 4.1 in evidence report M that sometime practitioners had to manage parents' expectations.

There was moderate quality evidence from sub-theme 9.7 that service providers lacked the expertise and knowledge needed to complete the EHC plan. The committee discussed that in practice EHC plans are often based on old information and therefore do not fulfil their purpose. The committee agreed that it is the responsibility of local authorities to ensure that EHC plans are based on up-to-date information, and are written by practitioners who have the right expertise and knowledge of the child or young person, and a recommendation was made to this effect [1.4.13]. Again, the committee made a strong recommendation because preparing good quality EHC plans is crucial to achieving the aims set out in the SEND Code of Practice (2015).

There was high quality evidence from sub-theme 9.11 that service providers experienced revisions to EHC plan paperwork and processes occurring without consultation or notice, which can result in additional work to transfer completed EHC plans to a new version. The committee reflected that this does happen in practice and is a source of inefficiency and frustration in the EHC plan process. Further, if additional work needs to be done to transfer plans onto new documents, this could cause delays in the provision of support for children and young people. The committee therefore recommended that local authorities should notify services before making changes to their processes for producing EHC plans, and should consider consulting services on these changes to minimise any disruption to the provision of care and make the best use of limited resources by reducing duplication of effort [1.17.11; 1.17.12]. There was also moderate quality evidence from sub-theme 6.5 that inconsistency across paperwork and procedures used in different services, regions and local authorities caused difficulties for centrally based services referring to local services, or when families lived in different counties or local authorities to where the child or young person attended school. The committee discussed whether it was possible to standardise paperwork or recommend that paperwork is not required to be submitted in a specific format as long as it has the required content but agreed that this would not be feasible and would either limit collaboration with children, young people and their families and carers when designing paperwork (if standardised paperwork was used) or undermine attempts to improve the quality of information submitted for EHC plans (if requirements were removed). Therefore, they did not make recommendations in this area.

There was moderate quality evidence from sub-theme 10.1 that both service users and service providers felt that the level of support provided did not always reflect the needs of the child, young person or their family and that those individuals who were more assertive in their communication seemed more likely to get the support they wanted compared to individuals who were more passive or less proactive. The committee discussed that as part of the needs assessment, the views of the child, young person and their family should be gathered, however they had experienced this not always happening in practice. Therefore, the committee felt it import to recommend that practitioners should help families to express their views in order to gauge the views of all children, young people and their families, not just those who were assertive and a record be kept of this information during the assessment process [1.3.7]. This is consistent with guidance in the SEND Code of Practice (2015) that the assessment process should enable children and young people and their parents to express their views.

There was moderate quality evidence in sub-theme 11.1 from both service users and service providers that professionals and staff lacked the necessary skills and knowledge to work effectively to meet the needs of children and young people. The committee were aware of current relevant guidance from the Care Quality Commission, the Nursing and Midwifery Council, the Royal College of Nursing and other professional governance organisations allied to medicine about training and competency in delegated clinical tasks and therefore recommended these are followed by staff to enable them to effectively meet children and young people's needs [1.15.27]. The committee noted that support workers can be delegated clinical care tasks for children and young people with severe complex needs. In these instances, employers would need to follow the same guidance, and a recommendation was made to reflect this [1.15.28]. If this guidance is not followed, then clinical tasks may not be performed safely and there would be the potential for harm to the child or young person.

There was very low quality evidence in sub-theme 11.3 from service providers that multi-agency training was important to bridge the gaps between professionals in different services, increase knowledge, awareness and skillsets, and to get everyone on the same page. The committee relayed experience of individuals working in silos with narrow focus, which had the potential to lead to conflicting advice and a subsequent detriment to the child or young person. The committee agreed that it was important for the staff of all three services to work collaboratively particularly in relation to the production of EHC plans, given their central importance in the SEND Code of Practice (2015). Therefore, the committee recommended that education, health and social care services work together to ensure that staff understand how their contributions affect EHC needs assessment, EHC plan outcomes, and how individual staff contributions fit together to show what support the child or young person needs [1.15.23]. This is consistent with SEND Code of Practice (2015) guidance that services should consider whether combined training would help professionals to meet the needs of children and young people in a more personalised way.

There was high quality evidence from sub-theme 11.4 that service providers valued the opportunity to learn from other services, particularly through observation, modelling and ongoing supervision and feedback. The committee agreed to recommend that services provide practitioners with opportunities to observe other practitioners working with the child or young person as this would facilitate integrated working [1.15.22].

There was moderate quality evidence from sub-theme 12.4 that service providers reported that EHC plans were not always followed through and viewed as a live document that required review and updating, and service users reported that there was a lack of implementation of EHC plans with support services listed in plans not being received. The committee acknowledged that the SEND Code of Practice (2015) provides guidance on detailing the resources needed to provide the support specified in a child or young person's EHC plan, however their experience aligned with the evidence that this guidance is not always followed in practice. Therefore, they made a recommendation to highlight the relevant section of the SEND Code of Practice to facilitate local authorities to follow it [1.4.12]. In addition, different NHS services need to input in specific sections of the EHC plan so that commissioners can see which services need to be provided from which budget lines. In the committee's experience this is often done poorly, with a lack of distinction between what therapeutic support is needed to educate or train the child or young person and what health and medical support they need to stay well. This causes issues with support being provided so they made recommendations to highlight the need provide this information more clearly when writing EHC plans and for commissioners to use this information when planning what services to provide [1.4.9; 1.4.10].

There was moderate quality evidence from sub-theme 15.1 that a lack of specific, measurable, attainable, relevant and timely (SMART) outcomes in EHC plans made it unclear what support will be needed, and who is responsible for providing it. Both service users and service providers felt that EHC plans lacked clarity in dictating responsibility and accountability for ensuring the delivery of service provisions, whilst the inclusion of SMART outcomes in EHC plans would enable service users and providers to hold services accountable and ensure all the necessary provisions are being delivered to support the child or young person. Therefore, the committee recommended that the special education, health and social care support required to help children and young people achieve the outcomes in their EHC plans, should be specified. Further the committee pointed out the outcome sandwich as a helpful tool that could be used to assist practitioners to write outcomes that are meaningful. The committee noted that the SEND Code of Practice (2015) specifies that outcomes in EHC plans should be SMART but that this is not universally done which leads to issues as described in the evidence. Therefore they highlighted the relevant paragraphs of the SEND Code of Practice (2015) to facilitate their implementation [1.4.3; 1.4.11].

There was low quality evidence from sub-theme 15.2 that service users felt concerned that a loss of service provision may occur as a result of recognising the strengths of the child or young person in their EHC plan. The committee agreed that this was a concern, particularly when a child or young person still relies on the support. The committee discussed the example of a child or young person beginning to making some independent journeys to school as part of an independent training package, but still requiring support with journeys on other occasions, such as transportation to a specialist after-school sports club. Therefore, the committee made a strong recommendation that the level of support provided only be reduced if the child or young person no longer requires it, otherwise there was a risk that any improvements made would not be maintained [1.4.22].

The committee discussed that the SEND Code of Practice (2015) recommends service provision is commissioned to meet the needs of the population in that local authority (following a joint strategic needs assessment). However, there was moderate quality evidence from sub-theme 6.8 that children and young people are required to fit within existing services rather than their needs determining what the services should be. This aligned with the committee's experience so they agreed it was it important to re-emphasise in their recommendations that services should be commissioned based on the child or young person's needs and that guidance on identifying the needs of children and young people, and on joint strategic needs assessments could be found in the SEND Code of Practice (2015) [1.17.9; 1.17.10].

There was moderate quality evidence from sub-theme 16.1 that a continued key worker or lead professional was important to maintain consistency and a positive relationship between service users and service providers at transition. Additionally, moderate quality evidence in sub-theme 17.1 from service users and service providers reported that preparations for adulthood and decision making for transition is often insufficient, inconsistent and left too late. It was felt by service users and providers that there was a lack of overarching support or expertise and a lack of coordination between services. The committee agreed that a named worker who oversees and coordinates transition would be effective in bridging the gap in coordination across education, health and social care and would mitigate the need for service users to act as go-betweens. Additionally, the committee agreed that consistency was necessary and felt that in order to avoid delays, detriments or the ceasing of care for the young person when transitioning, the named worker should hand over their responsibilities to someone in adult services [1.8.11]. The committee also noted that these concepts align with recommendations already made in the NICE guideline on transition from children's to adult's services for young people using health or social care services.

There was low quality evidence in sub-theme 17.2 that service users experienced differences in thresholds when transitioning from child to adult services and access to some adult services was dependent on access to other services. In the committee's experience there is variation between services in the age at which the transfer occurs between child and adult services. This results in an uncoordinated process where adherence to age-related service thresholds creates 'blind spots' in the services young people can access because they are 'too old' for child services but 'too young' for adult services. This creates a significant detriment to the care and support young people receive and potentially exposes them to harm (for example young people receiving their health care on adult wards with much older people or where a child is on protection plan but they are too old to go into child services and too young to go into adult services so they end up staying at home in a risky situation). The committee were confident that a consistent approach across services was needed to prevent these blind spots from happening. Based on their experience they recommended that education, health and social care services work with the young person to coordinate the age of transition to adult services. As local authorities are responsible for the EHC plan handover from child to adult services, the committee recommended that local authorities should ensure that this coordination happens in practice [1.8.4].

There were a number of sub-themes where the committee did not make a recommendation based on the qualitative evidence alone. For some sub-themes a recommendation was not made because the evidence from the sub-theme was consistent with a recommendation from other review questions, therefore the evidence was used as further support for those recommendations. These included sub-themes 2.1 (recommendation 1.2.9, see evidence report G), 6.4 (recommendation 1.8.13, see evidence report A), 7.2 (recommendations 1.1.43 and 1.1.45, see evidence report M), 14.1 (recommendation 1.3.9, see evidence report C) and 14.3 (recommendation 1.3.3, see evidence report C). For other themes, recommendations were not made because the committee agreed that the issue raised by the evidence would be reduced as a result of recommendations made elsewhere in the guideline (sub-themes 1.7, 6.2, 6.7, 7.3, 7.4, 8.5, 10.3, 11.2, 12.2, and 14.4). For other themes, the evidence available was not sufficient to support a recommendation because it was very low quality evidence for an intervention or service that would potentially have a large resource impact (sub-themes 5.1 and 10.4), did not provide enough information about how to address the issue raised by the evidence (sub-themes 4.2, 4.3, 5.6, 12.3 and 13.1), was a comment on an intervention without evidence of its effectiveness (sub-themes 11.5, 14.2, 14.5 and 15.4), or the population covered by the evidence was outside the scope of the guideline (sub-theme 5.4). Finally, there were some themes (sub-themes 5.3, 8.2, 9.1, 9.3, 9.9, 9.10, 10.2 and 15.3) commenting on the perceived impact of EHC plans or extending the SEND service provision up to age 25. These are now statutory requirements and so it was outside the remit of this guideline to make recommendations in these areas.

Cost effectiveness and resource use

No existing economic evidence was identified in this area and no economic analysis was undertaken.

The committee discussed cost implications associated with involving interpreters to assist with communication and explained that within health equality of access regulations would cover this and provision of independent interpreters is a requirement. In education, whilst there is no requirement for interpreters to be provided, this function is often undertaken informally by a family member. Where this is not possible an independent interpreter will be provided. In social care it is common practice to use interpreters where required. Therefore the recommendation would not represent a new cost.

The committee discussed resource implications associated with local authorities having to provide practitioners with training to understand the EHC needs assessment process and plan development. The committee explained that such training already exists. Also, the committee noted that services could do this in a variety of low-cost ways, for example remotely, pre-recorded sessions, as part of an induction package. The committee explained that it could reduce conflicting advice and encourage all three sectors to work together more efficiently. The committee was of the view that this could result in overall savings to services, for example by reducing duplication.

The committee discussed staff training, ongoing supervision, and competency assessment concerning carrying out delegated clinical tasks. The committee explained that other statutory bodies and professional governance organisations have guidance around this and it is current practice for this to be done - the recommendations serve to make this more explicit. Therefore they did not consider there would be substantial resource implications from implementing these recommendations. The committee noted that this recommendation might prevent the breakdown in cross-organisational working and prevent critical incidents that could have substantial financial implications to services and detrimental outcomes for children and young people.

The committee discussed training for practitioners to recognise social, emotional and mental health needs. Similarly, the committee explained that such training could be delivered in various low-cost ways, for example, remotely, pre-recorded sessions, as part of an induction package. Also, in some areas, such training already exists. The committee explained that the recommendation should result in those with social, emotional and mental health needs being identified earlier and facilitate earlier, less intensive intervention. It should also help prevent children and young people getting to crisis which is detrimental to their quality of life and more costly to address. The committee also noted that educational mental health practitioners (EMHPs) would be able to address low-level needs.

The committee explained that existing frameworks and processes (for example on training and competency, information sharing, monitoring and review) produced and used by local authorities and health commissioners to ensure the quality of statutory support commissioned directly through health and social care services will need to be applied to support commissioned by families through direct payments. This will ensure that all services supporting children and young people will receive the information needed to provide effective advice and support.

The committee explained that local authorities provide funding for social activities. However, transport costs to get a disabled child or young person to social activity aren’t generally included. This practice limits their ability to access that provision. The requirement to assess the full cost of providing the services agreed is there for health and education, but not in relation to social care provision, i.e. there is no obligation to provide for things such as travel costs to social activities. The practice is that direct payments do not cover such costs. There is often a standardised hourly rate for a direct payment that doesn’t take into account transport and those other aspects of support that need to happen for children and young people to access social services. As a result, the recommendation on this may mean that social services will have to assess such costs, potentially taking more time. The committee explained that the recommendation is about assessment, and in the case of social activities within social care, there is no requirement to provide for such costs and that there are local area thresholds for those provisions. However, the committee was hopeful that this might encourage services to think about their approach and provision differently, i.e. consider making provision for such costs in their direct payments or personal budgets. This may potentially result in an increase in the value of direct payments or personal budgets.

The committee explained that all other recommendations reflect current practice, are ways to improve knowledge or communication or re-iterate or provide supplementary guidance to requirements of the SEND Code of Practice (2015). Therefore, they are not expected to result in additional resource use.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.8 - 1.1.10, 1.1.14, 1.1.15, 1.1.17, 1.1.29, 1.1.31, 1.1.32, 1.1.36, 1.1.46, 1.1.47, 1.2.7, 1.3.1, 1.3.2, 1.3.4, 1.3.7, 1.3.8, 1.3.11, 1.3.12, 1.4.1, 1.4.3, 1.4.4, 1.4.9 - 1.4.13, 1.4.18, 1.4.22 - 1.4.24, 1.5.1 – 1.5.3, 1.6.3, 1.7.6, 1.8.4, 1.8.11, 1.14.1, 1.15.1, 1.15.3, 1.15.9 – 1.15.14, 1.15.16 - 1.15.19, 1.15.22, 1.15.23, 1.15.27, 1.15.28, 1.15.30 – 1.15.32, 1.16.4, 1.17.1, 1.17.3, 1.17.5, 1.17.9 - 1.17.13, 1.17.15, 1.17.16. Other evidence supporting these recommendations can be found in the evidence reviews on Views and experiences of service users (evidence report A), Supporting participation in education and social activities (evidence report F), Views and experiences of service providers (evidence report M), Commissioning, practice and service delivery models (evidence report N).

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Appendices

Appendix A – Review protocol

Review protocol for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	CRD42019151334
1.	Review title	What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?
2.	Review question	For users of health, social care and education services for disabled children and young people with severe complex needs, what are the perceived or experienced barriers and facilitators to joined-up care? For providers and practitioners of health, social care and education services for disabled children and young people with severe complex needs, what are the perceived or experienced barriers and facilitators to joined-up care?
3.	Objective	The views and experiences of service users, providers and practitioners are integral to improving the quality and performance of joined-up care between health, social care and education services. The aim of this review is to identify the barriers and facilitators to joined-up care between health, social care and education services for disabled children and young people with severe complex needs as perceived or experienced by the service users themselves, service providers and practitioners. The qualitative evidence from this review will be combined with quantitative evidence from other systematic reviews on effective joint commissioning, integration and joint working between practitioners across health, social care and education services to identify the optimal delivery of joined-up care.
4.	Searches	The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • Database of Abstracts of Reviews of Effects (DARE) • British Education Index (BEI)

ID	Field	Content
		• Educational Information Resources Center (ERIC) • Health Management Information Consortium (HMIC) • Applied Social Science Index and Abstracts (ASSIA) • Social Care Online • Social Policy and Practice • Social Science Citation Index • Social Services Abstracts • Sociological Abstracts • PsycINFO • CINAHL • Emcare Searches will be restricted by: • Date: 2013 onwards • Language: English Other searches: • Inclusion lists of systematic reviews • Kings Fund Reports (https://www.kingsfund.org.uk/publications) • Open Grey (if insufficient studies are found from other sources) If the main searches have not retrieved enough relevant material and the search needs to be widened, the review team will consider looking at the following resources: • Healthtalk.org • Youthhealthtalk.org • Patient Voices • Healthwatch • The Patient Experience Library • National Voices For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist

ID	Field	Content
		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: Disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support. 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. People who provide, or work in, health care, social care or educational services for disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support. Exclusion: Children and young people who do not have needs in all three areas of health, social care and education. Families and carers of children and young people who do not have needs in all three areas of health, social care and education. People who provide, or work in, health care, social care or educational services for children and young people who do not have needs in all three areas of health, social care and education.
7.	Phenomenon of interest	The views and experiences of service users, service providers and practitioners, specifically on the barriers and facilitators relating to joined-up care between health, social care and education services for disabled children and young people with severe complex needs. Service users: People using or eligible to use all three services; health, social care and education. Service providers: People providing one or more of the three services; health, social care and education. Practitioners: People working in one or more of the three services; health, social care and education
8.	Comparator/Reference standard/Confounding factors	Not applicable
9.	Types of study to be included	Systematic reviews of qualitative studies, and primary qualitative studies, that include semi-structured and structured interviews, focus groups, observations and surveys with free text questions. Qualitative evidence from this review will eventually be incorporated alongside other quantitative reviews. Conference abstracts will not be included.
10.	Other exclusion criteria	Published studies will not be included for the following reasons: • Published prior to 2013 • Not published in the English language • Non UK study Studies published prior to 2013 will not be considered as they will have limited relevance, due to legislative

ID	Field	Content
		changes since that date, specifically the Children and Families Care Act 2014. Studies published in languages other than English will not be considered due to time and resource constraints with translation. Studies published in countries other than the UK will not be considered due to international differences in health, social care and education services to those implemented in the UK.
11.	Context	All settings will be covered in which 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)	Themes specific to joined-up working will be identified from the literature. The guideline committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Budgets (boundaries / combined) • Thresholds and eligibility criteria including diagnosis • Disjointed commissioning & provision, cultures • Information governance/protection, • IT systems/data management and technology • Long term planning • Education & staff training (joint training) • Policy and legislation • Location (co-location, separate locations) • Transports • Adjustments, facilities and communication • Disruption to everyday life • Keyworkers and facilitators • Home-schooling • Age related transitions (e.g. children to adult services, primary to secondary school)
13.	Secondary outcomes (important outcomes)	Not applicable
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. Dual sifting will be performed on at least 10% of records; 90% agreement is required. Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria

ID	Field	Content	
		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. A standardised form will be used to extract data from studies. 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: • CASP checklist for qualitative studies The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.	
16.	Strategy for data synthesis	Qualitative review: Secondary thematic analysis will be used to synthesise the evidence from individual studies. The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, applicability, coherence and adequacy of data. Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Applicability of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question. Coherence of findings will be assessed by examining the clarity of the data and the consistency of the findings within each theme. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Combination with results from quantitative reviews: Qualitative and quantitative syntheses will conducted separately and then recommendations from the qualitative synthesis will be used to contextualize quantitative data, for example the acceptability and barriers to / facilitators of interventions reported in the quantitative reviews.	
17.	Analysis of sub-groups	Formal subgroup analyses are not appropriate for this question due to qualitative data, but the views and experience of the following groups will be considered separately if there is inconsistency or incoherence in the results of a given theme: • Children and young people • Family/carers • Providers (including commissioning and statutory organisations) • Practitioners	
18.	Type and method of review	☐	Intervention
		☐	Diagnostic
		☐	Prognostic
		☒	Qualitative

ID	Field	Content		
		☐	Epidemiologic	
		☒	Service Delivery	
		☐	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	28/08/19		
22.	Anticipated completion date	May 2021		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑ ☑	☐ ☐
		Piloting of the study selection process	☐ ☐	☐ ☐
		Formal screening of search results against eligibility criteria	☐ ☐	☐ ☐
		Data extraction	☐ ☐	☐ ☐
		Risk of bias (quality) assessment	☐ ☐	☐ ☐
		Data analysis	☐ ☐	☐ ☐
24.	Named contact	5a. Named contact National Guideline Alliance 5b Named contact e-mail 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		

ID	Field	Content	
		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=151334	
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
		☐	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	

ASSIA: Applied Social Science Index and Abstracts; BEI: British Education Index; CASP: Critical Appraisals Skills Programme; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; CINAHL: Cumulative Index to Nursing & Allied Health; DARE: Database of Abstracts of Reviews of Effects; EHCP: education, health and care plan; ERIC: Educational Information Resources Center; ERIC: Educational Information Resources Center; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HMIC: Health Management Information Consortium; HTA: Health Technology Assessment; IT: information and technology; NICE: National Institute for Health and Care Excellence; OECD: Organisation for Economic Co-operation and Development; PRESS: Peer Review of Electronic Search Strategies; SEN: special educational needs

Appendix B – Literature search strategies

Literature search strategies for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services 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: 06/09/2019

#	Searches
1	interview:.mp.
2	experience:.mp.
3	qualitative.tw.
4	or/1-3
5	mixed method?.ti,ab.
6	ADOLESCENT/ or MINORS/
7	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
8	exp CHILD/
9	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
10	exp INFANT/
11	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
12	exp PEDIATRICS/
13	p?ediatric$.ti,ab.
14	YOUNG ADULT/
15	young$ adult?.ti,ab.
16	or/6-15
17	exp DISABLED PERSONS/
18	exp MENTAL DISORDERS/
19	exp COMMUNICATION DISORDERS/
20	exp INTELLECTUAL DISABILITY/
21	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
22	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
23	SHCN.ti,ab.
24	or/17-23
25	16 and 24
26	DISABLED CHILDREN/
27	CSHCN.ti,ab.
28	"Education Health and Care plan?".ti,ab.
29	EHC plan?.ti,ab.
30	EHCP?.ti,ab.
31	or/25-30
32	(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/ or SOCIAL SUPPORT/) 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/)
33	((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 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
34	or/32-33
35	INTERINSTITUTIONAL RELATIONS/
36	INTERSECTORAL COLLABORATION/
37	"DELIVERY OF HEALTH CARE, INTEGRATED"/
38	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
39	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
40	(intersector$ or multisector$ or jointsector$).ti,ab.
41	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
42	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
43	((inter or multi or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or profession$)).ti,ab.
44	((institution$ or organi?ation$ or sector$ or agenc$ 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.
45	or/35-44
46	(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

#	Searches
	MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/)
47	(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 NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
48	(exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/) 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/)
49	or/46-48
50	"HEALTH SERVICES NEEDS AND DEMAND"/
51	DELIVERY OF HEALTH CARE/
52	COOPERATIVE BEHAVIOR/
53	COMMUNICATION/
54	INTERPROFESSIONAL RELATIONS/
55	or/50-54
56	((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 (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$)).ti,ab.
57	((health$ 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 (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$)).ti,ab.
58	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (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.
59	or/56-58
60	STATE MEDICINE/og [Organization & Administration]
61	CHILD HEALTH SERVICES/og [Organization & Administration]
62	ADOLESCENT HEALTH SERVICES/og [Organization & Administration]
63	EDUCATION/og [Organization & Administration]
64	exp EDUCATION, SPECIAL/og [Organization & Administration]
65	exp SOCIAL WORK/og [Organization & Administration]
66	or/60-65
67	31 and 34
68	31 and 45
69	31 and 49 and 55
70	31 and 59
71	31 and 66
72	or/67-71
73	limit 72 to english language
74	limit 73 to yr="2000 -Current"
75	4 and 74
76	5 and 74
77	or/75-76

Databases: Embase; and Embase Classic

Date of last search: 06/09/2019

#	Searches
1	interview:.tw.
2	exp HEALTH CARE ORGANIZATION/
3	experiences.tw.
4	or/1-3
5	mixed method?.ti,ab.
6	exp ADOLESCENT/
7	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
8	exp CHILD/
9	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
10	exp INFANT/
11	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
12	exp PEDIATRICS/

#	Searches
13	p?ediatric$.ti,ab.
14	YOUNG ADULT/
15	young$ adult?.ti,ab.
16	or/6-15
17	exp DISABLED PERSON/
18	exp MENTAL DISEASE/
19	INTELLECTUAL IMPAIRMENT/
20	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
21	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
22	SHCN.ti,ab.
23	or/17-22
24	16 and 23
25	HANDICAPPED CHILD/
26	CSHCN.ti,ab.
27	"Education Health and Care plan?".ti,ab.
28	EHC plan?.ti,ab.
29	EHCP?.ti,ab.
30	or/24-29
31	(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/ or SOCIAL SUPPORT/) 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/)
32	((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 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
33	or/31-32
34	PUBLIC RELATIONS/
35	INTERSECTORAL COLLABORATION/
36	INTEGRATED HEALTH CARE SYSTEM/
37	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
38	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
39	(intersector$ or multisector$ or jointsector$).ti,ab.
40	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
41	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
42	((inter or multi or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or profession$)).ti,ab.
43	((institution$ or organi?ation$ or sector$ or agenc$ or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
44	or/34-43
45	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/ or SOCIAL SUPPORT/)
46	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
47	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/ or SOCIAL SUPPORT/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
48	or/45-47
49	HEALTH CARE DELIVERY/
50	COOPERATION/
51	INTERPERSONAL COMMUNICATION/
52	or/49-51
53	((health$ 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 (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$)).ti,ab.
54	((health$ 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 (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.

#	Searches
55	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (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.
56	or/53-55
57	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
58	CHILD HEALTH CARE/ and ORGANIZATION/
59	EDUCATION/ and ORGANIZATION/
60	exp SPECIAL EDUCATION/ and ORGANIZATION/
61	SOCIAL WORK/ and ORGANIZATION/
62	or/57-61
63	30 and 33
64	30 and 44
65	30 and 48 and 52
66	30 and 56
67	30 and 62
68	or/63-67
69	limit 68 to english language
70	limit 69 to yr="2000 -Current"
71	4 and 70
72	5 and 70
73	or/71-72

Database: Health Management Information Consortium (HMIC)

Date of last search: 06/09/2019

#	Searches
1	interview:.mp.
2	experience:.mp.
3	qualitative.tw.
4	or/1-3
5	QUALITATIVE RESEARCH/
6	mixed method?.ti,ab.
7	exp YOUNG PEOPLE/
8	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
9	exp CHILDREN/
10	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
11	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
12	exp PAEDIATRICS/
13	p?ediatric$.ti,ab.
14	YOUNG ADULTS/
15	young$ adult?.ti,ab.
16	or/7-15
17	DISABLED PEOPLE/
18	exp DISABILITIES/
19	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
20	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
21	SHCN.ti,ab.
22	or/17-21
23	16 and 22
24	CSHCN.ti,ab.
25	"Education Health and Care plan?".ti,ab.
26	EHC plan?.ti,ab.
27	EHCP?.ti,ab.
28	or/23-27
29	(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 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 SOCIAL SUPPORT/ 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/)
30	((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?) and social$ and (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
31	or/29-30
32	COLLABORATION/
33	exp INTERAGENCY COLLABORATION/
34	INTERPROFESSIONAL COLLABORATION/

#	Searches
35	COLLABORATIVE CARE/
36	INTEGRATED PROVIDERS/
37	INTEGRATED CARE/
38	INTERDISCIPLINARY SERVICES/
39	JOINT WORKING/
40	HEALTH & SOCIAL SERVICES INTERACTION/
41	COMMUNICATION/
42	HEALTH SERVICE PROVISION/
43	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
44	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
45	(intersector$ or multisector$ or jointsector$).ti,ab.
46	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
47	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
48	((inter or multi or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or profession$)).ti,ab.
49	((institution$ or organi?ation$ or sector$ or agenc$ or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
50	or/32-49
51	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SOCIAL SUPPORT/ or SUPPORTIVE SOCIAL WORK/)
52	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
53	(exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SOCIAL SUPPORT/ or SUPPORTIVE SOCIAL WORK/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
54	or/51-53
55	((health$ 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$).ti,ab.
56	((health$ 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?)).ti,ab.
57	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
58	or/55-57
59	28 and 31
60	28 and 50
61	28 and 54
62	28 and 58
63	or/59-62
64	limit 63 to yr="2000 -Current"
65	4 and 64
66	5 and 64
67	6 and 64
68	or/65-67

Database: Social Policy and Practice

Date of last search: 06/09/2019

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

#	Searches
14	SHCN.ti,ab.
15	or/12-14
16	11 and 15
17	CSHCN.ti,ab.
18	"Education Health and Care plan?".ti,ab.
19	EHC plan?.ti,ab.
20	EHCP?.ti,ab.
21	or/16-20
22	((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?) and social$ and (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
23	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
24	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
25	(intersector$ or multisector$ or jointsector$).ti,ab.
26	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
27	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
28	((inter or multi or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or profession$)).ti,ab.
29	((institution$ or organi?ation$ or sector$ or agenc$ or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
30	or/23-29
31	((health$ 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$).ti,ab.
32	((health$ 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?)).ti,ab.
33	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
34	or/31-33
35	21 and 22
36	21 and 30
37	21 and 34
38	or/35-37
39	limit 38 to yr="2000 -Current"
40	4 and 39
41	5 and 39
42	or/40-41

1 **Database: PsycInfo**

2 **Date of last search: 06/09/2019**

#	Searches
1	experiences.tw.
2	interview:.tw.
3	qualitative.tw.
4	or/1-3
5	mixed method?.ti,ab.
6	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
7	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
8	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
9	PEDIATRICS/
10	p?ediatric$.ti,ab.
11	young$ adult?.ti,ab.
12	or/6-11
13	DISORDERS/
14	exp DISABILITIES/
15	PHYSICAL DISORDERS/
16	exp SENSE ORGAN DISORDERS/
17	exp MENTAL DISORDERS/
18	exp COMMUNICATION DISORDERS/
19	SPECIAL NEEDS/
20	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
21	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
22	SHCN.ti,ab.
23	or/13-22
24	12 and 23
25	CSHCN.ti,ab.
26	"Education Health and Care plan?".ti,ab.
27	EHC plan?.ti,ab.

#	Searches
28	EHCP?.ti,ab.
29	or/24-28
30	(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/ or SOCIAL SUPPORT/) 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/)
31	((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 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
32	or/30-31
33	INTEGRATED SERVICES/
34	INTERDISCIPLINARY TREATMENT APPROACH/
35	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
36	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
37	(intersector$ or multisector$ or jointsector$).ti,ab.
38	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
39	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
40	((inter or multi or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or profession$)).ti,ab.
41	((institution$ or organi?ation$ or sector$ or agenc$ or profession$ or care or service? or department$) adj5 (collaborat$ or coordinat$ or co-ordinat$ or cooperat$ or co-operat$ or integrat$ or partner$)).ti.
42	or/33-41
43	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/ or SOCIAL SUPPORT/)
44	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
45	(exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/ or SOCIAL SUPPORT/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
46	or/43-45
47	HEALTH SERVICE NEEDS/
48	HEALTH CARE DELIVERY/
49	COOPERATION/
50	COLLABORATION/
51	COMMUNICATION/
52	or/47-51
53	((health$ 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 (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$)).ti,ab.
54	((health$ 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 (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$)).ti,ab.
55	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (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.
56	or/53-55
57	29 and 32
58	29 and 42
59	29 and 46 and 52

#	Searches
60	29 and 56
61	or/57-60
62	limit 61 to english language
63	limit 62 to yr="2000 -Current"
64	4 and 63
65	5 and 63
66	or/64-65

Database: Emcare

Date of last search: 06/09/2019

#	Searches
1	interview:.tw.
2	exp HEALTH CARE ORGANIZATION/
3	experiences.tw.
4	or/1-3
5	mixed method?.ti,ab.
6	exp ADOLESCENT/
7	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab.
8	exp CHILD/
9	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab.
10	exp INFANT/
11	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab.
12	exp PEDIATRICS/
13	p?ediatric$.ti,ab.
14	YOUNG ADULT/
15	young$ adult?.ti,ab.
16	or/6-15
17	exp DISABLED PERSON/
18	exp MENTAL DISEASE/
19	INTELLECTUAL IMPAIRMENT/
20	(disable? or disabilit$ or handicap$ or retard$ or disorder? or impair$ or condition? or difficulty or difficulties or deficit? or dysfunct$).ti.
21	((sever$ or complex$ or special or high) adj3 need?).ti,ab.
22	SHCN.ti,ab.
23	or/17-22
24	16 and 23
25	HANDICAPPED CHILD/
26	CSHCN.ti,ab.
27	"Education Health and Care plan?".ti,ab.
28	EHC plan?.ti,ab.
29	EHCP?.ti,ab.
30	or/24-29
31	(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/ or SOCIAL SUPPORT/) 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/)
32	((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 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?)).ti,ab.
33	or/31-32
34	PUBLIC RELATIONS/
35	INTERSECTORAL COLLABORATION/
36	INTEGRATED HEALTH CARE SYSTEM/
37	(interinstitution$ or multiinstitution$ or jointinstitution$).ti,ab.
38	(interorgani?ation$ or multiorgani?ation$ or jointorgani?ation$).ti,ab.
39	(intersector$ or multisector$ or jointsector$).ti,ab.
40	(interagenc$ or multiagenc$ or jointagenc$).ti,ab.
41	(interprofession$ or multiprofession$ or jointprofession$).ti,ab.
42	((inter or multi or joint) adj3 (institution$ or organi?ation$ or sector$ or agenc$ or profession$)).ti,ab.
43	((institution$ or organi?ation$ or sector$ or agenc$ 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.
44	or/34-43
45	(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/ or SOCIAL SUPPORT/)
46	(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

#	Searches
	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/)
47	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/ or SOCIAL SUPPORT/) 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/)
48	or/45-47
49	HEALTH CARE DELIVERY/
50	COOPERATION/
51	INTERPERSONAL COMMUNICATION/
52	or/49-51
53	((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 (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$)).ti,ab.
54	((health$ 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 (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$)).ti,ab.
55	(social$ adj5 (educat$ or school$ or teach$ or headmaster? or headmistress$ or SENCO? or DfE?) adj5 (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.
56	or/53-55
57	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
58	CHILD HEALTH CARE/ and ORGANIZATION/
59	EDUCATION/ and ORGANIZATION/
60	exp SPECIAL EDUCATION/ and ORGANIZATION/
61	SOCIAL WORK/ and ORGANIZATION/
62	or/57-61
63	30 and 33
64	30 and 44
65	30 and 48 and 52
66	30 and 56
67	30 and 62
68	or/63-67
69	limit 68 to english language
70	limit 69 to yr="2000 -Current"
71	4 and 70
72	5 and 70
73	or/71-72

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

Date of last search: 06/09/2019

#	Searches
#1	interview*:ti,ab
#2	experience*:ti,ab
#3	qualitative:ti,ab
#4	#1 or #2 or #3
#5	"mixed method*":ti,ab
#6	[mh ^"ADOLESCENT"]
#7	[mh ^"MINORS"]
#8	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab
#9	[mh "CHILD"]
#10	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*):ti,ab
#11	[mh "INFANT"]
#12	(infan* or neonat* or newborn* or baby or babies):ti,ab
#13	[mh "PEDIATRICS"]
#14	(pediatric* or paediatric*):ti,ab
#15	[mh ^"YOUNG ADULT"]
#16	"young$ adult*":ti,ab
#17	#6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16
#18	[mh "DISABLED PERSONS"]

#	Searches
#19	[mh "MENTAL DISORDERS"]
#20	[mh "COMMUNICATION DISORDERS"]
#21	[mh "INTELLECTUAL DISABILITY"]
#22	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):ti
#23	((sever* or complex* or special or high) near/3 (need or needs)):ti,ab
#24	SHCN:ti,ab
#25	#18 or #19 or #20 or #21 or #22 or #23 or #24
#26	#17 and #25
#27	[mh ^"DISABLED CHILDREN"]
#28	CSHCN:ti,ab
#29	"Education Health and Care plan*":ti,ab
#30	EHC plan*:ti,ab
#31	EHCP*:ti,ab
#32	#26 or #27 or #28 or #29 or #30 or #31
#33	([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"]) 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"])
#34	((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 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*)):ti,ab
#35	#33 or #34
#36	[mh ^"INTERINSTITUTIONAL RELATIONS"]
#37	[mh ^"INTERSECTORAL COLLABORATION"]
#38	[mh ^"DELIVERY OF HEALTH CARE, INTEGRATED"]
#39	(interinstitution* or multiinstitution* or jointinstitution*):ti,ab
#40	(interorganisation* or interorganization* or multiorganisation* or multiorganization* or jointorganisation* or jointorganization*):ti,ab
#41	(intersector* or multisector* or jointsector*):ti,ab
#42	(interagenc* or multiagenc* or jointagenc*):ti,ab
#43	(interprofession* or multiprofession* or jointprofession*):ti,ab
#44	((inter or multi or joint) near/3 (institution* or organisation* or organization*or sector* or agenc* or profession*)):ti,ab
#45	((institution* or organisation* or organization* or sector* or agenc* 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
#46	#36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45
#47	([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"])
#48	([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"])
#49	([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"])
#50	#47 or #48 or #49
#51	[mh ^"HEALTH SERVICES NEEDS AND DEMAND"]
#52	[mh ^"DELIVERY OF HEALTH CARE"]
#53	[mh ^"COOPERATIVE BEHAVIOR"]
#54	[mh ^COMMUNICATION]
#55	[mh ^"INTERPROFESSIONAL RELATIONS"]
#56	#51 or #52 or #53 or #54 or #55
#57	((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 (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
#58	((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

#	Searches
	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 (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
#59	(social* near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (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
#60	#57 or #58 or #59
#61	[mh ^"STATE MEDICINE"/og]
#62	[mh ^"CHILD HEALTH SERVICES"/og]
#63	[mh ^"ADOLESCENT HEALTH SERVICES"/og]
#64	[mh ^EDUCATION/og]
#65	[mh "EDUCATION, SPECIAL"/og]
#66	[mh "SOCIAL WORK"/og]
#67	#61 or #62 or #63 or #64 or #65 or #66
#68	#32 and #35
#69	#32 and #46
#70	#32 and #50 and #56
#71	#32 and #60
#72	#32 and #67
#73	#68 or #69 or #70 or #71 or #72
#74	#68 or #69 or #70 or #71 or #72 with Cochrane Library publication date Between Jan 2000 and Aug 2019, in Cochrane Reviews
#75	#4 and #74
#76	#5 and #74
#77	#75 or #76
#78	#68 or #69 or #70 or #71 or #72 with Publication Year from 2000 to 2019, in Trials
#79	#4 and #78
#80	#5 and #78
#81	#79 or #80

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

Date of last search: 06/09/2019

#	Searches
1	((interview*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
2	((experience*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
3	((qualitative)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
4	#1 OR #2 OR #3
5	(("mixed method*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
6	MeSH DESCRIPTOR ADOLESCENT IN DARE
7	MeSH DESCRIPTOR MINORS IN DARE
8	(((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))
9	MeSH DESCRIPTOR CHILD EXPLODE ALL TREES IN DARE
10	(((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))
11	MeSH DESCRIPTOR INFANT EXPLODE ALL TREES IN DARE
12	(((infan* or neonat* or newborn* or baby or babies))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
13	MeSH DESCRIPTOR PEDIATRICS EXPLODE ALL TREES IN DARE
14	(((pediatric* or paediatric*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
15	MeSH DESCRIPTOR YOUNG ADULT IN DARE
16	(("young* adult*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
17	#6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16
18	MeSH DESCRIPTOR DISABLED PERSONS EXPLODE ALL TREES IN DARE
19	MeSH DESCRIPTOR MENTAL DISORDERS EXPLODE ALL TREES IN DARE
20	MeSH DESCRIPTOR COMMUNICATION DISORDERS EXPLODE ALL TREES IN DARE
21	MeSH DESCRIPTOR INTELLECTUAL DISABILITY EXPLODE ALL TREES IN DARE
22	(((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))
23	((((sever* or complex* or special or high) adj3 need*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
24	#18 OR #19 OR #20 OR #21 OR #22 OR #23
25	#17 AND #24
26	MeSH DESCRIPTOR DISABLED CHILDREN IN DARE

#	Searches
27	((CSHCN)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
28	((("Education Health" adj2 "Care plan*"))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
29	(("EHC plan*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
30	((EHCP*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
31	#25 OR #26 OR #27 OR #28 OR #29 OR #30
32	#4 AND #31
33	#5 AND #31
34	#32 OR #33

Database: Applied Social Sciences Index & Abstracts (ASSIA)

Date of last search: 06/09/2019

#	Searches
1	AB,TI(interview* or experience* or qualitative)
2	MAINSUBJECT.EXACT("QUALITATIVE RESEARCH")
3	1 or 2
4	AB,TI("mixed method?")
5	MAINSUBJECT.EXACT(ADOLESCENTS or CHILDREN or INFANTS or "YOUNG ADULTS")
6	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?")
7	5 or 6
8	MAINSUBJECT.EXACT("DEAF PEOPLE" OR "LEARNING DISABLED PEOPLE" OR "DISABLED PEOPLE" OR "DEVELOPMENTALLY DISABLED PEOPLE" OR "VISUALLY IMPAIRED PEOPLE" OR "BLIND PEOPLE" OR "HEARING IMPAIRED PEOPLE" OR "AUTISTIC PEOPLE" OR "MULTIPLY DISABLED PEOPLE" OR "BLIND-DEAF PEOPLE") OR MAINSUBJECT.EXACT.EXPLODE("PSYCHIATRIC DISORDERS") OR MAINSUBJECT.EXACT.EXPLODE("LANGUAGE DISORDERS")
9	TI(disable? or disabilit* or handicap* or retard* or disorder? or impair* or condition? or difficulty or difficulties or deficit? or dysfunct*)
10	AB,TI((sever* or complex* or special or high) near/3 need?)
11	AB,TI(SHCN)
12	8 or 9 or 10 or 11
13	7 and 12
14	MAINSUBJECT.EXACT.EXPLODE("DISABLED CHILDREN")
15	AB,TI(CSHCN or "Education Health and Care plan?" or "EHC plan?" or EHCP?)
16	13 or 14 or 15
17	(MAINSUBJECT.EXACT("HEALTH SERVICES" OR "COMMUNITY HEALTH SERVICES" OR "MENTAL HEALTH SERVICES") OR MAINSUBJECT.EXACT.EXPLODE("NATIONAL HEALTH SERVICES" OR "MEDICAL PROFESSIONALS")) AND MAINSUBJECT.EXACT.EXPLODE("SOCIAL CARE" OR "SOCIAL WORKERS" OR "SOCIAL WORK AGENCIES" OR "SOCIAL SERVICES AGENCIES" OR "SOCIAL SUPPORT") AND (MAINSUBJECT.EXACT(EDUCATION OR "ELEMENTARY EDUCATION" OR "REMEDIAL EDUCATION" OR "SECONDARY EDUCATION" OR "SPECIAL EDUCATION" OR UNIVERSITIES OR TEACHING OR "REMEDIAL TEACHING" OR TEACHERS OR "CLASSROOM ASSISTANTS" OR "HEAD TEACHERS" OR "SUPPLY TEACHERS" OR "TEACHING ASSISTANTS" OR "EDUCATION AUTHORITIES") OR MAINSUBJECT.EXACT.EXPLODE(SCHOOLS OR NURSERIES))
18	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?))
19	AB((health* or NHS or clinical or medical) near/10 social* near/10 (educat* or school* or teach* or DfE?))
20	17 or 18 or 19
21	MAINSUBJECT.EXACT("INTERAGENCY COLLABORATION" or "DOCTOR-SOCIAL WORKER COLLABORATION" or "INTERSECTORAL COOPERATION" or "INTEGRATED CARE PATHWAYS" or "INTEGRATED SERVICES" or "INTEGRATED MANAGEMENT" or "INTEGRATED SERVICES DIGITAL NETWORK" or "JOINT WORKING" or "INTERDISCIPLINARY APPROACH" or PARTNERSHIPS or COLLABORATION or COOPERATION or "COOPERATIVE BEHAVIOR" or COMMUNICATION)
22	AB,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 interprofession* or multiprofession* or jointprofession*)
23	AB,TI((inter or multi or joint) near/3 (institution* or organi?ation* or sector* or agenc* or profession*))
24	TI((institution* or organi?ation* or sector* or agenc* 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*))
25	21 or 22 or 23 or 24
26	TI((health* or NHS or clinical or medical) near/5 social* near/5 (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*))
27	TI((health* or NHS or clinical or medical) near/5 (educat* or school* or teach* or DfE?) near/5 (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*))
28	TI(social* near/5 (educat* or school* or teach* or DfE?) near/5 (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-

#	Searches
	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*))
29	26 or 27 or 28
30	16 and 20
31	16 and 25
32	16 and 29
33	30 or 31 or 32
34	3 and 33
35	4 and 33
36	34 or 35
	[Search then limited to 2000-current]

Databases: Social Services Abstracts; Sociological Abstracts; and ERIC (Education Resources Information Centre)

Date of last search: 06/09/2019

#	Searches
1	(AB,TI(interview* OR experience* OR qualitative OR "mixed method?") AND 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?") 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* OR complex* OR special OR high) NEAR/3 need?) OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND 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?))) OR (AB,TI(interview* OR experience* OR qualitative OR "mixed method?") AND 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?") 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* OR complex* OR special OR high) NEAR/3 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 interprofession* OR multiprofession* OR jointprofession* 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* OR team*)) OR (AB,TI(interview* OR experience* OR qualitative OR "mixed method?") AND 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?") 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* OR complex* OR special OR high) NEAR/3 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?))))
2	Additional limits - Date: From 01 January 2000 to 06 September 2019

Database: British Education Index

Date of last search: 06/09/2019

#	Searches
1	TX (interview* OR experience* OR qualitative OR "mixed method?") 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 educat* need?" OR "special 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 interprofession* OR multiprofession* OR jointprofession* 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* OR team*) Limiters - Publication Date: 20000101-20190931
2	TX (interview* OR experience* OR qualitative OR "mixed method?") 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

#	Searches
	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: 20000101-20190931
3	1 or 2

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

Date of last search: 06/09/2019

#	Searches
1	TX (interview* OR experience* OR qualitative OR "mixed method?") 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 interprofession* OR multiprofession* OR jointprofession* 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* OR team*) Limiters - Published Date: 20000101-20190931
2	TX (interview* OR experience* OR qualitative OR "mixed method?") 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* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) Limiters - Published Date: 20000101-20190931
3	TX (interview* OR experience* OR qualitative OR "mixed method?") 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 - Published Date: 20000101-20190931
4	1 or 2 or 3 Limiters - Published Date: 20000101-20190931

Database: Social Sciences Citation Index (SSCI)

Date of last search: 06/09/2019

#	Searches
# 1	TOPIC: (interview* or experience* or qualitative) Indexes=SSCI Timespan=2000-2019
# 2	TOPIC: ("mixed method$") Indexes=SSCI Timespan=2000-2019
# 3	TOPIC: ((adolescen* or teen* or youth* or young or juvenile$ or minors or highschool*)) Indexes=SSCI Timespan=2000-2019
# 4	TOPIC: ((child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid$ or kindergar* or boy$ or girl$)) Indexes=SSCI Timespan=2000-2019
# 5	TOPIC: ((infan* or neonat* or newborn* or baby or babies)) Indexes=SSCI Timespan=2000-2019
# 6	TOPIC: (p$ediatric*) Indexes=SSCI Timespan=2000-2019
# 7	TOPIC: ("young* adult$") Indexes=SSCI Timespan=2000-2019
# 8	#7 OR #6 OR #5 OR #4 OR #3 Indexes=SSCI Timespan=2000-2019
# 9	TITLE: ((disable$ or disabilit* or handicap* or retard* or disorder$ or impair* or condition$ or difficulty or difficulties or deficit$ or dysfunct*)) Indexes=SSCI Timespan=2000-2019
# 10	TOPIC: (((sever* or complex* or special or high) near/3 need$)) Indexes=SSCI Timespan=2000-2019
# 11	TOPIC: (SHCN) Indexes=SSCI Timespan=2000-2019

#	Searches
# 12	#11 OR #10 OR #9 Indexes=SSCI Timespan=2000-2019
# 13	#12 AND #8 Indexes=SSCI Timespan=2000-2019
# 14	TOPIC: (CSHCN) Indexes=SSCI Timespan=2000-2019
# 15	TOPIC: ("Education Health and Care plan$") Indexes=SSCI Timespan=2000-2019
# 16	TOPIC: ("EHC plan$") Indexes=SSCI Timespan=2000-2019
# 17	TOPIC: (EHCP$) Indexes=SSCI Timespan=2000-2019
# 18	#17 OR #16 OR #15 OR #14 OR #13 Indexes=SSCI Timespan=2000-2019
# 19	TITLE: (((health* or NHS or clinical or clinician$ or medical or medic$ 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$) or SLT or SLTs) and social* and (educat* or school* or teach* or headmaster$ or headmistress* or SENCO$ or DfE$))) Indexes=SSCI Timespan=2000-2019
# 20	TOPIC: (((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/10 social near/10 (education or educating or educator or educators or school or schools or teach or teaching or teachers))) Indexes=SSCI Timespan=2000-2019
# 21	#20 OR #19 Indexes=SSCI Timespan=2000-2019
# 22	TOPIC: ((interinstitution* or multiinstitution* or jointinstitution*)) Indexes=SSCI Timespan=2000-2019
# 23	TOPIC: ((interorgani$ation* or multiorgani$ation* or jointorgani$ation*)) Indexes=SSCI Timespan=2000-2019
# 24	TOPIC: ((intersector* or multisector* or jointsector*)) Indexes=SSCI Timespan=2000-2019
# 25	TOPIC: ((interagenc* or multiagenc* or jointagenc*)) Indexes=SSCI Timespan=2000-2019
# 26	TOPIC: ((interprofession* or multiprofession* or jointprofession*)) Indexes=SSCI Timespan=2000-2019
# 27	TOPIC: (((inter or multi or joint) near/3 (institution* or organi$ation* or sector* or agenc* or profession*))) Indexes=SSCI Timespan=2000-2019
# 28	TITLE: (((institution* or organi$ation* or sector* or agenc* 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=2000-2019
# 29	#28 OR #27 OR #26 OR #25 OR #24 OR #23 OR #22 Indexes=SSCI Timespan=2000-2019
# 30	TOPIC: (((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/5 social near/5 (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*))) Indexes=SSCI Timespan=2000-2019
# 31	TOPIC: (((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) near/5 (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*))) Indexes=SSCI Timespan=2000-2019
# 32	TOPIC: ((social near/5 (education or educating or educator or educators or school or schools or teach or teaching or teachers) near/5 (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*))) Indexes=SSCI Timespan=2000-2019
# 33	#32 OR #31 OR #30 Indexes=SSCI Timespan=2000-2019
# 34	#21 AND #18 Indexes=SSCI Timespan=2000-2019
# 35	#29 AND #18 Indexes=SSCI Timespan=2000-2019
# 36	#33 AND #18 Indexes=SSCI Timespan=2000-2019
# 37	#36 OR #35 OR #34 Indexes=SSCI Timespan=2000-2019
# 38	#37 AND #1 Indexes=SSCI Timespan=2000-2019
# 39	#37 AND #2 Indexes=SSCI Timespan=2000-2019
# 40	#39 OR #38 Indexes=SSCI Timespan=2000-2019

Database: Social Care Online

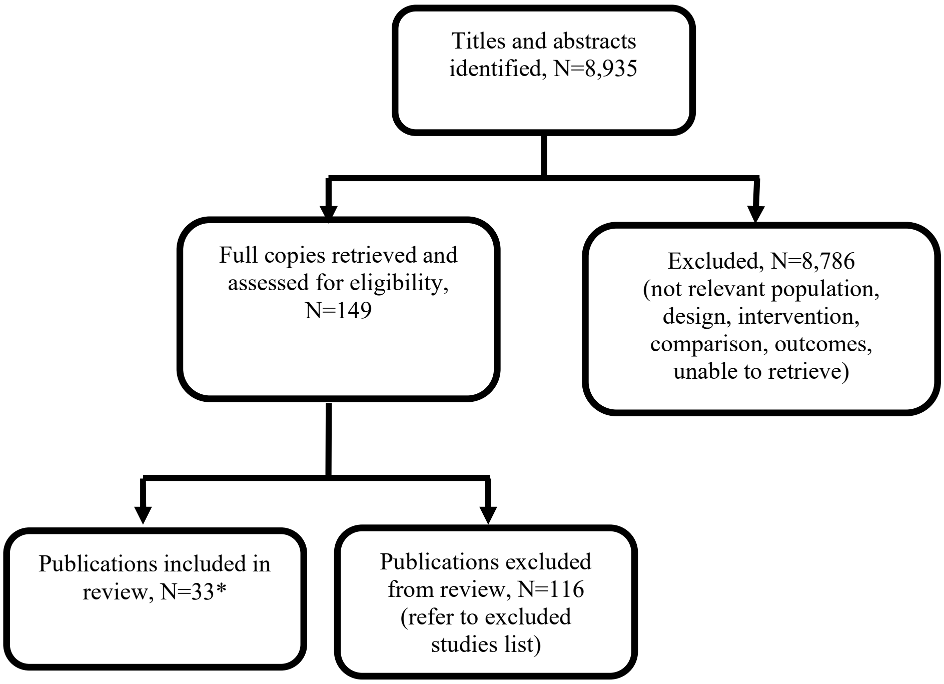
Date of last search: 06/09/2019

#	Searches
	AllFields:'qualitative or interview or experience'
	AND AllFields:'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 AllFields:'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 PublicationYear:'2000 2019'

Appendix C – Qualitative evidence study selection

Study selection for: What is the experience of disabled children and young people with severe complex needs and their families and carers of joint delivery of health, social care and education services?

Figure 2: Study selection flow chart



** Literature search and study selection undertaken for all qualitative questions simultaneously; 23 publications were included in the evidence review of service users (Evidence report A), 14 publications were included in the evidence review for views of service providers (Evidence report M) and 33/all papers were included for the evidence review of perceived barriers and facilitators (Evidence report K).*

Appendix D – Qualitative evidence

Evidence tables for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

Table 4: Evidence tables

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Full citation Adams Lorna, et al.,, Experiences of Education, Health and Care plans: a survey of parents and young people, 220, 2017 **Ref ID** 1105264 **Country/ies where study was carried out** UK (England) **Study type** Survey with free text questions **Study dates** Between 25th July and 28th November 2016 **Study**	**Characteristics** N (total)=13,643 responses received N=10,675 were from parents/carers answering principally about their own experiences of the EHC plan process (on behalf of a child/young person aged under 16) (78%) N=2,246 were from parents/carers answering on behalf of a young person aged 16+ (5%) N=722 were from young people aged 16+ answering about their own experiences (16%) *Gender of child/young person* Male: N=9,704 (71%) Female: N=3,756 (28%) *Age of child/young person* Under 5 years: N=1,087 (8%) 5-10 years: N=4,931 (36%) 11-15 years: N=4,690 (34%) 16-25 years: N=2,935 (22%)	**Setting** A nationally representative picture of parents and young people's experiences of the EHC needs assessments, planning process and resultant EHC plans in England **Data collection** Responses to these free text questions were recorded verbatim. **Data analysis** Survey data was reviewed to ensure no mistakes had been made during the data entering process e.g. logic checks of questionnaire routing and response options. Responses to free text questions were coded into themes (where possible an existing code was used – known as 'backcoding').	**Themes** Original theme: Acquired the funding / assistance that the child / young person needed/ The whole process takes too long • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ The process of getting an EHC plan takes too long and requires a lot of work Original theme: Difficulty meeting child's needs • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people Original theme: Staff lacking knowledge / poor quality information and advice	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Can't tell **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes **Q5: Were the data collected in a way that addressed the research issue?** Can't tell **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell **Q7: Have ethical issues been taken into consideration?** Yes: Participants had consented to being contacted for research

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
details: A survey of parents and young people with an EHC plan that had been created in the calendar year 2015 Participants were identified via two official databases: the National Pupil Database, and the Individualised Learner Record; 65,172 individuals were identified To maximise the accessibility of the survey, participants could complete it online, via a paper questionnaire and by	*Ethnicity of child/young person* White: N=10,845 (79%) Black and Minority Ethnic: N=2,281 (17%) Prefer not to say: N=517 (4%) *Education setting (attended at time of survey/ after EHC plan provided)* Specialist: N=4,999 (37%) Mixed: 2,247 (16%) Mainstream: 5,428 (40%) Not in education: N=259 (2%) Educated at home: N=90 (1%) Don't know / Prefer not to say: N=620 (5%) *Whether has SEN statement previously* Transferred from SEN Statement: N=8,513 (62%) No SEN statement previously: N=4,412 (32%) *Perception of types of need covered by the EHC Plan* Education: N=12,682 (93%) EHC plans are required to cover the child/young person's education needs. This figure is based on parent and young people's		• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Professionals, staff and families lack understanding of the EHC plan process ○ Professionals and staff lack the expertise and knowledge needed to complete the EHC plan Original theme: Support from school / college / teaching staff/Was kept informed / provided with clear information • Service users' involvement and relationships with service providers ○ Co-working improved when professionals worked closely with parents and kept them informed Original theme: Support from school / college / teaching staff/ • Professional and staff knowledge and training ○ Service providers having knowledge of the EHC plan process	purposes. Letters explained the purpose of the survey and how the survey data would be used. No ethics committee mentioned. **Q8: Was the data analysis sufficiently rigorous?** Can't tell **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** Commissioned by the Department for Education **Other information** Limitations reported on the survey: • The survey covers the views and opinions of parents and young people – the data collected therefore reflects their perceptions of what took place rather than facts • As only those with an EHC plan put in place in 2015 were surveyed, the data does not reflect any changes/improvements in provision since • Chapter 2 reports on variations in experience by geography at the local authority level. This analysis covers two thirds of local authorities in England due to an insufficient number of responses (less than 50) from the remaining third of local authorities

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
telephone. An Easy Read version was also made available as were face-to-face interviews and interviews in languages other than English. Participants were contacted by letter and invited to take part in an online survey. Where the child or young person named on the EHC plan was aged 16-25 years, the survey invitation was addressed to them directly; if under 16, the invitation was addressed to the parent or carer.	perceptions of the needs covered in the EHC plan and subsequently does not total 100%. It may also reflect cases where a child under 5 is waiting for education provision to start or the young person has left formal education Health: N=6,377 (47%) Social Care: N=6,483 (48%) *Primary SEND type* Autistic Spectrum Disorder: N=3,389 (24%) Speech, Language and Communication Needs: N=1,706 (13%) Social, emotional & mental health: n=1,592 (12%) Moderate Learning Difficulty: n=1,529 (11%) Severe Learning Difficulty: n=1,288 (9%) Physical Disability: n=763 (6%) Specific Learning Difficulty: n=634 (5%) Other Difficulty/Disability: n=522 (4%) Profound & Multiple Learning Difficulty: n=426 (3%) Hearing Impairment: n=289 (2%) Visual Impairment: n=194 (1%)			• The survey includes only those with an EHC plan in place at the time of fieldwork. It therefore excludes anyone who may have requested an EHC needs assessment or plan and been refused *The technical Report has been published alongside this document: Adams, L. Tindle, A. Basran, S. Dobie, S., Thomson, D., Robinson, D. and Shepherd, C. (2017) Experiences of education, health and care plans: A survey of parents and young people. London: Department for Education. Available at: http://dera.ioe.ac.uk/28758/1/Education__health_and_care_plans_parents_and_young_people_survey.pdf

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
After 4 weeks of no response a reminder letter, was sent providing details of the online survey as well as a paper questionnaire booklet and a reply-paid envelope. After 6 weeks non-responders for whom a telephone number was available were approached to take part over the telephone.	Multi-Sensory Impairment 48 (EHC plans are required to cover the child/young person's education needs. The proportion of children/young people not in education is based on self-reported respondent data. The majority of these responses (69%) are from those aged 16-25, so it is feasible that they might have left formal education at the time of the survey, or for younger children, in cases where they waiting for education provision to start) SEN support but no specialist assessment of type of need 25 (EHC plans are required to cover the child/young person's education needs. The proportion of children/young people not in education is based on self-reported respondent data. The majority of these responses (69%) are from those aged 16-25, so it is feasible that they might have left formal education at the time of the survey, or for younger children, in cases where they waiting for education provision to start) Not given (data missing on			

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	sample): n=1,238 (9%) **Inclusion criteria** Children and young people, and families of children and young people identified from the National Pupil Database and Individualised Learner Record as having an EHC plan in place in 2015 via an 'EHC plan marker' on the sample; who had consented to being contacted for research purposes; and both telephone and address information was available, to ensure they could be contacted. **Exclusion criteria** Anyone who may have requested an EHC needs assessment or plan and been refused			
Full citation Adams, Lorna, et, al, Education, Health and Care plans: a qualitative investigation into service user experiences of the planning	**Characteristics** N=25 N=13 (individuals who were satisfied with their EHC plan and the EHC plan process, in local authority areas with above average satisfaction overall N=12 (individuals who were dissatisfied with their EHC plan and the EHC plan process, in local authority areas with below average	**Setting** NR - face-to-face in-depth interviews **Data collection** The interviews were conducted face-to face by members of the research team at IFF Interview content was relatively fluid to allow for differences in individual stories, but interviews were underpinned by a	**Themes** Original theme: One individual can make a huge difference • Importance of key worker/lead professional ○ Key worker/lead professional is important for having a holistic view and coordinating services Original theme: Working together with more sustained face-to-face contact	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes **Q4 Was the recruitment strategy appropriate to the aims of the**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
process: research report, 85, 2018 **Ref ID** 1105485 **Country/ies where study was carried out** UK (England) **Study type** Primary qualitative study - Interviews (face to face with parents involved in the 2016 national survey) **Study dates** Interviews were conducted between 3rd April to 11th May 2017	satisfaction overall **Inclusion criteria** Participants from the sample of 13,643 parents and young people who had an EHC plan created in 2015 and responded to the 2016 survey and had given permission to be re-contacted for further research, at the end of the 2016 survey. (Therefore findings pertain to individuals with an EHC plan created in 2015). Of these, individuals who were satisfied with their EHC plan and the EHC plan process, in local authority areas with above average satisfaction overall And, individuals who were dissatisfied with their EHC plan and the EHC plan process, in local authority areas with below average satisfaction overall **Exclusion criteria** Individuals involved in creating a plan where there was a SEN Statement in place.	discussion guide (a series of set questions and probes) to ensure that all the necessary points were covered. At certain points in the interview, the responses that the participant had given within the survey were revisited and used as a starting point for more detailed discussion. A copy of the discussion guide was provided in the Appendices **Data analysis** Interviews were transcribed in full and summarised into an analysis framework under headings related to the objectives	between the family and professionals • Relationships between service providers ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working ○ Service providers failing to take responsibility and be effectively involved in collaborative working • Diagnosis and identification of needs first ○ Service providers having knowledge of the child or young person’s needs at the start of the process Original theme: A need for communication from local authorities throughout the process • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ The process of getting an EHC plan takes too long and requires a lot of work Original theme: A need for greater transparency about reasons for delays • Long waiting times for support	**research?** Yes **Q5: Were the data collected in a way that addressed the research issue?** Yes **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell **Q7: Have ethical issues been taken into consideration?** Yes Individuals approached had given permission to be re-contacted for further research, at the end of the 2016 survey. Information about permissions in Appendix I. No ethics information provided **Q8: Was the data analysis sufficiently rigorous?** Yes **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** Commissioned by the Department for Education **Other information** An evaluation of EHC plan quality was also conducted where the research team sought to obtain – with informed

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			○ Lack of urgency to provide support until the child/young person reaches crisis point	consent – a copy of the individual's EHC plan
Full citation Boesley, Lauren, Crane, Laura, Allen, Barnes Braun Childre Cole Corrigan Craston Crowne Curran Das Devecchi Emilson Estes Evans Gore Gray Green Gross Hagner Hayes Holburn Jones Kaehne Keyes Lehane Lever Lewis Mackenzie Mackenzie Morewood Neufeld Norwich Norwich Parsons Pearson Polanczyk Reardon Redwood	**Characteristics** N=16 (SENCOs) *Gender* n=15 females n=1 male *Setting* n=12 worked within a mainstream primary setting (children ages 5-11 years) n=4 worked within a mainstream secondary setting (children ages 11-16 years) *Teaching experience* Range: 4-25 years (M = 15.0 years, SD = 7.55) *SENCO experience* Range: 2-12 years (M = 6.5 years, SD = 3.04). *Greater than 4 years experience* n=13 (could draw on comparisons to the previous statutory guidance) *Geographical location within England (10 different counties)* east (n = 9; 56%) south-east (n = 3; 19%) London (n = 2; 13%) south-West (n = 2; 13%)	**Setting** Primary and secondary schools across England **Data collection** Semi-structured interviews via telephone (due to participants regional variation) were conducted at a time/date convenient for participants. Interviews were audio recorded and transcribed verbatim. Interviews varied in length between 25-47 minutes (M = 37.44, SD = 6.24) due to participants' experiences **Data analysis** Data were analysed using thematic analysis An essentialist framework was used to report the experiences, meaning and reality of participants utilising a data-driven, inductive approach Both authors familiarised themselves with the data by reviewing transcripts and establishing a	**Themes** Original theme: The perceived role of the SENCO in the EHC plan process: Managing misconceptions and disengagement from Health and Care services • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working ○ Mutual respect between professionals which allows equal opportunity to have opinions voiced and challenged • Introduction of EHC plans ○ EHC plans are primarily concentrated around education and place less emphasis on health and social care • Joined-up care requires a substantial amount of time, organisation and	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes **Q5: Were the data collected in a way that addressed the research issue?** Yes **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell **Q7: Have ethical issues been taken into consideration?** Yes **Q8: Was the data analysis sufficiently rigorous?** Yes **Q9: Is there a clear statement of findings?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Riglin Roaf Robertson Robertson Robertson Sanderson Simonoff Spivack Szwed Szwed Taylor-Brown Tissot Tissot Townsley Tsai White Woodward, 'Forget the health and care and just call them education plans': SENCOs' perspectives on education, health and care plans, Journal of Research in Special Educational Needs, 18, 36-47, 2018 **Ref ID** 1105535 **Country/ies where study was carried out**	**Inclusion criteria** SENCOs based in England and had undertaken an application for an EHC plan, or transferred a statement of SEN into an EHC plan. **Exclusion criteria** NR	preliminary set of codes, themes and subthemes, which were discussed and agreed upon. Definitions were established once themes were reviewed at a surface level, using a semantic approach	commitment ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals • Professional and staff knowledge and training ○ Misconceptions and lack of understanding from professionals lead to incorrect, or a lack of, advice and referrals • Service users' involvement and relationships with service providers ○ Co-working improved when professionals worked closely with parents and kept them informed • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Professionals, staff and families lack understanding of the EHC plan process Original theme: The perceived role of the SENCO in the EHC plan process: Managing parental expectations • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Professionals, staff and families lack understanding of	Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** NR **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

UK
Study type
Primary qualitative - semi-structured telephone interviews
Study dates
NR
			the EHC plan process
			
			Original theme: Procedural challenges and changes: an evolving process
			
			• Organisation of services
			  ○ Inconsistency across paperwork and procedures used in different services, regions and local authorities
			• Relationships between service providers
			  ○ Service providers failing to take responsibility and be effectively involved in collaborative working
			  ○ Mutual respect between professionals which allows equal opportunity to have opinions voiced and challenged
			  ○ Clear targets improved accountability and the distribution of responsibility across services
			  ○ Shared values and priorities promote joint working
			• Funding and resources
			  ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care
			• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			EHC plan) ○ A lack of available services is increasing demands for EHC plans ○ Time taken for EHC plans to be refined and embedded in practice ○ Revisions to EHC plan paperwork and processes made without consultation or notice ○ There is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services Original theme: Difficulties in accessing EHC plans for children with SEMH needs • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ An over emphasis on academic progress overshadowed other areas of need and impacted on the child/young person's ability to access to an EHC plan	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			○ Lack of understanding of, and difficulty providing evidence for, SEMH needs is a barrier to accessing EHC plans • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point Original theme: Difficulties in accessing EHC plans for children with SEMH needs. Difficulties validating SEMH needs • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ An over emphasis on academic progress overshadowed other areas of need and impacted on the child/young person's ability to access to an EHC plan ○ Children/young people need to reach a crisis point to access EHC plans ○ Lack of understanding of, and difficulty providing evidence for, SEMH needs is a barrier to accessing EHC plans • Introduction of EHC plans ○ EHC plans are primarily concentrated around education and place less emphasis on health and social care	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Attitudes and social stigma about service provisions ○ Low expectations of the ambitions and capability of children and young people	
Full citation Boyce, Tammy, Dahlmann-Noor, Annegret, Bowman, Richard, Keil, Sue, Support for infants and young people with sight loss: a qualitative study of sight impairment certification and referral to education and social care services, BMJ open, 5, e009622, 2015 **Ref ID** 914536 **Country/ies where study was carried**	**Characteristics** Total: n=78 *Hospital staff (3 teaching hospitals 2 district general): n=29* n=12 Consultant ophthalmologists (8 subspecialty paediatric ophthalmologists): Of the 12, 10 were qualified for over 10 years, 2 were qualified for over 5 years n=3 eye clinic liaison officer (ECLO) n=1 Optometrist n=5 Administrators n=6 Orthoptists n=2 Nurses *Education: n=8* n=7 qualified teachers of children and young people with vision impairment (QTVI) n=1 Manager *Social services: n=15* n=6 Managers n=5 Rehabilitation workers n=3 Administrators n=1 Social worker	**Setting** Hospital **Data collection** Interviews were digitally recorded with the participant's consent, lasted between 10 and 50 min and transcribed verbatim The interviews consisted of semi structured questions covering the following themes: Description and/or experience of certification and registration processes; Attitudes to and meaning of certification and registration; Role and relationships with relevant stakeholders (health, education, social services); and Improving experiences and systems. **Data analysis** Interview data were analysed thematically A list of deductive codes was initially created and inductive codes	**Themes** Original theme: Direct referral pathways • Information sharing ○ Sharing information to streamline processes and transition Original theme: Eye clinic liaison officers • Organisation of services ○ Having the right people involved and collaborating can overcome gaps in service provision Original theme: How to ensure early and consistent support • Relationships between service providers ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working Original theme: Ophthalmologists state	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes: No discussion on how they decided which method to use **Q4 Was the recruitment strategy appropriate to the aims of the research?** No: Participants were purposely selected from areas to provide examples of excellent, ordinary and common practice leading to recruitment bias **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: The setting for interviews was not justified **Q6: Has the relationship between researcher and participants been adequately considered?** Yes: The researcher was experienced

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
out UK (England) **Study type** Primary qualitative **Study dates** Interviews were completed between March and July 2014.	*Parents: n=26* n=26 Parents with 28 children n=22 Severely sight impaired, 6 sight impaired n=7 Infants and children with complex needs n=18 Diagnosed under age 1 n=10 Certified under age 1 Ethnicity (children): 26 white, 2 Asian Ethnicity (parents): 2 Asian (8%) (other ethnicities not reported) Gender (children): 12 Girls, 16 boys Income (parents) below £15 000/annum: 27% of parents (n=7) **Inclusion criteria** health, education and social care professionals involved in certifying and supporting infants and children with vision impairment parents of children who are certified as severely sight impaired or sight impaired **Exclusion criteria** NR	emerged during the second level of the thematic analysis	referral is offered before certification/Reasons for differences between parents' and clinicians' experiences • Organisation of services ○ Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial Original theme: Ophthalmologists state referral is offered before certification • Diagnosis and identification of needs first ○ Early identification of needs and making referrals before a diagnosis has been reached promotes early access to support Original theme: Parents wait for diagnosis and offer of certification of vision impairment (CVI) before being referred/Reasons for differences between parents' and clinicians' experiences • Diagnosis and identification of needs first ○ Diagnosis as the initial	in the topic and with the interview population **Q7: Have ethical issues been taken into consideration?** Yes: Ethics approval was deemed unnecessary and informed consent was obtained by all participants. No detail about how the research was described to participants **Q8: Was the data analysis sufficiently rigorous?** Yes: Limited detail provided on data analysis **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** The Royal National Institute of Blind People **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			mediation resulted in delays in referrals, access to services, and receiving information and support Original theme: Reasons for differences between parents' and clinicians' experiences - Professional and staff knowledge and training - Misconceptions and lack of understanding from professionals lead to incorrect, or a lack of, advice and referrals	

Full citation
Brooks, Fiona, Bloomfield, Linda, Offredy, Maxine, Shaughnessy, Philomena, Evaluation of services for children with complex needs: mapping service provision in one NHS
	Characteristics
	Interview or focus group
	n=7: parents of children with complex needs
	n=6 (mother), n=1 (father)
	age range of children: 3 - 10 years
	Conditions included: cystic fibrosis, spina bifida, microcephaly, biliary atresia and tuberous sclerosis.
	n=2: Children with complex health needs; 1 aged 6 years interviewed with her mother; 1 aged 10 years interviewed independently. (parents of both children participated in
		Setting
		For service users: interviews were mostly conducted in the family home. 1 interview was conducted at the parent's place of work
		For service providers: interviews took place at the professionals' place of work or by telephone if this was more convenient.
		Data collection
		semi-structured interviews and focus groups (A semi-structured interview schedule was used for both the focus groups and
			Themes
			Original theme: Communication and coordination between services
			- Relationships between service providers
			  - Service providers failing to take responsibility and be effectively involved in collaborative working
			- Importance of key worker/lead professional
			  - Key worker/lead professional is important for having a holistic view and coordinating services
			- Information sharing
			  - Information is not always
				Limitations
				Q1 Was there a clear statement of the aims of the research?
				Yes
				Q2 Was a qualitative methodology appropriate?
				Yes
				Q3 Was the research design appropriate to address the aims of the research?
				Yes
				Q4 Was the recruitment strategy appropriate to the aims of the research?
				Can't tell: Possible bias as recruitment was via the Lead Nurse for Children's Services
				Q5: Were the data collected in a

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

Trust, Primary health care research & development, 14, 52-62, 2013
Ref ID
914541
Country/ies where study was carried out
UK
Study type
Primary qualitative (described as an evaluative study with exploratory case study methodology)
Study dates
NR
	the study)
	Focus group (parents from the support group)
	n=7: Parents children had a range of complex needs: age ranged 1-16 years
	n=0: children taking part in the focus group.
	Interviews with stakeholders and professionals
	n=18 individual in-depth interviews including community paediatricians, nurses, therapists and teachers.
	Focus group (professionals and stakeholders)
	n=4: community nurses
	Inclusion criteria
	Service users: families with children between 12 months and 16 years of age who have continuing complex care needs
	Service providers: health professionals and stakeholders across the multidisciplinary teams. professionals must have significant input into children's and families' care within the study locality
	Exclusion criteria
	Children and their families who were the subject of
		individual interviews)
		Interviews lasted between 45 and 90 minutes, were audiotaped and transcribed verbatim.
		Interviews with parents and children started by asking them to describe a typical day of the child, to talk about their understanding of their child's condition and the impact these have on their lives.
		Data analysis
		Thematic analysis of the verbatim-transcribed qualitative data
		Open coding and subsequent thematic development and refinement was conducted, including the search for disconfirming evidence
		Transcripts were each coded by two researchers to allow for critical discussion and reframing and refinement of the coding frames
			shared nor sufficient to meet the needs of other services
			▪ Communication and support
			  ▪ More information and support for service users to understand and access the available services
			  ▪ Lack of communication (verbal and written) between services
			▪ Joined-up care requires a substantial amount of time, organisation and commitment
			  ▪ Workloads are negatively impacted by the cumbersome and onerous nature of paperwork and interprofessional working
			
			Original theme: Professional communication and family participation in decision making
			
			▪ An imbalanced distribution in the amount of support provided to children/young people
			  ▪ Individuals who shout the loudest are more likely to receive the desired support
			▪ Communication and support
			  ▪ More information and support for service users to understand and access the available services
				way that addressed the research issue?
				Yes
				Q6: Has the relationship between researcher and participants been adequately considered?
				No: The relationship between the researcher and participants has not been adequately considered
				Q7: Have ethical issues been taken into consideration?
				Yes: The study was deemed a service evaluation and did not require full Research Ethics Committee review. The research team applied British Sociological Association and British Psychological Society guidelines for ethical research and standard COREC informed consent procedures, including the right to withdraw.
				Q8: Was the data analysis sufficiently rigorous?
				Yes
				Q9: Is there a clear statement of findings?
				No: Findings not explicit, limited themes provided
				Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)
				Yes
				Source of funding
				NR
				Other information

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	either current or ongoing child protection proceedings or complaint proceedings against the NHS.			
Full citation Children's Commissioner for Wales, 'Don't hold back': transitions to adulthood for young people with learning disabilities, 40, 2018 **Ref ID** 1105580 **Country/ies where study was carried out** UK (Wales) **Study type** Report including an Evidence Review and Qualitative focus groups **Study dates** NR	**Characteristics** *Face to face focus groups* n=99 young people (aged 14-26 years) Speaking welsh: n=17%, Speaking some Welsh: n=25% Black or minority ethnic background: n=5% *Online questionnaire* n=187 parents of children and young people with learning disabilities (nearly all aged 14-25 *years)* *Focus groups* *n*=43 professionals from education, social care, health and voluntary services *Written submissions* n=6 6 national voluntary organisations **Inclusion criteria** young people with learning disabilities (reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their	**Setting** Focus groups **Data collection** NR **Data analysis** NR	**Themes** Original theme: Changing thresholds between child and adult services • Organisation of services ○ Lack of appropriate services ○ Rigid definition of, and criteria for, services leads to gaps in service provision • Transition ○ Differences in thresholds for accessing adult services compared with child services Original theme: Issues of access and delivery common to all statutory services • Transition ○ Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late • Funding and resources ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care • Organisation of services	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes: Not explicitly described **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes: It's not discussed how they decided which method to use **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Potential bias as participants were self-selected or chosen by their school or college to take part and over representation of rural Wales is over represented in the sample **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Data collection and setting not reported or justified and methods not explicit **Q6: Has the relationship between researcher and participants been adequately considered?** No: The relationship between

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	whole life) adults who care for young people with learning disabilities adults who work with young people with learning disabilities **Exclusion criteria** NR		○ Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services Original theme: Poor coordination and decision making • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments • Transition ○ Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in	researcher and participants has not been adequately considered **Q7: Have ethical issues been taken into consideration?** No: No mention of how the research was explained to participants, ethical approval, informed consent or confidentiality **Q8: Was the data analysis sufficiently rigorous?** No: No description of analysis process, unclear how themes were derived from the data or selected from the original sample **Q9: Is there a clear statement of findings?** Yes: No discussion on the credibility of findings **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: No integration with existing research **Source of funding** NR **Other information** https://www.edgehill.ac.uk/eprc/files/2018/07/CCfW-final-report-04072018.pdf

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			collaborative working Original theme: Personal organising and administration • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals • Communication and support ○ Lack of communication (verbal and written) between services • Information sharing ○ Information is not always shared nor sufficient to meet the needs of other services • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point Original theme: Support • Service users' involvement and relationships with service providers ○ Co-working improved when professionals worked closely	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			with parents and kept them informed • Importance of key worker/lead professional ○ Key worker/lead professional is important for having a holistic view and coordinating services • Organisation of services ○ Rigid definition of, and criteria for, services leads to gaps in service provision • Long waiting times for support ○ Delays from one service can impact access to other services Original theme: Accessing health services • Organisation of services ○ Rigid definition of, and criteria for, services leads to gaps in service provision ○ Lack of appropriate services Original theme: Commissioning and strategic planning • Organisation of services ○ Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			existing rigid service models would be beneficial ○ Rigid definition of, and criteria for, services leads to gaps in service provision • Funding and resources ○ Joint funding and strategic planning as a methods of supporting collaborative working Original theme: Professionals that coordinate • Importance of key worker/lead professional ○ Continuity of key worker/lead professional is important for consistency and relationships Original theme: Emotional impact of managing family life and a caring role • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point Original theme: Access to further education • Organisation of services ○ Lack of appropriate services • Transition	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			○ Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late	
Full citation Cohen, Wendy, McCartney, Elspeth, Crampin, Lisa, 22q11 deletion syndrome: Parents' and children's experiences of educational and healthcare provision in the United Kingdom, Journal of child health care, 21, 142-152, 2017 **Ref ID** 1054444 **Country/ies where study was carried out** UK **Study type**	**Characteristics** *Participants* N=34 N=1: young person (aged 16 years) N=25: parents N=8: carers *Informed of the study* 58%: Max Appeal 42%: 22 Crew **Inclusion criteria** adults aged 16 years and over with a confirmed genetic diagnosis of 22q11DS parents/carers of individuals of any age with such a diagnosis. **Exclusion criteria** NR	**Setting** Convenience sampling was used targeting those already involved with 22q11DS organizations The survey was nationally distributed via family support networks through the two national UK-based charities supporting those affected with 22q11DS: the Max Appeal and 22Crew via their website and social media. **Data collection** The survey's 'url' link was distributed through Max Appeal and 22Crew via their website and social media. Respondents were targeted via information displayed when the url link was opened. The survey was open to respondents for a four-month period. **Data analysis** For the survey questions, descriptive analysis was	**Themes** Original theme: Educational difficulties reported by respondents • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people Original theme: N/A (Under implications of the results) • Diagnosis and identification of needs first ○ Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Potential for bias due to convenience sample targeting those already involved with 22q11DS organizations **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Methods not explicit or justified **Q6: Has the relationship between researcher and participants been adequately considered?** No: The relationship between the researcher and participants has not been considered **Q7: Have ethical issues been taken**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Survey with free text questions **Study dates** NR: The survey was open to respondents for a four-month period.		performed under the following headings: educational support available educational difficulties reported by respondents Involvement of healthcare professionals For the free text responses, content analysis was conducted	- Information sharing ○ Sharing information increases understanding of the child or young person and their needs	**into consideration?** Yes: Ethics approved and consent to complete the survey were embedded within the survey however unclear how research was described to participants **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited detail on data analysis **Q9: Is there a clear statement of findings?** Can't tell: Lack of supporting evidence **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Limited integration with existing research. New areas of research not identified. **Source of funding** Glasgow Dental Hospital **Other information** Experiences of education and health care
Full citation Council for Disabled Children, Hamblin Emily, 'Realistic positivity': understanding the additional needs of young	**Characteristics** n=6: parents of 8 adopted children; n=13: professionals (managers, service leads or practitioners and 1 adoption policy and practice expert) n=19 total Children adopted from the UK system: n=7 (of these, n=6 across local authority boundaries) Children adopted from	**Setting** Interviews were conducted via the phone with the exception of one parent and two professionals who were interviewed in person **Data collection** Semi structured interviews with topic guides Interviews were transcribed verbatim Information from several	**Themes** Original theme: Joint working in assessment planning and provision - Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working Original theme: Response to new or	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes: it was not discussed how the researchers decided which method to

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
children placed for adoption, and supporting families when needs are unexpected, 87, 2018 **Ref ID** 1105592 **Country/ies where study was carried out** UK (England) **Study type** Primary qualitative **Study dates** NR	overseas: n=1 Needs of adopted children included: ADHD, attachment difficulties, attachment disorder, autism spectrum disorder and quasi-autism, complex health needs including heart problems, developmental delay, developmental trauma, developmental coordination disorder (dyspraxia), foetal alcohol spectrum disorders, foetal alcohol syndrome, genetic condition, hearing loss, learning difficulties, sensory processing disorder or sensory issues. (some of the needs were not formally diagnosed) Symptoms and behaviours also included: anxiety, violence and toileting issues Professionals worked in a range of areas including: adoption social work, adoption medical work, adoption policy, post-adoption therapeutic provision, early years and education, statutory services for children with SEN, specialist CAMHS **Inclusion criteria** Parent and profession interviewees with experience	other contributors was gathered by email **Data analysis** Thematically analysis using the Framework approach.	emerging concerns post placement • Organisation of services ○ Having the right people involved and collaborating can overcome gaps in service provision • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point Original theme: Significance of diagnosis • Diagnosis and identification of needs first ○ Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support • Organisation of services ○ Rigid definition of, and criteria for, services leads to gaps in service provision Original theme: Barriers and enablers to joint working • Relationships between service providers ○ Shared values and priorities promote joint working • Funding and resources	use **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Limited details on recruitment aside from that calls for interviewees were disseminated through adoption and disability related networks **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: The data collection setting and methods were not justified in the text **Q6: Has the relationship between researcher and participants been adequately considered?** No: the relationship between the researcher and participants does not appear to be adequately considered **Q7: Have ethical issues been taken into consideration?** No: No mention of consent or ethics, or how the research was explained to participants **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited detail provided on data analysis **Q9: Is there a clear statement of findings?** Can't tell: Limited participant quotes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	of parenting or supporting children: who had been placed for adoption or entered early permanence placements since 2010 (later extended to 2009) who were aged under five at the time for whom concerns relating to physical disability, learning disability or autism became apparent during or after adoption. **Exclusion criteria** NR		○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care Original theme: Sharing information and professional opinions • Information sharing ○ Information is not always shared nor sufficient to meet the needs of other services • Funding and resources ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care • Organisation of services ○ Importance of clear pathways for referrals between services Original theme: Roles and responsibilities • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working Original theme: Parental engagement with services and community resources	Yes: Limited discussion on existing knowledge or generalisability of findings **Source of funding** National Institute for Health Research (NIHR) Children's Policy Research Unit **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Communication and support ○ More information and support for service users to understand and access the available services Original theme: Respecting, involving and empowering adopters • Communication and support ○ More information and support for service users to understand and access the available services Original theme: Coordination and collaboration • Communication and support ○ More information and support for service users to understand and access the available services • Organisation of services ○ Lack of appropriate services Original theme: Accessibility of services • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Original theme: Professional availability, continuity and responsiveness • Importance of key worker/lead professional ○ Key worker/lead professional is important for having a holistic view and coordinating services	
Full citation Dillenburger, K., McKerr, L., Jordan, J. A., BASE project (vol.4): qualitative data analysis, 229, 2016 **Ref ID** 1104593 **Country/ies where study was carried out** UK (Northern Ireland) **Study type** Primary qualitative **Study dates** NR	**Characteristics** Note: Relevant quotes extracted for parents only n=14 parents of children (n=15) n=9 families with one child with autism; n=3 families with two children diagnosed with autism; n=2 families where both parents took part. Age range of Parents: 37-59 years Employment: n=7 were in employment (five in full time and two in part-time jobs); n=6 not in paid employment; n=1 retired. Gender of children: n=11 male, aged 8-27 years; n=4 female, aged 3-20 years Age range of children: 3-27 years Children living at home with their parents: n=13; children living away from home: n=2.	**Setting** Individual interviews (face to face and self-completion) were conducted by both researchers, either in the participants' home or office, whichever was preferred All but three interviews were audio-recorded; interviewers made contemporaneous notes in lieu of recording and all were subsequently transcribed On-line questionnaires were posted on SurveyMonkey. Links were distributed to gatekeepers who then circulated the link directly to their staff or members either via emails, staff newsletters, or online, using staff intranet services. Individual case studies	**Themes** Original theme: Statutory services in Health and Social Care • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes: Not discussed how the researchers decided which method to use **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Purposive sampling using agency and voluntary sector contacts as gatekeepers, and application of snowballing methods. **Q5: Were the data collected in a way that addressed the research issue?** Yes **Q6: Has the relationship between**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	Conditions of children: n=12 had one or more co-occurring conditions; n=3 had learning disabilities; n=2 had Attention Deficit Hyperactivity Disorder; n=3 had dyslexia; n=2 had dyspraxia; n=2 had sleep disorders; n=1 each had anxiety, Tourette's syndrome, asthma, and eczema. **Inclusion criteria** Health and social care professionals, Educationalists, Policy makers, Employers, Young people and adults with ASD, including those with intellectual and neurodevelopmental disabilities, Caregivers/parents of individuals with ASD **Exclusion criteria** NR	interviews were held in the organisations and lasted 1 - 1 ½ hours each. Two were audio-recorded, (by request one was not recorded) and subsequently transcribed **Data collection** semi structured interviews, questionnaire (alternative interview format and online surveys) and focus groups Service providers (health and social care professionals, educationalists, policy makers, and employers): individual interviews and online surveys Service users (young people and adults with ASD and their caregivers/parents): focus groups and individual interviews (10 students opted for online survey) **Data analysis** NR		**researcher and participants been adequately considered?** No: Does not appear that the potential relationship between researchers and participants has been considered **Q7: Have ethical issues been taken into consideration?** Yes **Q8: Was the data analysis sufficiently rigorous?** No: No detail provided on data analysis **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** Office of the First Minister and Deputy First Minister (OFMDFM) **Other information** Volume 4. Qualitative study using interviews and focus groups with individuals affected by autism and key professionals (e.g. educationists, employers, policy makers). total participants: n=848 *Professionals: (interviews and online surveys)* including health and social care, education, public sector and private sectors, and education professionals from across the sector *Individuals with autism: (focus groups and interviews)*

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				Individuals interviews: n=37 Focus groups, n=8 Individuals with autism and their carers, n=17 (interviews, 19 participants) Educational professionals, n=12 *Online questionnaires: n=808* Employees and further education/training and higher education staff, n=108 Individuals employed in government departments participating in the autism strategy, n=18 Students in FE/HE institutions, n=10 Individuals employed in provision of education and health and social care services such as education and library boards, teachers, GPs and health and social care trust employees *Case studies (individuals interviews): n=3* Managers of job placement for individuals with ASD: (3 interviews, 4 participants)

Full citation
Fox, Fiona, Aabe, Nura, Turner, Katrina, Redwood, Sabi, Rai, Dheeraj, "It was like walking without
	Characteristics
	<u>Characteristics of parents</u>
	total: n=15 parents
	gender: n=12 female, n=3 male
	Age: Mean = 36 years
	relationship status: n=11 married, n=4
	total number of children: range=3-8, mean=
	Language interview
		Setting
		Community centre or participants' own homes (according to preference)
		Data collection
		semi structured interviews lasting 45–95 min interviews explored the family's experiences of having a child with autism, from the first time they
			Themes
			Original theme: Accessing services
			- Communication and support
			  ○ More information and support for service users to understand and access the available services
			  ○ Lack of communication and support that address language and cultural
				Limitations
				Q1 Was there a clear statement of the aims of the research?
				Yes
				Q2 Was a qualitative methodology appropriate?
				Yes
				Q3 Was the research design appropriate to address the aims of the research?
				Yes

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
knowing where I was going": A Qualitative Study of Autism in a UK Somali Migrant Community, Journal of autism and developmental disorders, 47, 305-315, 2017 **Ref ID** 1077216 **Country/ies where study was carried out** UK (England) **Study type** Primary qualitative **Study dates** Interviews took place between July and September 2015	*conducted: n=8 Somali, n=5 English, n=2 both* *Characteristics of the children (of the parents interviewed)* n=17 diagnosis of autism; n=5 girls, n=12 boys Mean age (range): 7 years (4-13 years) From n=15 parents interviewed: Non verbal n=6; n=4 under the age of 5 years, n=2 5 years and over Speaking a little to full speech n=9; started talking n=3, talks a little n=2, One talks more n=1, Older talks more n=1 *Families with 2 children with autism* n=2; number of children each=2; twins aged 4 years, sisters aged 9 years and 4 years **Inclusion criteria** Parent to a child under 16 years of age who has a diagnosis of autism Identifying as a member of the Bristol Somali migrant community **Exclusion criteria** No exclusion criteria (when the two inclusion criteria were met)	became aware of their child's difference, through the process of diagnosis and their subsequent experiences of health, social and education services. interviews were audio recorded and a professional company transcribed transcripts were audio checked for accuracy adding passages when the Somali was not fully translated **Data analysis** transcripts were anonymised prior to analysis and analysed using inductive thematic analysis initial coding, the forming and refining of categories, searching for negative evidence and comparison across the data set at each stage of the analysis was performed codes identified in the transcripts were discussed, refined and agreed, and a thematic coding framework was drafted the coding structure was revised, merged and	barriers • Diagnosis and identification of needs first ○ Early identification of needs and making referrals before a diagnosis has been reached promotes early access to support Original theme: Education services • Service users' involvement and relationships with service providers ○ Co-working improved when professionals worked closely with parents and kept them informed Original theme: Learning and diagnosis • Diagnosis and identification of needs first ○ Parents identifying concerns and proactively seeking help Original theme: Social services • Long waiting times for support ○ Delays from one service can impact access to other services • Attitudes and social stigma about service provisions ○ Fear of, and stigma	**Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Some targeted sampling of parents of older children and fathers due to under representation in the sample **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Data collection and setting not justified **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: Co-interviewers facilitated interviews in both English and Somali to elicit detailed and personal accounts, however no examination of the researchers own role or how this may influence bias **Q7: Have ethical issues been taken into consideration?** Yes: Participants received an information sheet in Somali and English and full understanding was checked before interviews began. Written informed consent and ethic approval was obtained. Unclear how the research was explained to participants **Q8: Was the data analysis sufficiently rigorous?** Yes **Q9: Is there a clear statement of findings?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		refined to develop a coherent thematic summary which was discussed and agreed by the study team	○ associated with, social services	Yes: Due to limited space not all of the themes are presented **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Limited implications for policy **Source of funding** Supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care West (CLAHRC West) at University Hospitals Bristol NHS Foundation Trust. **Other information**
Full citation Griffith, Gemma Maria, et, al, Receiving an assessment and a potential diagnosis on the autistic spectrum: a thematic content analysis of parental experiences, Good Autism Practice, 14, 59-68, 2013 **Ref ID** 1103451	**Characteristics** n=10 biological parents (from 8 families); Father: n=3, Mother: n=7 Assessment service: n=3 from the social and communication (s/c) team, n=5 CAMHS (child and adolescent mental health services) Age range of children: 2-12 years (mean: 6.6 years) Gender of the children: n=2 female, n=6 male Diagnosis of children: n=4 Autism, n=2 Asperger syndrome, n=1 none **Inclusion criteria** NR **Exclusion criteria** NR	**Setting** face to face in a local clinic (n=7), or telephone (n=1) **Data collection** semi structured interviews were recorded on a digital recorder and transcribed **Data analysis** thematic content analysis	**Themes** Original themes: Support during the assessment process/Lack of post diagnostic support • Working across multiple services ○ Assigned consistent one point of contact or agency would be beneficial to joint working	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes: It was not discussed how the researchers decided which method to use **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: The data collection methods

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Country/ies where study was carried out UK (Wales) **Study type** Primary qualitative **Study dates** NR				and setting have not been justified **Q6: Has the relationship between researcher and participants been adequately considered?** No: The relationship between the researcher and participants has not been adequately considered **Q7: Have ethical issues been taken into consideration?** Yes: Ethical and informed consent (written and verbal) were obtained, but no discussion around these issues or how the research was explained to participants **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited detail on data analysis **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Limited discussion on implications to policy/practice **Source of funding** Welsh government ASD funds, allocated by the Conwy and Denbighshire ASK stakeholder group **Other information**
Full citation Hurt, Lisa, Langley, Kate, North, Kate,	**Characteristics** n=23 n=8 health professionals working within a NHS multi-	**Setting** Wales **Data collection** Focus group discussions	**Themes** Original theme: Barriers • Communication and support	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes: Study aimed to "describe and

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Southern, Alex, Copeland, Lauren, Gillard, Jonathan, Williams, Sharon, Understanding and improving the care pathway for children with autism, International journal of health care quality assurance, 32, 208-223, 2019 **Ref ID** 1095464 **Country/ies where study was carried out** UK (Wales) **Study type** Mixed methods - including qualitative workshops (focus group discussions)	disciplinary neurodevelopmental team from one health board in South Wales (psychiatrists, clinical psychologists, occupational and speech therapists) n=8 staff from a mainstream primary school in South Wales with two specialist ASD classes (teachers, teaching assistants and a speech therapist) n=7 parents of primary school children diagnosed with ASD **Inclusion criteria** Health professionals working within an NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists) staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist) parents of primary school children diagnosed with ASD Participants were aged over 18 years of age and able to provide written informed	with the same topic guide for each group Discussions lasted approximately 2 hours and, with consent, were audio recorded. A graphic illustrator captured the discussions as they were taking place which provided a visual account of the key themes discussed. Participants undertook creative writing exercises to express their experiences in narrative form **Data analysis** Thematic analysis was used to code the focus group data and extract the major themes from each group. The construction of the initial coding template was based upon the research topic and the themes that emerged from reading the first few transcripts. An iterative approach was used The transcripts were read by all the authors and the initial identification and coding of the themes was conducted by two authors Three types of triangulation	○ Lack of communication (verbal and written) between services ○ More information and support for service users to understand and access the available services • Information sharing ○ Inconsistent information provided to parents • Organisation of services ○ Importance of clear pathways for referrals between services ○ Inconsistency across paperwork and procedures used in different services, regions and local authorities ○ Lack of appropriate services • Diagnosis and identification of needs first ○ Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support • Working across multiple services ○ Assigned consistent one point of contact or agency would be beneficial to joint working Original theme: Enablers • Organisation of services ○ Importance of clear pathways	visualise the current care pathways, as experienced by health professionals, education professionals and families and understand the enablers and barriers when accessing or operationalising the pathways, to identify potential areas for better integration and collaboration" **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Participants were selected using convenience sampling and included health professionals, mainstream primary school staff and parents of primary school children. Small sample size and demographic information of participants not provided. **Q5: Were the data collected in a way that addressed the research issue?** Yes **Q6: Has the relationship between researcher and participants been adequately considered?** No: The relationship between the researchers and participants has not been adequately considered **Q7: Have ethical issues been taken**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Study dates September 2015	consent **Exclusion criteria** NR	were employed – data, method and investigator	for referrals between services	**into consideration?** Yes **Q8: Was the data analysis sufficiently rigorous?** Yes **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** NR **Other information**
Full citation Hutton, Eve, King, Annette, Parent/carer views on personal health budgets for disabled children who use rehabilitation therapy services, Disability & Society, 33, 254-271, 2018 **Ref ID** 786691	**Characteristics** Total: n=9 *Qualitative study type* focus group, n=2 face-to-face interviews, n=2 telephone, n=5 *Age of child* Range: 2-16 years Mean (calculated): 8.7 years *Gender of child* Girl, n=6 Boy, n=3 *Age and gender of child* Girl aged 16 years, n=1 Boy aged 13 years, n=2 Girl aged 13 years, n=2	**Setting** One region in the south of England **Data collection** A focus group/interview guide was developed to cover the following themes: • Getting the help you need when you need it (including questions around timely access to services and quality of the support provided) • personalised care (which included views on the proposed introduction of personalised budgets and how this might	**Themes** Original theme: Managing the budget • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments • Funding and resources ○ Personalised budgets and direct payments increase flexibility but also burden on the family to make decisions and arrange care	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes: To explore the views of parents and carers of disabled children on the NHS rehabilitation therapy services introduction of personal health budgets in one region in the south of England **Q2 Was a qualitative methodology appropriate?** Yes: Parents and carers views on personal health budgets "provide the basis for an analysis that considers their expectations and the challenges of delivering on the promise of a personal health budget when austerity measures are affecting child health services" **Q3 Was the research design appropriate to address the aims of**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Country/ies where study was carried out UK (England) **Study type** Primary qualitative - focus group or interview (face-to face or telephone) **Study dates** NR	Girl aged 5 years, n=1 Girl aged 2 years, n=1 Boy aged 2 years, n=1 Girl aged 18 months, n=1 *Relationship to child* mother, n=8 foster mother and father, n=1 *Current education place of child/young person* mainstream school, n=5 secondary school, n=1 nursery, n=1 none, n=2 *Interview format* group, n=2 in person (individual), n=1 telephone, n=6 **Inclusion criteria** Parents and primary carers of disabled children (aged 18 years or younger) from one region in the south of England who accessed at least two paediatric rehabilitation therapy services locally (e.g. physiotherapy, occupational therapy, and speech and language therapy). **Exclusion criteria** NR	affect care) - managing transition (exploring periods of change in support needs and the responsiveness of therapy services) Focus groups and interviews were recorded and transcribed verbatim. The focus group and face-to-face interviews lasted for around one hour, and telephone interviews were typically shorter (30–45 minutes). All participants received a summary of the findings at the end of the study. **Data analysis** Interview data were entered into NVIVO and analysed using 'framework analysis'		**the research?** Yes: Participants were invited to attend a focus group or one-to-one interview. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Participants included parents and carers of disabled children, and were recruited via therapy health teams and local parent groups. Small sample size (n=9), demographic information provided. **Q5: Were the data collected in a way that addressed the research issue?** Yes (partially): Focus groups and interviews were recorded and transcribed verbatim. Sample interview/focus group questions were provided in table 2. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: Unclear if the researcher critically examined their own role, or any potential bias and influence during the formulation of the research questions and data collection. **Q7: Have ethical issues been taken into consideration?** Yes: Ethics approval was obtained prior to the start of the study from the National Research Ethics Service and Research and Development approval from a local acute hospital. Informed

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				consent was obtained prior to the focus group/interviews. **Q8: Was the data analysis sufficiently rigorous?** Yes (partially): Description of the analysis process provided (framework analysis). **Q9: Is there a clear statement of findings?** Can't tell: Evidence for the potential benefits of personal health budgets but the potential drawbacks of personal budgets do not appear to be equally explored. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** The research was funded by a project grant from East Kent Hospitals University Foundation Trust (non industry) **Other information** A personal health budget is defined in the Children and Families Act (2014) as: An amount of money identified by the local authority to deliver all or some of the provision set out in an Education Health and Care Plan (EHCP). Personal health budgets, are available since 2014 for children who have an Education, Health and Care Plan Note the following study was referred

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				to in the paper but it is currently unpublished therefore does not meet the criteria for inclusion: Hutton, E., Annette King, K. Hamilton-West, and S. Hotham. 2016. Understanding the Support Needs of Disabled Children and Their Families in East Kent. Research Report. (Unpublished). https://create.canterbury.ac.uk/id/eprint/15067
Full citation Kaehne, Axel, Catherall, Chris, User involvement in service integration and carers' views of co-locating children's services, Journal of health organization and management, 27, 601-17, 2013 **Ref ID** 1095518 **Country/ies where study was carried out**	**Characteristics** Parents: n=3 **Inclusion criteria** Parent representatives involved in planning new co-located services for children (aged 0-19) with significant disabilities. **Exclusion criteria** No additional criteria reported.	**Setting** All parent representatives involved in planning the new services were contacted by the research team and agreed to participate in interviews. **Data collection** Data was collected through semi-structured interviews using a topic guide designed based on a review of the literature and interviews conducted with staff involved in planning the new services. No further information is provided about the topic guide and authors do not report how long interviews lasted and if they were conducted face-to-face or by telephone. Interviews were audio recorded and transcribed.	**Themes** Original theme: Perception of service changes • Joined-up care requires a substantial amount of time, organisation and commitment ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working Original theme: Role of parents in planning the new service • Service users' involvement and relationships with service providers ○ Families vary in their ability and willingness to make	**Limitations** **Q1 Was there a clear statement of the aims of the research?** No: The aim is stated to report the findings of a study of the new services, but does not state whether the intention was to capture subjective experiences of this, and/or whose experiences they were interested in. However, it can be inferred from the introduction that they were interested in the experiences of parent representatives. **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture experiences. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: Limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Recruited all parent

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
UK **Study type** Mixed methods, including interviews **Study dates** 2011-2012		**Data analysis** Data analysis was conducted independently by two researchers. Differences in interpretation were discussed and both researchers agreed the final summary.	decisions and be involved in care planning • Attitudes and social stigma about service provisions ○ Service providers not ‘buying in’ to approach Original theme: Unmet needs and how to address them through service changes • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services • Organisation of services ○ Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial ○ Rigid definition of, and criteria for, services leads to gaps in service provision • Communication and support ○ More information and support for service users to understand and access the available services	representatives involved in planning the new services. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Limited information is provided about the interview guide and format of interviews. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Can't tell: Ethical approval was obtained but there is no mention of informed consent, or methods for maintaining anonymity/confidentiality. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information is reported about data analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are presented clearly but there is no discussion of the credibility of the findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: The findings of the study are clearly discussed in the context of the literature but several limitations are noted, including the very small sample size and lack of generalisability (including to other learning disability

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				services in the UK) **Source of funding** Not industry funded. **Other information** Limited information is reported about the population eligible for the service and no information is available about the children of the parent representatives so it is difficult to determine if population has severe and complex needs. However, paper does report that services is for those with 'significant' disabilities.
Full citation Karim, K., Cook, L., O'Reilly, M., Diagnosing autistic spectrum disorder in the age of austerity, Child: care, health and development, 40, 115-123, 2014 **Ref ID** 990161 **Country/ies where study was carried out** UK	**Characteristics** Interviews: n=26* (this number of reported interviews does not match to the numbers reported below, which were extracted from table 1 in the paper) psychiatrists, n=7; educational psychologists, n=5; paediatrician, n=9 Participants were mostly female, ranging from early twenties up to early fifties. **Inclusion criteria** professionals from the National Health Service and two local education authorities including child and adolescent psychiatrists, community paediatricians and educational psychologists **Exclusion criteria**	**Setting** UK services **Data collection** Semi-structured interviews transcribed verbatim Multiple readings of the transcripts were undertaken by several members of the research team ensuring inter-coder reliability **Data analysis** Thematic analysis	**Themes** Original theme: A multi-professional/multi-agency or individual diagnosis? • Diagnosis and identification of needs first ○ Professionals were more committed to achieve multi-disciplinary working for complex diagnoses and had to rationalise making an independent diagnosis • Relationships between service providers ○ Negative professional relationships and disagreements inhibit joint working ○ Putting aside professional differences for the good of the child or young person	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Limited detail on recruitment strategy and number of participants reported in the text does not match those reported in the table **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Setting not reported, and

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

Study type
Primary qualitative
Study dates
NR
	NR		Original theme: Time and resources [for diagnosis of ASD]
			• Organisation of services
			  ○ Specialist services provide benefit but there is a lack of provisions to make these services available
			• Diagnosis and identification of needs first
			  ○ Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support
			• Funding and resources
			  ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care
				data collection methods and setting were not justified in the text
				Q6: Has the relationship between researcher and participants been adequately considered?
				No: The relationship between the researcher and participants has not been adequately considered
				Q7: Have ethical issues been taken into consideration?
				Yes: Ethics obtained, and written consent from departmental managers to approach professional staff. No discussion on issues around consent or ethics and no detail on how the research was explained to participants
				Q8: Was the data analysis sufficiently rigorous?
				Can't tell: Limited detail on analysis
				Q9: Is there a clear statement of findings?
				Yes
				Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)
				Yes
				Source of funding
				NR
				Other information

Full citation Kiernan, Joann, et, al, Mothers' perspectives	**Characteristics** n=10, parents (all mothers) agreed to be interviewed n=6, mothers reported that their child/children had	**Setting** Across England **Data collection** Semi-structured interviews took place at a time and	**Themes** Original theme: Square services, round needs • Communication and support	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes: The aim of the research was to determine the impact of behavioural

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
on the lived experience of children with intellectual disability and challenging behaviour, Journal of Intellectual Disabilities, 23, 175-189, 2019 **Ref ID** 1106176 **Country/ies where study was carried out** UK (England) **Study type** Primary qualitative - semi structured interviews **Study dates** NR	attended special educational provision n=12, child/children *Age of child/children (n=12)* Range, 7-18 years Mean, 13.6 years *Gender of child/children (n=12)* Girl, n=2 Boy, n=10 *Sex and age of child/children (n=12)* n=1, boy aged 18 n=1, girl aged 17 n=1, girl aged 16 n=3, boy aged 15 n=1, boy aged 14 n=2, boy aged 13 n=1, boy aged 11 n=1, boy aged 10 n=1, boy aged 7 *Diagnosis (as described by family participant)* n=1, Intellectual disability cerebral palsy n=1, severe intellectual disability n=1, profound and multiple intellectual disability n=5, autistic spectrum condition n=1, rare disorder, intellectual	venue chosen by participants with the principal researcher Interviews were recorded and transcribed **Data analysis** Thematic analysis Transcripts were individually coded and related back to the original research question First identification of codes was established through a process of reading the transcripts, listening to the audios and prolonged periods of reflection Secondly, the identification of experience and common meanings across the transcripts as a whole Finally, overarching or superordinate global themes were developed to represent the key messages deduced from the data.	○ Lack of communication (verbal and written) between services • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments Original theme: Belonging • Organisation of services ○ Specialist services provide benefit but there is a lack of provisions to make these services available ○ Mainstream services provide benefit but more effort and support is needed to integrate children and young people	needs (challenging behaviour) on the lives of children with an intellectual disability **Q2 Was a qualitative methodology appropriate?** Yes: Qualitative research is appropriate for the research goal; to determine "mothers perspectives on the lived experience of children with intellectual disabilities and behavioural needs". **Q3 Was the research design appropriate to address the aims of the research?** Yes: The research design was justified in the text **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Information and contact details about the study were disseminated through appropriate channels. Mothers of children diagnosed with intellectual disability, behavioural needs and special educational needs were invited to take part in an interview. Small sample size (n=10), demographic information provided. **Q5: Were the data collected in a way that addressed the research issue?** Yes (partially): Semi structured interviews were recorded and transcribed. Setting for the data collection is unclear, and methods not explicitly detailed.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	disability n=1, moderate intellectual disability n=1, attention deficit and hyperactivity disorder n=1, attention deficit disorder and oppositional defiance disorder **Inclusion criteria** Mothers of children whose behaviours had been described as challenging, based on parental disclosure of their child/children's diagnoses of intellectual disability, behavioural needs and special educational needs **Exclusion criteria** NR			**Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: Unclear whether researchers critically examined their own role, potential bias and influence during data collection. Partners in Policymaking (national network that supports families of people with an intellectual disability) aided the development of the research question. **Q7: Have ethical issues been taken into consideration?** Yes: Full ethical approval was obtained for the study via Manchester Metropolitan University ethics committee. Participant information sheets, consent forms and interview guides were produced. **Q8: Was the data analysis sufficiently rigorous?** Yes (partially) **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Unclear how the findings can be transferred to other populations, however the generalization of findings was described as not the aim of the study. **Source of funding** **Other information** All three services (services discussed

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				in general, service type not specified)
Full citation Kirk, Susan, Fraser, Claire, Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: a qualitative study, Palliative medicine, 28, 342-52, 2014 **Ref ID** 1077339 **Country/ies where study was carried out** UK **Study type** Primary qualitative **Study dates** February–July 2012	**Characteristics** n=35 interviews n=16 young people, n=16 parents (n=12 families), n=7 staff members n=9 young people were unable to directly participate due to their profound impairments and therefore parents were the key informants. <u>Characteristics of young people (n=16)</u> *Age (years)* 16-17, n=4 (25%) 18-22, n=8 (50%) 23-27, n=2 (12.5%) 28-31, n=2 (12.5%) (Mean age, 20.5 years) *Gender* Female, n=7 (44%) Male, n=9 (56%) *Family structure* Two parent, n=6 (37.5%) Lone parent, n=7 (43.8%) Unknown, n=3 (18.8%) *Condition/diagnosis (by ICD-10 category)* Duchenne muscular dystrophy, n=4 (25%) Other nervous system condition, n=4 (25%) Spinal muscular atrophy, n=3 (18.8%)	**Setting** Participants chose their preferred location for the interview Young people had the choice of being interviewed alone or accompanied **Data collection** In-depth, semi-structured interviews Interview audio recordings were transcribed verbatim. Interview topic guides were developed **Data analysis** Grounded theory approach Authors were involved in identifying and developing the codes/categories iteratively from the data	**Themes** Original theme: Transition to adult health and social care services • Communication and support ○ More information and support for service users to understand and access the available services • Organisation of services ○ Lack of appropriate services	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes **Q3 Was the research design appropriate to address the aims of the research?** Yes **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Limited detail on recruitment, potential bias as participants attending or working at one hospice were invited to participate **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: The methods and setting for data collection were not justified in the text **Q6: Has the relationship between researcher and participants been adequately considered?** No: The relationship between the researcher and participants has not been adequately considered **Q7: Have ethical issues been taken into consideration?** Yes: Ethics and informed consent was obtained. Participants were given

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	Down's syndrome, n=2 (12.5%) Congenital condition, n=2 (12.5%) Metabolic condition, n=1 (6.2%) Characteristics of parents *Relationship to young person (n=16)* Mother, n=12 (75%) Father, n=4 (25%) *Family structure (n=12)* Two parent, n=8 (66.7%) Lone parent, n=4 (33.3%) *Age of children (years) (n=12)* 16-17, n=0 18-22, n=9 (75%) 23-27, n=2 (16.7%) 28-31, n=1 (8.3%) Mean age=20.5 years *Gender of children (n=12)* Female, n=6 (50%) Male, n=6 (50%) *Condition/diagnosis by ICD category (n=12)* Cerebral palsy, n=4 (33.3%) Pervasive development disorder, n=2 (16.7%) Congenital condition, n=2 (16.7%) Down's syndrome, n=2 (16.7%) Metabolic condition, n=1 (8.3%) Other nervous system			assurances of anonymity/confidentiality and distress and safeguarding protocols were established **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited detail on data analysis **Q9: Is there a clear statement of findings?** Yes **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes **Source of funding** No specific grant from any funding agency in the public, commercial, or not-for-profit sectors. **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	condition, n=1 (8.3%) **Inclusion criteria** young people (aged over 16 years, not at an end-of life stage, from one children's hospice), parents and hospice workers **Exclusion criteria** NR			
Full citation McCartney, Elspeth, Muir, Margaret, Braun, Butterfield Coles Cullen Forbes Forbes Riddell Smits Wright, School leavers with learning disabilities moving from child to adult speech and language therapy (SLT) teams: SLTs' views of successful and less successful transition co-	**Characteristics** Speech and language therapists (SLT): n=7 (from 5 different teams; 2 child teams in secondary schools and 3 adult teams) **Inclusion criteria** SLTs involved in transition between child and adult SLT teams for school-leavers. **Exclusion criteria** No additional criteria reported.	**Setting** SLTs were purposively sampled via staff email and telephone lists of one Scottish health board. Snowball sampling techniques were also used by asking those interviewed early in the process so suggest other potential participants. The aim was to include at least one SLT from each team identified as being involved in transitions from schools. **Data collection** Interviews were conducted by one researcher, in workplaces and universities and lasted 40 to 45 minutes. Interviews were semi-structured and covered transition procedures used by their SLT team, one transition that was considered	**Themes** Original theme: Outside influences on SLT teams • Information sharing 　○ Accessing electronic patient records through an online portal will improve working Original theme: SLT team properties/SLT communication and information exchange • Transition 　○ Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late Original theme: SLT team properties • Joined-up care requires a substantial amount of time, organisation and commitment 　○ Lack of ongoing involvement from external agencies	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture views. **Q3 Was the research design appropriate to address the aims of the research?** Yes: Justification for research design is clearly explained. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Teams were purposively sampled to obtain views from those directly involved in school-leaver transitions. **Q5: Were the data collected in a way that addressed the research issue?** Yes: Content of interviews/focus groups/questionnaires appear to be appropriate to the aims of the research and data was audio recorded. **Q6: Has the relationship between**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
working practices, Journal of Research in Special Educational Needs, 17, 168-178, 2017 **Ref ID** 1105286 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** May 2013-June 2014		successful and what made it successful/what wasn't as good and could be done differently, and one transition that was less successful and why. Participants were asked specifically about transitions for school-leavers in the last 3 years that had speech, language, swallowing or communication needs (SLSC) and a learning disability. Participants received the questions in advance of the interview as part of the information package for the study. Interviews were audio recorded and transcribed and the participant was given the opportunity to review the transcript and make changes. **Data analysis** Data was analysed thematically using an inductive, data-driven approach (with no pre-specified themes) in NVivo. The researcher who conducted the interviews completed the initial analysis by reading and re-reading transcripts to	• Professional and staff knowledge and training ○ Misconceptions and lack of understanding from professionals lead to incorrect, or a lack of, advice and referrals ○ Opportunities to learn from, observe and model other services Original theme: SLT communication and information exchange • Communication and support ○ Lack of communication (verbal and written) between services	**researcher and participants been adequately considered?** Yes: Authors reports that both researchers were SLTs which facilitated access to, and gave them credibility with, the participants. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval and consent was obtained; data was anonymised and stored securely. **Q8: Was the data analysis sufficiently rigorous?** Yes: Approach for data analysis is clearly described, including processes for ensuring the credibility of the findings. **Q9: Is there a clear statement of findings?** Yes: Findings are clearly presented and attempts were made to ensure credibility. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: There is limited discussion of the findings in the context of what is already known although, implications for practice are discussed. The authors report that the data may be most applicable to outstanding examples of good/bad practice, rather than typical examples, although likely to still be relevant to other SLT teams. **Source of funding** Not industry funded.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		organise data into common themes. A constant comparative approach was used to ensure the integrity of the themes. A second researchers checked 50% of the data after initial codes had been assigned, and all of the data once it was organised into themes. A thematic map was developed collaboratively by the two researchers and refined until both authors agreed that is provided a full and accurate representation of the data.		**Other information**
Full citation McConkey, Roy, Gent, Clare, Scowcroft, Emma, Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: a multi-	**Characteristics** Family member: n=14 (11 mothers, 6 fathers) Key workers: n=17 Referrers: n=17 (social workers, psychologists and community nurses) **Inclusion criteria** Families, key workers and referrers of children currently receiving services from Action for Children, or had received services in the past 2 years. **Exclusion criteria** No additional criteria reported.	**Setting** Families and practitioners/providers were recruited from Action for Children in Glasgow, Edinburgh and Cardiff, who provide intensive support services for children with developmental disabilities and severely challenging behaviours (aged up to 19 years old). **Data collection** Semi-structured interviews were conducted face-to-face in a private room in the short break service, in family homes, or by	**Themes** Original theme: Benefits: Benefits to the children and young people • Information sharing ○ Development and sharing of a behaviour management plan provided benefit Original theme: Complexity: Complexity of services • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture perceptions. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: There is limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: A random sample was selected that did not differ significantly from the wider population. Included views from

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

informant study, Journal of applied research in intellectual disabilities : JARID, 26, 271-83, 2013
Ref ID
914709
Country/ies where study was carried out
UK
Study type
Qualitative
Study dates
2008-2010
		telephone. Most interviews were audio recorded; intensive notes were taken during the meeting, or immediately after, where people declined recording (2 instances). Audio recordings were transcribed verbatim.
		Data analysis
		Thematic analysis was undertaken to identify main themes and subthemes. Limited information is provided about the process of developing themes, and who was responsible for this. The authors report that findings were validated by the team of interviewers who collected the data, but it is not clear if this was done independently or as a group. Findings were then validated by steering groups comprising staff, parents and referrers (which included some of those interviewed), and the national steering group for the evaluation.
			and young people
			Original theme: Complexity: Complexity of the children
			- Organisation of services
			  - Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial
			Original theme: Future planning: Adult services
			- Organisation of services
			  - Lack of appropriate services
			Original theme: Negotiation: Amount of service provided
			- An imbalanced distribution in the amount of support provided to children/young people
			  - Individuals who shout the loudest are more likely to receive the desired support
			Original theme: Negotiation: The decision to use services
				families, keyworkers and referrers.
				Q5: Were the data collected in a way that addressed the research issue?
				Can't tell: Limited information provided about content/structure of semi-structured interviews.
				Q6: Has the relationship between researcher and participants been adequately considered?
				Yes: Authors report that researchers were independent of services.
				Q7: Have ethical issues been taken into consideration?
				Can't tell: Authors report that formal ethical approval was not needed as it was a service evaluation.
				Q8: Was the data analysis sufficiently rigorous?
				Can't tell: Limited information is provided about how themes were developed.
				Q9: Is there a clear statement of findings?
				Yes: Findings are clearly presented and process for validation of findings is described.
				Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)
				Yes: Contribution to the literature and directions for future research are discussed.
				Source of funding
				Not industry funded
				Other information

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Attitudes and social stigma about service provisions ○ Fear of, and stigma associated with, social services • Long waiting times for support ○ Lack of urgency to provide support until the child/young person reaches crisis point Original theme: Relationships/Relationships with families and young people • Service users' involvement and relationships with service providers ○ Co-working improved when professionals worked closely with parents and kept them informed Original theme: Relationships: Relationships between staff in other services • Relationships between service providers ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Original theme: Relationships: Relationships with families and young people • Working across multiple services ○ Sharing staff across multiple settings improved knowledge of the child	
Full citation McKean, Cristina, Law, James, Laing, Karen, Cockerill, Maria, Allon-Smith, Jan, McCartney, Elspeth, Forbes, Joan, A qualitative case study in the social capital of co-professional collaborative co-practice for children with speech, language and communication needs, International journal of language &	**Characteristics** **Profession:** Headteacher: n=8 SENCO: n=8 Classroom teacher: n=5 Higher level teaching assistant: n=2 Health visitor: n=2 Speech and language therapist: n=4 Educational psychologist: n=2 Language and communication teacher: n=2 **Inclusion criteria** Key professionals working with children with speech, language and communication needs **Exclusion criteria** No additional criteria reported.	**Setting** Schools and key professionals were recruited from one local authority in England and the related NHS trust. Eight schools were recruited that had varying levels of free school meals and identified speech, language and communication needs. Headteachers, SENCOs, class teachers and high-level teaching assistants were recruited directly from schools; the local authority facilitated access to educational psychologists and health visitors and the local NHS trust facilitated access to speech and language therapists via emails from service managers. **Data collection** Semi-structured interviews,	**Themes** Original themes: Agency and autonomy/Shared understanding of distribution of knowledge • Joined-up care requires a substantial amount of time, organisation and commitment ○ Lack of ongoing involvement from external agencies Original theme: Agency and autonomy • Joined-up care requires a substantial amount of time, organisation and commitment ○ Responsibility and resources are required to ensure plans are implemented and reviewed to accurately reflect changing needs Original themes: Child and family at centre/Collaborative practice adds value/SLCN is a priority	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture perspectives. **Q3 Was the research design appropriate to address the aims of the research?** Yes: Justification for research design clearly explained. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: Schools were selected to represent a range of social status (free school meals used as a proxy for social disadvantage) and speech, language and communication needs. An appropriate range of professionals was recruited from schools and the related NHS trusts and local authority. However, the authors state that as participation was voluntary, those with

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
communication disorders, 52, 514-527, 2017 **Ref ID** 1077422 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** October 2013-May 2014		lasting about 1 hour, were conducted with all participants covering barriers and facilitators to co-professional working, and social capital themes (e.g., the degree to which professionals felt they could rely on one another, whether they felt able to influence practice). Interviews followed a topic guide but did not use pre-defined questions. Participants were presented with views obtained from earlier interviews and given the opportunity to comment on them. Additionally, with the exception of headteachers, participants completed another interview where they were asked to reflect on and discuss a case where co-professional working was successful and a case where it was not successful. For some participants, the two interviews were conducted together as one, longer interview; three respondents were unable to complete the second interview. Interviews were	• Relationships between service providers ○ Shared values and priorities promote joint working Original themes: Child and family at centre/Nature of communication • Relationships between service providers ○ Mutual respect between professionals which allows equal opportunity to have opinions voiced and challenged Original themes: Child and family at centre/Negotiated, distributed and flexible actions/Responsibility is shared/Verbal communication • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working Original theme: Negotiated, distributed and flexible actions • Organisation of services ○ Using a more flexible	particularly positive or negative experiences may be more likely to participate. **Q5: Were the data collected in a way that addressed the research issue?** Yes: Content of interviews appear to be appropriate to the aims of the research and data appears to have been audio recorded (this is not explicitly stated but reference is made to both audio files and transcribing interviews verbatim. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: The composition of the research team is clearly considered as authors state that they represented a range of professions, allowing rich interpretation of the data and preventing bias towards any one profession. However, there is no discussion about how this may have impacted relationship with participants. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval and informed consent were obtained; participants were given opportunities to withdraw. Data was anonymised and held securely. **Q8: Was the data analysis sufficiently rigorous?** Yes: Approach for data analysis is clearly described, including processes

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		transcribed verbatim. **Data analysis** Data was analysed thematically using iterative methods. The first author completed the initial coding based on a-priori identified themes from social capital research; these were expanded and refined inductively based on the data. The first author then developed an initial set of themes along with a conceptual map of their relationships. This was reviewed by the wider research team and a second author coded a random selected of quotes to check reliability. Finally, findings were presented to relevant stakeholder groups to ascertain the validity, credibility and transferability of the findings.	approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial Original theme: Practical exchange of skills • Professional and staff knowledge and training ○ Opportunities to learn from, observe and model other services Original theme: Respect for others' contributions, with power hierarchies challenged • Funding and resources ○ Service providers have a lack of control over allocation of resources and there is a lack of transparency about decision making Original theme: Responsibility is shared • Long waiting times for support ○ Unavailability of staff able to complete the necessary paperwork/assessments	for ensuring the credibility and validity of the findings. **Q9: Is there a clear statement of findings?** Yes: Findings are clearly presented and attempts were made to ensure credibility. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: Implications for practice and commissioning are clearly discussed but the authors note that the context may not be generalisable to other settings as the local authority only had one NHS trust partner and staff in this region are relatively stable and have long standing relationships, which may present a more positive view than from other contexts/settings. **Source of funding** No sources of funding reported. **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Diagnosis and identification of needs first ○ Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support • Joined-up care requires a substantial amount of time, organisation and commitment ○ Responsibility and resources are required to ensure plans are implemented and reviewed to accurately reflect changing needs Original theme: Shared understanding of distribution of knowledge • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people Original theme: SLCN is a priority • Funding and resources ○ Competing priorities can impact the allocation of limited resources Original theme: Strong individual	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			relationships • Relationships between service providers ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working Original theme: Verbal communication • Communication and support ○ Lack of communication (verbal and written) between services • Joined-up care requires a substantial amount of time, organisation and commitment ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals	
Full citation Molteni, Paola, Guldberg, Karen, Logan, Nick, Bondy, Kasari Mesibov O'Neill Parsons	**Characteristics** **Profession:** Teacher: n=5 Teaching assistant: n=4 Care staff: n=7 Therapist: n=4 Head of department (Education and Psychology): n=2	**Setting** Teams were recruited from Sunfield, a 52-week independent residential special school which educates students with severe learning difficulties. The majority of students were residential and also had autistic spectrum	**Themes** Original theme: Challenging aspects of using the SCERTS Model: Assessment • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture perspectives/experiences. **Q3 Was the research design appropriate to address the aims of**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Prizant Prizant Reid Seligman Smith Smith Stake Strom Wittemeyer, Autism and multidisciplinary teamwork through the SCERTS model, BRITISH JOURNAL OF SPECIAL EDUCATION, 40, 137-145, 2013 **Ref ID** 1103529 **Country/ies where study was carried out** UK **Study type** Multi-methods approach involving questionnaires, observations, focus groups and interviews **Study dates** 2011	**Sex:** Female: n=16 Male: n=6 **Age range:** 23 to 64 **Educated to degree level:** n=15 **Years' experience working with people with autism:** 1-5: n=7 6-10: n=4 11-15: n=6 15-20: n=3 >20: n=2 **Inclusion criteria** Teams of professionals involved in implementing the SCERTS (Social Communication, Emotional Regulation, Transactional Support) model. **Exclusion criteria** No additional criteria reported.	disorders. The SCERTS model was implemented in 2011. **Data collection** Qualitative data was collected through focus groups (of the assessment process), semi-structured interviews and one open-ended question on a questionnaire. Focus groups lasted between 1 and 3 hours, and the researchers took an active part in the group. Individuals for interview (n=5) were identified during the focus groups based on their participation during the group. Semi-structured interviews were conducted using an interview schedule as a guide and both focus groups and interviews were recorded. A questionnaire was administered to all participants at the end of the assessment process which contained an open-ended question about personal opinions of SCERTS. **Data analysis** Interpretative Phenomenological Analysis (IPA) was used to analyse	• Joined-up care requires a substantial amount of time, organisation and commitment ○ Workloads are negatively impacted by the cumbersome and onerous nature of paperwork and interprofessional working Original theme: Challenging aspects of using the SCERTS Model: Teamwork • Joined-up care requires a substantial amount of time, organisation and commitment ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals • Attitudes and social stigma about service provisions ○ Service providers not 'buying in' to approach Original theme: Positive aspects of using the SCERTS Model: Assessment • Information sharing ○ Sharing information to streamline processes and transition Original theme: Positive aspects of using the SCERTS Model: Teamwork	**the research?** Yes: Justification for research design clearly explained. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Recruitment of overall participants was appropriate and authors provide rationale for why specific teams were selected to represent children with differing levels of communication. However, selecting participants for interviews based on involvement in focus groups may not result in a representative sample. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Limited information is provided about the interview guide and data saturation is not discussed. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: The authors clearly describe the collaboration between the researcher and key members of staff at the school, discuss the researchers involvement in the focus groups and discuss potential benefits of this, but whether this approach may have led to any biases is not discussed. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval and informed consent obtained.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		data collected from the focus groups and interviews. One research read and re-read the transcripts, identified key themes and connections between themes. The authors also report IPA was used to analyse quantitative data from the questionnaires but no further details are provided about this.	• Relationships between service providers ○ Clear targets improved accountability and the distribution of responsibility across services Original theme: Qualitative difference the SCERTS principles can make in the daily work of professionals working with children on the autism spectrum • Relationships between service providers ○ Mutual respect between professionals which allows equal opportunity to have opinions voiced and challenged ○ Shared values and priorities promote joint working	**Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information is provided about analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: The impact of the findings are clearly discussed, as are some directions for future research, but generalisability of the findings to other settings/approaches may be limited. **Source of funding** No sources of funding reported. **Other information**
Full citation National Autistic Society, School report 2015, 20, 2015 **Ref ID** 725393 **Country/ies where study**	**Characteristics** Parent/carer: n=1,431 Child/young person: n=231 **Inclusion criteria** Children and young people (aged under 25 years) with autism or parent/carer of children or young people with autism. **Exclusion criteria**	**Setting** Survey was based online. Setting/method of recruitment is not reported. **Data collection** Content of survey is not reported. Appears to have included both closed and open-ended questions based on data presented. **Data analysis**	**Themes** Original theme: Overall satisfaction with EHC assessment and planning process • Long waiting times for support ○ Replacements of statements with EHC plans resulted in delays to support provisions • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture experiences. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: No information is reported

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
was carried out UK **Study type** Survey **Study dates** June 2015-July 2015	No additional criteria reported.	Not reported	○ Professionals, staff and families lack understanding of the EHC plan process Original theme: Accessibility of the Local Offer • Communication and support ○ More information and support for service users to understand and access the available services	about research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Recruitment strategy is not reported. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Methods for data collection are not reported. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Can't tell: No information is reported. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: No information is reported. **Q9: Is there a clear statement of findings?** Can't tell: Findings are presented clearly but there is no discussion of the credibility of the findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Recommendations for the government, local authorities, schools and teachers are clearly presented. **Source of funding** No sources of funding reported. **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Full citation Palikara, O., Castro, S., Gaona, C., Eirinaki, V., Professionals' views on the new policy for special educational needs in England: ideology versus implementation, European Journal of Special Needs Education, 34, 83-97, 2019 **Ref ID** 1065416 **Country/ies where study was carried out** UK **Study type** Survey **Study dates** Not reported	**Characteristics** **Profession:** Educational psychologist: n=90 Speech and language therapist: n=24 Special educational needs co-ordinator: n=154 Headteacher: n=13 Teacher: n=12 Other: n=54 **Sex:** Female: n=307 Male: n=32 **Educated to degree level:** n=348 **Years of experience:** <1: n=4 1-4: n=18 5-10: n=64 11-20: n=131 >20: n=157 **Inclusion criteria** Professional groups working in special education. **Exclusion criteria** No additional criteria reported.	**Setting** The survey was distributed to schools/education establishments, educational psychology services, language services and other relevant professional organisations through a research network. **Data collection** The survey took 15-20 minutes to complete, was semi-structured and had three sections: participant characteristics and work experience, training received in relation to SEND reforms, opinion of main changes introduced by the Children and Families Act 2014 and the SEND Code of Practice. Three reminders were sent to complete the survey before it closed. Responses to the survey were anonymised. **Data analysis** Qualitative responses were analysed using inductive thematic analysis - no further information reported. Quantitative ratings were analysed using descriptive statistics	**Themes** Original theme: Extension of age range for service provision (0-25) • Funding and resources ○ Not enough funding or resources to support change from statements to EHC plans Original theme: Assessment of SEND involving education, health and care • Funding and resources ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care • Introduction of EHC plans ○ EHC plans are primarily concentrated around education and place less emphasis on health and social care Original theme: Replacement of statements of SEN with EHCPs • Organisation of services ○ Inconsistency across paperwork and procedures used in different services, regions and local authorities • Relationships between service	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture views/perspectives. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: There is limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: The survey appears to have been sent to a representative sample of professionals but those self-selecting to respond to a survey may give a biased sample. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Open-ended questions in the online consultation form provided the qualitative data, may not provide the necessary richness to address the research question. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval was obtained,

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		and ratings between professional groups were compared using one way ANOVAs.	providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Not all children/young people who need support meet the criteria for an EHC plan • Long waiting times for support ○ Replacements of statements with EHC plans resulted in delays to support provisions • Joined-up care requires a substantial amount of time, organisation and commitment ○ Workloads are negatively impacted by the cumbersome and onerous nature of paperwork and interprofessional working • Introduction of EHC plans ○ EHC plans are primarily concentrated around education and place less emphasis on health and social care ○ EHC plans have increased joint working and integration • Funding and resources ○ Not enough funding or resources to support change from statements to EHC plans	participation was voluntary and responses were anonymised. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information is provided about analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Contribution to the literature is clearly discussed and directions for future work are highlighted. **Source of funding** Not industry funded **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Professionals and staff lack the expertise and knowledge needed to complete the EHC plan • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people Original theme: Transition process to the new system for SEND provision: challenges • Funding and resources ○ Not enough funding or resources to support change from statements to EHC plans • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Professionals, staff and families lack understanding of the EHC plan process ○ Time taken for EHC plans to be refined and embedded in practice • Organisation of services ○ Inconsistency across	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			paperwork and procedures used in different services, regions and local authorities	
Full citation RIP STARS, et al.,, Defining quality and rights-based Education, Health and Care Plans (EHCPs) for disabled children and young people, 36, 2018 **Ref ID** 1105868 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** Not reported	**Characteristics** **Young people** **Age:** 13-25 **Sex:** n=9 female; n=6 male **Parent/carers:** n=9 mothers n=1 father **Professionals:** n=17; included SEN (head)teachers, SEND/Autism lead, SEN co-ordinator, educational psychologist, clinical leads/service directors/CEOs, lead/manager/assessment officer from Integrated Children's Disability Services, social worker, Depart for Education representative, expert in disability equality, independent supporter **Inclusion criteria** Not reported. **Exclusion criteria** Not reported.	**Setting** Setting/method of recruitment is not reported. **Data collection** Data collected through interviews and group discussion that were facilitated by one disabled young researcher and one researcher from Coventry University. No information reported about content or structure of interviews/group discussions. **Data analysis** Disabled young researchers and researchers from Coventry University worked together to analyse the data thematically. No further information reported.	**Themes** Original theme: Recognising children and young people's ambitions and strengths • Introduction of EHC plans ○ Recognising the child or young person's strengths can lead to loss of service provision • Attitudes and social stigma about service provisions ○ Low expectations of the ambitions and capability of children and young people Original theme: EHCPs that support independent living, choice and control • Transition ○ Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late • Organisation of services ○ Rigid definition of, and criteria for, services leads to gaps in service provision Original theme: Education and educational outcomes	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture views. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: There is limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Recruitment strategy is not reported. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: No information provided about content/structure of interviews or group discussions. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval and informed consent was obtained. The authors

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Organisation of services ○ Mainstream services provide benefit but more effort and support is needed to integrate children and young people Original theme: Some professionals were concerned about the lack of ambition in EHCPs for disabled young people's education • Organisation of services ○ Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial Original theme: Health • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working • Funding and resources ○ Funding is driven by special educational needs • Information sharing ○ Sharing information to	discuss the importance of ensuring the welfare and safety of the young disabled researchers and participants, that there was an informed choice about both being involved and able to withdraw and that anonymity and confidentiality were explained. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information reported about data analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Contribution to the literature is clearly discussed **Source of funding** Not industry funded **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			streamline processes and transition • Attitudes and social stigma about service provisions ○ Need to work at shifting attitudes to look holistically at meeting the needs of children/young people • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Not all children/young people who need support meet the criteria for an EHC plan Original theme: Accountability - Making sure what is in the EHCP is delivered • Introduction of EHC plans ○ Lack of SMART outcomes in EHC plans makes it unclear what support will be needed and who is responsible for providing it ○ EHC plans are primarily concentrated around education and place less emphasis on health and social care • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			• Joined-up care requires a substantial amount of time, organisation and commitment ○ Responsibility and resources are required to ensure plans are implemented and reviewed to accurately reflect changing needs • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ There is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints Original theme: Respecting the rights of disabled children and young people • Attitudes and social stigma about service provisions ○ Service providers not 'buying in' to approach • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Not all children/young people who need support meet the criteria for an EHC plan • Funding and resources ○ Lack of funding and resources is a barrier to providing services and	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			person-centred, joined-up care	
Full citation Rodriguez, Alison, King, Nigel, Sharing the care: the key-working experiences of professionals and the parents of life-limited children, International Journal of Palliative Nursing, 20, 165-172, 2014 **Ref ID** 344954 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** Not reported	**Characteristics** Professionals: n=21 Parents: n=20 (mothers: n=18; fathers: n=2) Characteristics of the children: Cancer: n=4 Cerebral palsy: n=3 Muscular dystrophy: n=1 Congenital disorder: n=1 Neurological disorder: n=1 Genetic disorder: n=10 **Inclusion criteria** Professionals working in paediatric care; parents of children with life limiting conditions. **Exclusion criteria** Parents who might find the research process too distressing (based on the opinion of link professionals).	**Setting** Participants were recruited form one UK county, including both urban and rural areas. Participants were identified by link professionals (e.g., senior community palliative care nurse, consultant paediatrician) and sent information packs about the study. Interested participants returned forms agreeing for the researcher to contact them. **Data collection** Qualitative data from professionals was collected via focus groups. Data from parents was collected via semi-structured interviews. Method of data collection for interviews (i.e., face-to-face or by telephone) is not reported. Focus groups and interviews were recorded and transcribed verbatim. **Data analysis** Data was analysed using inductive thematic analysis. An iterative approach was used, re-reading transcripts	**Themes** Original theme: The right help from the right person • Communication and support ○ Lack of communication (verbal and written) between services • Importance of key worker/lead professional ○ Key worker/lead professional is important for having a holistic view and coordinating services Original theme: Changing faces • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services ○ Families vary in their ability and willingness to fight for services Original theme: Great expectations—and disappointments • Service users' involvement and relationships with service providers	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture experiences. **Q3 Was the research design appropriate to address the aims of the research?** Yes: Justification for research design clearly explained. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Recruitment of overall participants was appropriate but exclusion of participants who researchers thought might find the interview experience distressing might have biased sample towards those with more positive experiences. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Interviews were semi-structured and audio recorded but authors do not report whether they were conducted face-to-face or by telephone and no information is provided about content of topic guide.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		to identify themes.	○ Families vary in their ability and willingness to make decisions and be involved in care planning • Communication and support ○ More information and support for service users to understand and access the available services	**Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval was obtained, participation was voluntary and informed consent was obtained. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information reported about data analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** No: There is limited discussion of implication for practice and authors note that data is not generalisable due to methods of recruitment and lack of diversity in parent sample. **Source of funding** Authors report there was no external funding. **Other information**
Full citation Sales, Niaomi,	**Characteristics** Parents: n=7 Professionals: n=9 (included	**Setting** Parents and professionals were contacted via the	**Themes** Original theme: Outcomes	**Limitations** **Q1 Was there a clear statement of the aims of the research?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Vincent, Kerry, Strengths and Limitations of the Education, Health and Care Plan Process from a Range of Professional and Family Perspectives, BRITISH JOURNAL OF SPECIAL EDUCATION, 45, 61-80, 2018 **Ref ID** 1105883 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** June 2016-August 2016	independent parent support workers, SENCos, medical professionals, social workers and educational psychologists) Child/young person: n=4; age range 10-17 **Inclusion criteria** Not reported **Exclusion criteria** Not reported	local Parent Partnership Service and all participants had experience of services before and after the introduction of the new SEND Code of Practice. The method of recruiting children and young people is not reported. **Data collection** Qualitative data from 11 of the parents and professionals was collected through face-to-face interviews conducted either at work or at home. The interviews ranged from 30 minutes to three hours (most completed within one hour) and were audio recorded and transcribed. The interviews covered understanding and experience of the EHC assessment process, including its strengths and limitations and the extent to which it changes ways of working between professionals and families. The views of 5 further parents were collected through a focus group which used the same questions as the interviews. Data was collected in the	• Introduction of EHC plans ○ Lack of SMART outcomes in EHC plans makes it unclear what support will be needed and who is responsible for providing it Original theme: A needs-based process? • An imbalanced distribution in the amount of support provided to children/young people ○ Looked after children are more likely to receive an EHC plan • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Children/young people need to reach a crisis point to access EHC plans • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments • Funding and resources ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care	Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intending to capture views and experiences. **Q3 Was the research design appropriate to address the aims of the research?** Yes: The research design was justified in the text (in order to capture a holistic view of the all those involved in the new assessment process). **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes/Can't tell: Recruitment strategy appears to be appropriate for parents and professionals but is not reported for children and young people. **Q5: Were the data collected in a way that addressed the research issue?** Yes: Content of interviews/focus groups/questionnaires appear to be appropriate to the aims of the research and data was audio recorded and/or written down. Questionnaires for children and young people were adapted to the individual to be accessible and non-threatening. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		form of post-it note responses to each question and written notes of the discussion. The views of the children and young people were collected via individually tailored questionnaires administered in the home setting and completed either with the assistance of the first author (n=1) or a parent (n=3). The questionnaires aimed to capture children's and young people's understanding of EHC plans, if and how they had helped them, whether they were involved in meetings and whether they had support to communicate their views. **Data analysis** Data was analysed through thematic analysis and was guided by the key interview questions. No further information reported.	○ Fighting against financial pressures Original theme: Multi-agency working • Joined-up care requires a substantial amount of time, organisation and commitment ○ Large time investment is needed by parents to coordinate services and manage appointments ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals • Relationships between service providers ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working Original theme: Extending the age range to 25 years • Organisation of services ○ Lack of appropriate services • Attitudes and social stigma about service provisions ○ Service providers not ‘buying in’ to approach	Yes: Authors report that ethical guidelines regarding informed consent, anonymity, the right to withdraw and storage of data were followed. Written consent to seek the views of children and young people was obtained from parents and verbal consent was obtained from the children and young people themselves. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information reported about data analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are clearly presented but there is limited discussion of credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Contribution to the literature is clearly discussed in terms of implications for professionals and directions for future research. **Source of funding** No sources of funding reported. **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

Full citation
Skipp, Amy, Hopwood, Vicky, A. S. K. Research, Mapping user experiences of the education, health and care process: a qualitative study, 100, 2016
Ref ID
1104921
Country/ies where study was carried out
UK
Study type
Qualitative
Study dates
May 2015-December 2015
	Characteristics
	Parents: n=77
	Child/young person: n=15
	<u>Whole sample</u>
	Age of child/young person: 0-5: n=19, 6-10: n=21; 11-15: n=15; 16+: n=22
	Needs of child/young person: behavioural/social/emotional: n=29; cognition and learning: n=27; communication and interaction: n=22; physical or sensory: n=16
	Transfer from statement: n=37
	New EHC plan: n=40
	Point in process: final plan: n=41; in progress: n=24; no plan (& no longer in progress): n=12
	Inclusion criteria
	Families and young people with experience of the EHC process.
	Exclusion criteria
	No additional criteria reported.
		Setting
		Families and young people were recruited through SEND teams within four local authorities in England. The local authorities were selected due to willingness to take part and to include broad range of location and population (in terms of ethnicity, socio-economic status and disabilities). Local authorities were instructed to select families to include a range of ages, needs parent engagement and experiences, as well as families at different stages of the EHC plan process, including those who had dropped out or not received a plan.
		Data collection
		Qualitative data from parents was collected via telephone interviews that lasted 35 to 95 minutes, using a semi-structured interview guide. Interviews covered parents expectation of, and satisfaction with, the EHC plan process, what impact they had on the family, and recommendations for improvement. Interviews
			Themes
			Original theme: Experiences of assessment/Experiences of planning/Experiences of putting plans into action
			• Relationships between service providers
			  ○ Service providers failing to take responsibility and be effectively involved in collaborative working
			Original theme: Experiences of assessment
			• Joined-up care requires a substantial amount of time, organisation and commitment
			  ○ Large time investment is needed by parents to coordinate services and manage appointments
			• Service users' involvement and relationships with service providers
			  ○ Co-working improved when professionals worked closely with parents and kept them informed
			• Long waiting times for support
			  ○ Unavailability of staff able to complete the necessary paperwork/assessments
			• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an
				Limitations
				Q1 Was there a clear statement of the aims of the research?
				Yes
				Q2 Was a qualitative methodology appropriate?
				Yes: Intending to capture experiences.
				Q3 Was the research design appropriate to address the aims of the research?
				Yes: Justification for research design clearly explained.
				Q4 Was the recruitment strategy appropriate to the aims of the research?
				Yes: Local authorities, families and children/young people were selected to obtain views from families and children with varying backgrounds and needs.
				Q5: Were the data collected in a way that addressed the research issue?
				Yes: Content of interviews/focus groups/questionnaires appear to be appropriate to the aims of the research and data was audio recorded and/or written down. Full details of the semi-structured interview guide are provided.
				Q6: Has the relationship between researcher and participants been adequately considered?
				Can't tell: Researchers were independent of services but unclear if the researchers considered potential

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		were audio recorded if parents gave permission. Qualitative data from children/young people was collected during focus groups which lasted 40 to 60 minutes. Focus groups covered what children/young people thought of their plan and the EHC plan process, and suggestions for improvement. Notes were taken from the focus group. **Data analysis** Data was analysed through thematic and explanatory analysis using a framework approach. This approach allows for data to be presented based on individual cases and themes, reduces the amount of data through summarisation and synthesis while retaining links to the original data, and results in comprehensive and transparent data analysis. The authors aimed to both identify general findings across the four local authorities and local findings specific to the area or local delivery. Data was	EHC plan) ○ There is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints Original theme: Experiences of identification • Diagnosis and identification of needs first ○ Early identification of needs and making referrals before a diagnosis has been reached promotes early access to support • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Professionals, staff and families lack understanding of the EHC plan process Original theme: Experiences of planning • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)	bias and influence during the formulation of the research questions and data collection. **Q7: Have ethical issues been taken into consideration?** Yes: Authors report that Department for Education ethical procedures and national guidance were followed, that participation was voluntary, participants gave informed consent and were free to withdraw consent. Anonymity of participants was maintained by changing names and key features that might reveal participants identities. **Q8: Was the data analysis sufficiently rigorous?** Yes: Approach for data analysis is clearly described, including processes for ensuring the credibility of the findings. **Q9: Is there a clear statement of findings?** Yes: Findings are clearly presented and attempts were made to ensure credibility. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Contribution to the literature, including recommendations for practice, are clearly discussed. **Source of funding** No sources of funding reported **Other information**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		analysed and organised into themes by two experienced researchers. Findings were triangulated with other recent evidence and practitioners and experts reviewed the findings and provided feedback.	○ The process of getting an EHC plan takes too long and requires a lot of work • Funding and resources ○ Lack of funding and resources is a barrier to providing services and person-centred, joined-up care Original theme: Experiences of planning/Sub-group variation • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ The process of getting an EHC plan takes too long and requires a lot of work Original theme: Experiences of planning/Experiences of putting plans into action • Introduction of EHC plans ○ Lack of SMART outcomes in EHC plans makes it unclear what support will be needed and who is responsible for providing it • Long waiting times for support ○ Additional assessments cause delays in implementing EHC plans	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

			Original theme: Overall family satisfaction with the EHC process
			• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)
			  ○ Time taken for EHC plans to be refined and embedded in practice
			Original theme: Sub-group variation
			• Importance of key worker/lead professional
			  ○ Key worker/lead professional is important for having a holistic view and coordinating services
			• Attitudes and social stigma about service provisions
			  ○ Low expectations of the ambitions and capability of children and young people
			• Organisation of services
			  ○ Lack of appropriate services
			  ○ Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial
			• Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			EHC plan) ○ Not all children/young people who need support meet the criteria for an EHC plan	
Full citation Smith, Lucy, Cameron, Genevieve, Vanson, Tim, Evaluation of the Special Educational Needs and Disability (SEND) Pathfinder Programme: impact research report: qualitative research with families (second cohort): research report, 92, 2014 **Ref ID** 1103975 **Country/ies where study was carried out**	**Characteristics** Families: n=31 (representing n=33 children/young people) **Characteristics of families:** Child age: 0-5 years: n=12 5-16 years: n=14 16-25 years: n=7 Child gender: Male: n=17 Female: n=16 Child needs: Autism: n=10 Learning disability: n=9 Physical disability: n=5 Learning and physical disabilities: n=6 Autism and learning disability: n=1 Autism and learning and physical disabilities: n=2 Child ethnicity: White: n=24 African: n=2 Caribbean: n=1 Mixed White and Asian: n=1 Mixed White and Black African: n=2 Mixed White and Black Caribbean: n=1	**Setting** Families with completed EHC plans were recruited from seven pathfinder areas. A target sample was agreed to gain a cross section of different age groups and pathfinder areas. Eligible families were sent invitation letters, which were followed up by recruitment calls. **Data collection** Interviews lasted about 50 to 90 minutes and were conducted face-to-face at the family home (n=15) or by telephone (n=16). In the majority of cases, interviews were recorded and transcribed. If the participant did not want to be recorded, detailed notes were taken. Two topic guides were developed, one for use with families of children and young people aged 5 to 25 years, and one for families of children aged 0 to 5 years. Both	**Themes** Original theme: Direct payments • Funding and resources ○ Personalised budgets and direct payments increase flexibility but also burden on the family to make decisions and arrange care • An imbalanced distribution in the amount of support provided to children/young people ○ Regional disparity in the availability of services Original theme: Dissatisfaction with process/ Not receiving the support and services in their plan • Joined-up care requires a substantial amount of time, organisation and commitment ○ Responsibility and resources are required to ensure plans are implemented and reviewed to accurately reflect changing needs Original theme: Dissatisfaction with	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intended to capture experiences. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: There is limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: A target sample was identified to provide a cross-section of different age groups and locations. **Q5: Were the data collected in a way that addressed the research issue?** Yes: Content of topic guides appear to be appropriate to the aims of the research and data was audio recorded and/or written down. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
UK **Study type** Qualitative **Study dates** January 2014-March 2014	Other Black or Asian background: n=-2 **Characteristics of interviews:** n=23 mother n=5 father n=2 mother and father n=1 sibling (primary carer) n=5 child/young person present for interview (in addition to the above) **Inclusion criteria** Families participating in the new EHC planning pathway and that received an EHC plan **Exclusion criteria** No additional criteria reported	topic guides covered learning about the family and child/young person, assessment and plans before the new system, getting involved in the pathfinder, the assessment process, the support planning process, the content of the EHC plan and how the plan was working. The topic guide for families of children aged 5 to 25 years included questions that were easy to read and understand for use with children and young people who were able to participate in the interview. For children who could not, or did not want to, participate in the interview, parents were given the opportunity to discuss the questions before the interview to capture the child's/young person's views. Families were sent a summary of the key points after the interview and given the opportunity to get in touch if they did not think it was an accurate reflection. **Data analysis** Data was entered into a	process • Long waiting times for support ○ Unavailability of staff able to complete the necessary paperwork/assessments • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ There is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints Original theme: Effectiveness of the key worker • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people Original theme: Joint working outside meetings/Sources and sufficiency of information • Communication and support ○ More information and support for service users to understand and access the	**into consideration?** Can't tell: No information is reported. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information reported about data analysis. **Q9: Is there a clear statement of findings?** No: There is limited reporting of quotes supporting themes and there is no discussion of the credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: Some recommendations are presented but the authors note that it was difficult to draw conclusions due to the wide variety of experiences reports and variability of the process across cases. **Source of funding** No sources of funding reported **Other information** Evaluation of the Special Educational Needs and Disability Pathfinder Programme (also reported by Spivack 2014, Thom 2014 and Thom 2015). Data reported is from the initial interviews of cohort 2 included in Thom 2015. Themes extracted from this paper do not appear in Thom 2015.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		matrix where rows represented individual participants and columns represented themes and subthemes. The researchers examined the relationships between themes and connections between themes and subgroups of participants. The research team worked together to discuss hypotheses and ensure a consistent approach was used.	available services Original theme: Joint working outside meetings • Relationships between service providers ○ Importance of understanding the roles, responsibilities and expectations of other professionals/staff Original theme: Negative experience of multi-agency meetings • Joined-up care requires a substantial amount of time, organisation and commitment ○ Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals Original theme: Positive experience of multi-agency meetings • Relationships between service providers ○ Shared values and priorities promote joint working ○ Clear targets improved accountability and the distribution of responsibility across services	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working Original theme: Receiving the support and services in their plan/Support and services not in the plan but still wanted • Organisation of services ○ Lack of appropriate services Original theme: Receiving the support and services in their plan • An imbalanced distribution in the amount of support provided to children/young people ○ Families vary in their ability and willingness to fight for services Original theme: Satisfaction with the process of getting a plan • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Time taken for EHC plans to be refined and embedded in practice Original theme: Support and services not	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			in the plan but still wanted • Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan) ○ Not all children/young people who need support meet the criteria for an EHC plan Original theme: Understanding of the process of the pathfinder • Importance of key worker/lead professional ○ Key worker/lead professional is important for having a holistic view and coordinating services	
Full citation Spivack Rhian, Craston Meera, Redman Rachel, Evaluation of the Special Educational Needs and Disability Pathfinder Programme: thematic	**Characteristics** Not reported. **Inclusion criteria** Lead professionals involved in collaborative working with social care. **Exclusion criteria** No additional criteria reported.	**Setting** Data was collected from five pathfinder areas. These areas were selected, through discussions with Department for Education and the Pathfinder Support Team, because they had reported strong social care engagement, covered a mix of geographical regions, rural and urban areas, and large and small areas, and each area had at least one pathfinder	**Themes** Original theme: Pathfinder expectations • Introduction of EHC plans ○ EHC plans have increased joint working and integration Original theme: Strategic mechanisms to support collaborative working • Relationships between service providers ○ Importance of understanding the roles, responsibilities and expectations of other	**Limitations** **Q1 Was there a clear statement of the aims of the research?** No: The aim stated is to review collaborative working arrangements with social care, but the aim does not state whether the intention was to capture subjective experiences of this. **Q2 Was a qualitative methodology appropriate?** Can't tell: Unclear statement of aims. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: Unclear statement of aims

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
report: collaborative working with social care: research report, 2014 **Ref ID** 1082106 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** March 2014-April 2014		champion. Data was collected from the following professionals: pathfinder leads/manager, leads for children's and adult's social care services, strategic and operational social care professionals/providers, the lead for specialist health and SED, and lead representative from the Association of Directors of Children’s Services. **Data collection** Qualitative data was collected through semi-structured interviews covering the following areas: the role of social care in meeting the SEND reforms, models of engagement and collaborative working, challenges in collaborative working, system changes/outcomes as a result of collaborative working with social care. Interviews lasted 1 to 2 hours and were conducted face-to-face where possible. Face-to-face interviews were recorded but it is unclear how data was captured from telephone interviews.	professionals/staff ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working ○ Shared values and priorities promote joint working • Professional and staff knowledge and training ○ Multi-agency training is important to bridge the gaps between professionals and get everyone on the same page • Funding and resources ○ Joint funding and strategic planning as a methods of supporting collaborative working	and limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Selection of pathfinder areas with strong social care engagement may have biased sample towards those with more positive experiences. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Limited information is provided about the interview guide, data saturation is not discussed and it is unclear how data from telephone interviews was captured. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Can't tell: No information is reported. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Themes were identified a-priori but methods for identifying these themes are not reported. Limited information is reported about data analysis. **Q9: Is there a clear statement of findings?** No: There is limited reporting of quotes supporting themes. **Q10: Is the research valuable for the**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		Data analysis Data for each pathfinder area was written up under the themes included in the topic guide. Following this, the research team looked across the data from different areas to identify commonalities and differences.		**UK? (a. Contribution to literature and b. Transferability)** Can't tell: Some implications for practice are discussed but there is limited discussion of the contribution of the evidence to the literature and evidence may be more representative of positive practice/collaboration than typical practice/collaboration. **Source of funding** No sources of funding reported. **Other information** Evaluation of the Special Educational Needs and Disability Pathfinder Programme (also reported by Smith 2014, Thom 2014 and Thom 2015)
Full citation Taylor Julie, et al.,, Disabled children and child protection in Scotland: an investigation into the relationship between professional practice, child protection and disability, 91, 2014 **Ref ID** 1103829	**Characteristics** Professionals: n=61 (including social work, education, police, voluntary organisations, health, child protection committee members) **Inclusion criteria** Experience of responding to at least two child protection cases involving a disabled child. **Exclusion criteria** No additional criteria reported.	**Setting** Six local authority areas were selected (from local authority and child protection register data) to cover a range of urban/rural and small/large areas and number of disabled children on child protection registers. In each local authority area, potential participants from social work, education, police, voluntary organisations and health were contacted by the researchers and asked to participate. Potential participants were identified	**Themes** Original theme: Benefits of interagency working/Information sharing and communication • Relationships between service providers ○ Importance of understanding the roles, responsibilities and expectations of other professionals/staff Original theme: Children's disability teams/Training experience and workload • Professional and staff knowledge and training ○ Professionals and staff lack the necessary skills and	**Limitations** **Q1 Was there a clear statement of the aims of the research?** No: The questions the study intended to address are clearly presented, but the aim does not state whether the intention was to capture subjective experiences. **Q2 Was a qualitative methodology appropriate?** Can't tell: Unclear statement of aims. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: Justification for research design is clearly explained but statement of aims is unclear. **Q4 Was the recruitment strategy appropriate to the aims of the**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Country/ies where study was carried out UK **Study type** Mixed methods, including interviews and focus groups **Study dates** Not reported		through contacting services directly and with the assistance of the Child Protection Committee Coordinator at WithScotland, key researchers and practitioners in the Scottish Sensory Centre and CALL Scotland Centre, and a member of Scottish Government (who also helped recruit Child Protection Committees). Authors do not report whether all eligible participants were contacted or, if not, how they were selected. **Data collection** Data from professionals, excluding Child Protection Committees, were collected via telephone interviews lasting roughly an hour, which were digitally recorded. Interviews covered areas identified by previous research, but the authors do not report what these areas were. Participants were also asked to give an example of good practice and an example where there were issues in identifying harm,	○ knowledge to work effectively to meet the needs of children and young people Original theme: Children's disability teams • Relationships between service providers ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working Original theme: Confidence and fear culture • Importance of key worker/lead professional ○ Key worker/lead professional is important for having a holistic view and coordinating services Original theme: Information sharing and communication • Information sharing ○ Sharing information increases understanding of the child or young person and their needs ○ Information is not always shared nor sufficient to meet the needs of other services	**research?** Can't tell: Local authority areas were selected to represent a range of areas with differing levels of disabled children on child protection registers, but it is unclear if method of selecting participants from these areas was appropriate. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Limited information provided about content/structure of interviews or focus groups. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Yes: Ethical approval and informed consent were obtained. Identifying information was removed from transcripts and incidents were only used as case studies if confidentiality/anonymity could be maintained. There was also a mechanism in place for disclosing any information that arose from interviews that was not already known to relevant authorities. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: No information is reported. **Q9: Is there a clear statement of findings?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		provision or uptake of interventions,, or interagency working, and how these issues were resolved. Data from Child Protection Committees were collected through focus groups and covered key themes and issues in responding to and supporting disabled children who may be at risk of harm, and interagency working. It is not clear if a topic guide was used. Two members of the research team took notes during the focus groups. **Data analysis** No information reported.	• Relationships between service providers ○ Negative professional relationships and disagreements inhibit joint working ○ Putting aside professional differences for the good of the child or young person • Service users' involvement and relationships with service providers ○ Co-working improved when professionals worked closely with parents and kept them informed	Can't tell: Findings are presented clearly but there is no discussion of the credibility of the findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Recommendations for practice and policy are clearly discussed. **Source of funding** Not industry funded. **Other information**
Full citation Thom Graham, Agur Maya, Daff Kerry, Evaluation of the Special Educational Needs and Disability Pathfinder Programme: thematic report: transition and	**Characteristics** Professionals: n=26 (including pathfinder lead/manager, service manager or transition leads in colleges, local authority services and voluntary community sector services) **Inclusion criteria** Not reported. Can be inferred that it is professionals responsible for engaging with post-16 providers and young people, and/or with experience of post-16	**Setting** Data was collected from four pathfinder areas. These areas were selected, through discussions with Department for Education and the Pathfinder Support Team, because they had been working with colleges and other post-16 providers during the SEND reform, had at least one pathfinder champion and represented a mix of rural/urban and large/small areas. Data	**Themes** Original theme: Experiences to date: Information flows have improved but there is more to do • Information sharing ○ Information is not always shared nor sufficient to meet the needs of other services Original theme: Experiences to date: Readiness for and use of Personal Budgets vary considerably across areas • Funding and resources	**Limitations** **Q1 Was there a clear statement of the aims of the research?** No: Review questions are clearly presented, but the aim does not state whether the intention was to capture subjective experiences. **Q2 Was a qualitative methodology appropriate?** Can't tell: Unclear statement of aims. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: Unclear statement of aims and limited discussion of justification

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
the engagement of post-16 providers: research report, 20, 2014 **Ref ID** 1103790 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** March 2014-April 2014	transitions for children and young people with SEND. **Exclusion criteria** No additional criteria reported.	was collected from the following professionals: pathfinder lead/manager, service manager or transition leads in colleges, other professionals from local authority services and voluntary community sector services. Professionals were selected to ensure a mix of education, training and employment, and community services, but authors do not report how they were selected/recruited. **Data collection** Interviews were recorded, lasted roughly one hour, and covered the following areas: involvement of post-16 providers in EHC plans/processes and transitions, post-16 provision, resource implications, support for young people during provision, and commissioning. Two topic guides were used, one for local authority representatives and one for providers; limited information is provided about these topic guides. **Data analysis**	○ Personalised budgets and direct payments increase flexibility but also burden on the family to make decisions and arrange care Original theme: Experiences to date: The focus to date has been very much around education • Relationships between service providers ○ Service providers failing to take responsibility and be effectively involved in collaborative working • Introduction of EHC plans ○ EHC plans are primarily concentrated around education and place less emphasis on health and social care Original theme: Implications arising: There is much to do • Attitudes and social stigma about service provisions ○ Need to work at shifting attitudes to look holistically at meeting the needs of children/young people Original theme: Long term issues: Providers working together	for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Can't tell: Selection of pathfinder areas that has been working with psot-16 providers and had a pathfinder champion may have biased sample towards those with more positive experiences. Further, no information is reported about how participants were recruited from these areas. **Q5: Were the data collected in a way that addressed the research issue?** Can't tell: Limited information is provided about the interview guide and data saturation is not discussed. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Can't tell: No information is reported. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Themes were identified a-priori but methods for identifying these themes are not reported. Limited information is reported about data analysis. **Q9: Is there a clear statement of findings?** No: There is limited reporting of quotes supporting themes.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		Data for each pathfinder area was written up under the themes included in the topic guide. Following this, the research team looked across the data from different areas to identify commonalities and differences.	• Organisation of services ○ Rigid definition of, and criteria for, services leads to gaps in service provision ○ Lack of appropriate services ○ Having the right people involved and collaborating can overcome gaps in service provision	**Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: Some implications for practice are discussed but there is limited discussion of the contribution of the evidence to the literature and evidence may be more representative of positive practice/collaboration than typical practice/collaboration. **Source of funding** No sources of funding reported. **Other information** Evaluation of the Special Educational Needs and Disability Pathfinder Programme (also reported by Smith 2014, Spivack 2014, and Thom 2015).
Full citation Thom Graham, et al.,, The Special Educational Needs and Disability Pathfinder Programme evaluation: final impact research report, 238, 2015 **Ref ID** 1139296 **Country/ies**	**Characteristics** Initial interviews: n=77 families, representing 79 children (unclear how many people participated in each interview; characteristics of families/children/young people not reported) Family members interviewed during initial interviews: Mother: n=61 Father: n=9 Mother and father: n=6 Sibling (primary carer): n=1 Child/young person (in addition to above): n=9 Characteristics of children from initial interviews:	**Setting** Families with completed EHC plans were recruited from 15 pathfinder areas. A target sample was agreed to gain a cross section of different age groups and pathfinder areas. Eligible families were sent invitation letters, which were followed up by recruitment calls. For follow-up interviews, the target was to cover a range of ages and areas but quotas were not set due to the small number of potential participants (those who had completed initial	**Themes** Original theme: Key worker and professional support • Importance of key worker/lead professional ○ Continuity of key worker/lead professional is important for consistency and relationships Original theme: Choosing support services • Service users' involvement and relationships with service providers ○ Families vary in their ability and willingness to make decisions and be involved in	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intended to capture experiences. **Q3 Was the research design appropriate to address the aims of the research?** Can't tell: There is limited discussion of justification for research design. **Q4 Was the recruitment strategy appropriate to the aims of the research?** Yes: A target sample was identified to provide a cross-section of different age groups and locations.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
where study was carried out UK **Study type** Mixed methods, including interviews **Study dates** December 2012-January 2015	Male: n=52 Female: n=27 Age - 0-5 years: n=22 Age - 5-16 years: n=33 Age - 16-25 years: n=24 Ethnicity - White: n=60 Ethnicity - Black/minority ethnic: n=15 Ethnicity - Not specified: n=2 Needs - Autism only: n=18 Needs - Learning disability only: n=23 Needs - Physical disability only: n=11 Needs - Learning and physical disability: n=17 Needs - Autism and learning disability: n=5 Needs - Autism, learning and physical disabilities: n=2 Follow-up interviews: n=40 families, representing 41 children/young people (unclear how many people participated in each interview) Family members interviewed during follow-up interviews: Mother: n=36 Father: n=2 Mother and father: n=2 Sibling (primary carer): n=1 Child/young person (in addition to above): n=3 Characteristics of children from follow-up interviews: Male: n=25	interviews). Pathfinder leads were consulted to check if there were any reasons families should not be re-contacted (e.g., due to a change in area or the health of child/young person or parent). **Data collection** Initial interviews lasted about 1.5-2 hours and follow-up interviews lasted about 45 minutes to 1 hour and were conducted face-to-face at the family home (initial interviews n=56; follow-up interviews n=29) or by telephone (initial interviews n=21; follow-up interviews n=11). In the majority of cases, interviews were recorded and transcribed. If the participant did not want to be recorded, detailed notes were taken. For the initial interviews, two topic guides were developed, one for use with families of children and young people aged 5 to 25 years, and one for families of children aged 0 to 5 years. Both topic guides covered learning about the family and child/young person,	care planning • Communication and support ○ More information and support for service users to understand and access the available services	**Q5: Were the data collected in a way that addressed the research issue?** Yes: Content of topic guides appear to be appropriate to the aims of the research and data was audio recorded and/or written down. **Q6: Has the relationship between researcher and participants been adequately considered?** Can't tell: No information is reported. **Q7: Have ethical issues been taken into consideration?** Can't tell: No information is reported. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information reported about data analysis. **Q9: Is there a clear statement of findings?** No: There is limited reporting of quotes supporting themes and there is no discussion of the credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Can't tell: Limited discussion of the contribution to the literature, implications for practice or generalisability of findings. **Source of funding** Not industry funded. **Other information** Evaluation of the Special Educational Needs and Disability Pathfinder Programme (also reported by Smith

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	Female: n=16 Age - 0-4 years: n=7 Age - 5-10 years: n=17 Age - 11-6 years: n=8 Age - 17+ years: n=9 Ethnicity - White: n=32 Ethnicity - Black/minority ethnic: n=9 Needs - Cognition and learning: n=17 Needs - Physical or sensory: n=11 Needs - Communication and interaction: n=8 Needs - Behaviour, emotional and social: n=1 Needs - Physical or sensory and cognition and learning: n=4 Existing statement/support: n=32 Note. Numbers are as reported in the paper but some characteristics appear to have been reported based on number of families, and others based on number of children; therefore, some of the numbers do not add up. **Inclusion criteria** Pathfinder families who had just completed EHC plans (at time of initial interviews). **Exclusion criteria** No additional criteria	assessment and plans before the new system, getting involved in the pathfinder, the assessment process, the support planning process, the content of the EHC plan and how the plan was working. The topic guide for families of children aged 5 to 25 years included questions that were easy to read and understand for use with children and young people who were able to participate in the interview. For children who could not, or did not want to, participate in the interview, parents were given the opportunity to discuss the questions before the interview to capture the child's/young person's views. For the follow-up interviews, one topic guide was used which covered what was new with the child and family, reviewing the plan, content of the plan, how the plan is working and overall reflections. Easy to read and understand questions were included for use with children and young people		2014, Spivack 2014 and Thom 2014).

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	reported.	who were able to participate in the interview. Families were sent a summary of the key points after the interview and given the opportunity to get in touch if they did not think it was an accurate reflection. **Data analysis** Data was entered into a matrix where rows represented individual participants and columns represented themes and subthemes. The researchers examined the relationships between themes and connections between themes and subgroups of participants. The research team worked together to discuss hypotheses and ensure a consistent approach was used.		
Full citation Young, L., Egdell, A., Swallow, V., Qualitative accounts of young-people, parents and staff involved	**Characteristics** Child/young person: n=2; both male, aged 19 and 23 years old Parent: n=4 mothers Professionals: n=15 (n=4 nurses; n=5 doctors; n=3 support workers; n=2 physiotherapists; n=1 social	**Setting** Young adults, parents and staff were recruited using opportunistic sampling by sending a letter to all families engaged with, and all staff working in, the service. **Data collection**	**Themes** Original theme: The need for a specialist short-break service • Organisation of services ○ Lack of appropriate services • Funding and resources ○ Staffing of services impacts	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?** Yes: Intended to capture views and perspectives. **Q3 Was the research design**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment

with a purpose-designed, pilot short-break service for 18-24year olds with life-limiting conditions, Children and Youth Services Review, 86, 142-150, 2018
Ref ID
1105987
Country/ies where study was carried out
UK
Study type
Qualitative
Study dates
Not reported
	worker)
	Inclusion criteria
	Young adults registered with a pilot short-break service for young adults aged 18–24 years with life-limiting conditions and were able to communicate their views (verbally or non-verbally); parents/carers of young adults registered with the service; health or social-care staff working with the service
	Exclusion criteria
	No additional criteria reported
		Qualitative data was collected via semi-structured interviews or focus groups depending on the preference of the participant. All young people and parents were interviewed individually; three professionals were interviewed individually and the rest participated in focus groups. Interview/focus groups followed a topic guide, were digitally recorded and transcribed.
		Data analysis
		Data was analysed thematically using the framework technique. This allows for abstracting data into themes without losing the original raw data.
			the quality of the service
			Original theme: Challenges of staffing and financing the service
			• Funding and resources
			  ○ Staffing of services impacts the quality of the service
			  ○ Fighting against financial pressures
			Original theme: Meeting young adults' complex needs and preferences
			• Relationships between service providers
			  ○ Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working
			Original theme: Suggestions for how to improve the service
			• Organisation of services
			  ○ Lack of appropriate services
				appropriate to address the aims of the research?
				Can't tell: There is limited discussion of justification for research design.
				Q4 Was the recruitment strategy appropriate to the aims of the research?
				Yes: All families/staff working in the service were offered the opportunity to take part. However, the sample is self-selecting which may introduce biases.
				Q5: Were the data collected in a way that addressed the research issue?
				Yes: Content of interviews/focus groups/questionnaires appear to be appropriate to the aims of the research and data was digitally recorded and transcribed. Full details of the topic guide are provided.
				Q6: Has the relationship between researcher and participants been adequately considered?
				Yes: Authors report that interviews were conducted by researchers with experience of working with vulnerable young adults with limited communication abilities. Authors also report that researchers were independent and participants were assured that participation would not impact subsequent care/service provision
				Q7: Have ethical issues been taken into consideration?
				Yes: Ethical approval was obtained,

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				written/verbal information was presented in an appropriate way for the participants' level of understanding, written consent was obtained for everyone apart from the young adults, who gave verbal consent and witnessed an advocate of their choice give written consent. All data was anonymised and kept securely. Efforts were made to minimise the potential for any harm, including psychological exploitation and intrusion into families lives. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information is provided about data analysis. **Q9: Is there a clear statement of findings?** Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. **Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** Yes: Contribution to the literature is clearly discussed. **Source of funding** Not industry funded. **Other information** Inclusion criteria states that young people who could not communicate verbally were eligible for inclusion but the limitations section says it was not

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				possible to elicit the views of non-verbal young adults. It is unclear if this is because of the skills of the researchers/research methods used or willingness of this group to participate. Another limitation noted is that no fathers or male carers were available to participate at the time of the study.

ADHD: attention deficit hyperactivity disorder; ANOVA: analysis of variance; ASD: autistic spectrum disorder; CALL: communication, access, literacy and learning; CAMHS: child and adolescent mental health services; CEO: chief executive officer; CLARHC: Collaboration for Leadership in Applied Health Research and Care; COREC: Central Office of Research Ethics Committees; ECLO: eye clinic liaison officer; EHC: education, health and care; FE: further education; GP: general practitioner; HE: higher education; ICD: international statistical classification of diseases and related health problems; IPA: interpretative phenomenological analysis; IQR: interquartile range; M: mean; NHS: National Health Service; NIHR: National Institute for Health Research; NR: not reported; OFMDFM: Office of the First Minister and Deputy First Minister; QTVI: qualified teacher of vision impaired children; SCERTS: Social Communication, Emotional Regulation and Transactional Support; SEN: special educational needs; SENCO: special educational needs co-ordinator; SEND: special educational needs and disabilities; SLSC: speech, language, swallowing or communication needs; SLT: speech and language therapy; SD: standard deviation

Appendix E – Forest plots

Forest plots for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F – GRADE CERQual tables

GRADE CERQual tables for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

Table 5: Evidence profile: Theme 1. Relationships between service providers

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 1.1: Negative professional relationships and disagreements inhibit joint working					
2 (Karim 2014; Taylor 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews	Service providers reported that sometimes there are negative relationships between professionals and that there can be disagreements when professional views are challenged. "You could sometimes get into a disagreement with those professionals because they felt that their professional view was being challenged, it's human nature isn't it? The more you challenge somebody the more entrenched they become." (Karim 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.2: Service providers failing to take responsibility and be effectively involved in collaborative working					
13 (Adams 2018; Boesley 2018; Brooks 2013; Children's Commissioner for Wales 2018; Council for Disabled Children 2018; Kaehne 2013; McKean 2017; Molteni 2013;	1 qualitative study using interviews; 6 qualitative studies using semi-structured interviews; 1 qualitative study using interviews and focus groups;	Service providers, parents and carers reported that there was a lack of people taking responsibility and being effectively involved in collaborative working. This included not attending multi-agency meetings or not preparing for meetings in advance, services not engaging with the process and being difficult to contact or communicate with, focusing on own roles rather than thinking holistically about the child or young person, and ineffective decision making due to having too many people involved or those involved failing to take responsibility for decision making. "I was told we were all going to meet together. The school didn't send any information or tell me it was for a transfer rather than just an annual review, but I'd read up so I knew. The Coordinator just told me to prepare for a very long	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Palikara 2019; RIP STARS 2018; Sales 2018; Skipp 2016; Thom 2014)	2 qualitative studies using semi-structured interviews and focus groups; 1 qualitative study using focus groups; 1 mixed methods study using semi-structured interviews, focus groups and open-ended question in questionnaire; 1 mixed methods survey using open-ended questions	meeting. I wrote 7 pages about what my daughter needed. When I turned up there was the SENCo, teacher, 1 to 1 supporter and EHCP coordinator. None of them had prepared reports or filled out any of the forms they were meant to. The SENCo only stayed 5 minutes and there was no Ed Psych there. Others hadn't sent in their reports. The meeting ended up being abandoned as none of the required documentation was there. That was when we looked for legal advice. We didn't know what else to do, they just didn't seem to be taking it seriously." (Skipp 2016)	Adequacy	None or very minor concerns	
Sub-theme 1.3: Importance of understanding the roles, responsibilities and expectations of other professionals/staff					
3 (Smith 2014; Spivack 2014; Taylor 2014)	1 qualitative study using interviews; 2 qualitative studies using semi-structured interviews	Service providers reported that closer multi-agency working had improved knowledge and understanding of others roles, strengths and weaknesses. They reported that this made it easier to have discussions with colleagues and focus on how to meet the needs of children and young people. In contrast, service providers, parents and carers who did not think joint working had improved thought this was due to lack of clarity on the roles, responsibility and expectations of other services.	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
		"I think multi-agency working, that's the biggest change I've seen in the last five years. We're speaking to partners, because we're doing that and because we're doing things generally, we understand what their strengths and weaknesses are and I think as long as we keep forging these good relationships… we can more easily highlight what needs to be done [Interview 13]." (Taylor 2014)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.4: Putting aside professional differences for the good of the child or young person					
2 (Karim 2014;	1 qualitative	Service providers reported that sometimes there are professional differences	Methodological	Major concerns	Moderate

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
Taylor 2014)	study using semi-structured interviews; 1 qualitative study using interviews	due to negative relationships between services and/or competing roles. However, they also reported that it was important to put aside these differences and work together for the good of the child. “I think there’s been a lot of debate I guess between the sort of educational world and the medical world about you know, who who um who can sort of diagnose this and who has the major role in this and I think we should probably stop arguing about that and just try to work together.” (Karim 2014)	limitations	about methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 1.5: Recurrent liaisons/conversations among professionals were valued to improve relationships and effective team working					
10 (Adams 2018; Boesley 2018; Boyce 2015; McConkey 2013; McKean 2017; Sales 2018; Smith 2014; Spivack 2014; Taylor 2014; Young 2018)	2 qualitative studies using interviews; 7 qualitative studies using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups	Service providers, parents and carers reported that relationships improved when providers liaised frequently, had been working together for an extended period of time and had the opportunity to meet face-to-face. Co-location of services also improved relationships by increasing opportunities for liaisons and conversations. Conversely, service providers reported that staff turnover could damage working relationships. “They were getting on very well ... [I could tell] just by the fact that they all spoke freely of conversations they had been having and were putting points across. I could tell they had spoken to one another and it wasn’t just a quick email or something so they seemed to be working as a team building it up.” (Adams 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.6: Mutual respect between professionals which allows equal opportunity to have opinions voiced and challenged					
3 (Boesley 2018; McKean 2017; Molteni 2013)	2 qualitative studies using semi-structured interviews; 1 mixed methods study	Service providers reported that mutual respect and viewing each other as equal partners increased openness and honesty which allowed service providers to voice their opinions and challenge those of others. This was seen to improve and streamline processes and lead to better joint working to meet the needs of the child or young person.	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
	using semi-structured interviews, focus groups, and open ended question in questionnaire	"I know them really well and they know me really well, so you can build up that kind of openness and honesty, and I can go to a Head or a SENCO in some of my schools and say, "It's not working really well in there", and they're not threatened by me saying that, they're not feeling it as a criticism, they're recognising that, actually, I'm there with them to say, "Right, what can we do?", and they take that." (McKean 2017)		checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.7: Shared values and priorities promote joint working					
6 (Boesley 2018; Council for Disabled Children 2018; McKean 2017; Molteni 2013; Smith 2014; Spivack 2014)	5 qualitative studies using semi-structured interviews; 1 mixed methods study using semi-structured interviews, focus groups and open ended question in questionnaire	Service providers, parents and carers reported that shared values and priorities, particularly being committed to collaborative working and using a child or young person centred approach, promoted joint working. "When you are all on the same page and you are all involved in making decisions and making a plan and then stick to it I think the change can come very quickly and it can be a very positive experience." (McKean 2017)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.8: Clear targets improved accountability and the distribution of responsibility across services					
3 (Boesley 2018; Molteni 2013; Smith 2014)	2 qualitative studies using semi-structured interviews; 1 mixed methods study using semi-structured interviews, focus groups and open ended question in questionnaire	Service providers, parents and carers reported that having clear targets and pathways that were agreed in front of other providers and parents improved accountability, the distribution of responsibility across services and made it more likely that providers would follow through on agreed actions. "Straightaway, in front of parents, [professionals] were allocated things to do...if it [hadn't been] written down and [typed up], [then] they wouldn't have known what actually happened. So everybody knew [what they were supposed to do] and they couldn't go back to saying, 'oh, I didn't know that'. (Mum, Area P, 5-16)" (Smith 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme; EHCP: education, health and care plans; SENCO: special educational needs co-ordinator

Table 6: Evidence profile: Theme 2. Communication and support

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 2.1: Lack of communication (verbal and written) between services					
7 (Brooks 2013; Children's Commission for Wales 2018; Hurt 2019; Kiernan 2019; McCartney 2017; McKean 2017; Rodriguez 2014)	3 qualitative studies using semi-structured interviews; 3 qualitative studies using focus groups; 1 qualitative study using semi-structured interviews and focus groups	Service providers and parents reported that there was a lack of communication between services. As a result, some services were not aware of a child or young person with disabilities and severe complex needs and/or the services they had received or were in need of. When services did communicate with each other, service providers reported that the information shared was not always sufficient. "When children have been admitted to hospital who have a community paediatric consultant, the information doesn't always flow back the other way, so when a child is discharged the community paediatrician might not even know they've been in hospital and not have any details of the admission." (Brooks 2013)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 2.2: Lack of communication and support that address language and cultural barriers					
1 (Fox 2017)	1 qualitative study using semi-structured interviews	Parents reported that language barriers, due to being new to the country, made it difficult for parents to find out about available services and that more support, for example service providers or link workers from the same background as families, is needed to help parents understand and access services. "When you're new to a country, it's just impossible for you to find all the different services available. The reason that causes further delay to our children or [accessing] services is because you haven't got the capacity, or the ability, or the understanding to access services … That's what causes, I think, a lot of the delays." (Fox 2017)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 2.3: More information and support for service users to understand and access the available services					
10 (Brooks 2013;	6 qualitative	Service providers, parents, carers and young people reported that families are	Methodological	Major concerns	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Council for Disabled Children 2018; Fox 2017; Hurt 2019; Kaehne 2013; Kirk 2014; National Autistic Society 2015; Rodriguez 2014; Smith 2014; Thom 2015)	studies using semi-structured interviews; 2 qualitative studies using focus groups; 1 qualitative study using semi-structured interviews and focus groups; 1 mixed methods survey using open-ended questions	not given enough information about what services are available and the roles of different professionals. Service providers reported that families can be bounced around different services and receive conflicting information, which is disempowering. Service providers, parents and carers reported that more support and information is needed to make families aware of their options and empower them to make decisions and access services. "The[y] kept asking me 'what other support do you think you need?'. How do I know what other support I need…? 'Can we help you' was another question they asked, 'can we help you to arrange other activities for her?' Well, what activities? (Mum, 5-16 year old)" (Thom 2015)	limitations	about methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme

Table 7: Evidence profile: Theme 3. Service users' involvement and relationships with service providers

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
Sub-theme 3.1: Co-working improved when professionals worked closely with parents and kept them informed					
7 (Adams 2017; Boesley 2018; Children's Commissioner for Wales 2018; Fox 2017; McConkey 2013; Skipp 2016; Taylor 2014)	1 qualitative study using interviews; 3 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using semi-structured interviews and	Families, children and young people reported good relationships with service providers when they were in regular contact, kept them informed about what was happening, and used the same approach families were using at home. Service providers valued professionals who had good communication with families, listened to what they wanted and were non-judgemental and non-directive. "We had regular meetings with the paediatrician and the Speech and Language therapist, Occupational Therapist and Educational Psychologist. They have all been in constant contact with us. After they assessed him, they phoned me, told me what they thought and got my opinion. I was sent a copy of every report and all the way along they told me what was going to happen next. I thought the assessment was really thorough." (Skipp 2016)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
	focus groups; 1 survey using open-ended questions				
Sub-theme 3.2: Families vary in their ability and willingness to make decisions and be involved in care planning					
3 (Kaehne 2013; Rodriguez 2014; Thom 2015)	2 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups	Parents reported that they did not always think it was appropriate for them to be involved in decision making due to limited knowledge and expertise. Similarly, service providers reported that it can be hard for parents to take on care planning and decision making. “They were, you know, lots of discussions about the different pathways that they have and. . . I couldn’t feel qualified to say, well, no, you don’t need that or you do need that or blah, blah, blah. So, yes, there was. . . and there was a lot of that because obviously there was a lot of different therapists and what have you, health people there, and you feel like you, you know a little bit more about what education and maybe social services, where they’re coming from, because I have no idea really why I feel that, but I do, and it’s a little bit more in layman’s terms. . . I don’t want to step on any therapists’ toes by saying you don’t need that, and then the therapist, you know, saying, well, this is what we need and the children need this. I mean, they’re the experts in it. [So] a lot of it went over my head.” (Kaehne 2013)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme

Table 8: Evidence profile: Theme 4. Attitudes and social stigmas about service provisions

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 4.1: Fear of, and stigma associated with, social services					
2 (Fox 2017; McConkey 2013)	2 qualitative studies using semi-structured interviews	Both service providers and parents reported that families were reluctant to engage with social care, but there were some differences in the reasons. Parents reported that they were scared that social service involvement could lead to their child being taken away, whereas service providers reported that there was a stigma associated with social services. “They’re a very typical working class family and an honest family and a hard working family. I think there is that sort of stigma you know that they don’t want social work involvement. K37” (McConkey 2013)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				minor concerns	
			Adequacy	Major concerns Studies did not offer rich data	
Sub-theme 4.2: Need to work at shifting attitudes to look holistically at meeting the needs of children/young people					
2 (RIP STARS 2018; Thom 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and focus groups	Service providers reported that work was needed to shift attitudes to think more holistically about children and young people with disabilities and severe complex needs in order to better meet their needs. “You couldn’t underestimate the challenge that we’re talking about here. Because we need to shift our own staff and our own organisation, and the new need to shift families’ thinking, we’ve got to shift an entire culture… to think about people with disabilities differently. So it’s a massive agenda…. [Pathfinder lead]” (Thom 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 4.3: Service providers not ‘buying in’ to approach					
4 (Kaehne 2013; Molteni 2013; RIP STARS 2018; Sales 2018)	2 qualitative studies using semi-structured interviews; 1 qualitative study using interviews and focus groups; 1 mixed methods study using semi-structured interviews, focus groups and open-ended	Service providers and parents reported that service providers do not always ‘buy in’ to the approach used. The approach referred to different across studies and quotes but challenges in implementing the approach due to lack of ‘buy in’ was common across studies. The approaches discussed included EHC plans and joint working, SEND provision in colleges, involvement of families and the SCERTS model for use with children and young people with autism. “You know we went to every meeting and we were on occasion asked what we were thinking and what have you, you know. There was an element of paying lip service to having parents at the meeting. It was as if, well, okay, what do we need to get this to go through? We need parents to be involved, so that then becomes something that they can take as a selling point to their respective agencies to say, we need to change, the parents want to change. . . If you like, we were being consulted at best.” (Kaehne 2013)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
	question in questionnaire			rich data	
Sub-theme 4.4: Low expectations of the ambitions and capability of children and young people					
3 (Boesley 2018; RIP STARS 2018; Skipp 2016)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and focus groups; 1 qualitative study using semi-structured interviews and focus groups	Service providers, parents, children and young people reported that service providers have low expectations and are not very good at recognising the ambitions and capability of children and young people. Service providers and parents reported that there were not sufficient opportunities to support children and young people to achieve their ambitions. "…because a lot of my children with autism are managing fairly well in their academic status, they're able to reach expected level, when they could actually achieve a lot more – not just, 'just below expected' or 'just making expected' but actually, they could be "exceeding expected" – that's not really ever considered." (Boesley 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme; EHC: education, health and care; SCERTS: Social Communication, Emotional Regulation, Transactional Support; SEND: special educational needs and disabilities

Table 9: Evidence profile: Theme 5. Funding and resources

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 5.1: Joint funding and strategic planning as a method of supporting collaborative working					
2 (Children's Commissioner for Wales 2018; Spivack 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using focus groups	Service providers reported that having different funding available for different services means that services are not working together to meet the needs of children and young people. In contrast, where joint funding and a single head of service was available for child and adult social services, which enabled shared objectives, infrastructure and leadership, this was reported to have improved transitions. "Different monies being available for different bits of the problems means people aren't working together." (Children's Commissioner for Wales 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Very low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				Studies did not offer rich data	
Sub-theme 5.2: Lack of funding and resources is a barrier to providing services and person-centred, joined-up care					
8 (Boesley 2018; Children's Commissioner for Wales 2018; Council for Disabled Children 2018; Karim 2014; Palikara 2019; RIP STARS 2018; Sales 2018; Skipp 2016)	4 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using interviews and focus groups; 1 qualitative study using semi-structured interviews and focus groups; 1 mixed methods survey using open-ended questions	Service providers reported that funding has decreased and that the availability of services is being driven by budgets, rather than needs of children and young people. For example, providers were being encourages to not apply for EHC plans due to a lack of funding and requests for services were being refused due to insufficient funding. Service providers also reported that there is limited resources and time available for making diagnoses. Parents reported that access to services has decreased due to budget cuts, options for further education appeared to be driven by budgets rather than the needs of the child or young person, and that there were delays in getting an EHC plan and it being implemented due to delays in funding for education. "…what was more emphasised was how not to apply for EHC plans because the funding isn't there – that was emphasised greatly – and that doesn't help SENCOs when you're faced with a child who's got significant needs." (Boesley 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 5.3: Not enough funding or resources to support change from statements to EHC plans					
1 (Palikara 2019)	1 mixed methods survey using open-ended questions	Service providers reported that there had not been enough funding, resources or training to support the change from statements to EHC plans. As a result, service providers were overstretched, there were delays in meeting targets and early EHC plans were poor quality. "What has been difficult is not reflected above. There has been nothing like enough government funding to support the transition or the implication of providing services and resources for an older age group. SEN Officers and schools have been horribly overstretched in managing this transition. (P359, SLT)" (Palikara 2019)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				The study offered moderately rich data	
Sub-theme 5.4: Funding is driven by special educational needs					
1 (RIP STARS 2018)	1 qualitative study using interviews and focus groups	Service providers reported difficulty in securing funding and resources for children and young people with significant healthcare needs if they did not also have a special education need. “I do have some significant health difficulties on some cases that I work with and sometimes they’re more difficult ones because the funding that comes attached to an EHC plan has to have a special educational need to access one of those and if they have significant healthcare needs but they don’t hit the criteria for continuing care funding or they drop below it after being in it, then there’s no additional funding going into schools to support those pupil’s medical needs and some of these pupils are tube fed, are on morphine constantly, needing significant medical intervention and schools are expected to fund that just on what they would get on any other pupil…” (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 5.5: Fighting against financial pressures					
2 (Sales 2018; Young 2018)	1 qualitative study using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups	Service providers reported that some providers fought against financial pressures to not apply for EHC plans due to a lack of funding and applied for plans based on needs rather than considering how provisions would be funded. Parents reported that there is a lot of pressure to accept services that are less costly than others, but thought it was important that parents continued to fight against such pressures until they got the services they wanted. “Some people seem to be very aware of the pressure of no money ... And some just seem to be “oh well ... that’s irrelevant”. And that’s the way it should be.” (Sales 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns Studies did not offer rich data	
Sub-theme 5.6: Competing priorities can impact the allocation of limited resources					

Study information		Description of theme or finding	CERQual assessment of the evidence		
1 (McKean 2017)	1 qualitative study using semi-structured interviews	Service providers reported that having different priorities competing for the same resources could affect how resources were allocated. “And it’s almost, are you brave enough to say, “Right, we’ll accept we’re going to have poor results [in Statutory Assessment Tests in later school years] for a couple of years while we plough everything in to early years to try and solve everything at that stage” but it’s a brave head-teacher who’ll allow the top end to slip…” (McKean 2017)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns The study did not offer rich data	
Sub-theme 5.7: Staffing of services impacts the quality of the service					
1 (Young 2018)	1 qualitative study using semi-structured interviews	Parents, children and young people reported that the staffing of services, particularly if there are limited staff available for the number of patients, impacted the quality of the service in terms of opportunities for the service user to engage in activities and interact with service providers. “I could not fault them as carers when he was in respite at [name of service] but he never got out on trips…if a nurse left the place there was no nurse left to care for the others. There would be maybe a couple of board games around the table … but they didn't have a sensory room and things to stimulate him.” (Young 2018)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns The study offered some rich data	
Sub-theme 5.8: Personalised budgets and direct payments increase flexibility but also the family’s responsibility for making decisions and arranging care					
3 (Hutton 2018; Smith 2014; Thom 2014)	2 qualitative studies using semi-structured interviews; 1 qualitative study using interviews and focus groups	Service providers, parents and carers reported that personal budgets and direct payments increased flexibility and gave families more choice about what services they use. Service providers also reported that families use personal budgets more wisely, and can get better deals, than local authorities. However, some parents reported that being responsible for a personal budget created additional responsibilities and were not sure if they were able, or wanted to, take on this responsibility. They were concerned that they did not have sufficient knowledge to make care decisions, questioned whether it would impact on ongoing professional involvement, and were already experiencing everyday pressures of caring for children and young people. “You could be sitting with a large pot of cash without really knowing what it is your child is supposed to need. Whereas from my perspective because I had [name of therapist] telling me, ‘This is what your child is likely to need,’ she then made the necessary referrals, we then got the people involved.” (Hutton	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	Minor concerns Some evidence is ambiguous or contradictory without a	

Study information		Description of theme or finding	CERQual assessment of the evidence		
		2018)		credible explanation for differences	
			Adequacy	None or very minor concerns	
Sub-theme 5.9: Service providers have a lack of control over allocation of resources and there is a lack of transparency about decision making					
1 (McKean 2017)	1 qualitative study using semi-structured interviews	Service providers reported frustration that a panel has to authorise additional resources to support a child or young person and that when requests are refused there is a lack of information about the reason for the refusal. “It [the request] always goes to a panel who decides, so that, there's a bit of frustration there, because, you know, you, it's almost like sending off your exam and sort of, "Well, we've filled in all the paperwork, I think I've done it right, I think I've got..." …and then it comes back, "No, just carry on the same", we go, "Oh no."” (McKean 2017)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns The study did not offer rich data	

CASP: critical appraisal skills programme; EHC: education, health and care; SEN: special educational needs; SENCO: special educational needs co-ordinator; SLT: speech and language therapist

Table 10: Evidence profile: Theme 6. Organisation of services

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 6.1: Rigid definition of, and criteria for, services leads to gaps in service provision					
5 (Children’s Commissioner for Wales 2018; Council for Disables Children 2018; Kaehne 2013; RIP STARS 2018; Thom 2014)	3 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using interviews and focus groups	Service providers, parents, carers and young people reported that there were gaps in service provision for a number of reasons. First, some providers reported that there is a narrow definition of social care and education services; for example, social care services focus on whether children are being cared for at home and are safe from abuse, as opposed to considering a wider range of issues related to social wellbeing. Second, providers reported that some services are diagnosis-specific, or have different age thresholds for when they will accept children and young people depending on their diagnosis. Parents also reported barriers to accessing services based on eligibility criteria such as age, location, or previous use of services. “[He] attended mainstream school. There is a lot of unnecessary criteria for adult mental health services as regards to whether your child went to a mainstream school the authority doesn’t regard them as having a learning	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
		disability even though they have. This then removes the right for them to see the disability team, so you see the regular team who can't help them because they have autism!! So you see no one as has happened to my son." (Children's Commissioner for Wales 2018)		Studies together offered moderately rich data	
Sub-theme 6.2: Specialist services provide benefit but there is a lack of provisions to make these services available					
2 (Karim 2014; Kiernan 2019)	2 qualitative studies using semi-structured interviews	Service providers reported that a specialist service for diagnosing children and young people would provide benefit as there was not enough time to make complex diagnoses within existing services, but funding was not available for this. Some parents reported that they had set-up a specialist play scheme, as there was no local service available, which provided benefit whilst it had run. "...we used to take thirty five kids a day, and we had charity status and it was great while it ran." (Kiernan 2019)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns Studies did not offer rich data	
Sub-theme 6.3: Mainstream services provide benefit but more effort and support is needed to integrate children and young people					
2 (Kiernan 2019; RIP STARS 2018)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and focus groups	Service providers and parents reported that more effort, support and training for education providers is needed to integrate children and young people into mainstream education. One parent also reported that their child had preferred a mainstream youth club compared with specialist provision. "Support for inclusive education, not just the one to one support but also our teachers and all of the staff in the school getting training to ensure that they are confident to include that young person both in the class room but also outside the class room to support the young person to build relationships with their peers." (RIP STARS 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 6.4: Lack of appropriate services					
10 (Children's Commissioner for Wales 2018;	6 qualitative studies using semi-	Service providers, families, parents, carers, children and young people reported that there were a lack of appropriate services available either due to eligibility criteria for services, including age, limited number of places available	Methodological limitations	Moderate concerns about methodological	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Council for Disabled Children 2018; Hurt 2019; Kirk 2014; McConkey 2013; Sales 2018; Skipp 2016; Smith 2014; Thom 2014; Young 2018)	structured interviews; 2 qualitative studies using focus groups; 2 qualitative studies using semi-structured interviews and focus groups	in appropriate services, or geographical location. This was particularly reported to be the case for young adult services available for children and young people post-16 years of age. "There's all this change – not only of them being adults but their safety net almost is taken away, cause he's going to stop school and then this (short breaks) is going to be taken away from him and other clubs and things that he goes – it's as if one door is shutting and then another one." (McConkey 2013)		limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 6.5: Inconsistency across paperwork and procedures used in different services, regions and local authorities					
3 (Boesley 2018; Hurt 2019; Palikara 2019)	1 qualitative study using semi-structured interviews; 1 qualitative study using focus groups; 1 mixed methods survey using open-ended questions	Service providers reported that the procedures and paperwork used varied across schools and local authorities, as did the evidence requested to support paperwork. This was particularly difficult for centrally based services referring to local services, or when families lived in different counties or local authorities to where the child or young person attended school. "Every local authority does things in a different way […]. So, we're a bit stuck because we're central and we're diverting families into something that's local that […] well, we really haven't got any control over whatsoever." (Hurt 2019)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 6.6: Importance of clear pathways for referrals between services					
2 (Council for Disabled Children 2018; Hurt 2019)	1 qualitative study using semi-structured interviews; 1 qualitative study using focus groups	Some service providers reported a lack of clear pathways for referral between services and that joint working between services was seen as something that happened on an ad hoc basis. However, service providers thought that there was now clearer guidance available on pathways and joint working once referrals had been received. "It's curious, isn't it; we don't have a very clear pathway of how to do that […] it's very individual, it's extremely variable and we generally work with the	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very	

Study information		Description of theme or finding	CERQual assessment of the evidence		
		people who are willing to work with us." (Hurt 2019)		minor concerns	
			Coherence	Minor concerns Some evidence is ambiguous or contradictory without a credible	
			Adequacy	Major concerns Studies did not offer rich data	
Sub-theme 6.7: Having the right people involved and collaborating can overcome gaps in service provision					
3 (Boyce 2015; Council for Disabled Children 2018; Thom 2014)	3 qualitative studies using semi-structured interviews	Service providers and parents reported that there are gaps in service provision but that these can be overcome when the right people, with intermediary roles and when individuals and services collaborate to meet the needs of children and young people. "There are gaps but when it suddenly works, when you get the appointments, or you get the right people involved, then the system can work." (Council for Disabled Children 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Very low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns Studies did not offer rich data	
Sub-theme 6.8: Using a more flexible approach where services are able to meet the individual needs of the child/young person, rather than fitting the child/young person within existing rigid service models would be beneficial					
7 (Boyce 2015; Children's Commissioner for Wales 2018; Kaehne 2013; McConkey 2013; McKean 2017; RIP STARS 2018; Skipp 2016)	4 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using interviews and	Service providers, parents and carers reported that services are inflexible and that children and young people are required to fit within existing services rather than asking what people need from services. However, some service providers reported that they used a flexible approach when developing plans and interpreting guidelines, including whether or not a diagnosis was necessary, in order to meet the needs of children and young people. "That they fit the young person rather than the young person fitting in with the system and that's difficult at the moment because of the way education success is measured really is pretty much determined by exam results and not much else." (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
	focus groups; 1 qualitative study using semi-structured interviews and focus groups			minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	

CASP: critical appraisal skills programme

Table 11: Evidence profile: Theme 7. Information sharing

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 7.1: Information is not always shared nor sufficient to meet the needs of other services					
5 (Brooks 2013; Children’s Commissioner for Wales 2018; Council for Disabled Children 2018; Taylor 2014; Thom 2014)	1 qualitative study using interviews; 2 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using semi-structured interviews and focus groups	Service providers reported that services do not always share information and that the information that is shared is not always sufficient due to a lack of understanding of the information needs of different service. Further, some service providers reported that they had relevant information about the child or young person but were not given the opportunity to contribute this information to assessments led by other services. Parents also reported that there was a lack of information sharing which required them to repeat information when coming into contact with different services. “I have to manage different health services- can be 5 or 6 different services. Managing paperwork which sometimes doesn’t get passed between health services leading to endless repeating of medical history” (Children’s Commissioner for Wales 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 7:2: Sharing information to streamline processes and transition					
3 (Boyce 2015; Molteni 2013; RIP STARS 2018)	1 qualitative study using semi-structured interviews; 1 qualitative study using	Service providers reported that they shared information between health and education services and that this had streamlined services. Other service providers and parents reported that greater sharing of information would streamline the process of receiving a diagnosis and transitioning from child to adult services.	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative	Low

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
	interviews and focus groups; 1 mixed methods study using semi-structured interviews, focus groups and open-ended question in questionnaire	“Information from the assessments would be very useful to pass onto adult providers who our students will be moving onto and for social workers and local authorities to evidence progress in other areas than academic.” (Molteni 2013)		checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 7.3: Sharing information increases understanding of the child or young person and their needs					
2 (Cohen 2017; Taylor 2014)	1 qualitative study using interviews; 1 survey using open-ended questions	Service providers reported that sharing information between services was one of the benefits of joint working because it provided more information about the needs of children and young people and gave the opportunity to pass on any concerns to other services. Parents and carers reported that better sharing of information and education from health to education services increased understanding of the needs and behaviours of children and young people. “Teachers failed to grasp how his conditions affected his ability to carry out school work until a [sic] occupational therapist met with his pr[imary] 2 teacher and explained how hypermobility especially affects him, feel there has been greater understanding from this teacher onwards that he has a lot of issues to deal with (he looks and behaves like any other child and we felt that they believed we were making more of it than there was). Believe a medical professional explaining how medical conditions affect the children would assist teachers with understanding what is going on with the child better and perhaps make allowances for their issues.” (Cohen 2017)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 7.4: Inconsistent information provided to parents					
1 (Hurt 2019)	1 qualitative study using focus groups	Service providers reported that the information given to parents from different services is often inconsistent. “They get different messages from everybody […].They get buffeted around alot, they don’t know where they are with it.” (Hurt 2019)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns Studies did not	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				offer rich data	
Sub-theme 7.5: Accessing electronic patient records through an online portal to improve working					
1 (McCartney 2017)	1 qualitative study using semi-structured interviews	Service providers reported that there were discrepancies in which services could access online electronic patient records and believed that being able to access such records would make joint working easier and increase identification of, and information sharing for, children and young people with disabilities and severe complex needs. "…the [adult SLT team] can use our [child SLT team's] database to find out whether a child is/has been known – we can't use their database but they can use ours. I believe when the electronic patient records come in that will be easier. [Now] the acute service is not on the same system so it won't tell us when children are in hospital for instance. … Community services (that's health and social work) will be able to tap into the same records but not acute [NHS services]." (McCartney 2017)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 7.6: Development and sharing of a behaviour management plan provided benefit					
1 (McConkey 2013)	1 qualitative study using semi-structured interviews	Families reported that the development and sharing of a behaviour management plan provided benefit in terms of helping the child or young person to acquire new skills and provide direction for new services working with the child or young person. "The most support that I got was from Action for Children because they have access to psychological services and the psychologist there drew up a behavioural management plan which staff stuck to and that did help quite considerably and also passed it on to school. And that same behaviour plan has been passed on to his new respite carers so they have an idea of where to start with him. F25" (McConkey 2013)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	

CASP: critical appraisal skills programme; NHS: National Health Service; SLT: speech and language therapist

Table 12: Evidence profile: Theme 8. Long waiting times for support

Study information			CERQual assessment of the evidence		
Number of	Design	Description of theme or finding	Criteria	Level of	Overall quality

Study information		Description of theme or finding	CERQual assessment of the evidence		
studies				**concern**	
Sub-theme 8.1: Lack of urgency to provide support until the child/young person reaches crisis point					
6 (Adams 2018; Boesley 2018; Children's Commissioner for Wales 2018; Council for Disabled Children 2018; Dillenburger 2016; McConkey 2013)	1 qualitative study using interviews; 3 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using semi-structured interviews, focus groups and questionnaire	Service providers and parents reported that there is a lack of urgency to provide support until the child or young person reaches crisis point. Some parents reported that the triggering point for being able to access services was when the child, young person or parent expressed suicidal thoughts or parents did not think they could continue to care for their child without support. Service providers and parents reported that children and young people might not have reached a crisis point if support was provided early and that it can be difficult to come back from reaching this point. Parents also reported children going into residential care as a result of not receiving support earlier. "I don't regret adopting; I just regret the fact that there isn't the support and the help when you need it and I know that a lot of it's due to funding, but you only then access any services when you are at crisis point, and if there were things around earlier you might not reach that crisis point." (Council for Disabled Children 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 8.2: Replacements of statements with EHC plans resulted in delays to support provisions					
2 (National Autistic Society 2015; Palikara 2019)	2 mixed methods surveys using open-ended questions	Service providers and parents reported that changing from statements to EHC plans had resulted in delays and that the legal limit of receiving an EHC plan within 20 weeks is often missed. Parents reported that this had delayed receiving support. "My child has a statement and has had a review in order to convert it into an EHC plan. Our LA is very behind – they have told us they will not meet the legal deadline, therefore she will start college in September with no support in place." (National Autistic Society 2015)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 8.3: Unavailability of staff able to complete the necessary paperwork/assessments					
3 (McKean 2017; Skipp 2016;	2 qualitative studies using semi-	Service providers and parents reported delays in support due to providers being unavailable to complete assessments and paperwork. Some parents reported that this caused anxiety for the child or young person as they did not	Methodological limitations	Minor concerns about methodological	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Smith 2014)	structured interviews; 1 qualitative study using semi-structured interviews and focus groups	know what was happening. “We were told there would be a delay as the Ed Psych had a backlog and nothing could be done without them. We were told we could get a private assessment instead if we were worried. We asked the paediatrician to write a report and sent him all the details. But he didn’t offer much direction. There was nothing in there about school or what help was actually needed.” (Skipp 2016)		limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 8.4: Additional assessment cause delays in implementing EHC plans					
1 (Skipp 2016)	1 qualitative study using semi-structured interviews and focus groups	Parents reported that once EHC plans had been received schools wanted to conduct their own assessments of the child or young person and that this delayed implementation of EHC plans. “We’d been through the whole plan and process and finally they found a school who said they’d take him. So he’s got to go there and be assessed again so that they can see what his needs are and how they think they will support him. It sounds odd after what we’ve been through but they’re saying they’ll look at other support he might need that’s not in the plan.” (Skipp 2016)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 8.5: Delays from one service can impact access to other services					
2 (Children’s Commission for Wales 2018; Fox 2017)	1 qualitative study using semi-structured interviews; 1 qualitative study using focus groups	Parents reported that delays in decision making and receiving support from one service could impact access to support from other services. “I’ve tried to contact social services, but I haven’t had one yet. It’s been a very long wait ... Yes. I can easily say, without the social services you can’t have anything.” (Fox 2017)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
				Studies together offered some rich data	

CASP: critical appraisal skills programme; Ed Psych: educational psychologist; EHC: education, health and care; LA: local authority

Table 13: Evidence profile: Theme 9. Difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 9.1: An over emphasis on academic progress overshadowed other areas of need and impacted on the child/young person's ability to access an EHC plan					
1 (Boesley 2018)	1 qualitative study using semi-structured interviews	Service providers reported that EHC plans overemphasise academic progress and educational needs. This was reported to be a barrier to receiving EHC plans for children and young people with health and social care needs that were not seriously behind expected academic levels. "…this is a child who's got autism, he's probably got PDA [Pathological Demand Avoidance], he's certainly got ADHD [Attention Deficit Hyperactivity Disorder] and ODD [Oppositional Defiant Disorder]; he's having serious mental health difficulties and yet they won't give him one ... he hasn't made the cut because he's not behind enough in his levels." (Boesley 2018)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 9.2: Lack of understanding of, and difficulty providing evidence for, SEMH needs is a barrier to accessing EHC plans					
1 (Boesley 2018)	1 qualitative study using semi-structured interviews	Service providers reported that there is a lack of understanding of social, emotional and mental health needs and that providing evidence of these needs is difficult and often requires external input or assessments. They also reported a lack of awareness of needs of children and young people with internalising symptoms that do not exhibit challenging behaviour. These factors can cause difficulty in accessing EHC plans for such children and young people if they do not also have special educational needs. "…a lot of [children on the autism spectrum] are self-harming, have problems with soiling and really high anxiety causing them to have a really stressful time ... yet none of that is ever considered, and trying to get them any mental health services is really difficult." (Boesley 2018)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 9.3: Not all children/young people who need support meet the criteria for an EHC plan					

Study information		Description of theme or finding	CERQual assessment of the evidence		
4 (Palikara 2019; RIP STARS 2018; Skipp 2016; Smith 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and focus groups; 1 qualitative study using semi-structured interviews and focus groups; 1 mixed methods survey using open-ended questions	Service providers, parents and carers reported that not all disabled children and young people who need support reach the threshold for EHC plans and that there is not a system in place to support these children and young people. Further, some children and young people may drop below the threshold for EHC plans once they have been received, due to making academic progress. Service providers reported that it is difficult for schools to meet significant health needs of children and young people without the funding attached to EHC plans. "Many children and young people who do not qualify for EHCPs still need lots of specialist support – including allied health professional involvement. This is not available under the current system. (P318, SLT)" (Palikara 2019)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 9.4: The process of getting an EHC plan takes too long and requires a lot of work					
3 (Adams 2017; Adams 2018; Skipp 2016)	1 qualitative study using interviews; 1 qualitative study using semi-structured interviews and focus groups; 1 survey using open-ended questions	Parents, children and young people reported that it took a long time to receive an EHC plan and that there was a lack of communication and information from service providers unless parents contacted providers. Some parents were satisfied with the outcome of the process and thought it had been worth the effort whereas others did not think that the plan had achieved much or had their application for an EHC plan denied. "The amount of time [taken to get the EHC plan] caused me to miss important time in school. This caused me to miss the whole of Year 10 meaning I was only [able] to complete 4 subjects for my GCSE's at my SEN school." (Adams 2017)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	Minor concerns Some evidence is ambiguous or contradictory without a credible explanation for differences	
			Adequacy	Moderate concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				Studies together offered some rich data	
Sub-theme 9.5: Children/young people need to reach a crisis point to access EHC plans					
2 (Boesley 2018; Sales 2018)	2 qualitative studies using semi-structured interviews	Service providers reported that children and young people often had to reach a crisis point, where exclusion from school or the family home was being considered, before needs were taken seriously and an EHC plan considered necessary. "…'it was only when we were talking about exclusion that people were able to come in." (Boesley 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns Studies did not offer rich data	
Sub-theme 9.6: Professionals, staff and families lack understanding of the EHC plan process					
5 (Adams 2017; Boesley 2018; National Autistic Society 2015; Palikara 2019; Skipp 2016)	1 qualitative study using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups; 2 mixed methods surveys using open-ended questions; 1 survey using open-ended questions	Service providers and parents reported neither providers nor families had a good understanding of the EHC plan process, particularly in the time shortly following their implementation. Both service providers and parents reported that service providers often could not answer queries from parents and some service providers thought people were just going through the motions of what had previously been done with statements. "During the review, myself and the teams around my children were confused about the process. They couldn't answer my questions, and admitted that they didn't understand the new system. I still have no information on the outcome of these reviews. All they say is that the process is held up." (National Autistic Society 2015)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 9.7: Professionals and staff lack the expertise and knowledge needed to complete the EHC plan					

Study information		Description of theme or finding	CERQual assessment of the evidence		
2 (Adams 2017; Palikara 2019)	1 mixed methods survey using open-ended questions; 1 survey using open-ended questions	Service providers and families reported that providers lacked the expertise and knowledge, including knowledge of special educational needs, required to complete EHC plans. This can lead to limited and out of date information being provided and significant effort from families to bring evidence together. "Plans that replace statements are often written with limited and out of date advice and are outsourced, written by people who have very limited knowledge of SEN - these are not better. A well written plan written with up to date and detailed information may be better. (P42, EP)" (Palikara 2019)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 9.8: There is a lack of transparency about decision making for EHC plans, timescales for review and processes for appeal or complaints					
4 (Boesley 2018; RIP STARS 2018; Skipp 2016; Smith 2014)	2 qualitative studies using semi-structured interviews; 1 qualitative study using interviews and focus groups; 1 qualitative study using semi-structured interviews and focus groups	Service providers reported that there is a lack of transparency about decision making for EHC plans. Some providers recognised that it is difficult to specify thresholds for EHC plans due to the different needs of children and young people but others reported frustration at having plan applications rejected without adequate explanation. Service providers also thought that families should be given more information about timescales and processes for complaints before the start of the process. Parents reported that they did not understand timescales for review or the process for appeals and complaints if they were not happy with the outcome of EHC plans. "Jordan's on a statement now. A letter came saying that our case was going to panel. These are the ones that make the decision. But this was before anyone had come out and seen him, or talked to us or anything. So this decision is just off of what I put in the form. What if I didn't do it right? I've heard you can't go back to them for another 6 months. I don't know if they can take his statement away." (Skipp 2016)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 9.9: A lack of available services is increasing demands for EHC plans					
1 (Boesley 2018)	1 qualitative study using semi-structured interviews	Service providers reported that insufficient service provision from local authorities, due to decreased resources, was increased the demand and number of applications for EHC plans. "…if there was proper provision from the LA then you wouldn't necessarily	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
		need too many children with EHC plans ... because we haven't got that provision, the LA are inundated, literally, with new applications." (Boesley 2018)		minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 9.10: Time taken for EHC plans to be refined and embedded in practice					
4 (Boesley 2018; Palikara 2019; Skipp 2016; Smith 2014)	2 qualitative studies using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups; 1 mixed methods survey using open-ended questions	Service providers reported that EHC plans had been introduced before they were fully refined which led to delays, the initial plans being poor quality, and different services using different versions of the plans. Some providers reported it would have been more efficient if more time was spent on the planning stage prior to implementation. Parents recognised that the early EHC plans were somewhat of a pilot and that everyone was getting used to the new system and hoped that future plans and processes would improve as people became more informed. "I feel the authority struggled with the additional workload and did not have time to put together coherent guidelines before they started the implementation. This meant the initial EHCPs were delayed and of poor quality. Subsequent paperwork has been reviewed a few times and different schools are using different versions. It would have been more effective and efficient if more time was spent on the planning to implement stage. (P260, SEN Unit manager)" (Palikara 2019)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 9.11: Revisions to EHC plan paperwork and processes made without consultation or notice					
1 (Boesley 2018)	1 qualitative study using semi-structured interviews	Service providers reported that revisions to the EHC paperwork occurs without any consultation or notice and this can require additional work as service providers need to transfer completed EHC plans to a new version. "…you get used to working with a particular format and then, all of a sudden, it gets changed, and to my knowledge there is no consultation ... it just happens." (Boeslet 2018)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	

ADHD: attention deficit hyperactivity disorder; CASP: critical appraisal skills programme; EHC: education, health and care; EHCP: education, health and care plans; EP: educational psychologist; GCSE: general certificate of secondary education; LA: local authority; ODD: oppositional defiant disorder; PDA: pathological demand avoidance; SEMH: social, emotional and mental health; SEN: special educational needs

Table 14: Evidence profile: Theme 10. An imbalanced distribution in the amount of support provided to children/young people

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 10.1: Individuals who shout the loudest are more likely to receive the desired support					
2 (Brooks 2013; McConkey 2013)	1 qualitative study using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups	Service providers and parents reported that the level of support provided did not always reflect the needs of families and that families who had a more assertive communication style were more likely to get the support they wanted than those who are less assertive or proactive. "Do you want the honest opinion? I think it's the people who shout the loudest get what they want and sometimes you have got young people with massive packages and it doesn't need to be that much, and we've got other people with no package." (McConkey 2013)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 10.2: Looked after children are more likely to receive an EHC plan					
1 (Sales 2018)	1 qualitative study using semi-structured interviews	Service providers reported that looked after children were more likely to receive an EHC plan than children with similar needs who are still with their families, unless they are at a point where they may not be able to stay in the family home. "…has to be really really bad"… "on the edge of care." (Sales 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns The study did not offer rich data	
Sub-theme 10.3: Families vary in their ability and willingness to fight for services					
2 (Rodriguez	1 qualitative	Some parents reported that they did not have the mental energy to challenge	Methodological	Major concerns	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
2014; Smith 2014)	study using semi-structured interviews; 1 qualitative study using focus groups	decisions when they were not happy with the amount of support received. Service providers reported that sometimes they have to fight for services on behalf of families. "We feel like we didn't want to push it because mentally, we just couldn't be bothered." (Smith 2014)	limitations	about methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 10.4: Regional disparity in the availability of services					
7 (Boesley 2018; Children's Commissioner for Wales 2018; Dillenburger 2016; Kaehne 2013; Rodriguez 2014; Skipp 2016; Smith 2014)	3 qualitative studies using semi-structured questionnaire; 2 qualitative studies using focus groups; 1 qualitative study using semi-structured interviews and focus groups; 1 qualitative study using semi-structured interviews, focus groups and questionnaire	Service providers, parents and carers reported that there was inconsistency in the type and quality of support available across different regions. "Late decision making and access to social care services. It definitely differs between areas. We have one Transition Plan Officer basically overseeing 200 Young people from two different teams." (Children's Commissioner for Wales 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	

CASP: critical appraisal skills programme; EHC: education, health and care

Table 15: Evidence profile: Theme 11. Professional and staff knowledge and training

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 11.1: Professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people					
7 (Adams 2017; Cohen 2017; McConkey 2013; McKean 2017; Palikara 2019; Smith 2014; Taylor 2014)	1 qualitative study using interviews; 3 qualitative studies using semi-structured interviews; 2 surveys using open-ended questions; 1 mixed methods survey using open-ended questions	Service providers, parents and carers reported that a lack of skills, knowledge and training was a barrier to working effectively with children and young people to meet their needs and manage behaviour. Service providers also reported that they were working beyond their knowledge and skills competencies, for example delivering specialist programmes without sufficient knowledge. Parents also reported that some service providers did not have the confidence and skills to work equally with other professionals and did not have sufficient knowledge about how the systems worked. “The school doesn't meet basic needs - like a basic daily therapy, a one-to-one therapy with the child. The staff support is not enough - people are not properly trained.” (Adams 2017)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 11.2: Misconceptions and lack of understanding from professionals lead to incorrect, or a lack of, advice and referrals					
3 (Boesley 2018; Boyce 2015; MCartney 2017)	3 qualitative studies using semi-structured interviews	Service providers reported that misconceptions and lack of understanding from professionals led to families being given incorrect advice about applying for an EHC plan. Service providers also reported that insufficient understanding of pathways can lead to a lack of appropriate referrals, for example between schools and adult SLT services. “…[health professionals] are always saying the school should apply for an EHC plan and actually, that’s just frankly wrong, misleading, and leads to parents feeling like they’re not being treated properly, when actually they’re given the wrong advice.” (Boesley 2018)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
Sub-theme 11.3: Multi-agency training is important to bridge the gaps between professionals and get everyone on the same page					
1 (Spivack 2014)	1 qualitative study using semi-structured interviews	Service providers reported that multi-agency training was important to bridge the gaps between professionals in different services, increase knowledge, awareness and skillsets, and to get everyone on the same page. "Structurally, it's not just seen as education anymore…all in it together…bring everyone on message" (Spivack 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Very low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns The study did not offer rich data	
Sub-theme 11.4: Opportunities to learn from, observe and model other services					
2 (McCartney 2017; McKean 2017)	2 qualitative studies using semi-structured interviews	Service providers reported that they valued the opportunity to learn from other services, particularly through observation, modelling and ongoing supervision and feedback. "I'd done lots of different courses and things, but I think you learn best when you actually either do it yourself or you're seeing something modelled. So …whenever [SLT] was in working with a child, I would just say to her, "Can I just sit and watch you doing whatever you're doing?" and she would be like, "Yeah, definitely" and that, that way I've sort of built up a really good relationship with [SLT], and watched her a lot. And there were even times when I got [SLT] to come in and just sort of watch me doing what I was doing, just to make sure I knew what I was doing, what I was supposed to be doing." (McKean 2017)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 11.5: Service providers having knowledge of the EHC plan process					
1 (Adams 2017)	1 survey using open-ended questions	Parents reported satisfaction with the EHC plan process when service providers had knowledge of the process and provided help and support. "My child's school was very helpful and knowledgeable about applying for the EHC plan. Once getting the help from EHC plan everything went very well, and I have been very pleased with the help given."	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
				checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme; EHC: education, health and care; SLT: speech and language therapist

Table 16: Evidence profile: Theme 12. Joined-up care requires a substantial amount of time, organisation and commitment

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 12.1: Large time investment is needed by parents to coordinate services and manage appointments					
6 (Children's Commissioner for Wales 2018; Cohen 2017; Hutton 2018; Kiernan 2019; Sales 2018; Skipp 2016)	2 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 qualitative study using interviews and focus groups; 1 qualitative study using semi-structured interviews and focus groups; 1 survey using open-ended questions	Parents and carers reported that they felt a sense of responsibility in driving the necessary care provisions and had to spend a lot of time and effort contacting and co-ordinating services due to a lack of communication between services. They also reported a large time investment was needed to attend and manage appointments. Similarly, service providers reported that well written plans, that got allocated the best resources, were down to the work that parents had put into the process. "I have found that I need to be a secretary and administrator to the multidisciplinary team that my son is supposed to have. If I don't chase them up the appointments don't come and the assessments get missed and we've even been discharged for missing an appointment due to illness. A clerical error which cost me months of phone calls to reinstate. They never communicate between departments. They rarely turn up to meetings for reviews we are inundated with organising all of the services constant involvement." (Children's Commissioner for Wales 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 12.2: Challenge to arrange meetings/discussions that are attended by all necessary staff/professionals					
7 (Boesley 2018; Children's Commissioner	5 qualitative studies using semi-	Service providers, parents and carers reported that it was difficult to arrange meetings and discussions that are attended by all necessary professionals. Parents reported needing to spend a lot of time and effort arranging meetings	Methodological limitations	Major concerns about methodological	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
for Wales 2018; Kaehne 2013; McKean 2017; Molteni 2013; Sales 2018; Smith 2014)	structured interviews; 1 qualitative study using focus groups; 1 mixed methods study using semi-structured interviews, focus groups and open-ended question in questionnaire	but that even when meetings are arranged months in advance some professionals do not attend. “There’s no point in us having an integrated meeting if only one of the three or four different types of organisations that we want to integrate are going to turn up for a meeting.” (Kaehne 2013)		limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 12.3: Lack of ongoing involvement from external agencies					
2 (McCartney 2017; McKean 2017)	2 qualitative studies using semi-structured interviews	Service providers reported that there was a lack of ongoing involvement from external agencies in schools, particularly SLT services whose responsibility is to set up support but do not stay involved once support is in place. SLTs reported that schools were informed about their responsibilities to take on the advice of external agencies, contact services if they are having any difficulties and refer children and young people to adult SLT teams when required but were not sure if schools understood this. Some service providers from external agencies reported that they did not think school staff adequately built on the training and advice provided and that they may need to provide more ongoing support. “…there’s a bit of me that wonders if schools realise their responsibility - certainly I always tell them it’s their responsibility to pass on information [to adult SLT services] about eating and about communication, because we’re therapists and we’re involved when there’s something that needs therapy, but once it’s all done and set up we don’t stay involved.” (McCartney 2017)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 12.4: Responsibility and resources are required to ensure plans are implemented and reviewed to accurately reflect changing needs					
3 (McKean 2017; RIP STARS 2018; Smith 2014)	2 qualitative studies using semi-structured interviews; 1 qualitative study using interviews and	Service providers reported that EHC plans are not always followed through and viewed as a live document that requires review and updating. They also reported that plans developed by external agencies are not always followed through. Parents reported that there was a lack of implementation of EHC plans and that a number of the support services listed in plans were not received. Some service providers reported that resources are not always available to implement plans in a timely manner and took responsibility for organising support provision through other means.	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
	focus groups	"We (the Local Authority) cannot micro manage the lives of, nor should we, of every child or young person with a plan. The plan is the route map, the plan should describe the journey and if it's well written, all of the steps on the journey. The school or the education provider, when it picks up that plan and agrees to offer a place is legally committing to providing what is written in that plan and in the vast majority of cases, it works reasonably well but the other thing of course you have to appreciate is, people change. So what is described in the plan in January 2018, by August 2018 may not be relevant or may have moved, particularly for very small children." (RIP STARS 2018)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 12.5: Workloads are negatively impacted by the cumbersome and onerous nature of paperwork and interprofessional working					
3 (Brooks 2013, Molteni 2013, Palikara 2019)	1 qualitative study using semi-structured interviews and focus groups; 1 qualitative study using focus groups, semi-structured interviews and one open-ended question on a questionnaire; 1 study using a semi-structured survey	Service providers expressed frustration with the cumbersome and onerous nature of paperwork, particularly with the replacement of statements of SEN with EHCPs which were felt to be unwieldy as a working document. The lack of training or knowledge from individuals in the writing of EHCPs was seen as a concern which led to discrepancies and a lack of consistency. Service providers reported that challenges when communicating with, and coordinating between services increased workloads and impacted on the number of cases they were able to manage. "The new documents are long-winded and cumbersome. They are not consistent, with regards to the information contained in them, as they are written by a range of different professionals with very little training. Statements were approximately 8 pages long, very clear and easy to find relevant information quickly. The new EHCPs are between 20-40 pages long and each one is quite different from another in terms of content and information. (Palikara 2019)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme; EHCP: education, health and care plan; SEN: special educational needs; SLT: speech and language therapist

Table 17: Evidence profile: Theme 13. Working across multiple services

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 13.1: Sharing staff across multiple settings improved knowledge of the child					
1 (McConkey 2013)	1 qualitative study using	Service users reported positive experiences with staff who had worked across multiple services. It was felt that working across multiple services gave staff an	Methodological limitations	Moderate concerns about	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
	semi-structured interviews	opportunity to observe the child/young person in different environments, therefore improving their knowledge and understanding of the child/young person. "What is great is the connection between the community sessions and the overnight respite – that works well you know, the staff being shared and knowing the child in different settings. Working across the two services that seems to be a smart way of doing things really." (McConkey 2013)		methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns The study offered some rich data	
Sub-theme 13.2: Assigned consistent one point of contact or agency would be beneficial to joint working					
2 (Griffith 2013, Hurt 2019)	1 qualitative study using semi-structured interviews; 1 qualitative study using focus groups	Service users reported feeling overwhelmed with navigating service provisions for the child/young person across multiple services and expressed the need for one consistent point of contact or agency. Servicer users felt that an assigned individual point of contact or agency within the system would simplify the process and benefit joint working. “It’s almost like you need some kind of secretary to help you out. Somebody that is attached to your child from day one. So they are on your back, chasing these agencies for you. They are on the phone all the time sending emails and chasing to find out what’s happening” (Hurt 2019)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme

Table 18: Evidence profile: Theme 14. Diagnosis and identification of needs first

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 14.1: Diagnosis as the initial mediation resulted in delays in referrals, access to services, and receiving information and support					
5 (Boyce 2015, Cohen 2017, Council For Disabled Children 2018, Hurt 2019, McKean 2017)	3 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 survey with free text questions	Service users and providers reported service provisions for the child/young person as diagnosis driven, where referrals, access to services and information and support could be deferred until a diagnosis was reached. Service providers reported complexities and delays in making diagnoses due to conditions not being 'clear-cut' or carrying out watchful waiting in case the condition improves as the child/young person matures. The delays to diagnosis was reported as frustrating by some service providers and they expressed dissatisfaction that many of the steps in the pathway required a diagnosis, rather than an examination of the child/young person's needs. Service users reported that delays to diagnosis and subsequent lack of referral, absence of information and exclusion from services had a lasting and significant impact on their lives. "Many of the adopters really want to have a diagnosis of ADHD or autism because that makes sense to other teams and it makes sense to the medical profession and with that comes resources and at the end of the day all the parents want. It's not to assess their children to death so they can label them; it's so they can access resources and the resources that are attached to disabilities team are the only team that works long term" (Council For Disabled Children 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 14.2: Professionals were more committed to achieving multi-disciplinary working for complex diagnoses and had to rationalise making an independent diagnosis					
1 (Karim 2014)	1 qualitative study using semi-structured interviews	Service providers felt that complex diagnoses could be subjective in nature, particularly when differences in presentation of the child/young person may be apparent, dependent on the environment. In such cases, service providers felt it crucial to engage multi-disciplinary working to minimise or negate variations. Frustration due to the time needed to engage the necessary individuals for multi-disciplinary working was expressed by some service providers, and led to them making an independent diagnosis. Making an independent diagnosis was expressed as relatively rare, and service providers felt the need to justify this course of action against the time taken. "We don't do identification on our own we never do it on our own it's part of our service policy if we suspect that a child has an autistic spectrum disorder we must set up a multi-agency team . . ." (Karim 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				moderately rich data	
Sub-theme 14.3: Early identification of needs and making referrals before a diagnosis has been reached promotes early access to support					
3 (Boyce 2015, Fox 2017, Skipp 2016)	3 qualitative studies using semi-structured interviews	Service users and providers expressed that early identification of needs and referral can be helpful in securing the necessary service provisions for the child/young person. Service providers stated that they had discussed cases with other professionals prior to diagnosis. "We had a good paediatrician who told us about the need for an EHC very early on. She's been involved with our family from 3 weeks old and helped set everything up with the nursery, liaising with education about what [my child] would need before the EHC process started." (Skipp 2016)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 14.4: Service providers having knowledge of the child or young person's needs at the start of the process					
1 (Adams 2018)	1 qualitative study using interviews	Service users felt that when service providers had a good grasp of the child/young person and their needs prior to the initial meeting, the EHC process was improved and lead to the more efficient progression of care. "They all knew [child] really well and were saying the same things. They have all been involved in her care since she was a baby. They all came together quickly as they realised [child] needed help and we needed to do something." (Adams 2018)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 14.5: Parents identifying concerns and proactively seeking help					

Study information		Description of theme or finding	CERQual assessment of the evidence		
1 (Fox 2017)	1 qualitative study using semi-structured interviews	Parents expressed how they had identified that the child/young person was different, or not developing in the same way as other children/young people and had proactively sought advice and/or diagnosis from service providers. “I told my health visitor. I phoned my health visitor and told them, ‘My son is not sitting properly. He doesn’t talk. He’s different from my other kids. What’s going on?’” (Fox 2017)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

ADHD: attention deficit hyperactivity disorder; CASP: critical appraisal skills programme; EHC: education, health and care

Table 19: Evidence profile: Theme 15. Introduction of EHC plans

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 15.1: Lack of SMART outcomes in EHC plans makes it unclear what support will be needed and who is responsible for providing it					
3 (RIP STARS 2018, Sales 2018, Skipp 2016)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews; 1 qualitative study using interviews and group discussions	Service users and providers felt that EHCPs were lacking specific, measurable, attainable, relevant and timely (SMART) outcomes for the child/young person, leaving plans open to interpretation. Resulting inconsistency was noticed in EHCPs produced locally, or in other areas leaving service users feeling that their plan for the child/young person may lack quality or content. Both service users and providers felt that EHCPs lacked clarity in dictating responsibility and accountability for ensuring the delivery of service provisions. It was felt that the inclusion of SMART outcomes in EHCPs would enable service users and providers to hold services accountable and ensure all the necessary provisions are being delivered to support the child/young person. "There was no school named on the plan. We were told to sign it and then this would be sorted. I didn’t know that wasn’t right then. They said that’s what they do around here because this bit can take so long because it’s about sorting out the money. They said if I didn’t agree with anything I could take it to tribunal. It was so much to take in, I felt overwhelmed to be honest. There’s nothing SMART in it. It doesn’t set out what actual support he needs or from who. It doesn’t say he needs watching because he might run off. They’ve suggested	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
		two schools but I think we should wait and see if he’s diagnosed with autism before we say which is best. One school have said they want to assess him themselves. It seems like doing the plan hasn’t got us anywhere." (Skipp 2016)			
Sub-theme 15.2: Recognising the child or young persons’ strengths can lead to loss of service provision					
1 (RIP STARS 2018)	1 qualitative study using interviews and group discussions	Service providers felt concerned that a loss of service provision may occur as a result of recognising the strengths of the child/young person in their EHCP. "One of our children plays football, loves playing football, he said I go to play football every week so we put that in the plan. It then came to transport and they said no he doesn’t need transport because he goes to football every week…who’s reading that plan is external and how they interpret what’s been put in that, and if it’s misinterpreted as an able child when it’s actually not…I mean this child was attending a very specialist special needs football club, but because they hadn’t said that..." (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns The study offered some rich data	
Sub-theme 15.3: EHC plans are primarily concentrated around education and place less emphasis on health and social care					
4 (Boesley 2018, Palikara 2019, RIP STARS 2018, Thom 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and group discussions; 1 qualitative study using interviews; 1 study using a semi-structured survey	Service providers felt that EHC plans were driven by education and thus judged primarily as education documents. They felt that EHC plans gave a false impression of the involvement of health and social care services, and in practice contain a lack of consideration of these services. As a result, some service providers expressed that the replacement of statements of SEND with EHC plans did not feel like an improvement in service provisions. “The only mandatory part of [the EHC plan] is the “E” ... the “H” and “C” part of it haven’t risen to prominence in the way people hoped.” (Boesley 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 15.4: EHC plans have increased joint working and integration					

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
2 (Palikara 2019, Spivack 2014)	1 qualitative study using semi-structured interviews; 1 study using a semi-structured survey	Service providers felt that EHC plans facilitated the remit for more integrated and joined-up working across services. "They are more person-centred, the plan is very outcome-based and easy to be implemented across a range of client groups and those with differing needs. It gives a good opportunity for involvement of further agencies if identified at the time of transfer." (Spivack 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	

CASP: critical appraisal skills programme; EHC: education, health and care; EHCP: education, health and care plans; SEND: special educational needs and disabilities; SMART: specific, measurable, attainable, relevant and timely

Table 20: Evidence profile: Theme 16. Importance of key worker or lead professional

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 16.1: Continuity of key worker/lead professional is important for consistency and relationships					
2 (Children's Commissioner for Wales 2018, Thom 2015)	2 qualitative studies using interviews	Service users conveyed the importance of a continued key worker or lead professional to maintain consistency and a positive relationship between service users and providers. Service users who had a named accessible person expressed confidence in their ability to coordinate transition and felt positively, even when the reality of transition may be unsuccessful. Comparatively, service users where the support of the key worker or lead professional ended prematurely felt negatively. “Having one key worker for the whole process is positive, even if the transition isn’t 100% successful; having that continuity is positive and also extending the support past the age we do now.” (Children's Commissioner for Wales 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
				minor concerns	
Sub-theme 16.2: Key worker/lead professional is important for having a holistic view and coordinating services					
8 (Adams 2018, Brooks 2013, Children's Commissioner for Wales 2018, Council For Disabled Children 2018, Rodriguez 2014, Skipp 2016, Smith 2014, Taylor 2014)	2 qualitative studies using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups; 3 qualitative studies using interviews; 2 qualitative studies using focus groups	Service users and providers felt that a key worker or lead professional who was able to see the complete picture was important to effectively coordinate services and secure all of the support that the child/young person was entitled to. Service users expressed difficulty in navigating a complex service system and valued the support and guidance of a designated key worker/lead professional who was essentially on their side and able to effectively manage the system. Service providers expressed the need for a named person such as a key worker/lead professional to take responsibility to arrange and organise meetings and ensure service users accessed all of the available support. "She [CAMHS caseworker] came in when we were really at a low point, she got to know us really well as a family. She was a big driving force for getting it sorted, she would ring the local authority, she was constantly chasing professionals who hadn't done assessments." (Adams 2018)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
			Adequacy	None or very minor concerns	

CAMHS: child and adolescent mental health services; CASP: critical appraisal skills programme

Table 21: Evidence profile: Theme 17. Transition

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 17.1: Preparation for adulthood and decision making for transition is insufficient, inconsistent and left too late					
3 (Children's Commissioner for Wales 2018, McCartney 2017, RIP STARS 2018)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and group discussions; 1 qualitative study using focus groups	Service users and providers expressed negative experiences relating to the preparation for adulthood and decision making for transition. Even though planning took place over several years prior to the child/young/person reaching 18 years of age, it was felt there was a lack of overarching support or expertise and a lack of coordination between services leading to late decision making. Service users felt forced to act as go-betweens across services and expressed worry and uncertainty. Service providers felt that preparations for adulthood were left too late and that outcomes for children/young people were not sufficiently clear in EHCPs, particularly in the social care section which should contain provisions to support young people to work towards. “I have been incredibly proactive in planning transition, but despite this the results coming through transition have been very poor, he is in the last year of	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
		education (one term to go) and we STILL don't have a provision for education or social support agreed." (Children's Commissioner for Wales 2018)		minor concerns	
Sub-theme 17.2: Differences in thresholds for accessing adult services compared with child services					
1 (Children's Commissioner for Wales 2018)	1 qualitative study using focus groups	Service users experienced a difference in thresholds when transitioning from child to adult services. Accessibility to some services was described as dependent on access to other services such as attendance at a non-mainstream school and adult mental health services. Service users felt the child/young person needed to fit into diagnoses and thresholds for adult services to receive the necessary support. "'[He] attended mainstream school. There is a lot of unnecessary criteria for adult mental health services as regards to whether your child went to a mainstream school the authority doesn't regard them as having a learning disability even though they have. This then removes the right for them to see the disability team, so you see the regular team who can't help them because they have autism!! So you see no one as has happened to my son." (Children's Commissioner for Wales 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns The study offered some rich data	

CASP: critical appraisal skills programme: EHCP: education, health and care plan

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services 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 are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

No evidence was identified which was applicable to this review question.

Appendix I – Economic model

Economic model for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services 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 are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

Qualitative studies

Table 22: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Abbott, David, Carpenter, John, "The things that are inside of you are horrible": Children and young men with Duchenne muscular dystrophy talk about the impact of living with a long-term condition, Child Care in Practice, 21, 67-77, 2015	Themes: No qualitative data relevant to the views or experiences of joined-up care/services.
Abbott, David, Townsley, Ruth, Watson, Debby, Multi-agency working in services for disabled children: what impact does it have on professionals?, Health & social care in the community, 13, 155-63, 2005	Publication date: Pre 2013
Abbott, Mandy, Bernard, Paul, Forge, Jenny, Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences, Clinical Child Psychology & Psychiatry, 18, 370-382, 2013	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Adams, Sherri, Cohen, Eyal, Mahant, Sanjay, Friedman, Jeremy N., Macculloch, Radha, Nicholas, David B., Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study, BMC pediatrics, 13, 10, 2013	Country: Canada
Adams, Sherri, Nicholas, David, Mahant, Sanjay, Weiser, Natalie, Kanani, Ronik, Boydell, Katherine, Cohen, Eyal, Adams, Adams Antonelli Attride-Stirling Batalden Bensing Berry Blumberg Cohen Cohen Cohen Coleman Committee Corbin Dewan Feudtner Gavin Guest Izumi Kuo Kuo Lind Lion Richards Wagner Wagner Wirth Yurcek, Care maps and care plans for children with medical complexity, Child: Care, Health and Development, 45, 104-110, 2019	Country: Canada.
Almqvist, Anna-Lena, Lassinantti, Kitty, Social Work Practices for Young People with Complex Needs: An Integrative Review: C & A C & A, Child & Adolescent Social Work Journal, 35, 207-219, 2018	International Integrative review. Themes: No relevant qualitative data. References checked for relevant UK papers from 2013 for inclusion.
Alonso Soriano, Claudia, Hill, Elisabeth L., Crane, Laura, Surveying parental experiences of receiving a diagnosis of developmental coordination disorder (DCD), Research in Developmental Disabilities, 43, 11-20, 2015	Design: Survey with quantitative results only.
Alves, Joao Manuel Nunes de Oliveira, Amendoeira, Jose Joaquim Penedos, Charepe, Zaida Borges, The parental care partnership in the view of parents of children with special	Themes: No views or experiences relevant to joined up care/services.

Study	Reason for Exclusion
health needs, A parceria de cuidados pelo olhar dos pais de criancas com necessidades especiais de saude., 38, e2016-70, 2017	
Anderson, Kristy A., Sosnowy, Collette, Kuo, Alice A., Shattuck, Paul T., Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies, Pediatrics, 141, S318-S327, 2018	Study design: Scoping review
Anderson, Lori S., Mothers of children with special health care needs: documenting the experience of their children's care in the school setting, The Journal of school nursing : the official publication of the National Association of School Nurses, 25, 342-51, 2009	Country and publication date: US, pre 2013.
Arcuri, G. G., McMullan, A. E., Murray, A. E., Silver, L. K., Bergthorson, M., Dahan-Oliel, N., Coutinho, F., Perceptions of family-centred services in a paediatric rehabilitation programme: strengths and complexities from multiple stakeholders, Child: Care, Health & Development, 42, 195-202, 2016	Country: Canada.
Barnert, Elizabeth S., Coller, Ryan J., Nelson, Bergen B., Thompson, Lindsey R., Chan, Vincent, Padilla, Cesar, Klitzner, Thomas S., Szilagyi, Moira, Chung, Paul J., Experts' Perspectives Toward a Population Health Approach for Children With Medical Complexity, Academic pediatrics, 17, 672-677, 2017	Themes: No qualitative data for extraction.
Beresford, Bryony, et, al, Transition to adult services and adulthood for young people with autistic spectrum conditions: final report, 210p., 2013	Population: Population not relevant; majority of participants were diagnosed with Asperger's syndrome (62%) and high functioning autism (11%) thus classified as ineligible for adult social care services. Other diagnoses included Autism spectrum disorder (5%) and Autism (22%).
Beresford, Bryony, et, al, Transition to adult services and adulthood for young people with autistic spectrum conditions: summary, 4p., 2013	Study design: Summary document
Boshoff, Kobie, Gibbs, Deanna, Phillips, Rebecca L., Wiles, Louise, Porter, Lisa, A metaâ synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis, Health & Social Care in the Community, 27, e143-e157, 2019	International qualitative meta-synthesis. Themes: No relevant qualitative data. References checked for relevant UK papers from 2013 for inclusion.
Boyden, Paul, Muniz, Michelle, Laxton-Kane, Martha, Listening to the Views of Children with Learning Disabilities: An Evaluation of a Learning Disability CAMHS Service, Journal of Intellectual Disabilities, 17, 51-63, 2013	Themes: No qualitative data relevant to the views or experiences of joined-up care/services. Study reports on one learning disability-child and adolescent mental health service only.
Bradshaw, Paul, Hall, Julia, The impact of disability on the lives of young children: analysis of data from the Growing Up in Scotland study, 2013	Study type: Quantitative data only
Bray, L., Shaw, N. J., Snodin, J., Living and managing with the long-term implications of neonatal chronic lung disease: The experiences	Themes: No qualitative data relevant to the views and experiences of joined-up care/services.

Study	Reason for Exclusion
and perspectives of children and their parents, Heart and Lung: Journal of Acute and Critical Care, 44, 512-516, 2015	
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	US and Australia Integrative review. No UK studies included.
Bromley, Jo, Hare, Dougal Julian, Davison, Kerry, Emerson, Eric, Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services, Autism : the international journal of research and practice, 8, 409-23, 2004	Design and publication date: Interview with quantitative data only, pre 2013
Campos, S. R., Soria, E. L., Liz, A. A., PRINCEP program: clinical program for specialized and integrated care of paediatric patients with complex chronic conditions, International Journal of Integrated Care, 16, 2016	Conference abstract
Chapman, M., Lacey, H., Jervis, N., Improving services for people with learning disabilities and dementia: Findings from a service evaluation exploring the perspectives of health and social care professionals, BRITISH JOURNAL OF LEARNING DISABILITIES, 46, 33-44, 2018	Population: Learning disabilities and dementia. Age unclear; study refers to a population aged 25 years plus when dementia screening, takes place.
Collins, Michelle, et, al, A break from caring for a disabled child: parent perceptions of the uses and benefits of short break provision in England, BRITISH JOURNAL OF SOCIAL WORK, 44, 1180-1196, 2014	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Commission for Social Care Inspection Commission for Healthcare, Audit, Inspection Mental Health Act, Commission, Commissioning services and support for people with learning disabilities and complex needs: National report of joint review, 2009	Design: National report. No qualitative data. Published pre 2013.
Crawford, T., Simonoff, E., Parental views about services for children attending schools for the emotionally and behaviourally disturbed (EBD): a qualitative analysis, Child: Care, Health & Development, 29, 481-91, 2003	Population: Does not meet criteria; emotionally and behaviourally disturbed children without comorbidities. Published pre 2013.
Danvers, Lesley, Freshwater, Dawn, Cheater, Francine, Wilson, Andrew, Providing a seamless service for children with life-limiting illness: experiences and recommendations of professional staff at the Diana Princess of Wales Children's Community Service, Journal of clinical nursing, 12, 351-9, 2003	Publication date: study published pre 2013.
Davies, Karen, Tensions in commissioning : services for children's speech, language and communication needs in one English region, Journal of Health Services, Research and Policy, 17, 2013	Study design and themes: Narrative review of case studies. No relevant qualitative data for extraction.
Dockrell, Julie E., Lindsay, Geoff, Letchford, Becky, Mackie, Clare, Educational provision for children with specific speech and language difficulties: perspectives of speech and language	Population: Does not meet criteria; children with specific speech and language difficulties without severity/complexity or comorbidities. Published pre 2013.

Study	Reason for Exclusion
therapy service managers, International journal of language & communication disorders, 41, 423-40, 2006	
Duff, M., Giles, B., Making the best of things: Raising a child with complex health needs that include respiratory technology dependence, Chest, 144, 2013	Publication type: Abstract
Duff, M., Giles, B., A constricted life: Growing up with complex health needs that include respiratory technology dependence, Chest, 144, 2013	Publication type: Abstract
Elder, Jennifer Harrison, Brasher, Susan, Alexander, Beverly, Identifying the Barriers to Early Diagnosis and Treatment in Underserved Individuals with Autism Spectrum Disorders (ASD) and Their Families: A Qualitative Study, Issues in mental health nursing, 37, 412-20, 2016	Themes: No views or experiences relevant to joined up care/services.
Feinberg, E., Silverstein, M., Ferreira-Cesar, Z., Integrating mental health services for mothers of children with autism, Psychiatric Services, 64, 930, 2013	Study design: Commentary/report
Fellin, Melissa, Desmarais, Chantal, Lindsay, Sally, An examination of clinicians' experiences of collaborative culturally competent service delivery to immigrant families raising a child with a physical disability, Disability and rehabilitation, 37, 1961-9, 2015	Country: Canada.
Flynn, A. P., Carter, B., Bray, L., Donne, A. J., Parents' experiences and views of caring for a child with a tracheostomy: A literature review, International Journal of Pediatric Otorhinolaryngology, 77, 1630-1634, 2013	International literature review. Themes: No relevant qualitative data for extraction. Included list checked for relevant UK studies from 2013.
Fortuna, Ron, The social and emotional functioning of students with an autistic spectrum disorder during the transition between primary and secondary schools, Support for Learning, 29, 177-191, 2014	Themes: No qualitative data relevant to views or experiences of joined-up care/services.
Fraser, Lorna, et, al, Children in Scotland requiring palliative care: identifying numbers and needs (The ChiSP Study), 59, 2015	Systematic Review Themes: No relevant qualitative data for extraction. Included studies list checked for relevant UK papers from 2013.
French, B., Sayal, K., Daley, D., Barriers and facilitators to understanding of ADHD in primary care: a mixed-method systematic review, European Child & Adolescent Psychiatry, 28, 1037-1064, 2019	International Systematic review. Themes: No relevant qualitative data for extraction. Included list checked for relevant UK papers from 2013.
Gaintza, Z., Ozerinjauregi, N., Arostegui, I., Educational inclusion of students with rare diseases: Schooling students with spina bifida, BRITISH JOURNAL OF LEARNING DISABILITIES, 46, 250-257, 2018	Themes: No relevant qualitative data on the views or experiences of joined up care/services.
Gallagher, A. L., Murphy, C. A., Conway, P. F., Perry, A., Engaging multiple stakeholders to improve speech and language therapy services in schools: an appreciative inquiry-based study, BMC Health Services Research, 19, 226, 2019	Country: Ireland.

Study	Reason for Exclusion
Gallagher, Aoife L., Murphy, Carol-Anne, Conway, Paul, Perry, Alison, Consequential differences in perspectives and practices concerning children with developmental language disorders: an integrative review, International journal of language & communication disorders, 54, 529-552, 2019	International integrative review. Themes: No relevant qualitative data for extraction. Included list checked for relevant UK papers from 2013.
Gaona, Carolina, Palikara, Olympia, Castro, Susana, 'I'm ready for a new chapter': The voices of young people with autism spectrum disorder in transition to postâ 16 education and employment, British Educational Research Journal, 45, 340-355, 2019	Themes: No qualitative data relevant to the view and experiences of joined up care/services.
Gauthier-Boudreault, C., Gallagher, F., Couture, M., How to plan transition to adulthood of youth with profound intellectual disability: Professionals' opinions, Journal of Intellectual Disability Research, 63, 818, 2019	Conference abstract
Gellasch, Patricia, Developmental Screening in the Primary Care Setting: A Qualitative Integrative Review for Nurses, Journal of Pediatric Nursing, 31, 159-171, 2016	International integrative review. Population: Children with developmental delays. Included studies list checked for relevant UK studies from 2013.
Geuze, Liesbeth, Goossensen, Anne, Parents caring for children with normal life span threatening disabilities: a narrative review of literature, Scandinavian Journal of Caring Sciences, 33, 279-297, 2019	International narrative review. Themes: No relevant qualitative data for extraction. Included list checked for relevant UK studies from 2013.
Hall, C. L., Newell, K., Taylor, J., Sayal, K., Hollis, C., Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: A national survey of mental health trusts in England, Journal of Psychopharmacology, 29, 39-42, 2015	Study design: Survey with quantitative data only.
Hebert, Michele L. J., Kehayia, Eva, Prelock, Patricia, Wood-Dauphinee, Sharon, Snider, Laurie, Does occupational therapy play a role for communication in children with autism spectrum disorders?, International journal of speech-language pathology, 16, 594-602, 2014	Country: Canada and US.
Heer, K., Rose, J., Larkin, M., The Challenges of Providing Culturally Competent Care Within a Disability Focused Team: A Phenomenological Exploration of Staff Experiences, Journal of Transcultural Nursing, 27, 109-116, 2016	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Heer, Kujit, Larkin, Michael, Rose, John, The experiences of British South Asian carers caring for a child with developmental disabilities in the UK, Tizard Learning Disability Review, 20, 228-238, 2015	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Hillis, Rowan, Brenner, Maria, Larkin, Philip J., Cawley, Des, Connolly, Michael, The Role of Care Coordinator for Children with Complex Care Needs: A Systematic Review, International journal of integrated care, 16, 12, 2016	International Systematic Review. Themes: No quantitative data relevant to the views or experiences of joined up care/services. Included list checked for relevant UK studies from 2013.
Hirano, Kara A., Rowe, Dawn, Lindstrom, Lauren, Chan, Paula, Systemic Barriers to	International meta-synthesis. Included studies checked for relevant UK studies from 2013.

Study	Reason for Exclusion
Family Involvement in Transition Planning for Youth with Disabilities: A Qualitative Metasynthesis, Journal of Child and Family Studies, 27, 3440-3456, 2018	
Hiremath, Girish, Kodroff, Ellyn, Strobel, Mary J., Scott, Melissa, Book, Wendy, Reidy, Cathy, Kyle, Shay, Mack, Denise, Sable, Kathleen, Abonia, Pablo, Spergel, Jonathan, Gupta, Sandeep K., Furuta, T. Glenn, Rothenberg, Marc E., Dellon, Evan S., Individuals affected by eosinophilic gastrointestinal disorders have complex unmet needs and frequently experience unique barriers to care, Clinics and research in hepatology and gastroenterology, 42, 483-493, 2018	Study design: Survey with quantitative data only.
Hopper, Amy, Dokken, Deborah, Ahmann, Elizabeth, Transitioning from pediatric to adult health care: the experience of patients and families, Pediatric nursing, 40, 249-52, 2014	Design: Case study
Hughes, Jane, Davies, Sue, Chester, Helen, Clarkson, Paul, Stewart, Karen, Challis, David, Learning disability services: user views on transition planning, Tizard Learning Disability Review, 23, 150-158, 2018	Population: Indirect - only 1/3 aged under 25 years
Hurrell, C., Batchelor, M., Maguire, S., Designing the optimal model for transition from child to adult services for young people with disabilities and/or developmental difficulties, Archives of Disease in Childhood, 104, A196, 2019	Conference abstract
Hutchings, Judy, Williams, Margiad Elen, Joined-up thinking, joined-up services, exploring coalface challenges for making services work for families with complex needs, Journal of Children's Services, 9, 31-41, 2014	Design: No qualitative data presented. Authors opinion and experience of services
In, Control, Report on the use of the Personal Outcomes Evaluation Tool (POET) for children with education health and care plans, 82, 2016	Design: Survey reporting quantitative data only.
Jacobs, Paula, MacMahon, Kenneth, Quayle, Ethel, Transition from school to adult services for young people with severe or profound intellectual disability: a systematic review utilizing framework synthesis, Journal of Applied Research in Intellectual Disabilities, 31, 962-982, 2018	International systematic review. Themes: No relevant qualitative data for extraction. Included list checked for relevant UK studies from 2013.
Kerin, Lorna, McNicholas, Fiona, Lawlor, Aine, Hearing the lived experience of young women with a rare genetic disorder 22q11.2DS regarding integrated care, International Journal of Integrated Care (IJIC), 17, 1-2, 2017	Conference abstract
King, Gillian A., Esses, Victoria M., Solomon, Nassisse, Akamatsu, Albright Ali Bailey Barnes Beresford Blacher Blair Blakemore Bronfenbrenner Brookins Bruce Chamba Cho Clarke Conger Crowley Darling Dilworth-Anderson Dilworth-Anderson Eifert Esses Esses Fiene Fong Forsyth Franck Gallegos Gallimore	Publication type: Book chapter

Study	Reason for Exclusion
Gannotti Groce Guendelman Harris Harris Hek Hernandez Ho Huer Ingstad James Jegatheesan Katbamna King King King King King King King King King King Kinzie Kummerer Lai Ledere Lerner Ma Martin Mayer McDonald McNaughton McWilliam Michelson Missiuna Moore Neufeld Newacheck Newacheck Newacheck Omidvar Overton Parette Park Povlsen Priestley Raina Rhoades Roberts Roberts Rogers-Dulan Rosenbaum Roush Rutter Schuman Shirk Silver Skrinda Sloper Sloper Smith Steven Stewart Su Sumsion Thorp Wampold Weisz Welterlin Wright Yu, Grigorenko, Elena L., Immigrant and refugee families raising children with disabling conditions: A review of the international literature on service access, service utilization, and service care experiences, U.S. immigration and education: Cultural and policy issues across the lifespan., 179-206, 2013	
Kirk, Susan, Perceptions of effective self-care support for children and young people with long-term conditions, Journal of Clinical Nursing, 21, 2013	Population: Participants with long-term conditions and no mention of severity or complexity.
Kruijsen-Terpstra, A. J., Ketelaar, M., Boeije, H., Jongmans, M. J., Gorter, J. W., Verheijden, J., Lindeman, E., Verschuren, O., Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review, Child: Care, Health & Development, 40, 787-96, 2014	Review. Included list checked for relevant studies, all pre 2013
Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., Rosenbaum, P., Factors affecting family-centred service delivery for children with disabilities, Child: care, health and development, 29, 357-66, 2003	Design: Survey with quantitative data only
Lenehan, Christine, Geraghty, Mark, Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges, 46, 2017	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Lindsay, Geoff, Ricketts, Jessie, Peacey, Lindy V., Dockrell, Julie E., Charman, Tony, Meeting the Educational and Social Needs of Children with Language Impairment or Autism Spectrum Disorder: The Parents' Perspectives, International Journal of Language & Communication Disorders, 51, 495-507, 2016	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Lindsay, S., Child and youth experiences and perspectives of cerebral palsy: A qualitative systematic review, Child: Care, Health and Development, 42, 153-175, 2016	Review. Included list checked for relevant studies, the 3 UK post-2013 papers do not meet inclusion criteria
Lindsay, Sally, Duncanson, Michelle, Niles-Campbell, Nadia, McDougall, Carolyn, Diederichs, Sara, Menna-Dack, Dolly, Applying an ecological framework to understand transition pathways to post-secondary education for youth with physical disabilities, Disability and	Country: Canada

Study	Reason for Exclusion
rehabilitation, 40, 277-286, 2018	
Macdonald, Elspeth, Mohay, Heather, Sorensen, Debra, Alcorn, Neil, McDermott, Brett, Lee, Erica, Members of the Mater, Cymhs Infant Mental Health Steering Committee, Current delivery of infant mental health services: are infant mental health needs being met?, Australasian psychiatry : bulletin of Royal Australian and New Zealand College of Psychiatrists, 13, 393-8, 2005	Population: Indirect - service not specific to children and young people with disabilities and severe complex needs
Macintyre, Gillian, The potential for inclusion: young people with learning disabilities experiences of social inclusion as they make the transition from childhood to adulthood, Journal of Youth Studies, 17, 857-871, 2014	Themes: No views or experiences relevant to joined up care/services
Maniatopoulos, Gregory, Le Couteur, Ann, Vale, Luke, Colver, Allan, Falling through the gaps: exploring the role of integrated commissioning in improving transition from children's to adults' services for young people with long-term health conditions in England, Journal of health services research & policy, 23, 107-115, 2018	Population: Insufficient information provided to determine if it meets inclusion criteria
Mansell, Ian, Wilson, Christine, 'It terrifies me, the thought of the future': Listening to the current concerns of informal carers of people with a learning disability, Journal of Intellectual Disabilities, 14, 21-31, 2010	Population: Indirect - includes adults >25 years old
Marly Akemi Shiroma, Nepomuceno, Roseney, Bellato, Laura Filomena Santos de, Araújo, Leandro Felipe, Mufato, Ways of weaving networks for the care by the family that is experiencing the chronic condition by adrenoleukodystrophy, Ciencia, Cuidado e Saude, 11, 156-165, 2012	Language: Non-English
Matsushima, Kanae, Kato, Toshihiro, Research on Positive Indicators for Teacher-Child Relationship in Children with Intellectual Disabilities, Occupational therapy international, 22, 206-16, 2015	Themes: No views or experiences relevant to joined up care/services
McConkey, R., Adams, L., Matching short break services for children with learning disabilities to family needs and preferences, Child: care, health and development, 26, 429-444, 2000	Design: Survey with quantitative data only
McKay, Sandra, Immigrant Children With Special Health Care Needs: A Review, Current problems in pediatric and adolescent health care, 49, 45-49, 2019	Insufficient presentation of included studies and qualitative results
McKevitt, Christopher, et, al, Seeking normality: parents' experiences of childhood stroke, Child: Care, 45, 89-95, 2019	Population: Indirect - 42% described as having 'no or mild deficit'
McLennan, J. D., Perry, R., Multi-informant perspectives on a pilot telepsychiatry behavioral consultation service to schools, Journal of the American Academy of Child and Adolescent Psychiatry, 55, S170, 2016	Conference abstract
McNeilly, P., Macdonald, G., Kelly, B., The participation of parents of disabled children and	Themes: No views or experiences relevant to

Study	Reason for Exclusion
young people in health and social care decisions, Child: care, health and development, 43, 839-846, 2017	joined up care/services
McNeilly, Patricia, Macdonald, Geraldine, Kelly, Berni, The participation of disabled children and young people: A social justice perspective, Child Care in Practice, 21, 266-286, 2015	Themes: No views or experiences relevant to joined up care/services
Meirinhos, Ana Rodríguez, Antolín-Suárez, Lucía, Oliva, Alfredo, Service needs of families of adolescents with mental health difficulties, International Journal of Integrated Care (IJIC), 16, 1-2, 2016	Conference abstract
Mimmo, L., Harrison, R., Time to care: A meta narrative review of the parental experience of hospitalisation with a child with intellectual disability, International Journal for Quality in Health Care, 30, 53, 2018	Conference abstract
Moss, Aidan, Miller, Robin, Models of community based integrated care for people with a learning disability and/or autism: evaluation findings from a national implementation programme, International Journal of Integrated Care (IJIC), 19, 1-2, 2019	Conference abstract
National, Voices, Integrated care: what do patients, service users and carers want?, 13p., 2013	Insufficient presentation of qualitative results. It is unclear if statements presented are the results of qualitative investigations or just consensus/author opinion
Neves, E. T., Silveira, A., Arrue, A. M., Pieszak, G. M., Zamberlan, K. C., Santos, R. P., Network of care of children with special health care needs, Texto e Contexto Enfermagem, 24, 399-406, 2015	Language: Non-English
Newlove-Delgado, Tamsin, Ford, Tamsin J., Stein, Ken, Garside, Ruth, 'You're 18 Now, Goodbye': The Experiences of Young People with Attention Deficit Hyperactivity Disorder of The Transition from Child to Adult Services, Emotional & Behavioural Difficulties, 23, 296-309, 2018	Themes: No views or experiences relevant to joined up care/services
Ooi, K. L., Ong, Y. S., Jacob, S. A., Khan, T. M., A meta-synthesis on parenting a child with autism, Neuropsychiatric Disease and Treatment, 12, 745-762, 2016	Review. Included list checked for relevant studies, the 1 UK post-2013 paper does not meet inclusion criteria
O'Reilly, M., Vostanis, P., Taylor, H., Day, C., Street, C., Wolpert, M., Service user perspectives of multiagency working: A qualitative study with children with educational and mental health difficulties and their parents, Child and Adolescent Mental Health, 18, 202-209, 2013	Population: Children with educational and mental health difficulties with no mention of severity or complexity of needs.
Pellicano, Elizabeth, et, al, My life at school: understanding the experiences of children and young people with special educational needs in residential special schools, 78, xvi, 2014	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Rafferty, Katherine A., Sullivan, Shelbie L., "You Know the Medicine, I Know My Kid": How Parents Advocate for Their Children Living With	Country: US

Study	Reason for Exclusion
Complex Chronic Conditions, Health communication, 32, 1151-1160, 2017	
Raghavan, R., Pawson, N., Small, N., Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity, Journal of Intellectual Disability Research, 57, 936-46, 2013	Themes: No views or experiences relevant to joined up care/services
Regulation,, Quality Improvement, Authority, Review of brain injury services in Northern Ireland, 61, 2015	Insufficient presentation of qualitative results
Richardson, Michelle, Moore, Darren A., Gwernan-Jones, Ruth, Thompson-Coon, Jo, Ukoumunne, Obioha, Rogers, Morwenna, Whear, Rebecca, Newlove-Delgado, Tamsin V., Logan, Stuart, Morris, Christopher, Taylor, Eric, Cooper, Paul, Stein, Ken, Garside, Ruth, Ford, Tamsin J., Non-pharmacological interventions for attention-deficit/hyperactivity disorder (ADHD) delivered in school settings: systematic reviews of quantitative and qualitative research, Health Technology Assessment, 19, 1-470, 2015	Review. Included list checked for relevant studies, all studies are pre-2013
Rintell, D., Cross, T., Shanks, A., Fico, C., Duffy, L., Camposano, S., Chitnis, T., Parents' experience of pediatric multiple sclerosis, Multiple Sclerosis, 20, 66, 2014	Conference abstract
Rix, Jonathan, Sheehy, Kieron, Fletcher-Campbell, Felicity, Crisp, Martin, Harper, Amanda, Exploring Provision for Children Identified with Special Educational Needs: An International Review of Policy and Practice, European Journal of Special Needs Education, 28, 375-391, 2013	Review. Included list checked for relevant studies, all studies are pre-2013
Roberts, H., Ingold, A., Liabo, K., Manzotti, G., Reeves, D., Bradby, H., Moving on: Transitions out of care for young people with learning disabilities in England and Sweden, BRITISH JOURNAL OF LEARNING DISABILITIES, 46, 54-63, 2018	Themes: No views or experiences relevant to joined up care/services
Rome, Aidan, et, al, Exploring transitions with disabled young people: our experiences, our rights and our views, Child Care in Practice, 21, 287-294, 2015	Themes: No views or experiences relevant to joined up care/services
Ruble, K., Jacobson, L., Pare-Blagoev, J., Thinking outside the clinic: Returning to school after diagnosis with childhood cancer, Psycho-Oncology, 27, 79, 2018	Conference abstract
Salmon, Jenny, Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences, The Canadian journal of clinical pharmacology = Journal canadien de pharmacologie clinique, 15, e191-213, 2008	Country: New Zealand
Samarasinghe, Shane, Now is the time: supporting disabled children and their families, 20, 2018	Themes: No views or experiences relevant to joined up care/services

Study	Reason for Exclusion
Scott, Lee, SEND: The schools and colleges experience. A report to the Secretary of State for Education by Lee Scott, 13, 2016	Insufficient presentation of qualitative results
Sezgin, Emre, Weiler, Monica, Weiler, Anthony, Lin, Simon, Proposing an Ecosystem of Digital Health Solutions for Teens With Chronic Conditions Transitioning to Self-Management and Independence: Exploratory Qualitative Study, Journal of medical Internet research, 20, e10285, 2018	Population: Indirect - included conditions not limited to disabilities with severe complex needs
Sheng-li, Wang, Social Work Involved in Sensory Integrative Dysfunction Children Based on Systematic Theory, Jiangnan Daxue Xuebao/Journal of Jiangnan University: Humanities & Social Sciences Edition, 9, 55-60, 2010	Setting: Non-OECD country (China)
Simpson, W., Brown, C., Nisbet, N., Metcalfe, R., Claisse, Z., Watson, L., A new model of autism spectrum disorder assessment and diagnosis by multiagency community-based teams in primary schools, Child and Adolescent Mental Health, 18, 187-190, 2013	Insufficient presentation of qualitative results
tang, Hsin-Yi, Thomas, Emily, Martinson, Jennifer, A Collaborative Approach for Attention Deficit and Hyperactivity Disorder, Communicating Nursing Research, 46, 304-304, 2013	Abstract only
Taylor, J., Stalker, K., Stewart, A., Disabled Children and the Child Protection System: A Cause for Concern, Child Abuse Review, 25, 60-73, 2016	Reports on the same population and themes as Taylor 2014. Additional themes are included in Taylor 2014.
Thompson, A., Senders, A., Borgatti, A., Bodden, K., Usher, C., Seibel, C., Shinto, L., On 'Dignity' and Finding a 'New Path': A qualitative analysis of participant experiences in the M3 program, Early Intervention in Psychiatry, 10, 195, 2016	Conference abstract
Townsley, Ruth, Abbott, David, Watson, Debby, Making a difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them, 2004	Publication type: Book
Trembath, David, Starr, Elizabeth, Supporting children with social communication and learning disabilities and their parents during the transition to school, Journal of Clinical Practice in Speech-Language Pathology, 19, 137-141, 2017	Country: Australia
Trotman, D., Enow, L., Tucker, S., Young people and alternative provision: Perspectives from participatory-collaborative evaluations in three UK local authorities, British Educational Research Journal, 45, 219-237, 2019	Population: Insufficient description of population but appears to be alternative provision due to behavioural issues and not necessarily disabilities with severe complex needs
Van Cleave, Jeanne, Boudreau, Alexy Arauz, McAllister, Jeanne, Cooley, W. Carl, Maxwell, Andrea, Kuhlthau, Karen, Care coordination over time in medical homes for children with special health care needs, Pediatrics, 135,	Country: USA

Study	Reason for Exclusion
1018-26, 2015	
Webb, Mary Anne, et, al, Living with adversity: a qualitative study of families with multiple and complex needs, 94, 2014	Population: Not children and young people with disabilities and severe complex needs. Multiple and complex needs are referring to poverty, domestic violence, parental illness etc.
Welch, Vicki, Collins, Michelle, Hatton, Chris, Emerson, Eric, Robertson, Janet, Wells, Emma, Langer, Susanne, Short Break and Respite Services for Disabled Children in England: Comparing Children's and Parents' Perspectives of Their Impact on Children, Children & Society, 28, 478-494, 2014	Themes: No views or experiences relevant to joined up care/services
Whicker, John J., Munoz, Karen, Nelson, Lauri H., Parent challenges, perspectives and experiences caring for children who are deaf or hard-of-hearing with other disabilities: a comprehensive review, International journal of audiology, 58, 5-11, 2019	Review. Included list checked for relevant studies, UK post-2013 studies either already included or do not meet inclusion criteria
Whitaker, E. M., Personalisation in children's social work: From family support to "the child's budget", JOURNAL OF INTEGRATED CARE, 23, 277-286, 2015	Themes: No views or experiences relevant to joined up care/services.
White, S., Spencer, S., A school-commissioned model of speech and language therapy, Child Language Teaching & Therapy, 34, 141-153, 2018	Population: Mainstream primary schools - motivation for commissioning SLT appears to be high levels of socially disadvantaged children (receiving 'Pupil Premium' funding) as opposed to children with disabilities and severe complex needs
Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., Trollor, J., Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review, Journal of Mental Health Research in Intellectual Disabilities, 11, 69-102, 2018	Review. Included list checked for relevant studies, UK post-2013 studies are not limited to children/young people
Zhou, H. Q., Roberts, P., Dhaliwal, S., Della, P., Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review, Journal of Clinical Nursing, 25, 3113-3130, 2016	Review. Included list checked for relevant studies, the 2 UK post-2013 studies do not meet inclusion criteria

OECD: Organisation for Economic Co-operation and Development; SLT: speech and language therapy
Literature search and study selection undertaken for all qualitative questions simultaneously. Therefore, studies listed in this table are those that are excluded from all 3 reviews

Economic studies

No economic evidence was identified for this review. See Supplement B for further information.

Appendix K – Research recommendations – full details

Research recommendations for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

No research recommendations were made for this review question.

Appendix L – Qualitative thematic maps

Qualitative thematic maps for review question: What are the barriers and facilitators perceived or experienced by users, providers and practitioners of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

Figure 3: Sub-theme map for relationships between service providers

Figure 4: Sub-theme map for communication and support

Figure 5: Sub-theme map for service users' involvement and relationships with service providers

Figure 6: Sub-theme map for attitudes and social stigma about service provisions

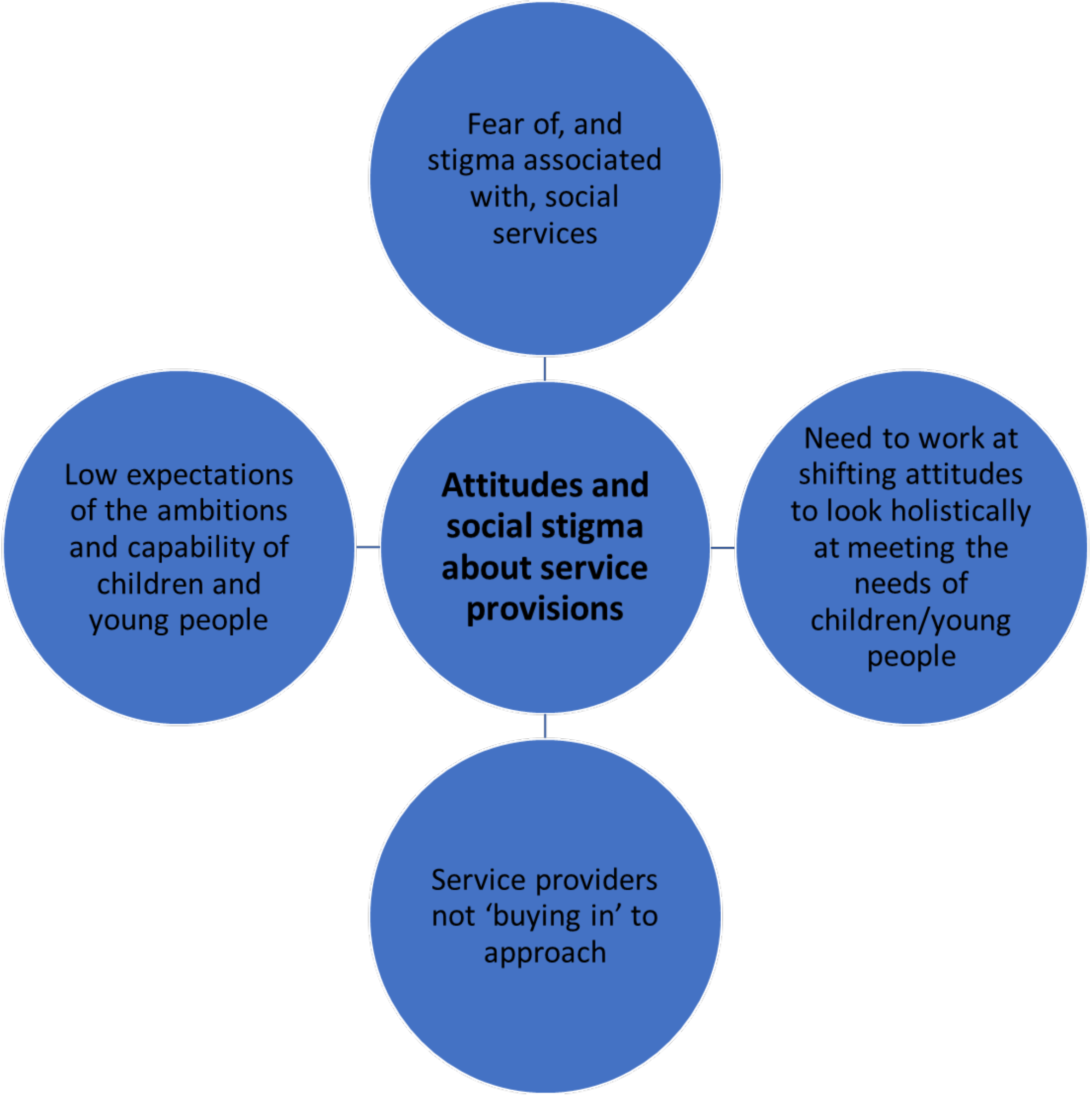


Figure 7: Sub-theme map for funding and resources

Figure 8: Sub-theme map for organisation of services

Figure 9: Sub-theme map for information sharing

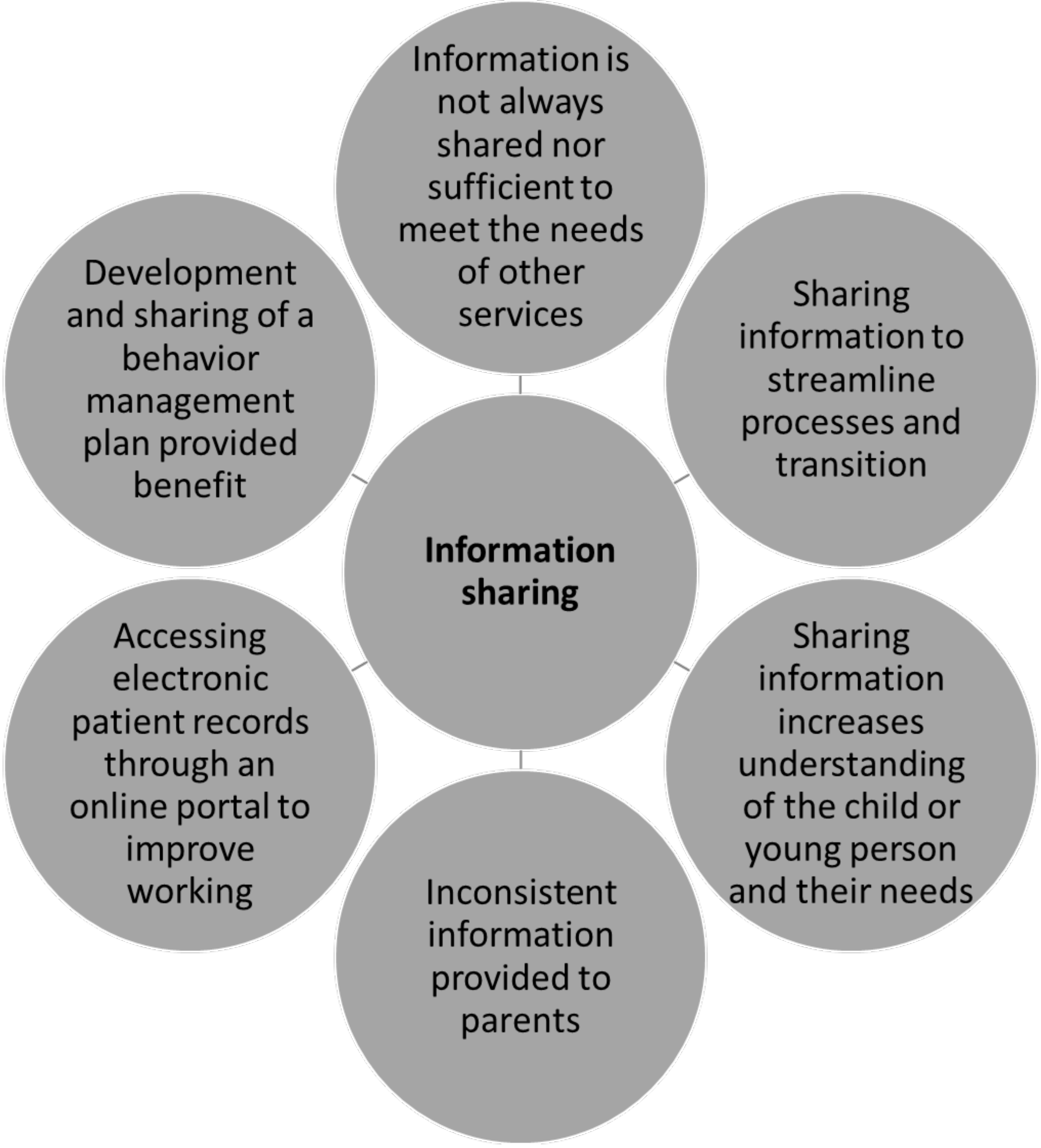


Figure 10: Sub-theme map for long waiting times for support

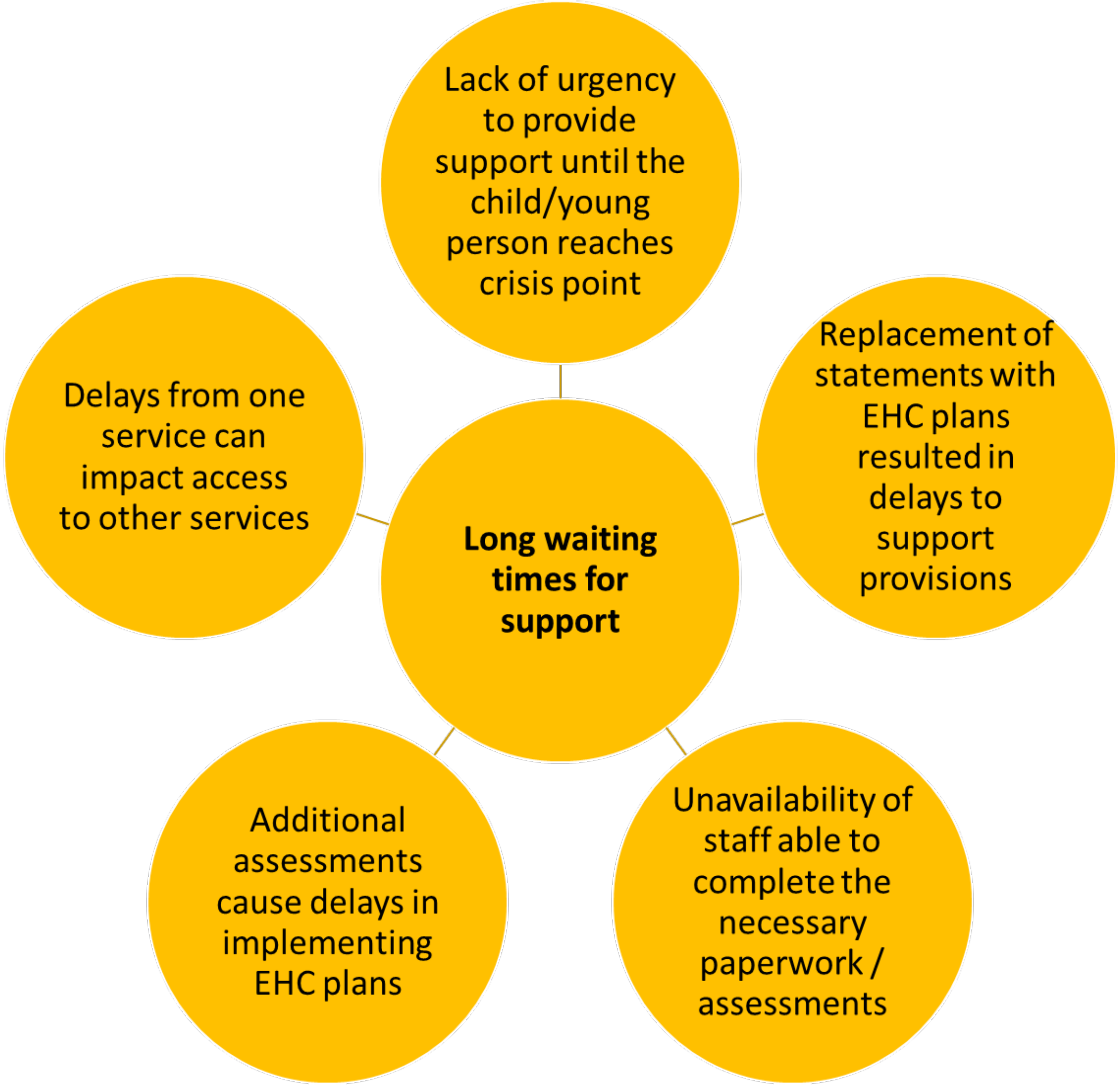
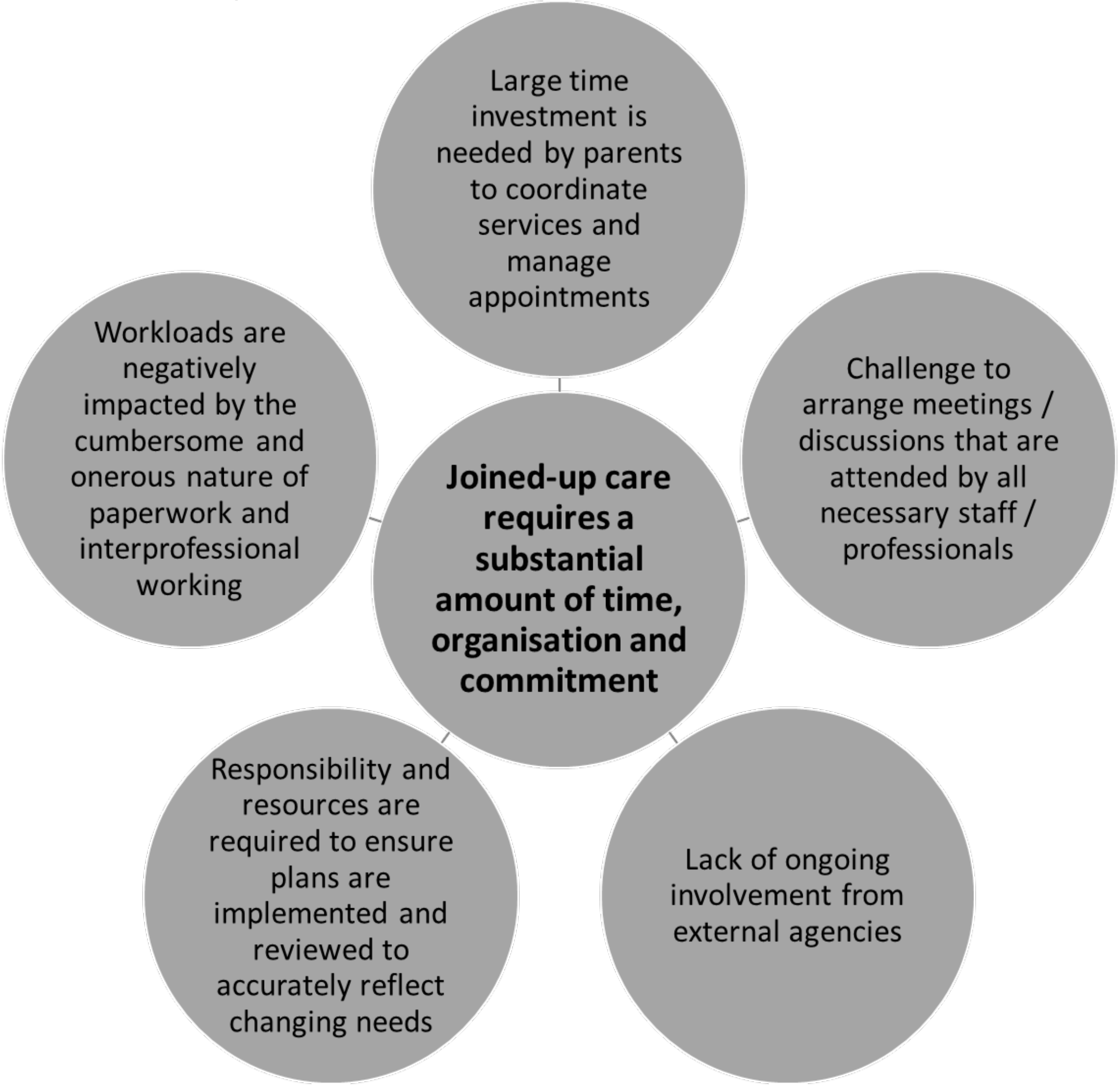


Figure 11: Sub-theme map for difficulty in obtaining an EHC plan (or replacing a statement of SEN with an EHC plan)

Figure 12: Sub-theme map for an imbalanced distribution in the amount of support provided to children/young people

Figure 13: Sub-theme map for professional and staff knowledge and training

Figure 14: Sub-theme map for joined-up care requires a substantial amount of time, organisation and commitment



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2 **Figure 15: Sub-theme map for working across multiple services**

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Figure 16: Sub-theme map for diagnosis and identification of needs first

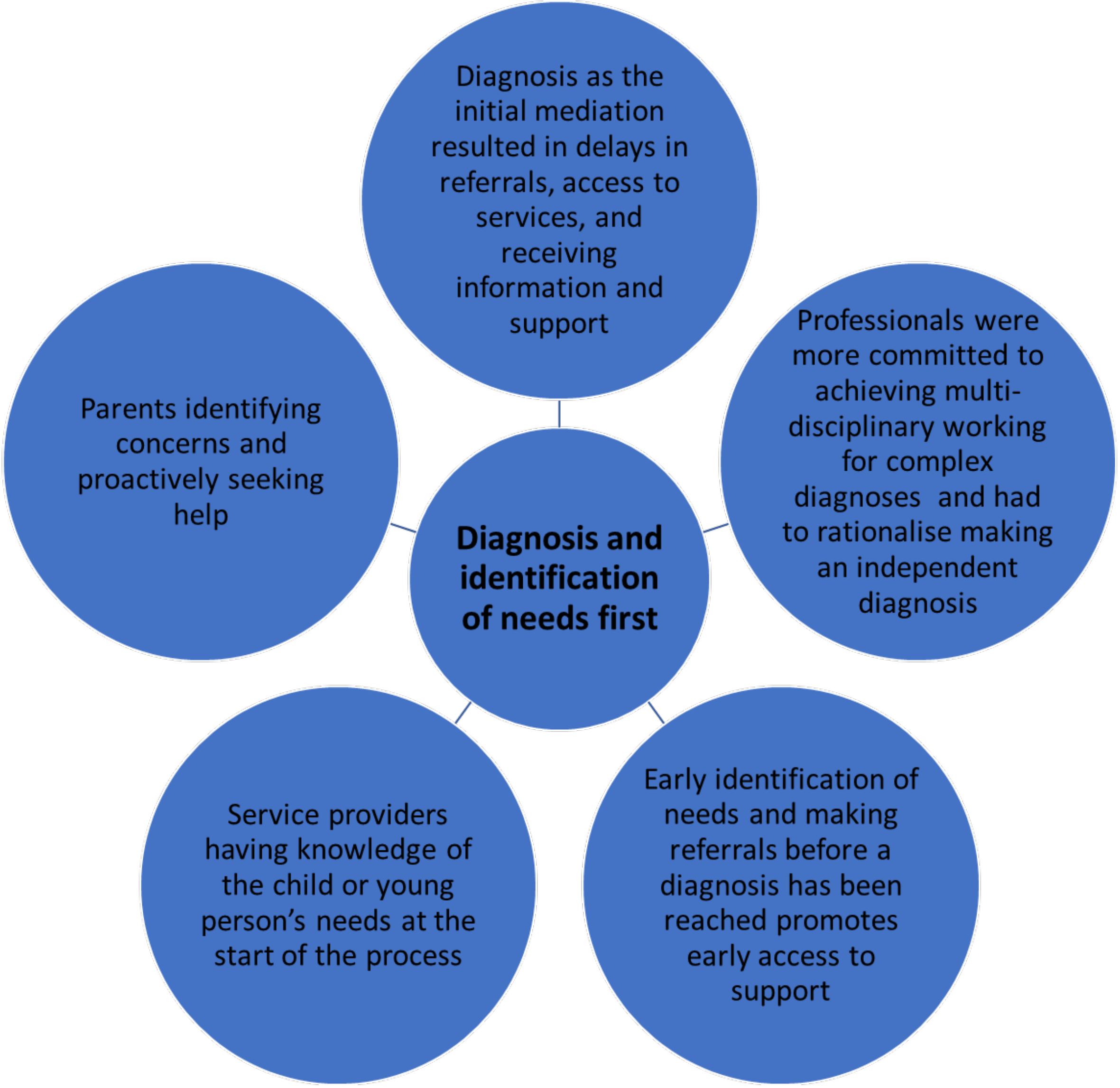

Figure 17: Sub-theme map for introduction of EHC plans

Figure 18: Sub-theme map for importance of key worker or lead professional

Figure 19: Sub-theme map for transition