National Institute for Health and Care Excellence

Draft for consultation

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

[A] Evidence review for views and experiences of service users

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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Views and experiences of service users

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.4, 1.1.9, 1.1.11, 1.1.15 - 1.1.18, 1.1.30, 1.1.34, 1.3.5, 1.3.6, 1.4.2, 1.4.16, 1.5.1, 1.5.4, 1.6.4, 1.8.10, 1.8.12, 1.8.13, 1.14.3, 1.15.29, 1.17.6, 1.17.8. Other evidence supporting these recommendations can be found in the evidence reviews on Barriers and facilitators of joined-up care (evidence report K), Views and experiences of service providers (evidence report M).

Review question

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?

Introduction

This review will examine the views and experiences of disabled children and young people with severe complex needs, their families and carers of joined-up care between health, social care and education services. This will be used to identity themes about the acceptability and accessibility of joined up services and the values and preferences of service users.

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 (PICO table)

Population	• Disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support • 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

Phenomenon of interest	The views and experiences of disabled children and young people with severe complex needs, their families and carers, using or eligible to use all three services (health, social care and education) on joined-up care between these services for disabled children and young people with severe complex needs. Potential themes include: • Shared decision making, person centred care and support, coproduction • Transition between services • Invisible conditions or disabilities • Carers who are themselves disabled • Ability to access the right provision for need, and the timeliness of that • Number of appointments • Tribunals and legal opinions; health care complaints • Discrimination or exclusion from integrated services by service providers • Out of area placements – residential schools (could be positive or negative) • Communication between professionals • Usefulness and impact of EHCP on provision • Negative experiences of joint working – e.g. navigating a large system (barriers, power imbalances) • Looked after children • Care coordinator / advocate / key worker • Proactive services – empowerment for self-care • Reasonable adjustments • Medical needs
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.

EHCP: education, health and care plans

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. Twenty-three qualitative studies were included in this review: Adams 2017, Adams 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, Kiernan 2019, Kirk 2014, McConkey 2013, National Autistic Society 2015, RIP STARS 2018, Rodriguez 2014, Sales 2018, Skipp 2016, Smith 2014, Thom 2015, and 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 joined-up care between education, health and social care services. Data collection methods included: surveys (Cohen 2017), surveys with free text or open ended questions (Adams 2017 and National Autistic Society

2015), interviews (Adams 2018, Kirk 2014, Smith 2014 and Thom 2015), interviews with group discussions or focus groups (Hutton 2018 and RIP STARS), semi structured interviews (Boyce 2015, Council for Disabled Children 2018, Fox 2017, Griffith 2013, Kiernan 2019, McConkey 2013, Rodriguez 2014 and Sales 2018), semi-structured interviews and focus groups (Brooks 2013, Skipp 2016 and Young 2018), focus groups and online questionnaires (Children's Commissioner for Wales 2018 and Hurt 2019), and questionnaires with free text questions and focus groups (Dillenburger 2016).

Study populations included disabled children and young people with severe complex needs and their families and carers

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	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 2015	**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, hearing impairment, visual impairment, multi-sensory impairment **Age Range (Mean):**	**Setting:** NR **Data collection:** Survey with free text questions	• The effects of EHC plans on service provisions • Feeling disillusioned/that services do not fully meet the needs of children or young people • A need for effective communication • Perceptions about the involvement of the children or young person

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		0 to 25 years (NR)		
Adams 2018 Education, Health and Social Care Services	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:** EHC plan in place in 2015 **Age Range (Mean):** NR	**Setting:** NR (face-to-face) **Data collection:** Interviews	- A need for effective communication - Feeling disillusioned/that services do not fully meet the needs of children or young people - The effects of EHC plans on service provisions - Perceptions about the involvement of the children or young person - Difficulty in navigating the service system - Access to information and advice was important - Desire to build good relationships with professionals and staff
Boyce 2015 Education, Health and Social Care Services	N=26 Parents of children who are certified as severely sight impaired or sight impaired	**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	- Desire to build good relationships with professionals and staff - Feeling disillusioned/that services do not fully meet the needs of children or young people
Brooks 2013 Health and Social Care Services	N=2 Children with complex needs (aged 6 and 10 years) N=7 Parents with children who have continuing complex care needs	**Needs or conditions:** Cystic fibrosis, spina bifida, microcephaly, biliary atresia, tuberous sclerosis **Age Range (Mean):** 1 to 16 years	**Setting:** Family home, parents place of work **Data collection:** Semi-structured interviews and focus groups	- Parents and carers wanted their opinions about the child/young person to be heard - Desire to build good relationships with professionals and staff

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		(NR)		
Children's 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	**Needs or conditions:** Learning disabilities **Age Range (Mean):** 14 to 26 years (NR)	**Setting:** NR **Data collection:** Focus groups and online questionnaires	• Service provisions for transition need to be improved • Parents and carers wanted their opinions about the child/young person to be heard • Feeling disillusioned/that services do not fully meet the needs of children or young people • Access to information and advice was important • Difficulty in navigating the service system
Cohen 2017 Education and Health Services	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	• Service provisions for transition need to be improved
Council for Disabled Children 2018 Education, Health and Social Care Services	N=6 Parents of adopted children with disabilities that became apparent during or after adoption	**Needs or conditions:** ADHD, attachment difficulties/disorder, ASD, complex health needs, developmental delay or trauma, dyspraxia, FASD/FAS, genetic condition, hearing loss, learning difficulties, sensory processing issues	**Setting:** Primarily telephone **Data collection:** Semi-structured interviews	• Desire to build good relationships with professionals and staff • Difficulty in navigating the service system • Parents and carers wanted their opinions about the child/young person to be heard • Diagnosis as fundamental to accessing the necessary service provisions • Feeling disillusioned/that services do not fully meet the needs of children or young

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
				people
Dillenburger 2016 Health and Social Care Services	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	• Parents and carers wanted their opinions about the child/young person to be heard • Diagnosis as fundamental to accessing the necessary service provisions • Difficulty in navigating the service system • Budgets made a difference to the care received • Feeling disillusioned/that services do not fully meet the needs of children or young people • Service provisions for transition need to be improved • Access to information and advice was important
Fox 2017 Education, Health and Social Care Services	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	• Access to information and advice was important • Desire to build good relationships with professionals and staff • A need for effective communication • Feeling disillusioned/that services do not fully meet the needs of children or young people
Griffith 2013 Education, Health and Social Care Services	N=10 Parents	**Needs or conditions:** Autism, Asperger syndrome, and no diagnosis **Age Range (Mean):**	**Setting:** Local clinic (face-to-face) **Data collection:** Semi-structured interviews	• Desire to build good relationships with professionals and staff • Diagnosis as fundamental to accessing the necessary service provisions

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		2 to 12 years (6.6 years)		• Difficulty in navigating the service system • Feeling disillusioned/that services do not fully meet the needs of children or young people • Access to information and advice was important
Hurt 2019 Education and Health Services	N=7 Parent of primary school children with ASD	**Needs or conditions:** ASD **Age Range (Mean):** NR	**Setting:** One health board and one primary school in South Wales **Data collection:** Focus groups	• Diagnosis as fundamental to accessing the necessary service provisions • Access to information and advice was important • Desire to build good relationships with professionals and staff • Feeling disillusioned/that services do not fully meet the needs of children or young people
Hutton 2018 Education, Health and Social Care Services	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	• Budgets made a difference to the care received
Kiernan 2019 Education, Health and Social Care Services	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	**Setting:** Preferred location **Data collection:** Semi-structured interviews	• Feeling disillusioned/that services do not fully meet the needs of children or young people • Desire to build good relationships with professionals and staff

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		Age Range (Mean): 7 to 18 years (13.6 years)		
Kirk 2014 Health and Social Care Services	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 not at an end-of life stage, from one children's hospice	**Needs or conditions:** Cerebral palsy, pervasive developmental disorder, duchenne muscular dystrophy, 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	**Setting:** Preferred location **Data collection:** Interview	• Service provisions for transition need to be improved
McConkey 2013 Health and Social Care Services	N=14 Family members of children currently receiving services from Action for Children, or had received services in the past 2 years	**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-structured	• Desire to build good relationships with professionals and staff • Short breaks and respite breaks provide benefit

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
			interviews	
National Autistic 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	**Needs or conditions:** Autism **Age Range (Mean):** NR	**Setting:** NR **Data collection:** Survey including open-ended questions	• Need for professionals and staff to be trained properly • Difficulty in navigating the service system
RIP STARS 2018 Education, Health and Social Care Services	N=15 Children and young people with disabilities N=10 Parent/carers of children and young people with disabilities	**Needs or conditions:** NR **Age Range (Mean):** 13 to 25 years (NR)	**Setting:** NR **Data collection:** Interviews and group discussions	• Access to information and advice was important • Perceptions about the involvement of the children or young person • The effects of EHC plans on service provisions • Feeling disillusioned/that services do not fully meet the needs of children or young people • Diagnosis as fundamental to accessing the necessary service provisions • Difficulty in navigating the service system
Rodriguez 2014 Unclear what services were involved	N=20 Parents of children with life limiting conditions	**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	• Difficulty in navigating the service system • Desire to build good relationships with professionals and staff • Parents and carers wanted their opinions about the child/young person to be heard • Short breaks and respite breaks provide benefit
Sales 2018 Education, Health and Social Care	N=4 Children and young people (aged 10 to 17)	**Needs or conditions:** NR	**Setting:** Work or home (face-to-face)	• The effects of EHC plans on service provisions

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
Services	N=7 Parents	**Age Range (Mean):** 10-17 years (NR)	**Data collection:** Semi-structured interviews	• Parents and carers wanted their opinions about the child/young person to be heard • Perceptions about the involvement of the children or young person
Skipp 2016 Education, Health and Social Care Services	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	• Desire to build good relationships with professionals and staff • Access to information and advice was important • Perceptions about the involvement of the children or young person • The effects of EHC plans on service provisions • Diagnosis as fundamental to accessing the necessary service provisions • Parents and carers wanted their opinions about the child/young person to be heard • Feeling disillusioned/that services do not fully meet the needs of children or young people
Smith 2014 Education, Health and Social Care Services	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, autism and learning disability, autism and learning and	**Setting:** Family home (face-to-face) and telephone **Data collection:** Interviews	• Desire to build good relationships with professionals and staff • A need for effective communication • Perceptions about the involvement of the children or young person • Parents and carers wanted their opinions about the child/young person to be heard

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		physical disabilities **Age Range (Mean):** 0 to 25 years (NR)		• The effects of EHC plans on service provisions • Budgets made a difference to the care received • Access to information and advice was important • Difficulty in navigating the service system • Feeling disillusioned/that services do not fully meet the needs of children or young people • Service provisions for transition need to be improved
Thom 2015 Education, Health and Social Care Services	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	• Parents and carers wanted their opinions about the child/young person to be heard • Desire to build good relationships with professionals and staff • Access to information and advice was important • The effects of EHC plans on service provisions • Budgets made a difference to the care received • Perceptions about the involvement of the children or young person • Short breaks and respite breaks provide benefit
Young 2018 Health and Social Care Services	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	**Needs or conditions:** NR **Age Range (Mean):** NR	**Setting:** Pilot short-break service for young adults aged 18–24 years with life-limiting	• Difficulty in navigating the service system • Perceptions about the involvement of the children or young person

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
	N=4 Mothers of young adults registered with the pilot service		conditions **Data collection:** Semi-structured interviews or focus groups	• Short breaks and respite breaks provide benefit • Desire to build good relationships with professionals and staff • A need for effective communication • Service provisions for transition need to be improved

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; 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:

- Desire to build good relationships with professionals and staff
- Access to information and advice was important
- A need for effective communication
- Difficulty in navigating the service system
- Feeling disillusioned/that services do not fully meet the needs of children or young people
- Diagnosis as fundamental to accessing the necessary service provisions
- The effects of EHC plans on service provisions
- Perceptions about the involvement of the children or young person
- Parents and carers wanted their opinions about the child/young person to be heard
- Need for professionals and staff to be trained properly
- Service provisions for transition need to be improved
- Budgets made a difference to the care received
- Short breaks and respite breaks provide benefit

The data from the included studies were synthesised and explored in a number of central themes and sub-themes (central themes shown in Figure 1; see appendix L for sub-theme maps).

Figure 1: Theme map

Summary of the qualitative evidence

The evidence generated 13 main themes from the views and experiences of children and young people with severe complex needs and their families and carers. Fourteen studies provided evidence relating to building good relationships with professionals and staff. Ten studies provided evidence relating to the importance of accessing information and advice. Twelve studies provided evidence relating to a need for effective communication. Thirteen studies provided evidence relating to feeling disillusioned/that services do not fully meet the needs of children or young people. Six studies provided evidence relating to diagnosis. Seven studies provided evidence relating to the effects of education and health care plans on service provisions. Eight studies provided evidence relating to perceptions about the involvement of the child or young person. Nine studies provided evidence relating to the opinions of parents and carers. One study provided evidence relating to training for professionals and staff. Six studies provided evidence relating to provisions for transition. Four studies provided evidence relating to budgets. Four studies provided evidence relating to short and respite breaks. 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

Economic 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 review focussed on the views and experiences of disabled children and young people with severe complex needs, their families and carers of joined-up care between health, social care and education services. 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

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall quality ranged from low to high. Concerns about the methodological limitations of the primary studies were assessed with the CASP checklist and ranged from “major” to “minor”. The most common issues were lack of consideration of the relationship between researcher and participants, an absence of a clear statement of findings, somewhat limited detail provided on data analysis, no discussion of informed consent issues and no detail on how research was described to participants, potential for recruitment bias, no justification for the data collection methods and setting, and limited or an absence of discussion of the contribution to the literature. Concerns about coherence ranged from “minor” to “no or very minor”. For the majority of review findings concerns were “no or very minor”, as there was no data that contradicted the findings nor was there ambiguous data. A small number of review findings demonstrated minor concerns due to vaguely described data in the underlying body of evidence. Concerns about relevance were “no 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 “moderate” to “no or very minor”. There were moderate concerns for review findings when evidence offered some rich data and minor concerns for review findings that were based on evidence offering moderately rich data. The number of studies used for each review finding ranged from 1 to 8.

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

Main theme 1: Desire to build good relationships with professionals and staff:

- Sub-theme 1.1: Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.2: Individual professionals/staff were valued as a source of support, expertise and advice. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.3: The opportunity to meet with professionals produced positive feelings. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.4: Having a good rapport with staff was valued and appreciated. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.5: Lack of time to communicate with professionals and staff produced feelings of anxiety. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.6: Wanting to be kept informed on the progression of care. The overall quality of this sub-theme was judged to be moderate.

Main theme 2: Access to information and advice was important:

- Sub-theme 2.1: One particular service provided the necessary information and support. The overall quality of this sub-theme was judged to be low.
- Sub-theme 2.2: Peer support as a beneficial source of information. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 2.3: More information and advice was needed. The overall quality of this sub-theme was judged to be low.
- Sub-theme 2.4: Feeling a need to proactively locate the necessary information from other sources. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 2.5: Frustration due to information that is out of date. The overall quality of this sub-theme was judged to be high.

Main theme 3: A need for effective communication:

- Sub-theme 3.1: Staff and professionals should tailor communication to suit the individual and circumstances. The overall quality of this sub-theme was judged to be low.
- Sub-theme 3.2: Difficult to understand complicated terminology. The overall quality of this sub-theme was judged to be moderate.

Main theme 4: Difficulty in navigating the service system:

- Sub-theme 4.1: Repeating the same information was exhausting and produced negative feelings. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 4.2: Getting the necessary care demanded significant energy and organisation. The overall quality of this sub-theme was judged to be low.
- Sub-theme 4.3: Feeling a need to constantly fight for the necessary support. The overall quality of this sub-theme was judged to be moderate.

Main theme 5: Feeling disillusioned/that services do not fully meet the needs of children or young people:

- Sub-theme 5.1: Opting out of seeking support due to disillusion of statutory provision. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.2: Distrust of services to take care of child young person when the parent is unable to. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.3: Frustration in lack of clarity as to how resources would be allocated. The overall quality of this sub-theme was judged to be high.
- Sub-theme 5.4: Lack of good quality support and input from services. The overall quality of this sub-theme was judged to be moderate.

- Sub-theme 5.5: Parents have felt the need to give up work to support the child. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 5.6: Need for specialist support or special provisions. The overall quality of this sub-theme was judged to be moderate.

Main theme 6: Diagnosis as fundamental to accessing the necessary service provisions.

- Sub-theme 6.1: Acceptance of an inaccurate diagnosis to access available resources. The overall quality of this sub-theme was judged to be low.
- Sub-theme 6.2: Improved access to services post diagnosis led to feelings of relief when receiving diagnosis. The overall quality of this sub-theme was judged to be low.
- Sub-theme 6.3: Frustration with the time taken and difficulty in obtaining a diagnosis. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 6.4: Questioning why medical history needs to be disclosed for access to services. The overall quality of this sub-theme was judged to be low.

Main theme 7: The effects of EHC plans on service provisions:

- Sub-theme 7.1: EHC plans led to improvements in support and/or outcomes of the child/young person. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 7.2: EHC plans provided reassurance that support will be in place to meet the needs of the child/young person. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 7.3: EHC plans were considered a good reflection of the individuality of the child/young person. The overall quality of this sub-theme was judged to be low.

Main theme 8: Perceptions about the involvement of the children or young person:

- Sub-theme 8.1: Children and young people felt positively about their involvement. The overall quality of this sub-theme was judged to be low.
- Sub-theme 8.2: Observations that the child/young person grew in confidence over a period of involvement. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 8.3: Feeling that input from the child or young person would lead to a more accurate reflection of their support needs. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 8.4: Children and young people had various levels of ability which affected their level of involvement and understanding. The overall quality of this sub-theme was judged to be moderate.

Main theme 9: Parents and carers wanted their opinions about the child/young person to be heard:

- Sub-theme 9.1: Parents/carers felt positively when given the opportunity to provide their views. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.2: Parents expressed negative feelings when their views were ignored. The overall quality of this sub-theme was judged to be high.
- Sub-theme 9.3: Parents felt they had expert knowledge about their child/young person. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.4: Praise for practitioners who valued the expertise of parents but maintained appropriate boundaries. The overall quality of this sub-theme was judged to be moderate.

Main theme 10: Need for professionals and staff to be trained properly:

- Sub-theme 10.1: Experiencing negative consequences due to inadequate understanding of the child/young person’s needs. The overall quality of sub-theme was judged to be moderate.

Main theme 11: Service provisions for transition need to be improved:

- Sub-theme 11.1: Transitioning through education services was challenging and produced varied experiences. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 11.2: Variation in age of transition across regions and services. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 11.3: Parents felt shut out once the child/young person reached adulthood. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 11.4: Reduction in support following transition. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 11.5: Transition was experienced as a period of uncertainty and stress. The overall quality of this sub-theme was judged to be moderate.

Main theme 12: Budgets made a difference to the care received:

- Sub-theme 12.1: Belief or experience that personal budgets or direct payments would make a positive impact. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 12.2: Uncertainty around the entitlement to, or effectiveness of personal budgets or direct payments. The overall quality of this sub-theme was judged to be moderate.

Main theme 13: Short breaks and respite breaks provide benefit:

- Sub-theme 13.1: Short breaks and respite breaks benefit the child/young person and the whole family. The overall quality of this sub-theme was judged to be moderate.

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-themes 1.4, 6.3, 9.3 and 9.4 that parents felt they had expert knowledge about their child or young person, stemming from knowing their child or young person best, intense caring responsibilities and being the person most alert to changes. Service users reported praise for practitioners who valued the expertise of parents but maintained appropriate boundaries. Additionally, service users felt that some professionals did not have the experience or appropriate knowledge to make diagnoses, or exhibited a watchful-wait policy that in some circumstances conflicted with the interests of parents who were living with the child or young person and felt their concerns were undermined or dismissed. Therefore, a recommendation was made for closer working with children, young people and their families so practitioners could draw on their expertise from their lived experience and build a positive working relationship with them, to better understand their needs [1.1.4].

There was moderate quality evidence from sub-theme 1.5 that a lack of time to communicate with professionals and staff produced feelings of anxiety amongst service users. Specifically, service users reported feeling as though they were not given adequate time to ensure they were providing their child’s exercise therapy in the correct way. In reflection of the evidence, the committee discussed the importance of providing both training and ongoing supervision. They 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. The committee agreed to recommend that practitioners follow this guidance to ensure that families and carers not only feel capable and confident to deliver delegated clinical tasks but are also competent and supported, and mechanisms are put in place for them to report problems should they occur [1.15.29].

There was moderate quality evidence from sub-themes 1.6 and 6.3 that services users wanted to be kept up-to-date with the progress of their child's or young person's care, including the drafting and progressing of their EHC plan, and providing adequate services and care regimens. Additionally, in sub-theme 4.2 service users expressed the need to expend a considerable amount of time and energy in order to constantly chase services for information, and frustration with the time taken and difficulty in obtaining a diagnosis. Families felt stressed and frustrated by the lack of information around delays, whilst families that were kept informed felt more positively. Therefore, the committee recommended that children, young people and their families be kept updated on the progress of their care, support, assessments and their EHC plan, and that the reasons for any delays should be explained [1.1.15]. They also recommended that practitioners use their knowledge about the responsibilities of other people and services to provide more wide-ranging and coordinated support and advice to children and young people and their families, to reduce the number of different people they have to contact [1.14.3].

There was moderate quality evidence from sub-theme 2.2 that service users benefited from speaking to other peers who had experience with the system. Therefore, the committee recommended that children, young people and their families be told how to access peer support [1.1.16]. In the committee's experience practitioners providing information on peer support groups would have a professional duty of care to make sure that any sources of support they provide is quality assured.

There was low, moderate and high quality evidence from sub-themes 2.3, 2.4 and 2.5, respectively, that service users needed more information and advice, including on their role in parenting, caring and supporting the child or young person. Service users felt that not all the necessary information was provided on aspects of the chid or young person's care such as policy, planning, process, service structures, assessment, and diagnosis, and that the support provided was limited and often based on out-dated information. There was moderate quality evidence from sub-theme 1.1 that families and carers were unacquainted with service providers and were unaware of their role in providing care for the child or young person. Confusion about the number and purpose of appointments was reported, and concerns about the people working in the service that were unknown to them. Therefore, the committee recommended that children, young people and their families are given up-to-date information and advice including information on delays or changes about the process and purpose of assessment and diagnosis, the care and support they are receiving, meetings they will be involved in and how to contribute their views, and relevant policies and processes. They made a strong recommendation that children, young people and their families are informed by education, health and social care services about the roles of the practitioners and services that are currently supporting them, and any services that they have been referred to for future support as having this information is necessary to providing high quality care [1.1.15].

There was low quality evidence from sub-theme 3.1 that service users appreciated when staff and professionals adapted their communication style to suit the individual and circumstances, including when delivering a diagnosis when feelings of shock, confusion, denial, upset and sadness were apparent. The committee discussed that ideally, practitioners would be used to dealing with sensitive conversations effectively as this is a corner stone of good practice. However, since the evidence had identified this doesn't always happen, the committee made strong recommendations to prompt staff and professionals to be empathetic and supportive when talking to children, young people and their families [1.1.9] and to address their feelings and help them to understand and reflect on the information they have received [1.1.11]. The committee also recommended, based on their knowledge and experience, that staff and professionals consider recording meetings so that service users have the opportunity to review the content in their own private space as it often takes time for people to assimilate the information they have been given, particularly when it involves a significant or life-changing event [1.1.30].

There was moderate quality evidence from sub-theme 3.2 that service users found it difficult to understand complicated terminology. The committee agreed to cross reference relevant recommendations on communicating and discussing complex information, and on tailoring information to individuals in NICE's guideline on babies, children and young people's experience of healthcare, and NICE's guideline on patient experience in adult NHS services [1.1.19]. This recommendation would be particularly relevant to those with cognitive impairments and communication needs and disorders.

There was moderate quality evidence from sub-theme 5.1 that service users felt disillusionment with statutory provisions and reported feeling little point in requesting help, leading to occasions where they opted out of seeking support. The committee felt that by speaking to and involving service users, this could potentially improve statutory provisions and subsequently reduce the disillusionment felt regarding current services. Therefore, the committee recommended that when commissioning services, commissioners should speak to disabled children, young people and their families, to find out what support they need, and involve them in the planning of services [1.17.6]. This aligns with the SEND Code of Practice (2015) which specifies that children and young people with special educational needs and disabilities and their parents must be engaged in commissioning decisions, so that users' experiences, ambitions and expectations can shape decisions on the services provided. For the same reasons, the committee agreed that disabled children and young people should be involved in the review of existing services. This also aligned with the SEND Code of Practice (2015) which specifies that children and young people with special educational needs and disabilities and their parents must be consulted when reviewing educational, training and social care provision [1.17.8].

There was moderate quality evidence from sub-theme 5.2 that service users felt distrust in services' ability to take care of the child or young person when they were unable to, for example when they became too old, fragile or vulnerable to push for services, or when they were deceased. The committee discussed their experience and relayed seeing parents and carers get worn down as time goes by; an evolutionary process resulting from looking after a child or young person with severe complex needs for a substantial number of years. It was agreed that a longer term view was needed, and the committee recommended that interagency teams provide information about the support options available to help service users make arrangements for when they cannot care for their child [1.6.4].

There was high quality evidence from sub-theme 5.3 that service users felt frustrated due to a lack of clarity about how resources would be allocated to the child or young person. To remedy this, the committee recommended that children, young people and their families are given clear information about the criteria for funding and support [1.3.6].

There was moderate quality evidence from sub-theme 5.4 that service users did not receive the level of support or input that they had expected from services. The committee agreed that in order to understand and potentially meet the expectations of service users, they would first need to be aware of what those expectations might be. Therefore, the committee recommended asking children and young people and their parents what they expect from services. In practice it may not be possible to meet all expectations, therefore the committee recommended explaining what services are available, the criteria for accessing them, and the reasons why support is not be provided [1.1.18; 1.3.5].

There was moderate quality evidence from sub-theme 8.4 of differing views regarding the involvement of children and young people. Whilst some service users felt that participation was inappropriate for their child or young person due to their age, or the nature of their special educational need or disability, others described attempts to fully involve the child or young person as positive. Therefore, the committee recommended asking children and young people how they would like to be involved in multidisciplinary and interagency review meetings about them, to facilitate their involvement as much as possible [1.1.34].

There was moderate and high quality evidence from sub-themes 9.1 and 9.2 that parents and carers felt positively when given the opportunity to provide their views, and conversely expressed negative feelings when their views were ignored. Most of the evidence related to EHC plans, where parents and carers felt negatively when comments on draft EHC plans were ignored, and positively when their involvement in the EHC process was valued and they had the opportunity to make amendments to the child or young person's EHC plan. The committee discussed that parents and carers had lived experience with the child or young person and had an important understanding of their associated needs. The committee felt it to be key to communicate to the parents and carers the value of their point of view, and to demonstrate this by clarifying to them how their concerns have been incorporated into the EHC plan. The committee recommended taking the views of parents and carers into account and explaining how their concerns have been addressed in the EHC plan, and if the concerns of the parent or carer cannot be addressed, explain why [1.4.2; 1.4.16]. They also agreed that if concerns cannot be addressed, it was important to record the reasons why because in the committees experience this would prevent disputes over what was said or agreed as this information isn't currently routinely recorded.

There was moderate quality evidence from sub-themes 1.3 and 10.1 that service users had experienced negative consequences due to inadequate understanding of the child's needs, and conversely felt positively when given the opportunity to meet with professionals face-to-face to discuss the needs of the child or young person. The committee discussed that understanding the child's needs may protect against negative consequences, therefore it was recommended that all practitioners involved in making decisions about a child or young person's support should get to know them well enough to understand their needs [1.1.4].

There was moderate quality evidence from sub-theme 11.3 that parents felt shut out once the child or young person reached adulthood, specifically that their experience of supporting the child or young person was often ignored once the child or young person reached adult services. The committee agreed that it was important for parents to be prepared beforehand about potential changes to their decision making ability once the young person reached adulthood and so made a strong recommendation [1.8.10].

There was moderate quality evidence from sub-theme 11.4 that service users experienced a loss of, or reduction in support following transition to adult services, particularly in children and young people with more complex, specialised needs. This was consistent with evidence from the qualitative review of barriers and facilitators of joined-up care (see evidence report K, sub-theme 6.4). The committee were aware of existing NICE guidance on transition that made recommendations on continuity of support that were relevant to the population of this guideline and so cross-referenced these [1.8.13].

There was moderate quality evidence from sub-theme 11.5 that service users experienced transition as a period of uncertainty and stress. The committee agreed that transition is not as well coordinated as other milestones. Based on their experience, they recommended the information related to transition that would need to be provided to make sure young people know what to expect. This was information about the adults needs assessment, timing of appointments, when decisions will be made, and which services will be involved in their care during and after transition would help service users know what to expect and so made a strong recommendation to that effect [1.8.12]. The committee also agreed to cross reference the NICE guideline on transition from children's to adults' services for young people using health or social care services [1.8.13].

There was moderate quality evidence from sub-theme 12.2 that service users felt uncertainty around the entitlement to, or effectiveness of personal budgets or direct payments. They were unsure what the funds could be used to purchase, whether they improved the child' or young person's access to services, and whether either would be applicable to their individual circumstances. The committee agreed that more information should be provided to children, young people and families to remedy this gap in understanding [1.5.1]. In addition, service users in sub-theme 12.2 expressed concerns about uneven provision, shortages in provision and a reduction in services, as a result of personal budgets and direct payments. Service users did not want to be disadvantaged and expressed concerns around having to prioritise within the constraints of a limited budget which may not be equivalent to the level of funding which is already available. There was moderate quality evidence from sub-theme 4.3 that service users felt a need to constantly fight for the necessary support. Provision and resources were not always forthcoming and service users needed to make requests and at times demands, to receive the necessary support. The committee noted, based on their experience, that sometimes direct payments made by the local authority to provide the services agreed in the needs assessment is only enough to cover the service itself but not any ancillary costs; for example the payment covers the cost of a social activity but not the transport costs required to access this activity. As a consequence, activities that the child or young personal may have enjoyed previously may no longer be affordable. Therefore, the committee recommended that local authorities assess the full cost of providing the services proposed in the needs assessment [1.5.4].

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 1.3.4, see evidence reports K and M), 4.1 (recommendation 1.1.43, see evidence report M), 6.1, 6.2 and 6.3 (recommendation 1.17.4, see evidence report C), and 8.1, 8.2 and 8.3 (recommendation 1.1.15, see evidence report B). For other themes, the evidence available was not sufficient to support a recommendation because it was moderate quality evidence for an intervention or service that would potentially have a large resource impact (sub-theme 11.2), did not provide enough information about how to address the issue raised by the evidence (sub-themes 1.2, 5.5, 5.6, 6.4 and 11.1) or it was a comment on an intervention without evidence of its effectiveness (sub-themes 12.1 and 13.1). Finally, there were some sub-themes (sub-theme 7.1, 7.2 and 7.3) commenting on the perceived impact of EHC plans. These are now statutory requirements and so it was outside the remit of this guideline to make recommendations in this area.

Cost effectiveness and resource use

No existing economic evidence was identified for this review.

The committee discussed the financial implications associated with the recommendation to provide training and ongoing supervision for parents who are delegated clinical tasks. The committee confirmed that this recommendation reflects current practice and would not have resource implications for services. The committee explained that the implementation of existing guidance is variable, i.e. the standard of training and support available is inconsistent across the country, with some pockets of poor practice. The recommendations in this area should make practice less variable.

The committee discussed the recommendation around considering recording appointments so the child or young person and their family can review the content later. The committee explained that keeping a record of appointments is standard practice across all three sectors but the format used to do so is variable, with audio and video recordings being more prevalent in health around significant or life-changing events in an individual's care pathway. Given that this recommendation was not based on evidence, the committee were not able to specify a particular format for keeping a record of appointments. They acknowledged that there could be costs associated with acquiring equipment if services chose to make audio or video recordings, but since the recommendation was flexible about the method of keeping a record, they did not expect it to result in significant additional resource requirements for services.

All other recommendations are either about providing information, already a requirement of the SEND Code of Practice (2015) or represent current practice for most services and would not have significant resource implications. There may be modest resource implications where practices are sub-optimal or services are underperforming.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.4, 1.1.9, 1.1.11, 1.1.15 - 1.1.18, 1.1.30, 1.1.34, 1.3.5, 1.3.6, 1.4.2, 1.4.16, 1.5.1, 1.5.4, 1.6.4, 1.8.10, 1.8.12, 1.8.13, 1.14.3, 1.15.29, 1.17.6, 1.17.8. Other evidence supporting these recommendations can be found in the evidence reviews on Barriers and facilitators of joined-up care (evidence report K), Views and experiences of service providers (evidence report M).

References – included studies

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Appendices

Appendix A Review protocols

Review protocol for review question: 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?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	CRD42019151318
1.	Review title	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?
2.	Review question	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?
3.	Objective	This review will examine the views and experiences of disabled children and young people with severe complex needs, their families and carers of joined-up care between health, social care and education services. This will be used to identity themes about the acceptability and accessibility of joined up services and the values and preferences of service users. 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

ID	Field	Content
		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 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 requiring 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. 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.
7.	Phenomenon of interest	The views and experiences of disabled children and young people with severe complex needs, their families and carers, using or eligible to use all three services (health, social care and education) on joined-up care between these services for disabled children and young people with severe complex needs.
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 United Kingdom (UK) study Studies published prior to 2013 will not be considered as they will have limited relevance due to legislative

ID	Field	Content
		changes, 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 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): • Shared decision making, person centred care and support, coproduction • Transition between services • Invisible conditions or disabilities • Carers who are themselves disabled • Ability to access the right provision for need, and the timeliness of that • Number of appointments • Tribunals and legal opinions; health care complaints • Discrimination or exclusion from integrated services by service providers • Out of area placements – residential schools (could be positive or negative) • Communication between professionals • Usefulness and impact of EHCP on provision • Negative experiences of joint working – e.g. navigating a large system (barriers, power imbalances) • Looked after children • Care coordinator / advocate / key worker • Proactive services – empowerment for self-care • Reasonable adjustments • Medical needs
13.	Secondary outcomes (important outcomes)	Not applicable

ID	Field	Content
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 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.

ID	Field	Content		
17.	Analysis of sub-groups	Formal subgroup analyses are not appropriate for this question due to qualitative data, but the views and experiences of the following groups will be considered separately if there is inconsistency or incoherence in the results for a given theme: • Children and young people • Family and carers		
18.	Type and method of review	☐	Intervention	
		☐	Diagnostic	
		☐	Prognostic	
		☒	Qualitative	
		☐	Epidemiologic	
		☒	Service Delivery	
		☐	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	28 August 2019		
22.	Anticipated completion date	12 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	☐ ☐	☐ ☐

ID	Field	Content
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 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?ID=CRD42019151318
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.

ID	Field	Content	
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; CDSR: Cochrane Database of Systematic Reviews; CASP: Critical Appraisal Skills Programme; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: database of Abstracts of Reviews of Effects; EHCP: Education and Health Care Plan; ERIC: Educational Information Resources Center; GRADE-CERQual: Grading of Recommendations Assessment-Confidence in the Evidence from Reviews of Qualitative research, Development and Evaluation; HMIC: Health Management Information Consortium; NICE: National Institute for Health and Care Excellence; UK: United Kingdom

Appendix B Literature search strategies

Literature search strategies for review question: 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?

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

#	Searches
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$)).ti.
45	or/35-44
46	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/)
47	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
48	(exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
49	or/46-48
50	"HEALTH SERVICES NEEDS AND DEMAND"/
51	DELIVERY OF HEALTH CARE/
52	COOPERATIVE BEHAVIOR/
53	COMMUNICATION/
54	INTERPROFESSIONAL RELATIONS/
55	or/50-54
56	((health$ 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

#	Searches
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/
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

#	Searches
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$)).ti,ab.
55	(social$ 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"

#	Searches
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/
35	COLLABORATIVE CARE/
36	INTEGRATED PROVIDERS/
37	INTEGRATED CARE/

#	Searches
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

#	Searches
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.
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

Database: PsycInfo

Date of last search: 06/09/2019

#	Searches
1	experiences.tw.
2	interview:.tw.

#	Searches
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.
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

#	Searches
	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
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/

#	Searches
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 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/)

#	Searches
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

#	Searches
#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"]
#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

#	Searches
	^"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 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

#	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
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?")

#	Searches
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-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 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 - 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 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

#	Searches
	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

#	Searches
	deficit$ or dysfunct*)) Indexes=SSCI Timespan=2000-2019
# 10	TOPIC: (((sever* or complex* or special or high) near/3 need$)) Indexes=SSCI Timespan=2000-2019
# 11	TOPIC: (SHCN) Indexes=SSCI Timespan=2000-2019
# 12	#11 OR #10 OR #9 Indexes=SSCI Timespan=2000-2019
# 13	#12 AND #8 Indexes=SSCI Timespan=2000-2019
# 14	TOPIC: (CSHCN) Indexes=SSCI Timespan=2000-2019
# 15	TOPIC: ("Education Health and Care plan$") 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

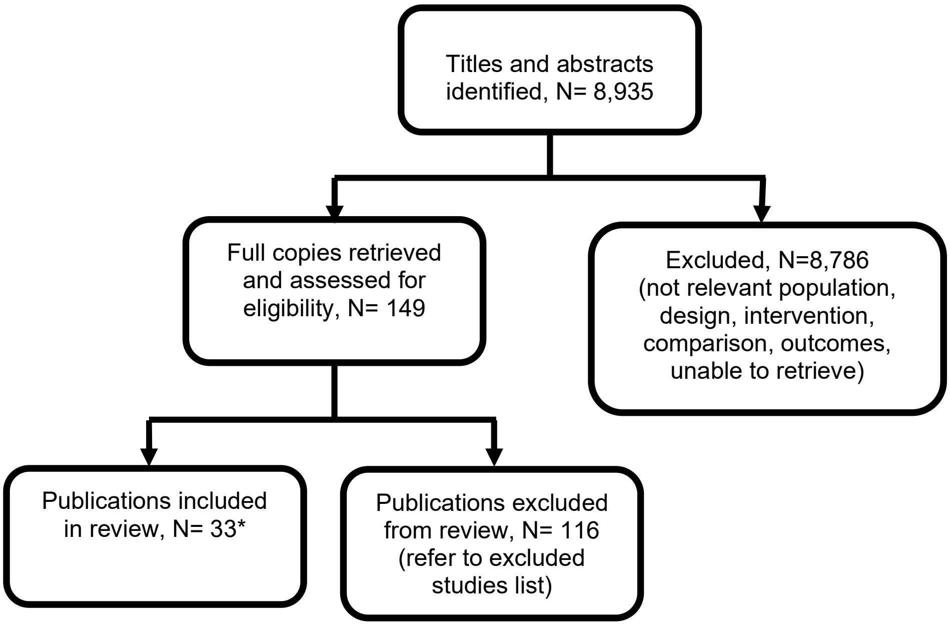
#	Searches
	AllFields:'qualitative or interview or experience'

#	Searches
	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 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?

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	**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%)	**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** Original theme: Acquired the funding / assistance that the child / young person needed The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Difficulty meeting child's needs Feeling disillusioned/that services do not fully meet the needs of children or young people Lack of good quality support and input from services Original theme: Was kept informed / provided with clear information A need for effective communication Staff and professionals should tailor communication to suit the individual 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?** 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Study dates Between 25th July and 28th November 2016 Study 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	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%) *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%)	themes (where possible an existing code was used – known as 'backcoding').	circumstances Perceptions about the involvement of the children or young person Children and young people had various levels of ability which affected their level of involvement and understanding	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 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

Study details	**Participants**	**Methods**	**Themes (information in bullet points are theme(s) applied after thematic synthesis)**	**Quality assessment**
the accessibility of the survey, participants could complete it online, via a paper questionnaire and by 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	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 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			**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 • 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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
years, the survey invitation was addressed to them directly; if under 16, the invitation was addressed to the parent or carer. 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	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%)			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
the telephone.	Hearing Impairment: n=289 (2%) Visual Impairment: n=194 (1%) 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			

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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Adams, Lorna, et, al, Education, Health and Care plans: a qualitative investigation into service user experiences of the planning 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	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 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	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 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	Original theme: Dedicated specialist support A need for effective communication Difficult to understand complicated terminology Feeling disillusioned/that services do not fully meet the needs of children or young people Need for specialist support or special provisions Original theme: Having the EHC plan ready before a transition period The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Involving the child/young person in a meaningful manner Perceptions about the involvement of the children or young person Feeling that input from the child or young person would lead to a more accurate reflection of their support needs Original theme: Involving young children Perceptions about the involvement of the	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
involved in the 2016 national survey) **Study dates** Interviews were conducted between 3rd April to 11th May 2017	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.	an analysis framework under headings related to the objectives	children or young person Children and young people had various levels of ability which affected their level of involvement and understanding Original theme: A need for communication from local authorities throughout the process Difficulty in navigating the service system Getting the necessary care demanded significant energy and organisation Original theme: A need for accessible information and support for families Access to information and advice was important Feeling a need to proactively locate the necessary information from other sources Original theme: Managing the logistics of getting an EHC plan Difficulty in navigating the service system Getting the necessary care demanded significant energy and organisation Desire to build good relationships with professionals and staff Individual professionals/staff were valued as a source of support, expertise and advice	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 consent – a copy of the individual's EHC plan

Study details	**Participants**	**Methods**	**Themes (information in bullet points are theme(s) applied after thematic synthesis)**	**Quality assessment**
			Original theme: A need for greater transparency about reasons for delays Desire to build good relationships with professionals and staff Wanting to be kept informed on the progression of care Original theme: Involvement of the child/young person Perceptions about the involvement of the children or young person Children and young people had various levels of ability which affected their level of involvement and understanding	
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	**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)	**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	**Themes** Original theme: Eye clinic liaison officers Desire to build good relationships with professionals and staff Individual professionals/staff were valued as a source of support, expertise and advice Feeling disillusioned/that services do not fully meet the needs of children or young people Lack of good quality support and input from 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: No discussion on how they decided which method to use

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
certification and referral to education and social care services, BMJ open, 5, e009622, 2015 **Ref ID** 914536 **Country/ies where study was carried out** UK (England) **Study type** Primary qualitative **Study dates** Interviews were completed between March and July 2014.	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 *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	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 emerged during the second level of the thematic analysis		**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 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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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			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**
Full citation Brooks,	**Characteristics**	**Setting** For service users:	**Themes** Original theme: Professional	**Limitations** **Q1 Was there a clear statement of**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Fiona, Bloomfield, Linda, Offredy, Maxine, Shaughnessy, Philomena, Evaluation of services for children with complex needs: mapping service provision in one NHS Trust, Primary health care research & development, 14, 52-62, 2013 **Ref ID** 914541 **Country/ies where study was carried out** UK **Study type** Primary	*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 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*	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 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	communication and family participation in decision making Parents and carers wanted their opinions about the child/young person to be heard Parents felt they had expert knowledge about their child/young person Desire to build good relationships with professionals and staff Wanting to be kept informed on the progression of care	**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 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
qualitative (described as an evaluative study with exploratory case study methodology) **Study dates** NR	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 either current or ongoing child protection proceedings or complaint proceedings against the NHS.	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		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
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	**Setting** Focus groups **Data collection** NR **Data analysis** NR	**Themes** Original theme: Personal organising and administration Service provisions for transition need to be improved Parents felt shut out once the child/young person reached adulthood Parents and carers wanted their opinions about the child/young person to be heard Parents/carers felt positively when given the opportunity to provide their views Original theme: Parental concerns for their young person with a learning disability Feeling disillusioned/that services do not fully meet the needs of children or young people Distrust of services to take care of child or young person when the parent is unable to Original theme: Managing work and caring duties Feeling disillusioned/that services do not fully meet the needs of children or young people Parents have felt the need to give up work to support the child	**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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	activities – for example household tasks, socialising or managing money – which affects someone for their whole life) adults who care for young people with learning disabilities adults who work with young people with learning disabilities **Exclusion criteria** NR		Need for specialist support or special provisions Original theme: Young people's views on the role of parents Access to information and advice was important More information and advice was needed Original theme: Access to further education Service provisions for transition need to be improved Services lack ownership/responsibility during transition Original theme: Changing thresholds between child and adult services Service provisions for transition need to be improved Reduction in support following transition Variation in age of transition across regions and services Original theme: Poor coordination and decision making Difficulty in navigating the service system Getting the necessary care demanded significant energy and organisation	**researcher and participants been adequately considered?** No: The relationship between 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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Original theme: Issues of access and delivery common to all statutory services Service provisions for transition need to be improved Transition was experienced as a period of uncertainty and stress	NR **Other information**
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	**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	**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	**Themes** Original theme: Educational difficulties reported by respondents Service provisions for transition need to be improved Transitioning through education services was challenging and produced varied experiences	**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**

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** Survey with free text questions **Study dates** NR: The survey was open to respondents for a four-month period.	parents/carers of individuals of any age with such a diagnosis. **Exclusion criteria** NR	opened. The survey was open to respondents for a four-month period. **Data analysis** For the survey questions, descriptive analysis was 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		**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 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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				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 children placed for adoption, and supporting families when needs are unexpected, 87, 2018 **Ref ID** 1105592	**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 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,	**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 other contributors was gathered by email **Data analysis** Thematically analysis using the Framework approach.	**Themes** Original theme: Professional availability, continuity and responsiveness Desire to build good relationships with professionals and staff Lack of time to communicate with professionals and staff produced feelings of anxiety Original theme: Respecting, involving and empowering adopters Difficulty in navigating the service system Feeling a need to constantly fight for the necessary support Original theme: Recognising and working with boundaries of responsibility Difficulty in navigating the service system Getting the necessary care demanded significant energy and organisation	**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?** Can't tell: Limited details on recruitment aside from that calls for

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 **Study dates** NR	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 of parenting or supporting children: who had been placed for adoption or entered early		Parents and carers wanted their opinions about the child/young person to be heard Praise for practitioners who valued the expertise of the parent or carer but maintained the appropriate boundaries Original theme: Diagnoses and supporting evidence Diagnosis as fundamental to accessing the necessary service provisions Frustration with the time taken and difficulty in obtaining a diagnosis Improved access to services post diagnosis led to feelings of relief when receiving diagnosis Feeling disillusioned/that services do not fully meet the needs of children or young people Need for specialist support or special provisions Original theme: significance of diagnosis Diagnosis as fundamental to accessing the necessary service provisions Acceptance of an inaccurate diagnosis to access available resources Original theme: Access to appropriate assessments and provision	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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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		Diagnosis as fundamental to accessing the necessary service provisions Improved access to services post diagnosis led to feelings of relief when receiving diagnosis	**Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability)** 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**
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**	**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	**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	**Themes** Original theme: Diagnosis process Parents and carers wanted their opinions about the child/young person to be heard Parents felt they had expert knowledge about their child/young person Diagnosis as fundamental to accessing the necessary service provisions Frustration with the time taken and difficulty in obtaining a diagnosis Original theme: Delayed diagnosis Difficulty in navigating the service system	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
UK (Northern Ireland) **Study type** Primary qualitative **Study dates** NR	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. 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	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 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	Repeating the same information was exhausting and produced negative feelings Diagnosis as fundamental to accessing the necessary service provisions Frustration with the time taken and difficulty in obtaining a diagnosis Original theme: Statutory services. Direct Payments Budgets made a difference to the care received Belief or experience that personal budgets or direct payments would make a positive impact Original theme: Statutory services in Health and Social Care Feeling disillusioned/that services do not fully meet the needs of children or young people Opting out of seeking support due to disillusion of statutory provision Need for specialist support or special provisions Service provisions for transition need to be improved Reduction in support following transition	**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 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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	individuals with ASD **Exclusion criteria** NR	interviews (10 students opted for online survey) **Data analysis** NR	Original theme: Statutory services in Health and Social Care. Crisis Care. Feeling disillusioned/that services do not fully meet the needs of children or young people Lack of good quality support and input from services Original theme: Statutory services in Health and Social Care. Transition support Service provisions for transition need to be improved Reduction in support following transition Original theme: Daily living and quality of life. Statutory support Access to information and advice was important Feeling a need to proactively locate the necessary information from other sources	**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)* *Individuals interviews: n=37* Focus groups, n=8 Individuals with autism and their carers, n=17 (interviews, 19 participants)

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				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	**Characteristics** *Characteristics of parents* *total: n=15 parents* *gender: n=12 female, n=3 male* *Age: Mean = 36 years*	**Setting** Community centre or participants' own homes (according to preference) **Data collection** semi structured interviews lasting 45–95 min	**Themes** Original theme: Learning and Understanding Access to information and advice was important More information and advice was needed	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology appropriate?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
walking without 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	*relationship status: n=11 married, n=4* *total number of children: range=3-8, mean=* *Language interview 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	interviews explored the family's experiences of having a child with autism, from the first time they 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	Feeling a need to proactively locate the necessary information from other sources Original theme: Learning and diagnosis Desire to build good relationships with professionals and staff Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person A need for effective communication Staff and professionals should tailor communication to suit the individual and circumstances Original theme: Accessing Services A need for effective communication Difficult to understand complicated terminology Desire to build good relationships with professionals and staff Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person Original theme: Education services Feeling disillusioned/that services do not fully meet the needs of children or young	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: 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
between July and September 2015	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)	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 refined to develop a coherent thematic summary which was discussed and agreed by the study team	people Need for specialist support or special provisions	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?** 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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
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 **Country/ies where study was carried out** UK (Wales) **Study type** Primary	**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 theme: Perspectives on diagnostic teams Desire to build good relationships with professionals and staff Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person Original theme: Receiving a diagnosis Diagnosis as fundamental to accessing the necessary service provisions Improved access to services post diagnosis led to feelings of relief when receiving diagnosis Original theme: Lack of post diagnostic support Difficulty in navigating the service system Feeling a need to constantly fight for the necessary support Getting the necessary care demanded significant energy and organisation Feeling disillusioned/that services do not fully meet the needs of children or young	**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 and setting have not been justified **Q6: Has the relationship between researcher and participants been**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
qualitative **Study dates** NR			people Lack of good quality support and input from services Access to information and advice was important Feeling a need to proactively locate the necessary information from other sources	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				Other information
Full citation Hurt, Lisa, Langley, Kate, North, Kate, 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**	**Characteristics** n=23 n=8 health professionals working within a NHS multi-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	**Setting** Wales **Data collection** Focus group discussions 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.	**Themes** Original theme: Barriers Diagnosis as fundamental to accessing the necessary service provisions Frustration with the time taken and difficulty in obtaining a diagnosis Access to information and advice was important Frustration due to information that is out of date More information and advice was needed Desire to build good relationships with professionals and staff Lack of time to communicate with professionals and staff produced feelings of anxiety Feeling disillusioned/that services do not fully meet the needs of children or young people Frustration in lack of clarity as to how resources would be allocated Distrust of services to take care of child or young person when the parent is unable to	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes: Study aimed to "describe and 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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
out UK (Wales) **Study type** Mixed methods - including qualitative workshops (focus group discussions) **Study dates** September 2015	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 consent **Exclusion criteria** NR	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 were employed – data, method and investigator		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 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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				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 **Country/ies where study was carried out** UK (England)	**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*	**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 affect care) managing transition (exploring periods of change in support needs and the responsiveness of therapy services) Focus groups and	**Themes** Original theme: Parent and carer views on personal health care budgets Budgets made a difference to the care received Belief or experience that personal budgets or direct payments would make a positive impact Uncertainty around the entitlement to, or effectiveness of personal budgets or direct payments Original theme: Potential benefits of personal health budgets Budgets made a difference to the care received Belief or experience that personal budgets or direct payments would make a positive impact Original themes: Equipment; Equivalence of services; Managing the budget Budgets made a difference to the care received	**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 the research?** Yes: Participants were invited to attend a focus group or one-to-one interview.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Study type Primary qualitative - focus group or interview (face-to face or telephone) **Study dates** NR	Girl aged 16 years, n=1 Boy aged 13 years, n=2 Girl aged 13 years, n=2 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*	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'	Uncertainty around the entitlement to, or effectiveness of personal budgets or direct payments	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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			Research and Development approval from a local acute hospital. Informed 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)

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				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 to in the paper but it is currently unpublished and 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 Kiernan, Joann, et, al, Mothers' perspectives on the lived experience of children with intellectual disability and challenging behaviour,	**Characteristics** n=10, parents (all mothers) agreed to be interviewed n=6, mothers reported that their child/children had attended special educational provision n=12, child/children	**Setting** Across England **Data collection** Semi-structured interviews took place at a time and venue chosen by participants with the principal researcher Interviews were recorded	**Themes** Original theme: Square services, round needs Feeling disillusioned/that services do not fully meet the needs of children or young people Lack of good quality support and input from services Desire to build good relationships with	**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 needs (challenging behaviour) on the lives of children with an intellectual disability **Q2 Was a qualitative methodology appropriate?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
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	*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	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.	professionals and staff Individual professionals/staff were valued as a source of support, expertise and advice	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
	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 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			**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)**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	and special educational needs **Exclusion criteria** NR			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 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**	**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. Characteristics of young people (n=16) *Age (years)* 16-17, n=4 (25%) 18-22, n=8 (50%)	**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**	**Themes** Original theme: Transition to adult health and social care services Service provisions for transition need to be improved Services lack ownership/responsibility during transition Transition was experienced as a period of uncertainty and stress Reduction in support following transition	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
1077339 **Country/ies where study was carried out** UK **Study type** Primary qualitative **Study dates** February–July 2012	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%) Down's syndrome, n=2 (12.5%) Congenital condition, n=2 (12.5%) Metabolic condition, n=1	Grounded theory approach Authors were involved in identifying and developing the codes/categories iteratively from the data		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 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	(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%)			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
	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 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 McConkey, Roy, Gent, Clare, Scowcroft, Emma, Perceptions of effective support	**Characteristics** Family member: n=14 (11 mothers, 6 fathers) Key workers: n=17 Referrers: n=17 (social workers, psychologists and community nurses)	**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	**Themes** Original theme: Negotiation: The decision to use services Desire to build good relationships with professionals and staff Families/carers were unacquainted with professionals/staff and were unaware of	**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.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
services to families with disabled children whose behaviour is severely challenging: a multi-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	**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.	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 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	their role in providing care for the child/young person Original theme: Relationships/ Relationships: Relationships with families and young people Desire to build good relationships with professionals and staff Having a good rapport with staff was valued and appreciated Original theme: Relationships: Relationships with families and young people Short breaks and respite breaks provide benefit Short breaks and respite breaks benefit the child/young person and the whole family Original themes: Benefits: Benefits to the children and young people/ Benefits: Benefits to siblings/ Benefits: Benefits to parents Short breaks and respite breaks provide benefit Short breaks and respite breaks benefit the child/young person and the whole family	**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 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.

Study details	**Participants**	**Methods**	**Themes (information in bullet points are theme(s) applied after thematic synthesis)**	**Quality assessment**
		validated by steering groups comprising staff, parents and referrers (which included some of those interviewed), and the national steering group for the 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**
Full citation National Autistic Society, School report 2015, 20,	**Characteristics** Parent/carer: n=1,431 Child/young person: n=231	**Setting** Survey was based online. Setting/method of recruitment is not reported. **Data collection**	**Themes** Original theme: Consequences of getting it wrong Need for professionals and staff to be trained properly	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
2015 **Ref ID** 725393 **Country/ies where study was carried out** UK **Study type** Survey with free text questions **Study dates** June 2015-July 2015	**Inclusion criteria** Children and young people (aged under 25 years) with autism or parent/carer of children or young people with autism. **Exclusion criteria** No additional criteria reported.	Content of survey is not reported. Appears to have included both closed and open-ended questions based on data presented. **Data analysis** Not reported	Experiencing negative consequences due to inadequate understanding of the child/young person's needs Original theme: Resorting to legal challenges Difficulty in navigating the service system Feeling a need to constantly fight for the necessary support	**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 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				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**
Full citation RIP STARS, et al.,, Defining quality and rights-based Education, Health and Care Plans (EHCPs) for disabled	**Characteristics** **Young people** **Age:** 13-25 **Sex:** n=9 female; n=6 male **Parent/carers:** n=9 mothers	**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	**Themes** Original theme: Accessible information for disabled children and young people about EHCPs Access to information and advice was important Feeling a need to proactively locate the necessary information from other sources One particular service provided the	**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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
children and young people, 36, 2018 **Ref ID** 1105868 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** Not reported	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.	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.	necessary information and support Original theme: Involvement of disabled children and young people in their EHCP Perceptions about the involvement of the children or young person Children and young people had various levels of ability which affected their level of involvement and understanding Original theme: A quality “About Me” Section The effects of EHC plans on service provisions EHC plans were considered a good reflection of the individuality of the child/young person Perceptions about the involvement of the children or young person Feeling that input from the child or young person would lead to a more accurate reflection of their support needs Original theme: Recognising children and young people's ambitions and strengths The effects of EHC plans on service provisions EHC plans were considered a good reflection of the individuality of the child/young person	**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 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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Original theme: EHCPs that support independent living, choice and control Feeling disillusioned/that services do not fully meet the needs of children or young people Lack of good quality support and input from services Original theme: Health Diagnosis as fundamental to accessing the necessary service provisions Questioning why medical history needs to be disclosed for access to services Difficulty in navigating the service system Repeating the same information was exhausting and produced negative feelings Original theme: Accountability - Making sure what is in the EHCP is delivered Difficulty in navigating the service system Feeling a need to constantly fight for the necessary support **R**Original theme: Accessible information for disabled children and young people about EHCPs	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**
Full citation	**Characteristics**	**Setting**	**Themes**	**Limitations**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
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	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).	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 to identify themes.	Original theme: Great expectations—and disappointments Difficulty in navigating the service system Repeating the same information was exhausting and produced negative feelings Original theme: The right help from the right person Desire to build good relationships with professionals and staff Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person Individual professionals/staff were valued as a source of support, expertise and advice Original theme: Changing faces Parents and carers wanted their opinions about the child/young person to be heard Parents felt they had expert knowledge about their child/young person Short breaks and respite breaks provide benefit Short breaks and respite breaks benefit the child/young person and the whole family	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Difficulty in navigating the service system Feeling a need to constantly fight for the necessary support	were conducted face-to-face or by telephone and no information is provided about content of topic guide. **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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				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, 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**	**Characteristics** Parents: n=7 Professionals: n=9 (included 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	**Setting** Parents and professionals were contacted via the 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	**Themes** Original theme: Outcomes The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Involving and valuing parents Parents and carers wanted their opinions about the child/young person to be heard Parents/carers felt positively when given the opportunity to provide their views Original theme: Ascertaining the views of children and young people Perceptions about the involvement of the children or young person	**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 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
1105883 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** June 2016-August 2016		(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 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	Children and young people had various levels of ability which affected their level of involvement and understanding	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?** 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.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		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.		**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**
Full citation Skipp, Amy, Hopwood, Vicky, A. S. K. Research, Mapping user	**Characteristics** Parents: n=77 Child/young person: n=15 **Whole sample**	**Setting** Families and young people were recruited through SEND teams within four local authorities in England. The local authorities were	**Themes** Original theme: Experiences of identification Desire to build good relationships with professionals and staff	**Limitations** **Q1 Was there a clear statement of the aims of the research?** Yes **Q2 Was a qualitative methodology**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
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	**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.	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 were audio recorded if parents gave permission. Qualitative data from children/young people was	The opportunity to meet with professionals and staff produced positive feelings Access to information and advice was important More information and advice was needed Original theme: Experiences of assessment Perceptions about the involvement of the children or young person Feeling that input from the child or young person would lead to a more accurate reflection of their support needs The effects of EHC plans on service provisions EHC plans were considered a good reflection of the individuality of the child/young person Diagnosis as fundamental to accessing the necessary service provisions Frustration with the time taken and difficulty in obtaining a diagnosis Original theme: Experiences of planning The effects of EHC plans on service provisions EHC plans provided reassurance that	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		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 analysed and organised into themes by two	support will be in place to meet the needs of the child/young person Parents and carers wanted their opinions about the child/young person to be heard Parents expressed negative feelings when their views were ignored Parents felt they had expert knowledge about their child/young person Original theme: Experiences of putting plans into action Desire to build good relationships with professionals and staff Having a good rapport with staff was valued and appreciated Original theme: Experiences of support Access to information and advice was important Peer support as a beneficial source of information Desire to build good relationships with professionals and staff Individual professionals/staff were valued as a source of support, expertise and advice Original theme: Sub-group variation Feeling disillusioned/that services do not	independent of services but unclear if the researchers considered potential 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)**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		experienced researchers. Findings were triangulated with other recent evidence and practitioners and experts reviewed the findings and provided feedback.	fully meet the needs of children or young people Lack of good quality support and input from services Original theme: Experiences of planning Parents and carers wanted their opinions about the child/young person to be heard Parents/carers felt positively when given the opportunity to provide their views	Yes: Contribution to the literature, including recommendations for practice, are clearly discussed. **Source of funding** No sources of funding reported **Other information**
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	**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	**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	**Themes** Original themes: The role played by the key worker; Effectiveness of the key worker; Interactions with professionals Desire to build good relationships with professionals and staff Individual professionals/staff were valued as a source of support, expertise and advice Original theme: Positive experience of multi-agency meetings Desire to build good relationships with professionals and staff The opportunity to meet with professionals and staff produced positive feelings Original theme: Child/family-centred focus	**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

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
report, 92, 2014 **Ref ID** 1103975 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** January 2014-March 2014	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 Other Black or Asian background: n=-2 **Characteristics of interviews:** n=23 mother n=5 father	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 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	Desire to build good relationships with professionals and staff Having a good rapport with staff was valued and appreciated Original theme: Interactions with professionals A need for effective communication Staff and professionals should tailor communication to suit the individual and circumstances Original theme: Direct involvement of children and young people Perceptions about the involvement of the children or young person Feeling that input from the child or young person would lead to a more accurate reflection of their support needs Original theme: Outcomes Parents and carers wanted their opinions about the child/young person to be heard Parents/carers felt positively when given the opportunity to provide their views Original theme: Satisfaction with the process Desire to build good relationships with professionals and staff	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 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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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	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 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.	The opportunity to meet with professionals and staff produced positive feelings Having a good rapport with staff was valued and appreciated The effects of EHC plans on service provisions EHC plans were considered a good reflection of the individuality of the child/young person Original theme: Dissatisfaction with process Desire to build good relationships with professionals and staff Wanting to be kept informed on the progression of care Original theme: Degree of choice The effects of EHC plans on service provisions EHC plans provided reassurance that support will be in place to meet the needs of the child/young person Original theme: Direct payments Budgets made a difference to the care received Belief or experience that personal	**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
			budgets or direct payments would make a positive impact Original theme: Need for information Access to information and advice was important Peer support as a beneficial source of information Original theme: Receiving the support and services in their plan The effects of EHC plans on service provisions EHC plans provided reassurance that support will be in place to meet the needs of the child/young person Original theme: Not receiving the support and services in their plan Desire to build good relationships with professionals and staff Wanting to be kept informed on the progression of care Original theme: New or increased services The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Budgets made a difference to the care received Belief or experience that personal budgets or direct payments would make a positive impact Original theme: Improvements in existing support The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Other outcomes Perceptions about the involvement of the children or young person Observations that the child/young person grew in confidence over a period of involvement Children and young people felt positively about their involvement Feeling that input from the child or young person would lead to a more accurate reflection of their support needs Difficulty in navigating the service system Repeating the same information was exhausting and produced negative feelings	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			Feeling disillusioned/that services do not fully meet the needs of children or young people Lack of good quality support and input from services Original theme: New or increased services The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Negative outcomes Service provisions for transition need to be improved Transition was experienced as a period of uncertainty and stress	
Full citation Thom Graham, et al.,, The Special Educational Needs and Disability Pathfinder Programme evaluation:	**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:	**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	**Themes** Original theme: Child/family-centred process Parents and carers wanted their opinions about the child/young person to be heard Parents/carers felt positively when given the opportunity to provide their views Original theme: Joint working	**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**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
final impact research report, 238, 2015 **Ref ID** 1139296 **Country/ies where study was carried out** UK **Study type** Mixed methods, including interviews **Study dates** December 2012-January 2015	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: 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	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 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	Desire to build good relationships with professionals and staff Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person Original theme: Key worker and professional support Desire to build good relationships with professionals and staff Individual professionals/staff were valued as a source of support, expertise and advice Original theme: Information provision and the local offer Access to information and advice was important Feeling a need to proactively locate the necessary information from other sources Original theme: Health and wellbeing The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Social contact, independence and confidence	**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 into consideration?** Can't tell: No information is reported. **Q8: Was the data analysis sufficiently rigorous?** Can't tell: Limited information reported

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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 Female: n=16 Age - 0-4 years: n=7	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, 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	Budgets made a difference to the care received Belief or experience that personal budgets or direct payments would make a positive impact Perceptions about the involvement of the children or young person Feeling that input from the child or young person would lead to a more accurate reflection of their support needs Original theme: Experience of education and aspirations The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person Original theme: Parental outcomes Desire to build good relationships with professionals and staff Having a good rapport with staff was valued and appreciated The effects of EHC plans on service provisions EHC plans led to improvements in support and/or outcomes of the child/young person	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 2014, Spivack 2014 and Thom 2014).

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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	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 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	Short breaks and respite breaks provide benefit Short breaks and respite breaks benefit the child/young person and the whole family	

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	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 reported.	used.		
Full citation Young, L., Egdell, A., Swallow, V., Qualitative accounts of young-people, parents and staff involved with a purpose-designed, pilot short-break service for 18-24year olds with life-limiting conditions, Children and Youth Services Review, 86,	**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 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	**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** 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	**Themes** Original theme: The need for a specialist short-break service Difficulty in navigating the service system Feeling a need to constantly fight for the necessary support Original theme: Decision making when using or delivering the service Perceptions about the involvement of the children or young person Children and young people felt positively about their involvement Short breaks and respite breaks provide benefit Short breaks and respite breaks benefit the child/young person and the whole	**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 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?**

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
142-150, 2018 **Ref ID** 1105987 **Country/ies where study was carried out** UK **Study type** Qualitative **Study dates** Not reported	adults registered with the service; health or social-care staff working with the service **Exclusion criteria** No additional criteria reported	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.	family Original theme: Challenges of staffing and financing the service Desire to build good relationships with professionals and staff Having a good rapport with staff was valued and appreciated A need for effective communication Staff and professionals should tailor communication to suit the individual and circumstances Original theme: Suggestions for how to improve the service Service provisions for transition need to be improved Reduction in support following transition	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, written/verbal information was presented in an appropriate way for

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

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

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 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?

Table 5: Evidence profile: Theme 1. Desire to build good relationships with professionals and staff

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: Families/carers were unacquainted with professionals/staff and were unaware of their role in providing care for the child/young person					
5 (Fox 2017, Griffith 2013, McConkey 2013, Rodriguez 2014, Thom 2015)	4 qualitative studies using semi-structured interviews; 1 qualitative study using focus groups; 1 mixed methods study using interviews	Service users struggled to recall the names and/or roles of professionals/staff involved in the care of the child/young person. Confusion about the number and purpose of appointments, and concerns about the people working in the service that were unknown to them were also reported. “There were different people who used to observe X* in nursery. They had notebooks and were writing down information as X* came to the nursery. I didn’t know exactly who they were, but I’m assuming it was this lady who has sent them to observe them to maybe make the decision of what was wrong with her” (Fox 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	

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 1.2: Individual professionals/staff were valued as a source of support, expertise and advice					
7 (Adams 2018, Boyce 2015, Kiernan 2019, Rodriguez 2014, Skipp 2016, Smith 2014, Thom 2015)	2 qualitative studies using interviews; 3 qualitative studies study using semi-structured interviews; 1 qualitative study using focus groups; 1 mixed methods study using interviews	Service users identified with one individual professional that had been particularly valuable in providing support, expertise and advice to the family and the child/young person. Some services were not necessarily involved but provisions were provided because of the work of the individual professional. Individual professionals included key workers, advocates assistant, eye clinic liaison officers and nurses. "The behaviour nurse was the best thing that ever happened. Hugely intensive I have to say but the advice and time and support that he spent with us as a family, trying to understand the triggers, trying to find the right kind of methods to work with him, was phenomenally beneficial" (Kiernan 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 1.3: The opportunity to meet with professionals produced positive feelings					
2 (Skipp 2016, Smith 2014)	1 qualitative study using interviews; 1 qualitative study using semi-structured interviews	Service users felt positively when given the opportunity to meet with professionals face-to-face and discuss the needs of their child/young person. "We were invited to an evening at the school with other parents. The whole team were there and they explained everything to us that was going to happen. We could ask questions and get to talk to all the staff. It was good to meet them and put faces to names. There was the SENCO from our child's school and the EHC co-ordinator and her boss. The parent partnership people were there and we were told that they could help us, but we don't think we'll need it." (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	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
				concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 1.4: Having a good rapport with staff was valued and appreciated					
5 (McConkey 2013, Skipp 2016, Young 2018, Smith 2014, Thom 2015)	1 qualitative study using interviews; 3 qualitative studies using semi-structured interviews; 1 mixed methods study using interviews	Service users felt better supported when relationships with staff were positive and involved staff who were willing to work with, and learn from families, as well as share their own professional expertise. Some service users felt concern that the child/young person's medical needs would not be effectively met, but having a support network of professionals to draw on reduced this anxiety. "I see them really as friends rather than workers and carers … whereas in school I wouldn't really be getting involved with her teacher very often (because) there was only one teacher to so many kids, so there wasn't really a rapport with the teachers as what there is a rapport when I meet staff at X." (McConkey 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 1.5: Lack of time to communicate with professionals and staff produced feelings of anxiety					
2 (Council For Disabled	1 survey with free text	Service users wanted more time to sit down and talk with professionals and staff and presented with negative feelings when they were unable	Methodological	Moderate concerns	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Children 2018, Hurt 2019)	questions; 1 mixed methods study using focus groups	to. One service user recounted worry after being presented with the results of their child/young person's assessment via letter, and another felt that they were not given adequate time to ensure they were providing their child's exercise therapy in the correct way. "They didn't have time to talk to me so I was left feeling quite frightened I guess and worried thinking 'this sounds huge, this sounds really serious, I don't really know what it is" (Council For Disabled Children 2018)	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 1.6: Wanting to be kept informed on the progression of care					
3 (Adams 2018, Brooks 2013, Smith 2014)	2 qualitative studies using interviews; 1 qualitative study using semi-structured interviews	Service users wanted to be kept up-to-date with the progress of their child/young person's care. This included the drafting and progressing of their EHC plan, and providing adequate services and care regimens (particularly when the child/young person was hospitalised). Some families felt stressed and frustrated by lack of information around delays, while families that were kept informed felt more positively. "'None of it has been delivered but I do know it's in hand because I've had phone calls from people saying, 'I haven't been able to get it to you but I haven't forgotten about this', which is nice. I feel like it's not just on the backburner or I'll do that later. Somebody is doing something about it." (Smith 2014)	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	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
				concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	

EHC: education health and care; SENCO: special educational needs coordinator

Table 6: Evidence profile: Theme 2. Access to information and advice was important

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: One particular service provided the necessary information and support					
1 (RIP STARS 2018)	1 qualitative study using interviews and group discussions	Service users would have liked more access to information and support. In one case, the information about EHC plans was provided by education services and this led to a positive experience. "Yes because we did through school and because it was a special school they did it very well, they understood everything in detail" (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	Minor concerns Some evidence is ambiguous or contradictory without a	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
				credible explanation for differences	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 2.2: Peer support as a beneficial source of information					
2 (Skipp 2016, Smith 2014)	1 qualitative study using interviews; 1 qualitative study using semi-structured interviews	Service users benefited from speaking to other peers who had experience with the system to gain an independent perspective, and to confirm that the information they received from services was correct. "I got lots of information from the service but it made a real difference to hear it from a local woman whose son was older than mine, but with the same sort of needs. She'd got a plan and told me about local schools and what questions to ask" (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 2.3: More information and advice was needed					
4 (Children'S	2 qualitative	Service users needed more information and advice about diagnosis	Methodological	Moderate	Low

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Commissioner For Wales 2018, Fox 2017, Hurt 2019, Skipp 2016)	studies using semi-structured interviews; 1 qualitative study using focus groups; 1 mixed methods study using focus groups	and processes including the role of others, and their role in parenting, caring and supporting the child/young person. "I was so depressed. I didn't know where to turn to and I had to get used to being in this position. It wasn't all out there. You really have to search for it. There was nothing that said here's the information if your child is bad at school, no leaflet. Nothing said what is happening or these are the steps. It wasn't good at all. If there was more information for parents in my situation, who didn't know what was going on, that's what's needed." (Skipp 2016)	limitations	concerns about methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	Minor concerns Some evidence is ambiguous or contradictory without a credible explanation for differences	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 2.4: Feeling a need to proactively locate the necessary information from other sources					
6 (Adams 2018, Dillenburger 2016, Fox 2017, Griffith 2013, RIP	2 qualitative studies using interviews; 2 qualitative studies using semi-	Service users felt that not all the necessary information was provided on aspects of the chid/young person's care such as policy, planning, process, service structures, assessment, and diagnosis. As a result, families felt a need to rely on other sources of information such as attending conferences, training sessions, voluntary support groups, researching on-line, relatives and friends. Some families felt they may	Methodological limitations	Moderate concerns about methodological limitations of the evidence	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
STARS 2018, Thom 2015)	structured interviews; 1 qualitative study using interviews and group discussions; 1 mixed methods study using interviews	be disadvantaged if they were less able or proactive in accessing information. "I spent hours on the computer and going to places just to find out what is available, and luckily we are proactive so we do find them, but some people are not and they need that guidance." (Thom 2015)		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 2.5: Frustration due to information that is out of date					
1 (Hurt 2019)	1 mixed methods study using focus groups	Service users felt that after diagnosis, the support provided was limited and often based on out-dated information. "They gave me a sheet that they did about ten years ago. And said, off you go. Looked them all up, they didn't exist anymore" (Hurt 2019)	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	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
				The study offered moderately rich data	

EHC: education health and care

Table 7: Evidence profile: Theme 3. A need for effective communication

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: Staff and professionals should tailor communication to suit the individual and circumstances					
4 (Adams 2017, Fox 2017, Smith 2014, Young 2018)	2 qualitative studies using semi-structured interviews; 1 qualitative study using interviews; 1 survey with free text questions	Service users appreciated when staff and professionals adapted their communication style to suit the individual and circumstances. This included adapting language when speaking to children to ensure they understand effectively, and relating to young adults in a way that was not patronising. Also when delivering the news of diagnosis when feelings of shock, confusion, denial, upset and sadness were apparent. "They understand [Child] is different, so they might, you know, talk to her differently - not like she's a baby, but, you know, maybe for her to understand better." (Smith 2014)	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	Minor	

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
				concerns Studies together offered moderately rich data	
Sub-theme 3.2: Difficult to understand complicated terminology					
2 (Adams 2018, Fox 2017)	1 qualitative study using interviews; 1 qualitative study using semi-structured interviews	Service users encountered complicated terminology during the process of accessing services and proficient English speakers reported that terms or words used were incomprehensible. One service user that received specialist SEND centre support in understanding the terminology had a stronger grasp of the final EHC plan content. "You have to do it by yourself. But if you are not doing good what you want to do and you are not thinking and sometimes you can get more terminology words on their reports or sometimes you cannot understand it, you have to get a dictionary, whatever it is." (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	Minor concerns Studies together offered moderately rich data	

EHC: education health and care; SEND: special educational needs and disability

Table 8: Evidence profile: Theme 4. Difficulty in navigating the service system

Study information	**Description of theme or finding**	**CERQual assessment of the evidence**

Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 4.1: Repeating the same information was exhausting and produced negative feelings					
4 (Dillenburger 2016, RIP STARS 2018, Rodriguez 2014, Smith 2014)	2 qualitative studies using interviews; 1 qualitative study using interviews and group discussions; 1 qualitative study using focus groups	Service users expressed frustration and a feeling of reliving traumatic experiences when having to provide the same details about the child/young person on multiple occasions. Service users felt that if staff/professionals were to communicate effectively with one another this would reduce the effort needed to repeat information and reduce negative feelings. "“We have had over 20 professionals in our home ... and we have had to tell each and every one of them about our child and their illness history and what the plan is, it’s exhausting” (Rodriguez 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	
Sub-theme 4.2: Getting the necessary care demanded significant energy and organisation					
4 (Adams 2018, Children's Commissioner For Wales 2018, Council For Disabled Children 2018, Griffith 2013)	1 qualitative study using interviews; 1 qualitative study using focus groups; 2 qualitative studies using semi-structured interviews	Service users expressed the need to expend a considerable amount of time and energy in order to constantly chase services for information, and conduct administrative work in relation to their request for a plan. Service users expected services to take more ownership of their cases, and expressed a need for resilience to cope with the stress and challenges in navigating a complex process whilst also caring for their child/young person. Transition was mentioned as a period that lacked coordination and so decisions were delayed. "You've got to learn and understand how all the different departments work within health and education, and then do a nice big mind gap and link them together, because the process is very complex and trying to	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
		get hold of the information isn't the easiest thing to do" (Griffith 2013)		concerns	
			Coherence	Minor concerns Some evidence is ambiguous or contradictory without a credible explanation for differences	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 4.3: Feeling a need to constantly fight for the necessary support					
6 (Council For Disabled Children 2018, Griffith 2013, National Autistic Society 2015, RIP STARS 2018, Rodriguez 2014, Young 2018)	3 qualitative studies using semi-structured interviews; 1 qualitative study using interviews and group discussions; 1 qualitative study using focus groups; 1 survey with free text	Service users felt they were constantly fighting the system rather than having a collaborative relationship with services. Provision and resources were not always forthcoming and service users needed to make requests and at times demands to receive the necessary support. "Everything is a fight, from fighting to get specially fitted shoes to getting respite care to prevent us breaking down.” (Rodriguez 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	

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
	questions		Adequacy	None or very minor concerns	

Table 9: Evidence profile: Theme 5. Feeling disillusioned/that services do not fully meet the needs of children or 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 5.1: Opting out of seeking support due to disillusion of statutory provision					
1 (Dillenburger 2016)	1 qualitative study using interviews	Service users felt disillusionment with statutory provisions and thought there was little point in requesting help so opted out of seeking support. “We get no help, but I don’t want that kind of help, I have no energy for it.” (Dillenburger 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 The study offered moderately rich data	
Sub-theme 5.2: Distrust of services to take care of child young person when the parent is unable to					
2 (Children's Commissioner	1 qualitative study using	Parents felt that they coordinated most of the services for their child/young person, and expressed a fear of what would happen to the	Methodological limitations	Moderate concerns	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
For Wales 2018, Hurt 2019)	focus groups; 1 mixed methods study using focus groups	child/young person when they became too old, fragile or vulnerable to push for services, or when they deceased. "My biggest, darkest fear is dying and leaving him alone in the world. I don't trust anyone to look after him as well as I do...and there have been so many instances where society, where those who are supposed to support us have let us down." (Children's Commissioner For Wales 2018		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 5.3: Frustration in lack of clarity as to how resources would be allocated					
1 (Hurt 2019)	1 mixed methods study using focus groups	Service users appreciated that there was a lack of resources, but expressed frustration due to a lack of clarity in how resources would be allocated to the child/young person. "That is standard response […] 'The money will follow the child.' Well, that's fine but the child's got to be in the system for the money to follow […]. How do you get the child to get in the system?" (Hurt 2019)	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	

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
				minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 5.4: Lack of good quality support and input from services					
8 (Adams 2017, Boyce 2015, Dillenburger 2016, Griffith 2013, Kiernan 2019, RIP STARS 2018, Skipp 2016, Smith 2014)	4 qualitative studies using semi-structured interviews; 2 qualitative studies using interviews; 1 qualitative study using interviews and group discussions; 1 survey with free text questions	Service users reported not receiving the level of support or input that they expected from services. This was reported by a number of service users after diagnosis when they were left feeling that they had to cope on their own. Some reported being fobbed off and frustrated, and that the ethos of a new system did not translate into practice such as quality input from health and care services. "We'd read all about how everyone would be at this meeting and we'd sort it all out in one go. I really wanted it to be better. But surprise surprise the CAMHS team still can't make time to provide anything useful and the paediatrician still can't communicate with us like humans. On paper it looked great, but the reality is still the same as before." (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	None or very minor concerns	
Sub-theme 5.5: Parents have felt the need to give up work to support the child					
1 (Children's Commissioner For Wales 2018)	1 qualitative study using focus groups	Parents felt the need to give up work completely, or work part-time due to difficulty in managing work and caring duties. This was particularly apparent in single parents and women. "I had to give up full time work because of school and health appointments for my son. Now I work part time a few hours to boost my	Methodological limitations	Major concerns about methodological limitations of the evidence	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
		carers' allowance." (Children's Commissioner For Wales 2018)		as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 5.6: Need for specialist support or special provisions					
5 (Adams 2018, Children's Commissioner For Wales 2018, Council For Disabled Children 2018, Dillenburger 2016, Fox 2017)	2 qualitative studies using semi-structured interviews; 2 qualitative studies using interviews; 1 qualitative study using focus groups	Specialist support and special provisions were viewed as beneficial by service users and they expressed a need for these to be provided to improve the care of the child/young person. Some parents indicated receiving specialist support from a SEND centre, however others pursued access to specialists and detailed, comprehensive assessments or treatments which sometimes led to expensive consultation costs. "The presentation looks like developmental trauma, looks like attachment issues, it looks like ADHD, can look like autistic spectrum, it can look like lots of different things and that's part of the problem and it's only now that we've got to go a specialist [...] where they have the skills to unpack all those different complex strands" (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	

ADHD: attention deficit hyperactivity disorder; CAMHS: child and adolescent mental health services; SEND: special educational needs and disability

Table 10: Evidence profile: Theme 6. Diagnosis as fundamental to accessing the necessary 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 6.1: Acceptance of an inaccurate diagnosis to access available resources					
1 (Council For Disabled Children 2018)	1 qualitative study using semi-structured interviews	Service users reported that some diagnoses may not attract early resources, therefore children/young people may be given an imprecise diagnosis to receive the appropriate care. "Currently in education a diagnosis of foetal alcohol syndrome does not attract all the resources that would be required […] so, that they want is for you to give him the diagnosis of autism but sometimes you can't […] straight away" (Council For Disabled Children 2018)	Methodological limitations	Major 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	Minor concerns The study offered moderately rich data	
Sub-theme 6.2: Improved access to services post diagnosis led to feelings of relief when receiving diagnosis					
2 (Council For	2 qualitative	Service users expressed relief at receiving a diagnosis due to	Methodological	Moderate	Low

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Disabled Children 2018, Griffith 2013)	studies using semi-structured interviews	experiencing barriers in accessing services without a diagnosis, and a belief that they would now be able to access the appropriate services and gain the necessary support for the child/young person. "He just looked at [my child] and he went, "he's got foetal alcohol syndrome" and I went, (long sigh) and then deflated" (Council For Disabled Children 2018)	limitations	concerns about methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	Minor concerns Some evidence is ambiguous or contradictory without a credible explanation for differences	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 6.3: Frustration with the time taken and difficulty in obtaining a diagnosis					
4 (Council For Disabled Children 2018, Dillenburger 2016, Hurt 2019 Skipp	2 qualitative studies using semi-structured interviews; 1 qualitative	Services users felt they were only able to effectively utilise services once the child/young person had a diagnosis and expressed frustration with the time taken and difficulty in obtaining a diagnosis. Service users felt that some professionals did not have the experience or appropriate knowledge to diagnose, or exhibited a watchful-wait policy that in some circumstances conflicted with the interests of parents who were living	Methodological limitations	Moderate concerns about methodological limitations of the evidence	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
2016)	study using interviews; 1 mixed methods study using focus groups	with the child/young and felt their concerns were undermined or dismissed. "They said he had the abilities of a six-year-old, which came as a real shock to us. He's 15 and nothing's ever been picked up or mentioned to us before. When we told the schools, right from primary, we thought he was struggling they just said he needed to pay more attention. All that time we've lost…" (Skipp 2016)		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 6.4: Questioning why medical history needs to be disclosed for access to services					
1 (RIP STARS 2018)	1 qualitative study using interviews and group discussions	Young people expressed concerns over the need to provide details of their health condition to access services. "Why can't we ask for access needs without having to disclose our medical history? Can't an EHCP be on a need to know basis?" (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	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
				The study offered some rich data	

EHCP: education health and care plan

Table 11: Evidence profile: Theme 7. The effects of EHC plans on 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 7.1: EHC plans led to improvements in support and/or outcomes of the child/young person					
5 (Adams 2017, Adams 2018, Sales 2018, Smith 2014, Thom 2015)	3 qualitative studies using interviews; 1 mixed methods study using interviews; 1 survey with free text questions	Service users expressed positive views about EHC plans and felt they had led to improved support and/or outcomes in the child/young person. "Initially before he started [primary school] there were concerns he wouldn't be able to catch up with things. On his initial assessments in September / October he was only achieving up to 24-36 months on things but on his recent parent evening, in the majority of areas, he is reaching up to 60 months which is age equivalent, so the proof [of whether or not the plan is helping to achieve the agreed outcomes] is in the pudding." (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	
Sub-theme 7.2: EHC plans provided reassurance that support will be in place to meet the needs of the child/young person					
2 (Skipp 2016, Smith 2014)	1 qualitative study using semi-structured	Service users felt their views and wishes were captured and reflected in the EHC plan and that it offered a sense of reassurance that services would continue in the future.	Methodological limitations	Moderate concerns about methodologica	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
	interviews; 1 qualitative studies using interviews	"Everything about the plan is spot on. It's great. Our family story was written by me with our family worker and shows our dreams for Sonny. That he'll go shopping, have his own money, be his own person and live as independent a life as possible. I feel it sets out how he's going to develop and how we'll be supported." (Skipp 2016)		l 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 7.3: EHC plans were considered a good reflection of the individuality of the child/young person					
3 (RIP STARS 2018, Skipp 2016, Smith 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews; 1 qualitative study using interviews and group discussions	Service users felt EHC plans were personal and tailored to reflect a full and complete picture of the individuality of the child/young person, not just in an academic context but to include all their needs, as well as their strengths and ambitions for the future. "I actually think everything should be included because everything makes the young person who they are which in my son's case it's in his views and aspirations and it talks about him been sociable and having his football, his computer, what he likes, what we are concerned about, where he has problems; then it has a summary of his special educational strengths and needs; it talks about him been lively and strong willed (which he is). So, on my son's I don't think anything is omitted because it talks about social, educational well-being, communication, interactions; seems to have everything in there." (RIP STARS 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	

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Moderate concerns Studies together offered some rich data	

EHC: education health and care

Table 12: Evidence profile: Theme 8. Perceptions about the involvement of the children or young person

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 8.1: Children and young people felt positively about their involvement					
2 (Smith 2014, Young 2018)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews	Young adults felt happy when involved in decision making about their own care, and described taking ownership as an empowering experience. "I have had quite a lot of input and some support workers can also drive my [adapted] van…so I can decide on the day where I'm going." (Young 2018)	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	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
				differences	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 8.2: Observations that the child/young person grew in confidence over a period of involvement					
1 (Smith 2014)	1 qualitative study using interviews	Giving the child/young person the opportunity to voice their opinions led to an increase in their confidence and the ability to express their views. "As the meetings went along I felt like she was hosting it, you know, because she got more comfortable with everyone there." (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	Minor concerns The study offered moderately rich data	
Sub-theme 8.3: Feeling that input from the child or young person would lead to a more accurate reflection of their support needs					
5 (Adams 2018,	1 qualitative study using semi-	Service users felt that input from the child/young person was important, positive and empowering, and yielded useful information that led to	Methodological limitations	Moderate concerns about	Moderate

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
RIP STARS 2018, Skipp 2016, Smith 2014, Thom 2015)	structured interviews; 2 qualitative studies using interviews; 1 qualitative study using interviews and group discussions; 1 mixed methods study using interviews	support that more accurately reflected their views about their needs. "They should be allowed, you know, to say what they want to do, what they think, because I might think that he wants something completely different. If I'd gone in without him I might have said something different, whereas he's actually in there, so it's his decision." (Smith 2014)		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 8.4: Children and young people had various levels of ability which affected their level of involvement and understanding					
4 (Adams 2017, Adams 2018, RIP STARS 2018, Sales 2018)	2 qualitative studies using interviews; 1 qualitative study using interviews and group discussions; 1 survey with free text questions	Service users felt that the involvement and understanding of the child/young person was dependent on their level of ability. Some service users felt that participation was inappropriate for their child/young person's age, or nature of their special educational need or disability, while others described attempts to fully involve the child/young person as positive, despite ultimately failing to have much impact on the process or the final plan. "There was no way he would have coped with all the different questions. So, I would do one question, he would have a fit, and then we would maybe get two sentences out and then I would write them" (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	

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
				concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	

Table 13: Evidence profile: Theme 9. Parents and carers wanted their opinions about the child/young person to be heard

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: Parents/carers felt positively when given the opportunity to provide their views					
5 (Children's Commissioner For Wales 2018, Sales 2018, Skipp 2016, Smith 2014, Thom 2015)	1 qualitative study using semi-structured interviews; 2 qualitative studies using interviews; 1 qualitative study using focus groups; 1 mixed methods study using interviews	Service users expressed positive feelings when they had the opportunity to provide their views and felt that their views have been heard. The chance to provide feedback on what was working well and what was working less well was appreciated, as well as co-producing EHC plans with a multi-agency team. Some service users expressed that the EHC process provided more opportunities to be involved compared to the previous statements. "For the Statement process there was no involvement for the parents' but in relation to the EHC process, 'At no point did I feel that I was any less valued or professional than they were. It was really good." (Sales 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 9.2: Parents expressed negative feelings when their views were ignored					

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
1 (Skipp 2016)	1 qualitative study using semi-structured interviews	Parents expressed negative feelings when their views were not given sufficient weight in final decisions or adequately reflected in the EHC plan. "I took the time to read through and consider the draft plan. I made comments on it and sent these back to the council. The plan was then re-issued in its original state with none of the comments or changes. I'd just been ignored!" (Skipp 2016)	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 9.3: Parents felt they had expert knowledge about their child/young person					
4 (Brooks 2013, Dillenburger 2016, Rodriguez 2014, Skipp 2016)	2 qualitative studies using semi-structured interviews; 1 qualitative study using interviews; 1 qualitative study using focus groups	Parents felt they had developed an expert status about their child/young person, stemming from knowing their child/young person best, intense caring responsibilities and being the one most alert to changes. Parents expressed knowledge of their child/young person's diagnosis prior to professional diagnosis. In some cases, parents felt they were not respected as experts by professionals and/or responded to defensively, and had informally appealed against panel recommendations that they did not agree with. "I think sometimes doctors don't realise that we know so much about our children; we've not got any medical training but we've had so much input over the years that we often can, and do, know what's wrong with our child. You have to go and tell the doctor what's wrong and it doesn't always go down very well" (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	

Study information		Description of theme or finding	CERQual assessment of the evidence		
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 9.4: Praise for practitioners who valued the expertise of parents but maintained appropriate boundaries					
1 (Council For Disabled Children 2018)	1 qualitative study using semi-structured interviews	Service users expressed praise for practitioners that had valued their expertise as parents of the child/young person, but had also maintained appropriate professional boundaries. "They've treated me as an adult without being patronising, because I obviously know some of the system, but without letting me do it all because I know some of the system" (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	Minor concerns The study offered moderately rich data	

EHC: education health and care

Table 14: Evidence profile: Theme 10. Need for professionals and staff to be trained properly

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

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: Experiencing negative consequences due to inadequate understanding of the child/young person's needs					
1 (National Autistic Society 2015)	1 survey with free text questions	Service users experienced severe consequences threatening to reduce the life chances of the child/young person and cause greater health and support needs due to incorrect decisions from professionals who have inadequate understanding of the child/young person and their needs. "My son ended up suicidal and on Prozac aged ten, due to lack of understanding, lack of appropriate educational placement and no support. The SEN Tribunal Judge put his serious mental health difficulties down to his inadequate education and a lack of understanding of his needs, rather than his autism." (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 The study offered moderately rich data	

SEN: special educational needs

Table 15: Evidence profile: Theme 11. Service provisions for transition need to be improved

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: Transitioning through education services was challenging and produced varied experiences					
1 (Cohen 2017)	1 survey with free text questions	Service users expressed varying experiences and challenges when transitioning through the different stages of education services. "My son had fantastic support in primary school but not very good at secondary school" (Cohen 2017)	Methodological limitations	Major concerns about methodological limitations of	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns The study offered moderately rich data	
Sub-theme 11.2: Variation in age of transition across regions and services					
1 (Children's Commissioner For Wales 2018)	1 qualitative study using focus groups	Service users experienced considerable variation in thresholds between child and adult services across regions and services. Transition in social care was experienced at different ages depending on locality, and the withdrawal of child services to prepare for adult services prior to these being available. "You get dropped at 16,17,18" (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	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				The study offered moderately rich data	
Sub-theme 11.3: Parents felt shut out once the child/young person reached adulthood					
1 (Children's Commissioner For Wales 2018)	1 qualitative study using focus groups	Parents felt that their experience of supporting the child/young person was often ignored once the child/young person reached adult services. "Adult services do not recognise the parents' role and so you get shut out." (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 The study offered moderately rich data	
Sub-theme 11.4: Reduction in support following transition					
4 (Children's Commissioner For Wales 2018, Dillenburger 2016, Kirk 2014, Young	2 qualitative studies using semi-structured interviews; 1 qualitative study using	Service users reported a loss of, or reduction in services following transition, particularly for those with complex, specialised needs. Service users experienced discontinuation of support, care and understanding once the child/young person approached adulthood and transitioned into adult services. Service users reported being signed off prior to transition and therefore unable to access adult services, and services ceasing once the child/young person reached 18 years and	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
2018)	interviews; 1 qualitative study using focus groups	having to apply for adult services. "It's been a nightmare really, we've gone from 28 nights a year respite on the Home from Home scheme it's called, and four hours a week through children's services on the Voucher scheme. Well now E's turned 18 that has all stopped. … nothing's been done, so all services have stopped, we've no adult budget for her, we've no care plan, we've no support package, there's just nothing … at the minute we're just in the black hole of nowhere … everybody seems to be discharging her; we've been discharged from the physios, discharged from the OT, discharged from the dietician." (Kirk 2014)		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 11.5: Transition was experienced as a period of uncertainty and stress					
3 (Children's Commissioner For Wales 2018, Kirk 2014, Smith 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews; 1 qualitative study using focus groups	Service users described transition as a period of uncertainty and experienced considerable anxiety over the availability of future services and support for the child/young person. Service users experienced stress navigating the bureaucracy around transition, and worry due to late decision making despite transition planning taking place over several years. "It was one of the worst years, I mean, in my life, I found it really stressful and frustrating and that was due to the lack of transition into, supposedly, adult services and the frustrations … I knew it wouldn't be easy, but a lot of it, I think, was just made really difficult, unnecessarily harder than it needed to be, because any change is hard, isn't it? But when you just feel so isolated and so, I just get frustrated, … it's nearly beaten me, last year I just felt, like, you know, throwing the towel in, it just, really, really broke me and I just can't believe how frustrating it was and unnecessarily difficult." (Kirk 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	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				together offered moderately rich data	

OT: occupational therapist

Table 16: Evidence profile: Theme 12. Budgets made a difference to the care received

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 12.1: Belief or experience that personal budgets or direct payments would make a positive impact					
4 (Dillenburger 2016, Hutton 2018, Smith 2014, Thom 2015)	2 qualitative studies using interviews; 1 qualitative study using focus groups or interview; 1 mixed methods study using interviews	Service users experienced or perceived that personal budgets or direct payments would have a positive impact on the care of the child/young person by allowing autonomy and flexibility to organise care that matched the needs of the family and child/young person. "… there was …a residential home, where they can go for a weekend or so … it's not fit for purpose, the whole building isn't fit for purpose. There were no other options like family placement, adult family placement ... [I said] I'm sorry, I'm not prepared to go with this particular residential place and [son] said 'Well I will go for my tea but I'm not staying over here', and that's why we went for Direct Payments." (Dillenburger 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	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
Sub-theme 12.2: Uncertainty around the entitlement to, or effectiveness of personal budgets or direct payments					
1 (Hutton 2018)	1 qualitative study using focus groups or interview	Service users expressed uncertainty as to whether personal budgets or direct payments applied to them or not, what could be purchased with the funds and whether they improved the child/young person's access to services. Service users did not want to be disadvantaged by having a personal budget or direct payment and expressed concerns around having to prioritise within the constraints of a limited budget which may not be equivalent to the level of funding which is already available. Service users were concerned that personal budgets or direct payments may result in uneven provision with high demand for some services leading to shortages in provision and a reduction in services that were considered less desirable. Some service users could see the potential of a personal budget or direct payment however they were unsure whether either would be applicable to their circumstances. "I don't know if it's only very profoundly disabled children who are entitled to that budget or quite how that works, and no one's ever suggested that I would be entitled to a budget" (Hutton 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	Minor concerns The study offered moderately rich data	

Table 17: Theme 13. Short breaks and respite breaks provide benefit

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: Short breaks and respite breaks benefit the child/young person and the whole family					
4 (McConkey 2013, Rodriguez 2014, Thom 2015, Young	2 qualitative studies using semi-structured interviews; 1	Service users felt that short and respite breaks were beneficial to the child/young person by providing opportunities to get away from everyday life at home, try new activities, see new places and be amongst friends. Short and respite breaks were also viewed as beneficial to the whole family as they allowed parents to spend time	Methodological limitations	Major concerns about methodological limitations of	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
2018)	qualitative study using focus groups; 1 mixed methods study using interviews	with, and provide attention to other children in the family, and to address other practical demands such as household chores. "It lets me get out and about with (names his sister) without pressure and it also gives her respite because at 3 o'clock in the morning when you are 10 years old and you are needing your sleep, you don't need N disturbing you. So the breaks benefit all of us individually and as a whole." (McConkey 2013)		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	

Appendix G Economic evidence study selection

Economic evidence study selection for review question: 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?

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 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?

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

Appendix I Economic model

Economic model for review question: 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?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: 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?

Qualitative studies

Table 18: 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,	Themes: No views or experiences relevant to

Study	Reason for Exclusion
Amendoeira, Jose Joaquim Penedos, Charepe, Zaida Borges, The parental care partnership in the view of parents of children with special health needs, A parceria de cuidados pelo olhar dos pais de criancas com necessidades especiais de saude., 38, e2016-70, 2017	joined up care/services.
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

Study	Reason for Exclusion
Bray, L., Shaw, N. J., Snodin, J., Living and managing with the long-term implications of neonatal chronic lung disease: The experiences and perspectives of children and their parents, Heart and Lung: Journal of Acute and Critical Care, 44, 512-516, 2015	Themes: No qualitative data relevant to the views and experiences of joined-up care/services.
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,	Population: Does not meet criteria; children with

Study	Reason for Exclusion
Becky, Mackie, Clare, Educational provision for children with specific speech and language difficulties: perspectives of speech and language therapy service managers, International journal of language & communication disorders, 41, 423-40, 2006	specific speech and language difficulties without severity/complexity or comorbidities. Published pre 2013.
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	Country: Ireland.

Study	Reason for Exclusion
in schools: an appreciative inquiry-based study, BMC Health Services Research, 19, 226, 2019	
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.

Study	Reason for Exclusion
Hirano, Kara A., Rowe, Dawn, Lindstrom, Lauren, Chan, Paula, Systemic Barriers to Family Involvement in Transition Planning for Youth with Disabilities: A Qualitative Metasynthesis, Journal of Child and Family Studies, 27, 3440-3456, 2018	International meta-synthesis. Included studies checked for relevant UK studies from 2013.
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-	Publication type: Book chapter

Study	Reason for Exclusion
Anderson Dilworth-Anderson Eifert Esses Esses Fiene Fong Forsyth Franck Gallegos Gallimore 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	Country: Canada

Study	Reason for Exclusion
pathways to post-secondary education for youth with physical disabilities, Disability and 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

Study	Reason for Exclusion
McNeilly, P., Macdonald, G., Kelly, B., The participation of parents of disabled children and young people in health and social care decisions, Child: care, health and development, 43, 839-846, 2017	Themes: No views or experiences relevant to 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.

Study	Reason for Exclusion
Rafferty, Katherine A., Sullivan, Shelbie L., "You Know the Medicine, I Know My Kid": How Parents Advocate for Their Children Living With Complex Chronic Conditions, Health communication, 32, 1151-1160, 2017	Country: US
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:	Themes: No views or experiences relevant to

Study	Reason for Exclusion
supporting disabled children and their families, 20, 2018	joined up care/services
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	Country: USA

Study	Reason for Exclusion
over time in medical homes for children with special health care needs, Pediatrics, 135, 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 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?

No research recommendations were made for this review question.

Appendix L Qualitative thematic maps

Qualitative themes for review question: 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 3: Thematic map for the experiences of joint delivery of health, social care and education services

Figure 4: Sub-theme map for desire to build good relationships with professionals and staff

Figure 5: Sub-theme map for access to information and advice was important

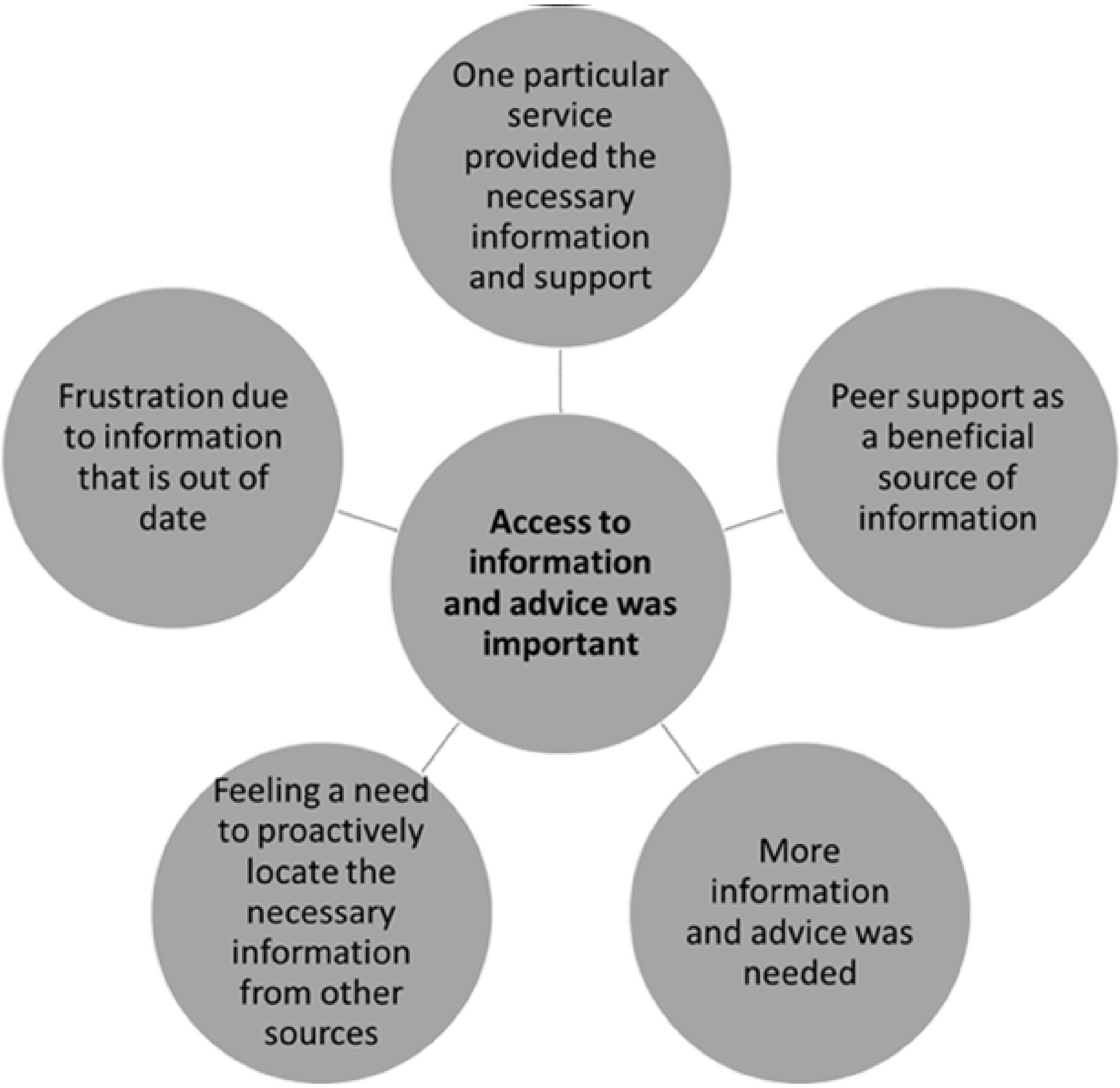


Figure 6: Sub-theme map for a need for effective communication

Figure 7: Sub-theme map for difficulty in navigating the service system

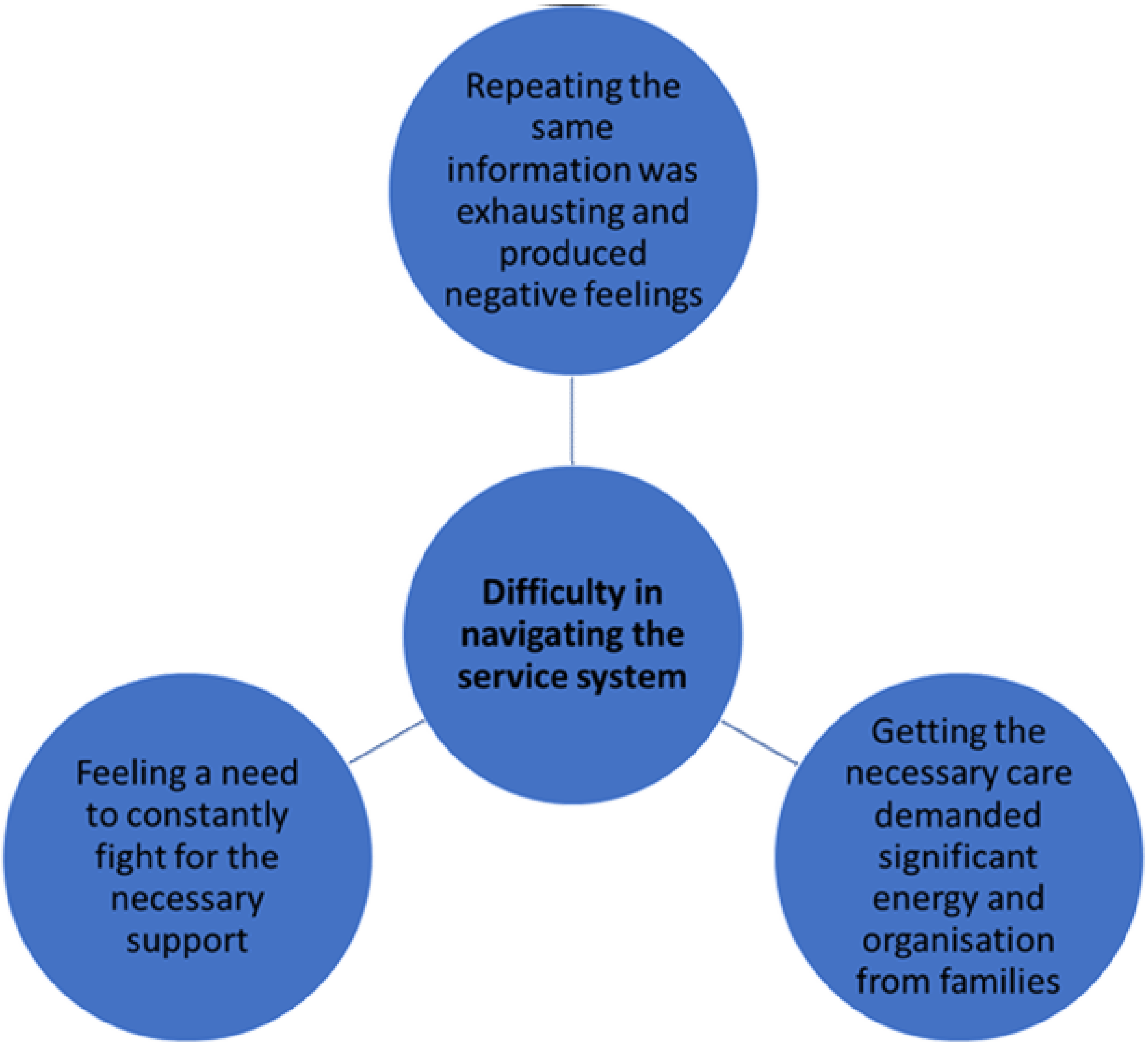


Figure 8: Sub-theme map for feeling disillusioned/ that services do not fully meet the needs of children or young people

Figure 9: Sub-theme map for diagnosis as fundamental to accessing the necessary service provisions

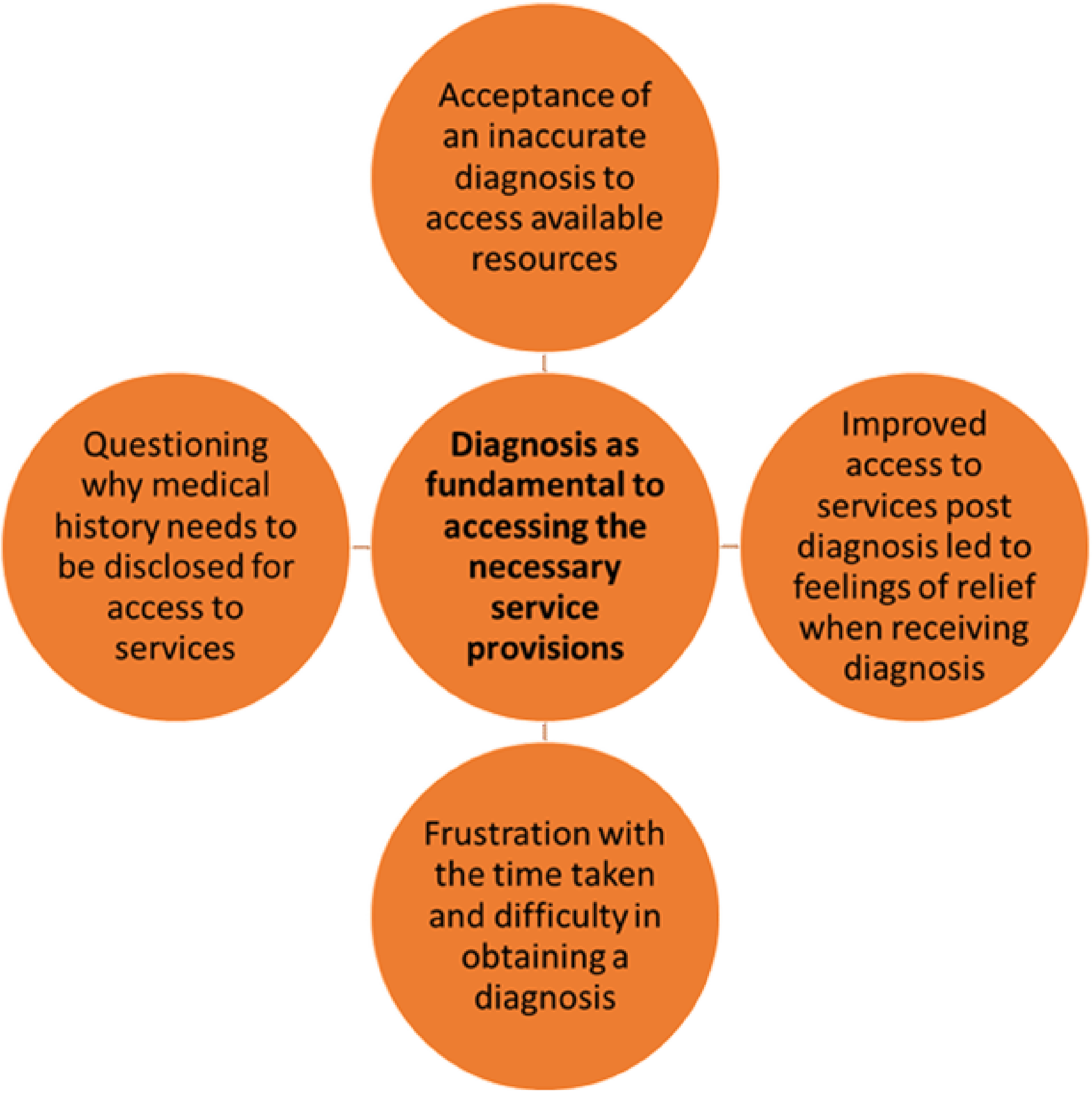


Figure 10: Sub-theme map for the effects of EHC plans on service provisions

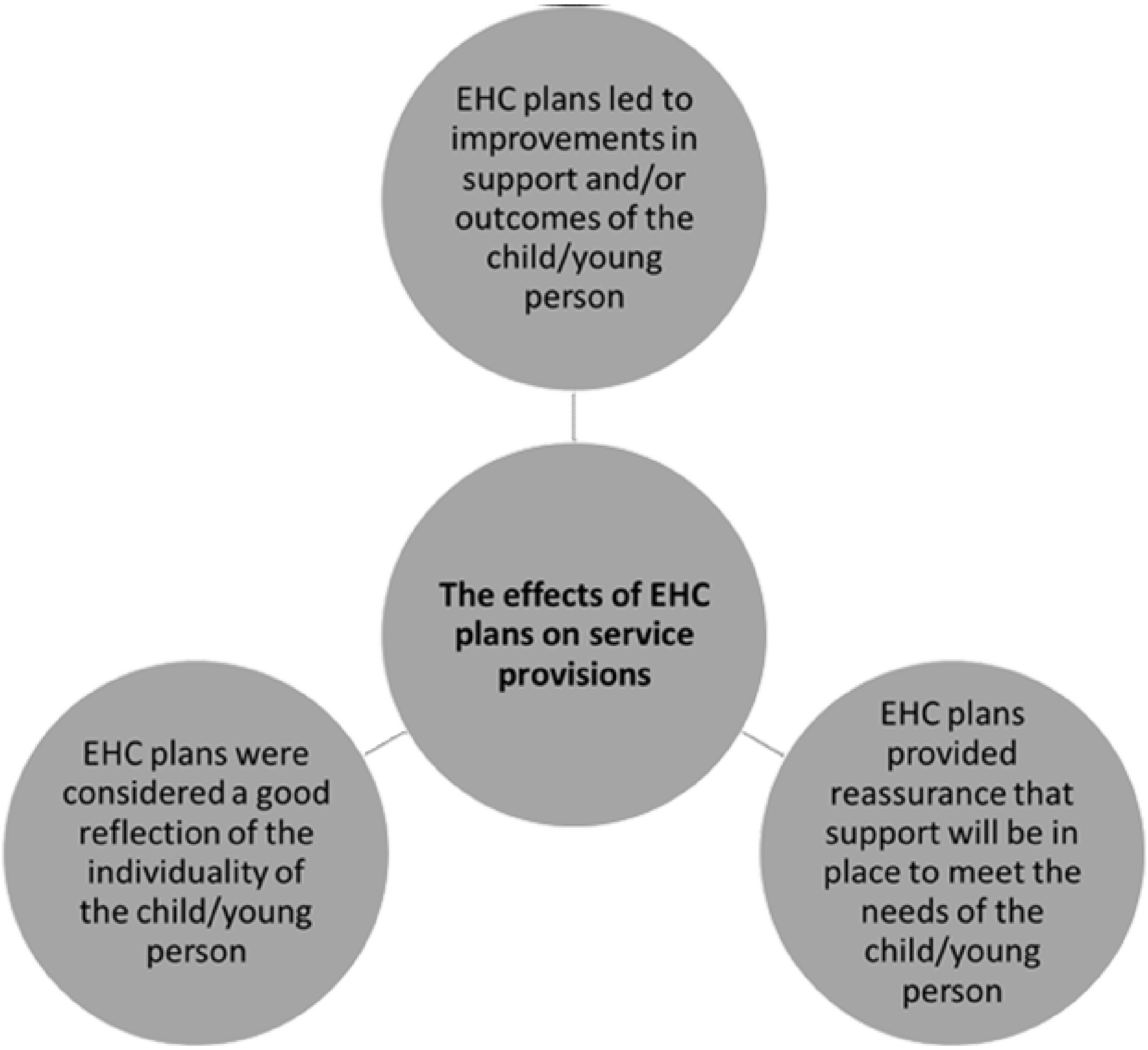


Figure 11: Sub-theme map for perceptions about the involvement of the children or young person

Figure 12: Sub-theme map for parents and carers wanted their opinions about the child/young person to be heard

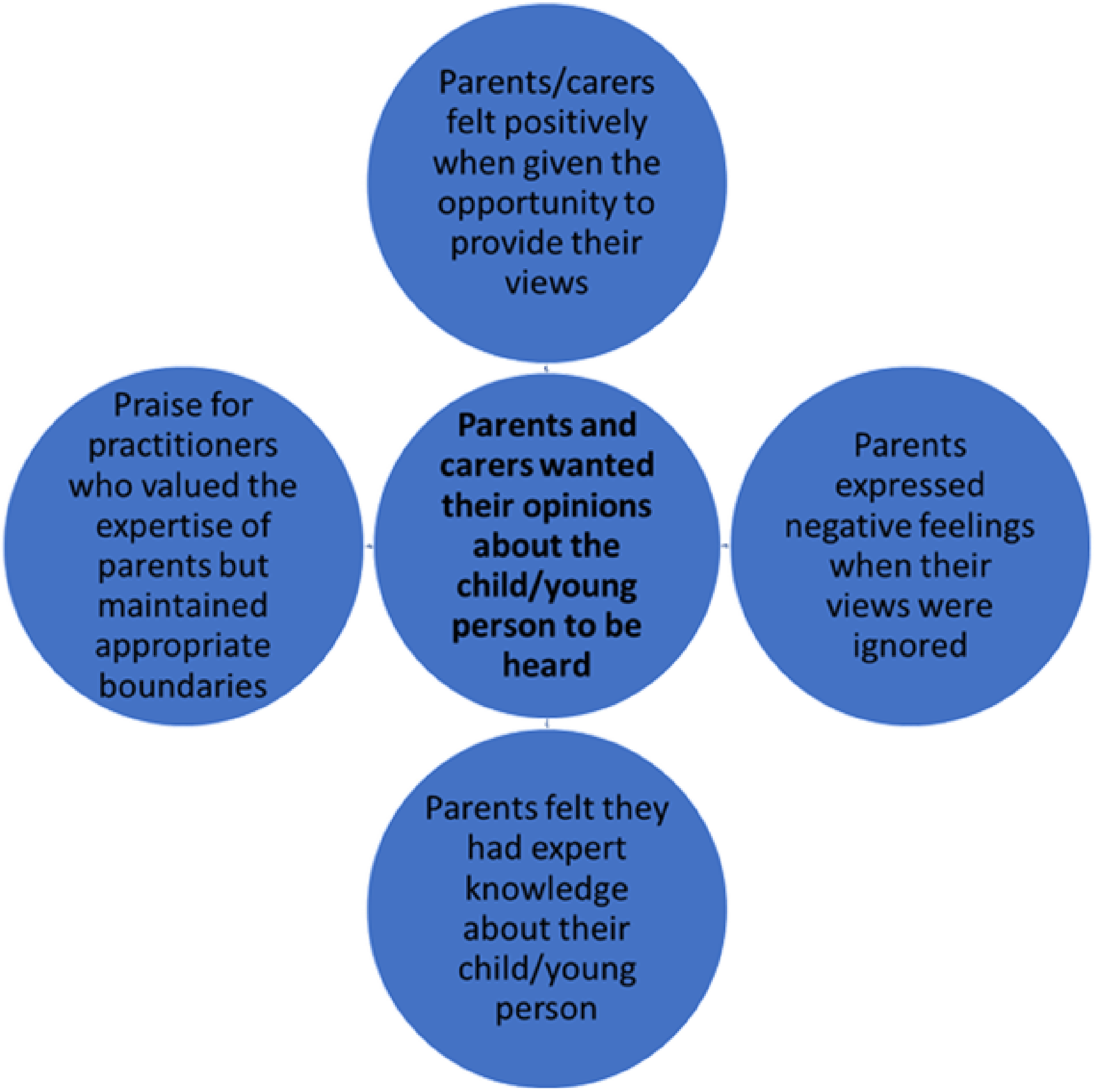


Figure 13: Sub-theme map for need for professionals and staff to be trained properly

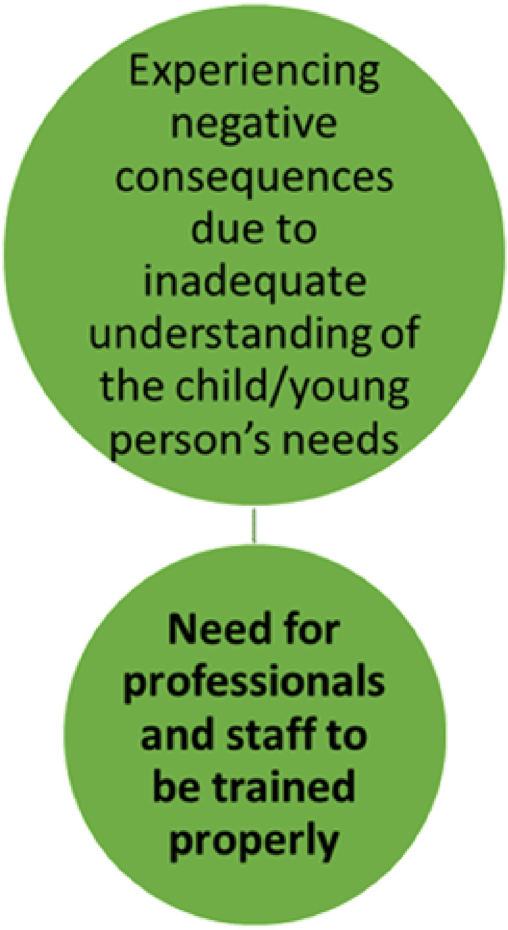


Figure 14: Sub-theme map for service provisions for transition need to be improved

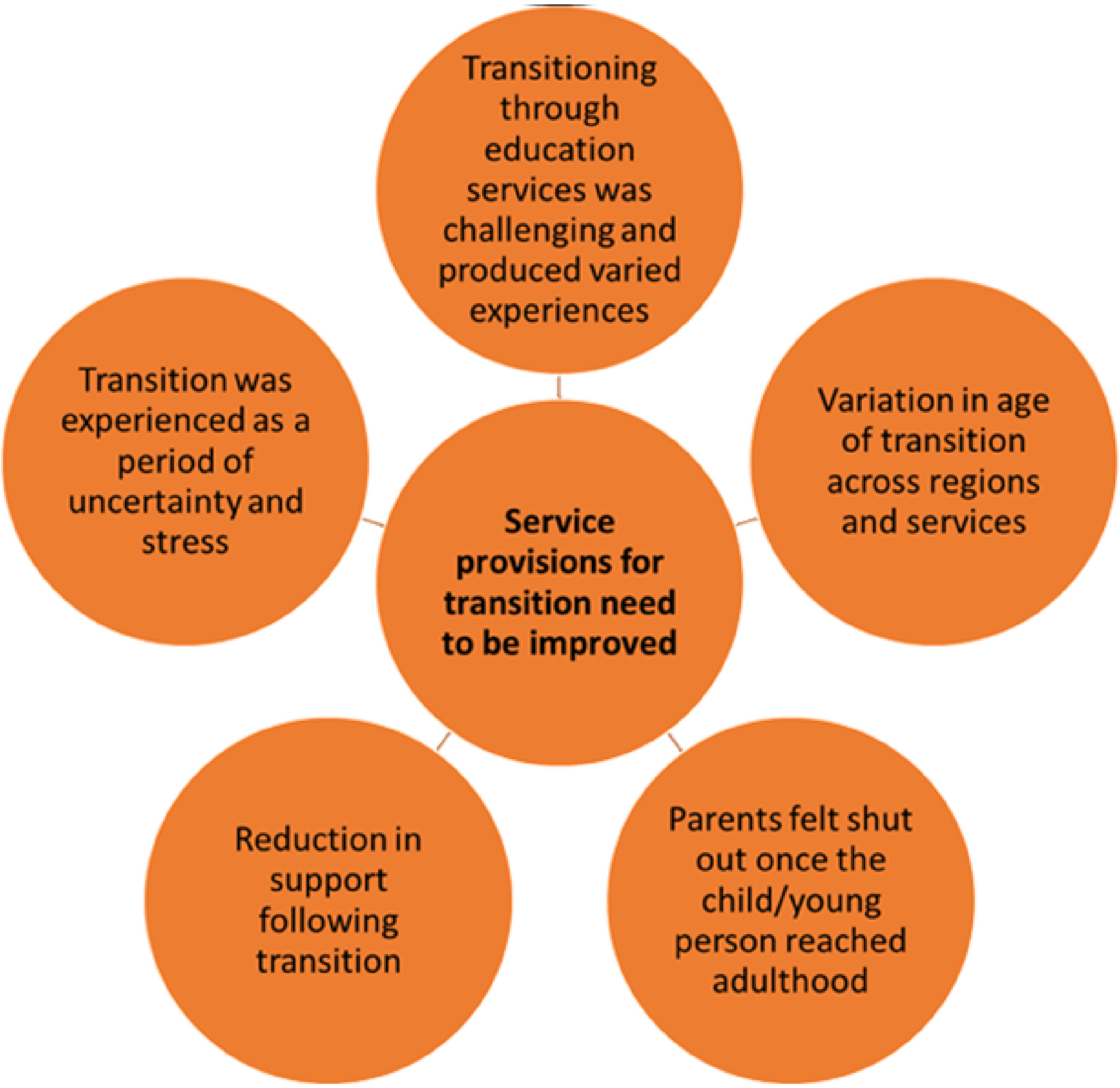


Figure 15: Sub-theme map for budgets made a difference to the care received

Figure 16: Sub-theme map for short breaks and respite breaks provide benefit