

National Institute for Health and Care Excellence

Final

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

[M] Evidence review of views and experiences of service providers

NICE guideline NG213

Evidence reviews

March 2022

Final

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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Views and experiences of service providers

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1, 1.1.2, 1.1.6, 1.1.8, 1.1.10, 1.1.16, 1.1.17, 1.1.29, 1.1.34, 1.1.43, 1.1.44, 1.1.51 - 1.1.54, 1.1.57, 1.3.5, 1.3.10, 1.4.1, 1.4.2, 1.4.5, 1.4.8, 1.4.13 - 1.4.16, 1.4.23, 1.8.3, 1.14.2, 1.15.5, 1.15.17. Other evidence supporting these recommendations can be found in the evidence reviews on Views and experiences of service users (evidence report A), Barriers and facilitators of joined-up care (evidence report K).

Review question

What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

Introduction

This review will examine the views and experiences of commissioners, providers and practitioners of joined-up care between health, social care and education services for disabled children and young people with severe complex needs. This will be used to identify themes about the acceptability and accessibility of joined up services.

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

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

Summary of the protocol

See Table 1 for a summary of the population, phenomenon of interest and context characteristics of this review.

Table 1: Summary of the protocol

Population	<ul style="list-style-type: none"> Commissioners and providers of, and practitioners working in, health, social care or educational services for disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support.
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Phenomenon of Interest	<p>The views and experiences of commissioners, providers and practitioners on joint working between health, social care and education services for disabled children and young people with severe complex needs.</p> <ul style="list-style-type: none"> • Commissioning, providing or practitioner working in one or more of the three services; health, social care and education. <p>Potential themes include:</p> <ul style="list-style-type: none"> • Respect and understanding of contributions from other services • Joint budgets • Funding arrangements (e.g. cost is entirely picked up by education in some settings) • Joint contracts (e.g. section 75 arrangements – pooled budgets and shared risks) • Co-location • Joint IT systems/data management • Policy and legislation (across services) • Nature of partnerships or integration (what do they mean in practice) • Managing transfer between services • Capacity • Workforce (mix of skills, cultural attitude and staff retention) • Footprint of integrated services – may not be geographical overlap • Accessibility of services • Entry point into health / social care system • Shared decision making, person centred care and support, coproduction • 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	<p>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.</p> <p>Studies sought will be those published in the English language from the UK, from 2013 until the date the searches are run.</p>

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

1.1.1.1 Included studies

Fourteen qualitative studies were included in this review (Boesley 2018; Boyce 2015; Children's Commissioner for Wales 2018; Council for Disabled Children 2018; Hurt 2019; McConkey 2013; Molteni 2013; Palikara 2019; RIP STARS 2018; Rodriguez 2014; Sales 2018; Spivack 2014; Taylor 2014; 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 commissioners, providers and practitioners of joined-up care between education, health and social care services. Data collection methods included: semi-structured survey (Palikara 2019); interviews (Taylor 2004), semi-structured interviews (Boesley 2018; Boyce 2015; Council for Disabled Children 2018; McConkey 2013; Sales 2018; Spivack 2014), focus groups (Children's Commissioner for Wales 2018; Hurt 2019; Rodriguez 2014), interviews and group discussions (RIP STARS 2018), semi-structured interviews or focus groups (Young 2018), and focus groups, semi-structured interviews and a questionnaire with an open-ended question (Molteni 2013). Study populations included professionals from education, health and social care services. The included studies are summarised in Table 2.

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

1.1.1.2 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
Boesley 2018 Education, Health and Social Care Services	N=16 SENCOs based in England and had undertaken an application for an EHC plan, or transferred a statement of SEN into an EHC plan.	Needs or conditions: NR Age Range (Mean): NR	Setting: Primary and secondary schools across England (telephone) Data collection: Semi-structured interviews	<ul style="list-style-type: none"> Information and support Relationships between service providers and service users Involvement of families and carers Experience of EHC plans Child/young person centred approach
Boyce 2015 Education, Health and Social Care Services	N=35 Health, education and social care professionals involved in certifying and supporting infants and children with vision impairment	Needs or conditions: Severely sight impaired or sight impaired (including infants and children with complex needs)	Setting: Hospital Data collection: Semi-structured interviews	<ul style="list-style-type: none"> Service provider knowledge and training

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		Age Range (Mean): NR		
Children's Commissioner for Wales 2018 Education, Health and Social Care Services	N=43 Professionals from education, health, social care and voluntary services who work with young people with learning disabilities	Needs or conditions: Learning disabilities Age Range (Mean): 14 to 26 years (NR)	Setting: NR Data collection: Focus groups	<ul style="list-style-type: none"> • Relationships between service providers and service users • Child/young person centred approach
Council for Disabled Children 2018 Education, Health and Social Care Services	N=13 Professionals with experience of supporting 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	<ul style="list-style-type: none"> • Service provider knowledge and training • Relationships between service providers and service users
Hurt 2019 Education and Health Services	N=16 Health and education professionals working within an NHS multidisciplinary neurodevelopmental team and a mainstream primary school	Needs or conditions: ASD Age Range (Mean): NR	Setting: One health board and one primary school in South Wales Data collection: Focus groups	<ul style="list-style-type: none"> • Relationships between service providers and service users • Involvement of families and carers
McConkey 2013 Health and Social Care Services	N=34 Key workers and Referrers of children currently receiving services from Action for Children, or had received services in the	Needs or conditions: Developmental disabilities and severely challenging behaviours	Setting: In a private room in the short break service/family homes (face-to-face), and	<ul style="list-style-type: none"> • Short breaks and respite breaks provide benefit • Relationships between service providers and service users

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
	past 2 years	Age Range (Mean): Up to 19 years (NR)	telephone Data collection: Semi-structured interviews	<ul style="list-style-type: none"> • Child/young person centred approach
Molteni 2013 Education and Health Services	N=22 Teams of professionals involved in implementing the Social Communication, Emotional Regulation, Transactional Support (SCERTS) model	Needs or conditions: Severe learning difficulties Age Range (Mean): NR	Setting: NR Data collection: Focus groups, semi-structured interviews and one open-ended question on a questionnaire	<ul style="list-style-type: none"> • Child/young person centred approach • Service provider knowledge and training
Palikara 2019 Education, Health and Social Care Services	N=374 Professionals working in special education	Needs or conditions: NR Age Range (Mean): NR	Setting: Survey distributed through research network Data collection: Semi-structured survey	<ul style="list-style-type: none"> • Improved transition • Child/young person centred approach • Involvement of families and carers • Experience of EHC plans
RIP STARS 2018 Education, Health and Social Care Services	N=17	Needs or conditions: NR Age Range (Mean): 13 to 25	Setting: NR Data collection: Interviews and group discussions	<ul style="list-style-type: none"> • Information and support • Involvement of children and young people • Child/young person centred approach • Involvement of families and carers • Experience of EHC plans
Rodriguez 2014 Unclear what services were involved	N=21 Professionals working in paediatric care	Needs or conditions: Cancer, cerebral palsy, muscular dystrophy, congenital	Setting: One UK county, including both urban and rural areas	<ul style="list-style-type: none"> • Relationships between service providers and service users • Information and support • Involvement of

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
		disorder, neurological disorder, genetic disorder Age Range (Mean): NR	Data collection: Focus groups	families and carers
Sales 2018 Education, Health and Social Care Services	N=9	Needs or conditions: NR Age Range (Mean): NR	Setting: Work or home (face-to-face) Data collection: Semi-structured interviews	<ul style="list-style-type: none"> • Involvement of families and carers • Child/young person centred approach • Involvement of children and young people • Improved transition
Spivack 2014 Education, Health and Social Care Services	N=NR Lead professionals involved in collaborative working with social care.	Needs or conditions: NR Age Range (Mean): NR	Setting: NR (face-to-face) and telephone Data collection: Semi-structured interviews	<ul style="list-style-type: none"> • Child/young person centred approach
Taylor 2014 Education, Health and Social Care Services	N=61 Professionals with experience of responding to at least two child protection cases involving a disabled child.	Needs or conditions: NR Age Range (Mean): NR	Setting: Telephone Data collection: Interviews	<ul style="list-style-type: none"> • Service provider knowledge and training • Relationships between service providers and service users • Information and support • Involvement of children and young people
Young 2018 Health and Social Care Services	N=15 Health or Social Care staff working the pilot service	Needs or conditions: NR Age Range (Mean): NR	Setting: Pilot short-break service for young adults aged 18–24 years with life-limiting conditions	<ul style="list-style-type: none"> • Service provider knowledge and training • Relationships between service providers and service users • Information and support • Involvement of

Study	Population	Description of child/young person	Methods	Themes applied after thematic synthesis
			Data collection: Semi-structured interviews or focus groups	children and young people

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; SCERTS: social communication, emotional regulation, transactional support; SEN: special educational needs; SENCO: special educational needs coordinator

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:

- Child/young person centred approach
- Involvement of children and young people
- Involvement of families and carers
- Relationships between service providers and service users
- Information and support
- Service provider knowledge and training
- Experience of EHC plans
- Improved transition
- 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 **Error! Reference source not found.**; see appendix L for sub-theme maps).

Figure 1: Theme map**Summary of the qualitative evidence**

The evidence generated 9 main themes from the views and experiences of commissioners, providers and practitioners. Nine studies provided evidence relating to a child or young person centred approach. Three studies provided evidence relating to the involvement of children and young people. Six studies provided evidence relating to the involvement of the child or young person's families and carers. Seven studies provided evidence relating to relationships between service providers and service users. Four studies provided evidence relating to information and support. Four studies provided evidence relating to knowledge and training. Three studies provided evidence relating to experience of Education, Health and Care (EHC) plans. Two studies provided evidence relating to improved transition. Two studies provided evidence relating to the benefit of short breaks and respite breaks. The quality of the evidence ranged from very low to high.

See appendix F for full GRADE-CERQual tables.

Economic evidence**1.1.1.3 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.

1.1.1.4 Excluded studies

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

Summary of included economic evidence

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

Economic model

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

Evidence statements

1.1.1.5 Economic

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

The committee's discussion and interpretation of the evidence

1.1.1.6 The outcomes that matter most

The review focussed on the views and experiences of commissioners, providers and practitioners of joined-up care between health, social care and education services for disabled children and young people with severe complex needs. 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.

1.1.1.7 The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall quality ranged from very low to high. Concerns about the methodological limitations of the primary studies were assessed with the CASP checklist and ranged from “major” to “none or very minor”. The most common issues were lack of consideration of the relationship between researcher and participants, somewhat limited detail provided on data analysis, no justification for the data collection methods and setting, lack of information about recruitment and potential for recruitment bias and an absence of a clear statement of findings. Concerns about coherence ranged from “moderate” to “none or very minor”. For all but one of the review findings, concerns were “none or very minor”, as there was no ambiguous data nor data that contradicted the findings. For the remaining finding, most of the evidence was contradictory. Concerns about relevance were “none or very minor” for all of the review findings. This is because no evidence from a substantially different context as the review question was included in the review. Concerns about adequacy ranged from “major” to “none or very minor”. There were major concerns where the evidence did not offer rich data, moderate concerns where the evidence offered some rich data, and minor concerns when the evidence offered moderately rich data. The number of studies used for each review finding ranged from 1 to 7.

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

Main theme 1: Child/young person centred approach

- Sub-theme 1:1: Using a child/young person centred approach is valued. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1:2: Children and young people benefit from using a consistent approach. The overall quality of this sub-theme was judged to be very moderate.
- Sub-theme 1.3: Service providers are falling short of using a child/young person centred approach. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.4: Recognising the child/young person's potential and supporting them to reach it. The overall quality of this sub-theme was judged to be moderate.

- Sub-theme 1.5: Importance of separating the views of the child or young person from the views of parents. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 1.6: Respecting the rights of the child or young person. The overall quality of this sub-theme was judged to be moderate.

Main theme 2: Involvement of children and young people

- Sub-theme 2.1: EHC plans have increased focus on views of child/young person. The overall quality of this sub-theme was judged to be high.
- Sub-theme 2.2: Importance of accurately capturing the views of the child/young person. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 2.3: Involvement of the child/young person should depend on their understanding. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 2.4: Supporting children and young people to prepare for meetings and communicate their views. The overall quality of this sub-theme was judged to be low.
- Sub-theme 2.5: Using accessible language in EHC plans would enable children and young people to be involved and improve accountability. The overall quality of this sub-theme was judged to be moderate.

Main theme 3: Involvement of families and carers

- Sub-theme 3.1: Involvement of families is valued and improves relevancy, accuracy and usefulness of EHC plans. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 3.2: Involvement of families can be limited and depends on individual service providers. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 3.3: Families as providers of care. The overall quality of this sub-theme was judged to be low.

Main theme 4: Relationships between service providers and service users

- Sub-theme 4.1: Managing parents' expectations. The overall quality of this sub-theme was judged to be high.
- Sub-theme 4.2: Individuals or services going above and beyond to deliver a good service. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 4.3: Families are less accepting of key workers who have not had much involvement with the family. The overall quality of this sub-theme was judged to be very low.
- Sub-theme 4.4: People making decisions are out of touch with the needs of the child/young person. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 4.5: Meetings with professionals can be intimidating for service users. The overall quality of this sub-theme was judged to be moderate.

Main theme 5: Information and support

- Sub-theme 5.1: Service users should be given more information and support throughout the EHC plan process. The overall quality of this sub-theme was judged to be high.
- Sub-theme 5.2: Sharing information reduces distress for service users and makes the best use of resources. The overall quality of this sub-theme was judged to be moderate.

Main theme 6: Service provider knowledge and training

- Sub-theme 6.1: Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build expertise. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme: 6.2: More training and multi-agency work is needed to communicate effectively with children/young people. The overall quality of this sub-theme was judged to be moderate.

Main theme 7: Experience of EHC plans

- Sub-theme 7.1: Information in EHC plans is not always accurate. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 7.2: Challenges due to timing of introducing EHC plans. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 7.3: Introduction of EHC plans has reduced the impact of service provider bias on access to assessment. The overall quality of this sub-theme was judged to be very low.

Main theme 8: Improved transition

- Sub-theme 8.1: Extending service provision to 25 has (or should) improve transitions. The overall quality of this sub-theme was judged to be moderate.

Main theme 9: Short breaks and respite breaks provide benefit

- Sub-theme 9.1: Short breaks benefit whole family. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.2: The amount of respite provided should be balanced and responsive to families' needs. The overall quality of this sub-theme was judged to be moderate.
- Sub-theme 9.3: Young adult (short break) services should be offered up to age 30. The overall quality of this sub-theme was judged to be moderate.

1.1.1.8 Benefits and harms

Where the qualitative evidence integrates with quantitative evidence, links are discussed in the associated quantitative reviews. This discussion covers qualitative evidence only. There was moderate quality evidence from sub-theme 1.3 that service providers are falling short of using a child or young person centred approach and are not adequately capturing the child or young person's perspective; and from sub-theme 6.2 that there was a lack of available training in how to adapt communication and make better use of communication aids for children and young people with communication difficulties and that multi-agency work was required to improve this. The committee agreed that providing practitioners with training would help to address the issues identified by the evidence. The committee felt strongly that it would be more effective and cost effective for services to work together to develop training in

these areas, and for multi-agency training to be delivered as this provides the opportunity to learn from other services about their roles and responsibilities, helps to build positive working relationships and a shared understand of children and young people's needs [1.15.17]. Further, there was moderate quality evidence, from sub-theme 1.4 that children and young people's potential may be underestimated and that good EHC plans should recognise their aspirations and think about long term options. This was supported by the committee's understanding of the SEND Code of Practice (2015) which highlights the importance of supporting children and young people to achieve their ambitions. Therefore, the committee recommended that views, life goals and ambitions should be focused on during planning and decision making [1.1.1; 1.4.1] and that these should be reviewed to ensure they are relevant and will support the child or young person to reach their full potential [1.4.16]. The committee agreed, based on their experience, that cultural backgrounds and preferences can impact on the views, life goals and ambitions of individuals and so recommended that practitioners also take this into account [1.1.1]. The also committee recognised, based on their experience, that those children and young people with the most complex needs may not be able to actively participate in planning or decision making. They recommended that the views of those who know the child or young person best are also taken into account to ensure that the perspective of the child or young person is fully represented [1.1.2]. This would be particularly relevant to those with profound and multiple learning disabilities and severe cognitive impairments.

The committee discussed that options for disabled children and young people after compulsory education are not limited to further education, and that there are options such as supported internships that children, young people and their families may not be aware of. Therefore, the committee agreed it was important that all options are discussed with the child or young person and their families in sufficient detail to allow for informed decision making and for children and young people to formulate long-term goals and outcomes [1.8.3]. The committee recommended that professionals raise queries with each other if they think professionals' expectations for the child or young person are unrealistic [1.4.5]. Evidence from the evidence report K (theme 16) highlighted that key workers are seen as important for having a holistic view of the child or young person and coordinating services. However, very low quality evidence from sub-theme 4.3 highlighted that families are less accepting of key workers who have not had much involvement with the family. Therefore, the committee recommended that the person providing key working support is part of the interagency team and is someone who the child or young person is comfortable with and who knows them and their needs well. The committee also agreed that it would be beneficial if the person providing key working support is from the service where the child or young person has the most needs as they will have better knowledge of how to navigate the system. Therefore, the committee included this within the recommendation [1.15.5]. This aligns with providing emotional and practical support as part of a trusting relationship, one of the main functions of key working support specified in the SEND Code of Practice (2015).

There was high quality evidence from sub-themes 4.1 and 5.1 that more information and support was needed throughout the EHC plan process, and that sometimes it was necessary to manage parents and carers' expectations regarding the outcomes of EHC plans and what they may help with. This evidence was supported by evidence report A, sub-theme 2.1 and evidence report K, sub-theme 9.6. Therefore, the committee agreed it was important to discuss expectations with children and young people and their parents and carers and explain the purpose and process of EHC needs assessment and EHC plans, including how they can be involved, how their views will be incorporated, which services will be involved and what will happen if an EHC plan is not issued [1.3.5].

Although recording the views of children and young people in EHC plans is mandatory, there was moderate quality evidence from sub-theme 1.1 and 2.2 that this is not always done

adequately. This aligned with the experience of the committee and so they supported recording children and young people's views in EHC plans [1.4.8] and recommended that children and young people are encouraged to give their views and be involved in decisions where possible [1.1.6; 1.1.8]. Recording the views of the child or young person in EHC plans and being clear about which parts are their contributions would be particularly relevant for those with cognitive impairments and communication needs and disorders. They also recommended, based on moderate quality evidence from sub-theme 1.5, that parents, carers and advocates think about how they can support the child or young person to do this and how services can help [1.1.10]. Helping children and young people to understand their options and to prepare for meetings was thought to help them to communicate their views during meetings and, therefore, the committee made recommendations in support of this based on the evidence in sub-theme 2.4 and evidence report A, sub-theme 8.2 [1.1.29]. This was thought to be particularly important for children and young people who use communication aids, as they may prefer to prepare a script in advance of the meeting to enable them to communicate their views more easily. Further, children with cognitive impairments and learning disabilities will benefit from additional lead in time to process information and consider their views. Those with poor literacy will also benefit from having time to prepare for meetings and discussions. This aligns with the requirements in the Children and Families Act 2014 about supporting children, young people and parents to participate in decisions. In addition, the committee's understanding of the SEND code of practice is that it recommends including time to prepare for discussions and meetings.

There was moderate quality evidence from sub-theme 2.2 that children and young people's views are not always captured accurately and that it was important to make sure views are not rewritten in a way that changes the meaning. Therefore, the committee recommended that they are recorded using the child or young person's own words, or equivalent form of communication for children who do not communicate verbally [1.4.13]. This would be particularly important for those with communication needs or disorders and sensory impairments. The low quality evidence from sub-theme 2.4 also highlighted the importance of having a flexible approach to collecting views that took into account the child or young person's age, developmental level and communication skills and the difficulty of capturing the views of children and young people with cognitive impairments and severe communication difficulties. Therefore, the committee recommended that practitioners should take this flexible approach [1.1.16]. This may require finding out what communication formats and media children and young people prefer so that this format can be used when communicating with them; therefore, the committee made a recommendation in support of this [1.1.17]. This recommendation would be particularly relevant to those with cognitive impairments, communication needs and disorders and sensory impairments

There was some moderate quality evidence from sub-theme 2.5 that using accessible language in EHC plans would increase the involvement of children and young people and improve accountability. The committee noted that certain sections of the plan would need to be written in technical language (for example information about health), however the sections about outcomes and support provision needed to be understandable to the child or young person (which would be particularly relevant for those with communication difficulties and poor literacy) [1.4.14]. Further, they recommended that practitioners check with the child or young person if the plan makes sense to them, that they can understand the plan outcomes and that they agree with the content [1.4.15]. The committee acknowledged that it may be difficult to do this for some children and young people but recommended that this is done to the extent that is possible. In the committee's understanding, these recommendations align with the principles and requirements on preparation of EHC plans in the SEND Code of Practice (2015), which state that "EHC plans should be clear, concise, understandable and accessible

to parents, children, young people, providers and practitioners. They should be written so they can be understood by professionals in any local authority.”

There was moderate quality evidence from sub-theme 1.6 highlighting the importance of respecting children and young people’s rights to privacy and to be involved in decisions. Additionally, there was moderate quality evidence from sub-theme 4.5 that attending meetings with large numbers of professionals can be intimidating. Therefore, the committee agreed it was important to hold meetings in private and not invite more people than necessary to meetings [1.1.34]. The committee were of the view that the experiences of children at a peer level are different to those of practitioners who are providing care for disabled children and young people with severe complex needs. Getting this peer level perspective, extends the understanding of the practitioners providing care and can also demonstrate strengths and interests of the child or young person that practitioners will not have observed due to the different dynamic of the relationship. This enables a broader view of what the child or young person is capable of so practitioners can make better judgements about their future abilities and adjust outcomes accordingly. Based on this the committee agreed that children and young people having the opportunity to invite siblings or friends to share their views on the disabled child/young persons’ strengths and interests would be of value [1.1.43].

There was some moderate quality evidence from sub-theme 5.2 that needing to repeat information is difficult, especially when discussing sensitive information and that sharing information would reduce the need to repeat information. This was consistent with evidence from the other qualitative reviews that repeating information is exhausting and produces negative feelings (see evidence report A, sub-theme 4.1), information sharing is not sufficient (see evidence report K, sub-theme 7.1) and increasing information sharing would streamline processes (see evidence report K, sub-theme 7.2). This aligns with the approach advocated in the SEND Code of Practice (2015) in relation to sharing information during the EHC needs assessment and planning process, so that children and young people and their families do not have to repeat the same information. Therefore, the committee made a recommendation in support of sharing information [1.1.54]. Given the evidence above about privacy and in light of data protection regulations, the committee agreed it was important to ask for and record informed consent before sharing information, and ask children and young people and their parents and carers if there is any information that they do not want to be shared and the implications of doing this. Equally it was important to explain what information will be shared without their consent, for example in relation to safeguarding. They also recognised that some practitioners may have closer relationships with the family than others so agreed it was important that children and young people and their parents and carers are asked who they would prefer to discuss sensitive information with [1.1.51]. The committee also agreed that organisational policies on consent and relevant legislation and statutory guidance would need to be followed [1.1.52; 1.1.53]. Finally, the committee agreed it was important that children, young people and their families are asked about their information sharing preferences regularly, for example at EHC plan reviews, as changes in family circumstances may affect who information should be shared with [1.1.57].

There was very moderate quality evidence from sub-theme 1.2 that using a consistent approach when interacting with children and young people was beneficial, in terms of being more predictable and helping them to generalise across different settings. This aligned with the experience of the committee that interacting in a consistent way helps children and young people know what to expect and feel more safe and confident in their interactions with services, so they made a recommendation in support of this [1.1.44]. Further, they recommended that handovers are arranged when there is a change in practitioners working with children and young people to avoid disruptions in care and the need for children and young people or their parents and carers to repeat information [1.14.2]. The committee made a recommendation based on their experience, supporting joint working between services before

an EHC plan is issued [1.3.10] as they agreed it was important that joint working begins as soon as it has been recognised that a child has severe complex needs to ensure they get the support they need and ease the transition to an EHC plan.

The committee's understanding of the SEND code of practice and legislation in the Children and Families Act 2014 is that parents and carers must be consulted throughout the EHC plan process. However, the evidence from sub-theme 3.2 suggested that sometimes this is limited and only done in a tokenistic way. There was also evidence in evidence report A (sub-themes 9.1 and 9.2) supporting that parents and carers felt positively when given the opportunity to provide their views, and conversely expressed negative feelings when their views were ignored. Based on this, the committee made a recommendation in support of their involvement throughout the assessment, production and review of EHC plans [1.4.2].

The committee discussed that, based on their experience, there are occasions when parents or carers may decline an EHC plan. For example, if they are unhappy with the educational provision specified in a plan they may decline the plan as accepting it would mean they were legally obligated to send their child to the specified provision. The committee agreed that in these circumstances it is important to still engage with parents and carers so that their children do not become lost to services. The committee recommended discussing reasons for declining a plan and addressing any concerns, discussing the potential implications of deciding not to have an EHC plan, and agreeing what ongoing support will be provided with the parents or carers to ensure that the best possible support can be provided for the child or young person, within the constraints of not having an EHC plan or the funding that is attached to this. Discussing the reasons for declining the plan would be particularly relevant where stigma or different cultural views may be impacting on the decision. The committee also agreed that parents and carers need to be made aware of how to request an EHC needs assessment in future, in case their circumstances or views change. Finally, the committee agreed it was important to consider if declining a plan may cause a safeguarding issue, and follow local safeguarding processes if needed [1.4.23].

There were a number of sub-themes where the committee did not make a recommendation based on the qualitative evidence alone. For one sub-theme (sub-theme 6.1), a recommendation was not made because the evidence from the sub-theme was consistent with a recommendation from another review question (recommendation 1.14.3, see evidence report C) and, therefore, the evidence was used as further support for that recommendation. In contrast, for one sub-theme (sub-theme 3.3), recommendations were not made because the evidence (that families could probably provide more care and be less reliant on services) contradicted other themes where there was stronger evidence, such as sub-theme 3.2 in evidence report K which showed it can be hard for parents to take on care planning and decision making). For other themes, the committee agreed that the issue raised by the evidence would be reduced as a result of recommendations made elsewhere in the guideline (sub-themes 4.2 and 9.3), or 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 9.1), did not provide enough information about how to address the issue raised by the evidence (sub-themes 4.4 and 9.2), or was very specific and the committee were unsure of its relevance to the wider population covered by the guideline (sub-theme 2.3). Finally, there were some themes (sub-themes 3.1, 7.1, 7.2, 7.3 and 8.1) commenting on the perceived impact of EHC plans or extending the SEND service provision up to age 25. These are now statutory requirements and so it was outside the remit of this guideline to make recommendations in these areas.

1.1.1.9 Cost effectiveness and resource use

No existing economic evidence was identified for this review and no economic analysis was undertaken.

There may be some resource implications associated with making processes more consistent and transparent across education, health and social care services. However, this will potentially lead to more efficient and coordinated practices across the sectors, resulting in cost savings. Such an approach will also have benefits to children and young people and their parents and carers. For example, having meetings in the same venue will make it more accessible to children and young people; having more joint/coordinated meetings will mean services use staff time efficiently.

The committee noted that currently services are required to develop suitable and sufficient training for their workforce, but this is done within individual services and not usually across sectors. Therefore, education, health and social care services working together to develop joint training will be a change in practice, but this is unlikely to have additional resource implications because the training specified in the recommendation exists in at least one of the sectors already. The committee also highlighted that by developing joint training, it could enable practitioners from some sectors to receive training which they may not have done under a siloed way of working, as it was not deemed necessary for their role. Such an approach may also help build positive working relationships and a shared understanding of children and young people's needs and ultimately result in better and more timely care and improved outcomes for children and young people with disabilities and severe complex needs, i.e. quality-adjusted life year gains. The committee also noted that if all three sectors organised joint interagency training, it would result in efficiencies and cost savings to all three sectors.

The committee also discussed that needing to repeat information is difficult for children and young people and their parents and carers, especially when talking about sensitive issues. Sharing information would reduce the need to repeat information, make processes more efficient, cut out duplication and make better use of staff time. The committee explained that there might be some resource implications associated with establishing processes to share information. However, cost savings due to more efficient processes and people having the correct information at the right time will result in better care and outcomes and will outweigh any cost increases. In addition, removing the need for children and young people and their families and carers to repeat information is in line with the committee's understanding of the SEND Code of Practice (2015).

The committee discussed that more staff time might be required to implement some recommendations, for example consulting with and involving children and young people and their parents and carers to get their views and help them prepare for meetings. However, for most services, these recommendations represent current practice so would only have modest resource implications, if any, which are justifiable as such care is likely to lead to improvements in children's and young people's experience of care and quality of life and aligns with legislation and statutory guidance.

1.1.1.10 **Other factors the committee took into account**

The committee were aware of areas of legislation that are not being consistently followed in practice, specifically, whether or not commissioners engage and consult with children and young people and their parents and carers when commissioning services [RQ11.2; Consensus A] and how they ensure their participation is effective [RQ3.1D; RQ 11.2; sub-theme 1.5]. Therefore, the committee made recommendations in support of these actions. This is further supported by evidence report K which showed gaps in service provision.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1, 1.1.2, 1.1.6, 1.1.8, 1.1.10, 1.1.16, 1.1.17, 1.1.29, 1.1.34, 1.1.43, 1.1.44, 1.1.51 - 1.1.54, 1.1.57, 1.3.5, 1.3.10, 1.4.1, 1.4.2, 1.4.5, 1.4.8, 1.4.13 - 1.4.16, 1.4.23, 1.8.3, 1.14.2, 1.15.5, 1.15.17. Other evidence supporting these recommendations can be found in the evidence reviews on Views and experiences of service users (evidence report A), Barriers and facilitators of joined-up care (evidence report K).

References – included studies**1.1.1.11 Qualitative****Boesley 2018**

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Council for Disabled Children, Hamblin E., 'Realistic positivity': understanding the additional needs of young children placed for adoption, and supporting families when needs are unexpected, London: Council for Disabled Children, 2018. Available at: <https://www.basw.co.uk/resources/realistic-positivity-understanding-additional-needs-young-children-placed-adoption-and>

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Hurt, L., Langley, K., North, K., Southern, A., Copeland, L., Gillard, J., Williams, S., Understanding and improving the care pathway for children with autism, *International Journal of Health Care Quality Assurance*, 32, 208-223, 2019

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McConkey, R., Gent, C., Scowcroft, E., Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: a multi-informant study, *Journal of Applied Research in Intellectual Disabilities*, 26, 271-83, 2013

Molteni 2013

Molteni, P., Guldberg, K., Logan, N., Autism and multidisciplinary teamwork through the SCERTS model, *British Journal of Special Education*, 40, 137-145, 2013

Palikara 2019

Palikara, O., Castro, S., Gaona, C., Eirinaki, V., Professionals' views on the new policy for special educational needs in England: ideology versus implementation, *European Journal of Special Needs Education*, 34, 83-97, 2019

RIP STARS 2018

RIP STARS, Defining quality and rights-based Education, Health and Care Plans (EHCPs) for disabled children and young people, Coventry: Coventry University, 2018. Available at: <https://ripstarsnet.files.wordpress.com/2018/10/ripstars-finalreport2018-2.pdf>

Rodriguez 2014

Rodriguez, A., King, N., 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

Sales 2018

Sales, N., Vincent, K., 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

Spivack 2014

Spivack R., Craston M., Redman R., Evaluation of the Special Educational Needs and Disability Pathfinder Programme: Thematic report: Collaborative working with social care: Research report, London: Department for Education, 2014. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/342287/RR356D_-_Social_Care_Thematic_Report.pdf

Taylor 2014

Taylor J., Stalker, K., Fry, D., Stewart, A., Disabled children and child protection in Scotland: An investigation into the relationship between professional practice, child protection and disability, Glasgow: University of Strathclyde, 2014. Available at: <https://strathprints.strath.ac.uk/46601/1/00447850.pdf>

Young 2018

Young, L., Egdell, A., Swallow, V., Qualitative accounts of young-people, parents and staff involved with a purpose-designed, pilot short-break service for 18-24 year olds with life-limiting conditions, *Children and Youth Services Review*, 86, 142-150, 2018

1.1.1.12 Other**Department for Education and Department for Health 2015**

Department for Education and Department for Health, Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf [Accessed 05/11/2020]

Appendices

Appendix A – Review protocol

Review protocol for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	CRD42019151325
1.	Review title	What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?
2.	Review question	What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?
3.	Objective	<p>This review will examine the views and experiences of commissioners, providers and practitioners of joined-up care between health, social care and education services for disabled children and young people with severe complex needs. This will be used to identify themes about the acceptability and accessibility of joined up services.</p> <p>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.</p>
4.	Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> • 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) • 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

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ID	Field	Content
		<ul style="list-style-type: none"> • Social Services Abstracts • Sociological Abstracts • PsycINFO • CINAHL • Emcare <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> • Date: 2013 onwards • Language: English <p>Other searches:</p> <ul style="list-style-type: none"> • Inclusion lists of systematic reviews • Kings Fund Reports (https://www.kingsfund.org.uk/publications) • Open Grey (if insufficient studies are found from other sources) <p>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:</p> <ul style="list-style-type: none"> • Healthtalk.org • Youthhealthtalk.org • Patient Voices • Healthwatch • The Patient Experience Library • National Voices <p>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</p> <p>The full search strategies for all databases will be published in the final review.</p>
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:

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Views and experiences of service providers

ID	Field	Content
		Commissioners and providers of, and practitioners working in, health, social care or educational services for disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support. Exclusion: Commissioners and providers of, and practitioners working in, health, social care or educational services for children and young people who do not have needs in all three areas of health, social care and education.
7.	Phenomenon of interest	The views and experiences of commissioners, providers and practitioners on joint working between health, social care and education services for disabled children and young people with severe complex needs. Commissioning, providing or practitioner working in one or more of the three services; health, social care and education.
8.	Comparator/Reference standard/Confounding factors	Not applicable
9.	Types of study to be included	Systematic reviews of qualitative studies, and primary qualitative studies, that include semi-structured and structured interviews, focus groups, observations and surveys with free text questions. Qualitative evidence from this review will eventually be incorporated alongside other quantitative reviews. Conference abstracts will not be included.
10.	Other exclusion criteria	Published studies will not be included for the following reasons: <ul style="list-style-type: none"> • Published prior to 2013 • Not published in the English language • Non UK study <p>Studies published prior to 2013 will not be considered as they will have limited relevance due to legislative changes, specifically the Children and Families Care Act 2014.</p> <p>Studies published in languages other than English will not be considered due to time and resource constraints with translation.</p> <p>Studies published by 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.</p>
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 committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): <ul style="list-style-type: none"> • Respect and understanding of contributions from other services • Joint budgets • Funding arrangements (e.g. cost is entirely picked up by education in some settings) • Joint contracts (e.g. section 75 arrangements – pooled budgets and shared risks)

ID	Field	Content
		<ul style="list-style-type: none"> • Co-location • Joint IT systems/data management • Policy and legislation (across services) • Nature of partnerships or integration (what do they mean in practice) • Managing transfer between services • Capacity • Workforce (mix of skills, cultural attitude and staff retention) • Footprint of integrated services – may not be geographical overlap • Accessibility of services • Entry point into health / social care system • Shared decision making, person centred care and support, coproduction • 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
14.	Data extraction (selection and coding)	<p>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.</p> <p>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.</p>

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Views and experiences of service providers

ID	Field	Content				
		<p>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.</p> <p>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.</p>				
15.	Risk of bias (quality) assessment	<p>Quality assessment of individual studies will be performed using the following checklists:</p> <ul style="list-style-type: none"> • CASP checklist for qualitative studies <p>The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.</p>				
16.	Strategy for data synthesis	<p>Qualitative review:</p> <p>Secondary thematic analysis will be used to synthesise the evidence from individual studies.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>Combination with results from quantitative reviews:</p> <p>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.</p>				
17.	Analysis of sub-groups	<p>Formal subgroup analyses are not appropriate for this question due to qualitative data, but the views and experience of the following groups will be considered separately if there is inconsistency or incoherence in the results of a given theme:</p> <ul style="list-style-type: none"> • Service: health, social care or education • Joint provision versus non-joined up provision • Commissioners versus providers versus practitioners • Commissioners and providers of services to under 16 year olds versus others • Practitioners working in services for under 16 year olds versus others 				
18.	Type and method of review	<table border="0"> <tr> <td><input type="checkbox"/></td> <td>Intervention</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Diagnostic</td> </tr> </table>	<input type="checkbox"/>	Intervention	<input type="checkbox"/>	Diagnostic
<input type="checkbox"/>	Intervention					
<input type="checkbox"/>	Diagnostic					

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Views and experiences of service providers

ID	Field	Content		
		<input type="checkbox"/>	Prognostic	
		<input checked="" type="checkbox"/>	Qualitative	
		<input type="checkbox"/>	Epidemiologic	
		<input checked="" type="checkbox"/>	Service Delivery	
		<input type="checkbox"/>	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	28/08/19		
22.	Anticipated completion date	May 2021		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
		Piloting of the study selection process	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
		Formal screening of search results against eligibility criteria	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
		Data extraction	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
		Risk of bias (quality) assessment	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
		Data analysis	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
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.		

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Views and experiences of service providers

ID	Field	Content
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10113
29.	Other registration details	None
30.	Reference/URL for published protocol	https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=151325
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
32.	Keywords	Child, infant, young person, disability, health care, education, social care, service delivery, service organisation
33.	Details of existing review of same topic by same authors	None
34.	Current review status	<input checked="" type="checkbox"/> Ongoing
		<input type="checkbox"/> Completed but not published
		<input type="checkbox"/> Completed and published
		<input type="checkbox"/> Completed, published and being updated
		<input type="checkbox"/> Discontinued
35.	Additional information	None
36.	Details of final publication	www.nice.org.uk

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Views and experiences of service providers

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

Appendix B – Literature search strategies

Literature search strategies for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

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

Date of last search: 06/09/2019

#	Searches
1	interview:.mp.
2	experience:.mp.
3	qualitative.tw.
4	or/1-3
5	mixed method?.ti,ab.
6	ADOLESCENT/ or MINORS/
7	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
8	exp CHILD/
9	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
10	exp INFANT/
11	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
12	exp PEDIATRICS/
13	p?ediatric\$.ti,ab.
14	YOUNG ADULT/
15	young\$ adult?.ti,ab.
16	or/6-15
17	exp DISABLED PERSONS/
18	exp MENTAL DISORDERS/
19	exp COMMUNICATION DISORDERS/
20	exp INTELLECTUAL DISABILITY/
21	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$).ti.
22	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
23	SHCN.ti,ab.
24	or/17-23
25	16 and 24
26	DISABLED CHILDREN/
27	CSHCN.ti,ab.
28	"Education Health and Care plan?".ti,ab.
29	EHC plan?.ti,ab.
30	EHCP?.ti,ab.
31	or/25-30
32	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
33	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or Dfe?).ti,ab.
34	or/32-33
35	INTERINSTITUTIONAL RELATIONS/
36	INTERSECTORAL COLLABORATION/
37	"DELIVERY OF HEALTH CARE, INTEGRATED"/
38	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
39	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
40	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
41	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
42	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
43	((inter or multi or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or profession\$)).ti,ab.
44	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
45	or/35-44
46	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or

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Views and experiences of service providers

#	Searches
	MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/)
47	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
48	(exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/ or SOCIAL SUPPORT/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
49	or/46-48
50	"HEALTH SERVICES NEEDS AND DEMAND"/
51	DELIVERY OF HEALTH CARE/
52	COOPERATIVE BEHAVIOR/
53	COMMUNICATION/
54	INTERPROFESSIONAL RELATIONS/
55	or/50-54
56	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
57	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or Dfe?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
58	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or Dfe?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
59	or/56-58
60	STATE MEDICINE/og [Organization & Administration]
61	CHILD HEALTH SERVICES/og [Organization & Administration]
62	ADOLESCENT HEALTH SERVICES/og [Organization & Administration]
63	EDUCATION/og [Organization & Administration]
64	exp EDUCATION, SPECIAL/og [Organization & Administration]
65	exp SOCIAL WORK/og [Organization & Administration]
66	or/60-65
67	31 and 34
68	31 and 45
69	31 and 49 and 55
70	31 and 59
71	31 and 66
72	or/67-71
73	limit 72 to english language
74	limit 73 to yr="2000 -Current"
75	4 and 74
76	5 and 74
77	or/75-76

Databases: Embase; and Embase Classic

Date of last search: 06/09/2019

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

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Views and experiences of service providers

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

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#	Searches
55	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster\$ or headmistress\$ or SENCO? or DfE?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
56	or/53-55
57	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
58	CHILD HEALTH CARE/ and ORGANIZATION/
59	EDUCATION/ and ORGANIZATION/
60	exp SPECIAL EDUCATION/ and ORGANIZATION/
61	SOCIAL WORK/ and ORGANIZATION/
62	or/57-61
63	30 and 33
64	30 and 44
65	30 and 48 and 52
66	30 and 56
67	30 and 62
68	or/63-67
69	limit 68 to english language
70	limit 69 to yr="2000 -Current"
71	4 and 70
72	5 and 70
73	or/71-72

Database: Health Management Information Consortium (HMIC)

Date of last search: 06/09/2019

#	Searches
1	interview:.mp.
2	experience:.mp.
3	qualitative.tw.
4	or/1-3
5	QUALITATIVE RESEARCH/
6	mixed method?.ti,ab.
7	exp YOUNG PEOPLE/
8	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
9	exp CHILDREN/
10	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
11	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
12	exp PAEDIATRICS/
13	p?ediatric\$.ti,ab.
14	YOUNG ADULTS/
15	young\$ adult?.ti,ab.
16	or/7-15
17	DISABLED PEOPLE/
18	exp DISABILITIES/
19	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$).ti.
20	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
21	SHCN.ti,ab.
22	or/17-21
23	16 and 22
24	CSHCN.ti,ab.
25	"Education Health and Care plan?".ti,ab.
26	EHC plan?.ti,ab.
27	EHCP?.ti,ab.
28	or/23-27
29	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SOCIAL SUPPORT/ or SUPPORTIVE SOCIAL WORK/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
30	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) and social\$ and (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?)).ti,ab.
31	or/29-30
32	COLLABORATION/
33	exp INTERAGENCY COLLABORATION/
34	INTERPROFESSIONAL COLLABORATION/

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

Database: Social Policy and Practice

Date of last search: 06/09/2019

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

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Views and experiences of service providers

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

Database: PsycInfo

Date of last search: 06/09/2019

#	Searches
1	experiences.tw.
2	interview:.tw.
3	qualitative.tw.
4	or/1-3
5	mixed method?.ti,ab.
6	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
7	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
8	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
9	PEDIATRICS/
10	p?ediatric\$.ti,ab.
11	young\$ adult?.ti,ab.
12	or/6-11
13	DISORDERS/
14	exp DISABILITIES/
15	PHYSICAL DISORDERS/
16	exp SENSE ORGAN DISORDERS/
17	exp MENTAL DISORDERS/
18	exp COMMUNICATION DISORDERS/
19	SPECIAL NEEDS/
20	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunc\$).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.

FINAL

Views and experiences of service providers

#	Searches
28	EHCP?.ti,ab.
29	or/24-28
30	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/ or SOCIAL SUPPORT/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
31	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?)).ti,ab.
32	or/30-31
33	INTEGRATED SERVICES/
34	INTERDISCIPLINARY TREATMENT APPROACH/
35	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
36	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
37	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
38	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
39	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
40	((inter or multi or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or profession\$)).ti,ab.
41	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
42	or/33-41
43	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/ or SOCIAL SUPPORT/)
44	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
45	(exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/ or SOCIAL SUPPORT/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
46	or/43-45
47	HEALTH SERVICE NEEDS/
48	HEALTH CARE DELIVERY/
49	COOPERATION/
50	COLLABORATION/
51	COMMUNICATION/
52	or/47-51
53	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
54	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
55	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
56	or/53-55
57	29 and 32
58	29 and 42
59	29 and 46 and 52

FINAL

Views and experiences of service providers

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

Database: Emcare

Date of last search: 06/09/2019

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

#	Searches
	SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
47	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/ or SOCIAL SUPPORT/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
48	or/45-47
49	HEALTH CARE DELIVERY/
50	COOPERATION/
51	INTERPERSONAL COMMUNICATION/
52	or/49-51
53	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
54	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
55	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
56	or/53-55
57	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
58	CHILD HEALTH CARE/ and ORGANIZATION/
59	EDUCATION/ and ORGANIZATION/
60	exp SPECIAL EDUCATION/ and ORGANIZATION/
61	SOCIAL WORK/ and ORGANIZATION/
62	or/57-61
63	30 and 33
64	30 and 44
65	30 and 48 and 52
66	30 and 56
67	30 and 62
68	or/63-67
69	limit 68 to english language
70	limit 69 to yr="2000 -Current"
71	4 and 70
72	5 and 70
73	or/71-72

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

Date of last search: 06/09/2019

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

FINAL

Views and experiences of service providers

#	Searches
#19	[mh "MENTAL DISORDERS"]
#20	[mh "COMMUNICATION DISORDERS"]
#21	[mh "INTELLECTUAL DISABILITY"]
#22	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):ti
#23	((sever* or complex* or special or high) near/3 (need or needs)):ti,ab
#24	SHCN:ti,ab
#25	#18 or #19 or #20 or #21 or #22 or #23 or #24
#26	#17 and #25
#27	[mh ^"DISABLED CHILDREN"]
#28	CSHCN:ti,ab
#29	"Education Health and Care plan*":ti,ab
#30	EHC plan*:ti,ab
#31	EHCP*:ti,ab
#32	#26 or #27 or #28 or #29 or #30 or #31
#33	(([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh ^"HEALTH PERSONNEL"]) and ([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"]) and ([mh ^EDUCATION] or [mh "EDUCATION, SPECIAL"] or [mh ^SCHOOLS] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^UNIVERSITIES] or [mh ^TEACHING] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#34	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or "general practitioner*" or GP or GPs or "occupational therapist*" or OT or OTs or "allied health professional*" or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 social* near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*)):ti,ab
#35	#33 or #34
#36	[mh ^"INTERINSTITUTIONAL RELATIONS"]
#37	[mh ^"INTERSECTORAL COLLABORATION"]
#38	[mh ^"DELIVERY OF HEALTH CARE, INTEGRATED"]
#39	(interinstitution* or multiinstitution* or jointinstitution*):ti,ab
#40	(interorganisation* or interorganization* or multiorganisation* or multiorganization* or jointorganisation* or jointorganization*):ti,ab
#41	(intersector* or multisector* or jointsector*):ti,ab
#42	(interagenc* or multiagenc* or jointagenc*):ti,ab
#43	(interprofession* or multiprofession* or jointprofession*):ti,ab
#44	((inter or multi or joint) near/3 (institution* or organisation* or organization* or sector* or agenc* or profession*)):ti,ab
#45	((institution* or organisation* or organization* or sector* or agenc* or profession* or care or service* or department*) near/5 (collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partner*)):ti
#46	#36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45
#47	(([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"])
#48	(([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh ^EDUCATION] or [mh "EDUCATION, SPECIAL"] or [mh ^SCHOOLS] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^UNIVERSITIES] or [mh ^TEACHING] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#49	(([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"]) and ([mh ^EDUCATION] or [mh "EDUCATION, SPECIAL"] or [mh ^SCHOOLS] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^UNIVERSITIES] or [mh ^TEACHING] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#50	#47 or #48 or #49
#51	[mh ^"HEALTH SERVICES NEEDS AND DEMAND"]
#52	[mh ^"DELIVERY OF HEALTH CARE"]
#53	[mh ^"COOPERATIVE BEHAVIOR"]
#54	[mh ^COMMUNICATION]
#55	[mh ^"INTERPROFESSIONAL RELATIONS"]
#56	#51 or #52 or #53 or #54 or #55
#57	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 social* near/5 (service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#58	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or

FINAL

Views and experiences of service providers

#	Searches
	AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or coordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#59	(social* near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#60	#57 or #58 or #59
#61	[mh ^"STATE MEDICINE"/og]
#62	[mh ^"CHILD HEALTH SERVICES"/og]
#63	[mh ^"ADOLESCENT HEALTH SERVICES"/og]
#64	[mh ^EDUCATION/og]
#65	[mh "EDUCATION, SPECIAL"/og]
#66	[mh "SOCIAL WORK"/og]
#67	#61 or #62 or #63 or #64 or #65 or #66
#68	#32 and #35
#69	#32 and #46
#70	#32 and #50 and #56
#71	#32 and #60
#72	#32 and #67
#73	#68 or #69 or #70 or #71 or #72
#74	#68 or #69 or #70 or #71 or #72 with Cochrane Library publication date Between Jan 2000 and Aug 2019, in Cochrane Reviews
#75	#4 and #74
#76	#5 and #74
#77	#75 or #76
#78	#68 or #69 or #70 or #71 or #72 with Publication Year from 2000 to 2019, in Trials
#79	#4 and #78
#80	#5 and #78
#81	#79 or #80

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

Date of last search: 06/09/2019

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

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

Database: Applied Social Sciences Index & Abstracts (ASSIA)

Date of last search: 06/09/2019

#	Searches
1	AB, TI(interview* or experience* or qualitative)
2	MAINSUBJECT.EXACT("QUALITATIVE RESEARCH")
3	1 or 2
4	AB, TI("mixed method?")
5	MAINSUBJECT.EXACT(ADOLESCENTS or CHILDREN or INFANTS or "YOUNG ADULTS")
6	AB, TI(adolescen* or teen* or youth* or young or juvenile? or minors or highschool* or child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid? or kindergar* or boy? or girl? or infan* or neonat* or newborn* or baby or babies or p?ediatric* or "young* adult?")
7	5 or 6
8	MAINSUBJECT.EXACT("DEAF PEOPLE" OR "LEARNING DISABLED PEOPLE" OR "DISABLED PEOPLE" OR "DEVELOPMENTALLY DISABLED PEOPLE" OR "VISUALLY IMPAIRED PEOPLE" OR "BLIND PEOPLE" OR "HEARING IMPAIRED PEOPLE" OR "AUTISTIC PEOPLE" OR "MULTIPLY DISABLED PEOPLE" OR "BLIND-DEAF PEOPLE") OR MAINSUBJECT.EXACT.EXPLODE("PSYCHIATRIC DISORDERS") OR MAINSUBJECT.EXACT.EXPLODE("LANGUAGE DISORDERS")
9	TI(disable? or disabilit* or handicap* or retard* or disorder? or impair* or condition? or difficulty or difficulties or deficit? or dysfunct*)
10	AB, TI((sever* or complex* or special or high) near/3 need?)
11	AB, TI(SHCN)
12	8 or 9 or 10 or 11
13	7 and 12
14	MAINSUBJECT.EXACT.EXPLODE("DISABLED CHILDREN")
15	AB, TI(CSHCN or "Education Health and Care plan?" or "EHC plan?" or EHCP?)
16	13 or 14 or 15
17	(MAINSUBJECT.EXACT("HEALTH SERVICES" OR "COMMUNITY HEALTH SERVICES" OR "MENTAL HEALTH SERVICES") OR MAINSUBJECT.EXACT.EXPLODE("NATIONAL HEALTH SERVICES" OR "MEDICAL PROFESSIONALS")) AND MAINSUBJECT.EXACT.EXPLODE("SOCIAL CARE" OR "SOCIAL WORKERS" OR "SOCIAL WORK AGENCIES" OR "SOCIAL SERVICES AGENCIES" OR "SOCIAL SUPPORT") AND (MAINSUBJECT.EXACT(EDUCATION OR "ELEMENTARY EDUCATION" OR "REMEDIAL EDUCATION" OR "SECONDARY EDUCATION" OR "SPECIAL EDUCATION" OR UNIVERSITIES OR TEACHING OR "REMEDIAL TEACHING" OR TEACHERS OR "CLASSROOM ASSISTANTS" OR "HEAD TEACHERS" OR "SUPPLY TEACHERS" OR "TEACHING ASSISTANTS" OR "EDUCATION AUTHORITIES") OR MAINSUBJECT.EXACT.EXPLODE(SCHOOLS OR NURSERIES))
18	TI((health* or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or "general practitioner?" or GP? or "occupational therapist?" or OT? or "allied health professional?" or AHP? or "speech therapist?" or "language therapist?" or SLT?) and social* and (educat* or school* or teach* or headmaster? or headmistress* or SENCO? or DfE?))
19	AB((health* or NHS or clinical or medical) near/10 social* near/10 (educat* or school* or teach* or DfE?))
20	17 or 18 or 19
21	MAINSUBJECT.EXACT("INTERAGENCY COLLABORATION" or "DOCTOR-SOCIAL WORKER COLLABORATION" or "INTERSECTORAL COOPERATION" or "INTEGRATED CARE PATHWAYS" or "INTEGRATED SERVICES" or "INTEGRATED MANAGEMENT" or "INTEGRATED SERVICES DIGITAL NETWORK" or "JOINT WORKING" or "INTERDISCIPLINARY APPROACH" or PARTNERSHIPS or COLLABORATION or COOPERATION or "COOPERATIVE BEHAVIOR" or COMMUNICATION)
22	AB, TI(interinstitution* or multiinstitution* or jointinstitution* or interorgani?ation* or multiorgani?ation* or jointorgani?ation* or intersector* or multisector* or jointsector* or interagenc* or multiagenc* or jointagenc* or interprofession* or multiprofession* or jointprofession*)
23	AB, TI((inter or multi or joint) near/3 (institution* or organi?ation* or sector* or agenc* or profession*))
24	TI(((institution* or organi?ation* or sector* or agenc* or profession* or care or service? or department*) near/5 (collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partner*))
25	21 or 22 or 23 or 24
26	TI((health* or NHS or clinical or medical) near/5 social* near/5 (service? or department? or institution* or organi?ation* or sector* or agenc* or provider? or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership? or partnering or network* or inter or multi or joint* or across or share? or sharing or together or communicat* or barrier? or facilitat* or deliver*))
27	TI((health* or NHS or clinical or medical) near/5 (educat* or school* or teach* or DfE?) near/5 (service? or department? or institution* or organi?ation* or sector* or agenc* or provider? or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership? or partnering or network* or inter or multi or joint* or across or share? or sharing or together or communicat* or barrier? or facilitat* or deliver*))
28	TI(social* near/5 (educat* or school* or teach* or DfE?) near/5 (service? or department? or institution* or organi?ation* or sector* or agenc* or provider? or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-

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Views and experiences of service providers

#	Searches
	operat* or integrat* or partnership? or partnering or network* or inter or multi or joint* or across or share? or sharing or together or communicat* or barrier? or facilitat* or deliver*))
29	26 or 27 or 28
30	16 and 20
31	16 and 25
32	16 and 29
33	30 or 31 or 32
34	3 and 33
35	4 and 33
36	34 or 35
	[Search then limited to 2000-current]

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

Date of last search: 06/09/2019

#	Searches
1	(AB, TI(interview* OR experience* OR qualitative OR "mixed method?") AND AB, TI(adolescenc* 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 dysfunc* 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(adolescenc* 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 dysfunc* 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(adolescenc* 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 dysfunc* 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 (adolescenc* 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 dysfunc* OR "sever* need?" OR "complex* 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 (adolescenc* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR

#	Searches
3	impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND AB (((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))) Limiters - Publication Date: 20000101-20190931
1 or 2	

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

Date of last search: 06/09/2019

#	Searches
1	TX (interview* OR experience* OR qualitative OR "mixed method?") AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR department? OR institution* OR organi?ation* OR sector* OR agenc* OR provider? OR policy OR policies OR collaborat* OR coordinat* OR co-ordinat* OR cooperat* OR co-operat* OR integrat* OR partnership? OR partnering OR network* OR inter OR multi OR joint* OR across OR share? OR sharing OR together OR communicat* OR barrier? OR facilitat* OR deliver* OR team*) Limiters - Published Date: 20000101-20190931
2	TX (interview* OR experience* OR qualitative OR "mixed method?") AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND AB ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) Limiters - Published Date: 20000101-20190931
3	TX (interview* OR experience* OR qualitative OR "mixed method?") AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI ((((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))) Limiters - Published Date: 20000101-20190931
4	1 or 2 or 3 Limiters - Published Date: 20000101-20190931

Database: Social Sciences Citation Index (SSCI)

Date of last search: 06/09/2019

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

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Views and experiences of service providers

#	Searches
# 12	#11 OR #10 OR #9 Indexes=SSCI Timespan=2000-2019
# 13	#12 AND #8 Indexes=SSCI Timespan=2000-2019
# 14	TOPIC: (CSHCN) Indexes=SSCI Timespan=2000-2019
# 15	TOPIC: ("Education Health and Care plan\$") Indexes=SSCI Timespan=2000-2019
# 16	TOPIC: ("EHC plan\$") Indexes=SSCI Timespan=2000-2019
# 17	TOPIC: (EHCP\$) Indexes=SSCI Timespan=2000-2019
# 18	#17 OR #16 OR #15 OR #14 OR #13 Indexes=SSCI Timespan=2000-2019
# 19	TITLE: (((health* or NHS or clinical or clinician\$ or medical or medic\$ or physician\$ or consultant\$ or nurse\$ or general practitioner\$ or GP or GPs or occupational therapist\$ or OT or OTs or allied health professional\$ or AHP or AHPs or ((speech or language) near/3 therapist\$) or SLT or SLTs) and social* and (educat* or school* or teach* or headmaster\$ or headmistress* or SENCO\$ or DfE\$))) Indexes=SSCI Timespan=2000-2019
# 20	TOPIC: (((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/10 social near/10 (education or educating or educator or educators or school or schools or teach or teaching or teachers))) Indexes=SSCI Timespan=2000-2019
# 21	#20 OR #19 Indexes=SSCI Timespan=2000-2019
# 22	TOPIC: (((interinstitution* or multiinstitution* or jointinstitution*)) Indexes=SSCI Timespan=2000-2019
# 23	TOPIC: (((interorganisation* or multiorganisation* or jointorganisation*)) 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 organisation* or sector* or agenc* or profession*)) Indexes=SSCI Timespan=2000-2019
# 28	TITLE: (((institution* or organisation* 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 organisation* 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 organisation* 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 organisation* or sector* or agenc* or provider\$ or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership\$ or partnering or network* or inter or multi or joint* or across or share\$ or sharing or together or communicat* or barrier\$ or facilitat* or deliver*)) Indexes=SSCI Timespan=2000-2019
# 33	#32 OR #31 OR #30 Indexes=SSCI Timespan=2000-2019
# 34	#21 AND #18 Indexes=SSCI Timespan=2000-2019
# 35	#29 AND #18 Indexes=SSCI Timespan=2000-2019
# 36	#33 AND #18 Indexes=SSCI Timespan=2000-2019
# 37	#36 OR #35 OR #34 Indexes=SSCI Timespan=2000-2019
# 38	#37 AND #1 Indexes=SSCI Timespan=2000-2019
# 39	#37 AND #2 Indexes=SSCI Timespan=2000-2019
# 40	#39 OR #38 Indexes=SSCI Timespan=2000-2019

Database: Social Care Online

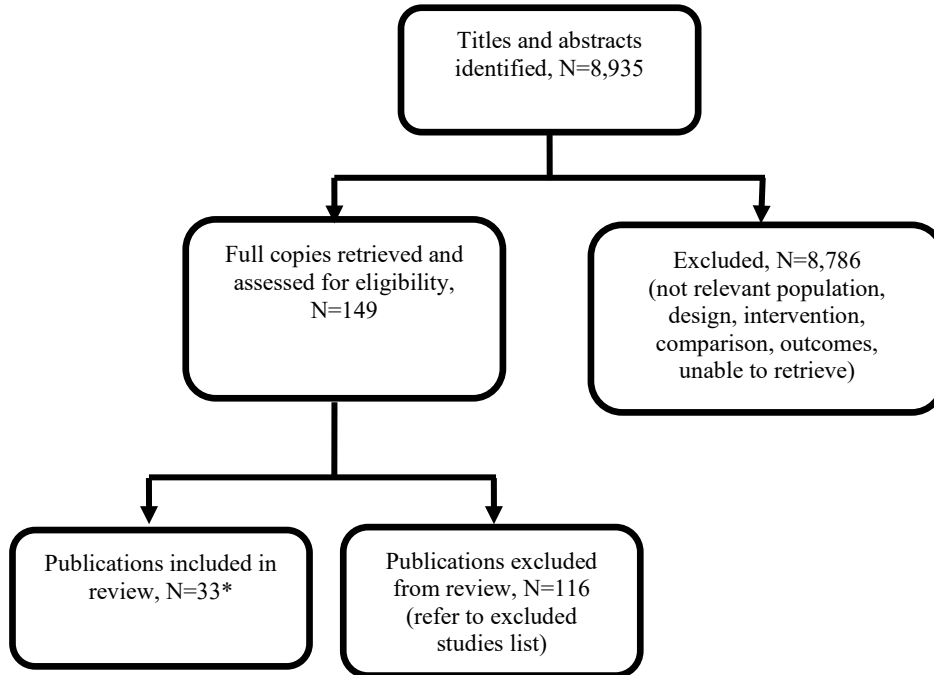
Date of last search: 06/09/2019

#	Searches
	AllFields:'qualitative or interview or experience'
	AND AllFields:'disabled or disability or disabilities or handicap or retard or disorder or impaired or impairment or condition or difficulty or difficulties or deficit or dysfunction or "special need" or "complex need"'
	AND AllFields:'child or children or schoolchild or schoolchildren or "school age" or "school aged" or preschool or toddler or kid or kindergarden or boy or girl or infant or neonate or newborn or baby or babies or pediatric or paediatric or "young people" or "young adults"'
	AND PublicationYear:'2000 2019'

Appendix C – Qualitative evidence study selection

Study selection for: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

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 commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

Table 4: Evidence tables

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>Full citation Boesley, Lauren, Crane, Laura, Allen, Barnes Braun Childre Cole Corrigan Craston Crowne Curran Das Devecchi Emilson Estes Evans Gore Gray Green Gross Hagner Hayes Holburn Jones Kachne Keyes Lehane Lever Lewis Mackenzie Mackenzie Morewood Neufeld Norwich Norwich Parsons Pearson Polanczyk Reardon Redwood</p>	<p>Characteristics N=16 (SENCOs) Gender n=15 females n=1 male Setting n=12 worked within a mainstream primary setting (children ages 5-11 years) n=4 worked within a mainstream secondary setting (children ages 11-16 years) Teaching experience Range: 4-25 years (M = 15.0 years, SD = 7.55) SENCO experience Range: 2-12 years (M = 6.5 years, SD = 3.04). Greater than 4 years experience n=13 (could draw on comparisons to the previous statutory guidance) Geographical location within England (10 different counties) east (n = 9; 56%) south-east (n = 3; 19%)</p>	<p>Setting Primary and secondary schools across England Data collection Semi-structured interviews via telephone (due to participants regional variation) were conducted at a time/date convenient for participants. Interviews were audio recorded and transcribed verbatim. Interviews varied in length between 25-47 minutes (M = 37.44, SD = 6.24) due to participants' experiences Data analysis Data were analysed using thematic analysis An essentialist framework was used to report the experiences, meaning and reality of participants utilising a data-driven, inductive approach Both authors familiarised themselves with the data by reviewing transcripts</p>	<p>Themes Original theme: The perceived role of the SENCO in the EHC plan process: Managing parental expectations</p> <ul style="list-style-type: none"> • Information and support <ul style="list-style-type: none"> ○ Service users should be given more information and support throughout the EHC plan process • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Managing parents' expectations • Involvement of families and carers <ul style="list-style-type: none"> ○ Involvement of families is valued and improves relevancy, accuracy and usefulness of EHC plans <p>Original theme: Procedural challenges and changes: an evolving process</p> <ul style="list-style-type: none"> • Experience of EHC plans <ul style="list-style-type: none"> ○ Challenges due to timing of introducing EHC plans • Child/young person centred approach <ul style="list-style-type: none"> ○ Using a child/young person 	<p>Limitations Q1 Was there a clear statement of the aims of the research? Yes Q2 Was a qualitative methodology appropriate? Yes Q3 Was the research design appropriate to address the aims of the research? Yes Q4 Was the recruitment strategy appropriate to the aims of the research? Yes Q5: Were the data collected in a way that addressed the research issue? Yes Q6: Has the relationship between researcher and participants been adequately considered? Can't tell Q7: Have ethical issues been taken into consideration? Yes Q8: Was the data analysis sufficiently rigorous? Yes Q9: Is there a clear statement of findings? Yes</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>Riglin Roaf Robertson Robertson Robertson Sanderson Simonoff Spivack Szwed Szwed Taylor-Brown Tissot Tissot Townesley Tsai White Woodward, 'Forget the health and care and just call them education plans': SENCOS' perspectives on education, health and care plans, Journal of Research in Special Educational Needs, 18, 36-47, 2018 Ref ID 1105535 Country/ies where study was carried out UK Study type</p>	<p>London (n = 2; 13%) south-West (n = 2; 13%) Inclusion criteria SENCOs based in England and had undertaken an application for an EHC plan, or transferred a statement of SEN into an EHC plan. Exclusion criteria NR</p>	<p>and establishing a preliminary set of codes, themes and subthemes, which were discussed and agreed upon. Definitions were established once themes were reviewed at a surface level, using a semantic approach</p>	<p>centred approach is valued</p> <p>Original theme: Difficulties in accessing EHC plans for children with SEMH needs. Difficulties validating SEMH needs</p> <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Recognising the child or young person's potential and supporting them to reach it 	<p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes Source of funding NR Other information</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
Primary qualitative - semi-structured telephone interviews Study dates NR				
Full citation Boyce, Tammy, Dahlmann-Noor, Annegret, Bowman, Richard, Keil, Sue, Support for infants and young people with sight loss: a qualitative study of sight impairment certification and referral to education and social care services, BMJ open, 5, e009622, 2015 Ref ID 914536 Country/ies where study was carried	Characteristics Total: n=78 <i>Hospital staff (3 teaching hospitals 2 district general): n=29</i> n=12 Consultant ophthalmologists (8 subspecialty paediatric ophthalmologists): Of the 12, 10 were qualified for over 10 years, 2 were qualified for over 5 years n=3 eye clinic liaison officer (ECLO) n=1 Optometrist n=5 Administrators n=6 Orthoptists n=2 Nurses <i>Education: n=8</i> n=7 qualified teachers of children and young people with vision impairment (QTVI) n=1 Manager <i>Social services: n=15</i> n=6 Managers n=5 Rehabilitation workers	Setting Hospital Data collection Interviews were digitally recorded with the participant's consent, lasted between 10 and 50 min and transcribed verbatim The interviews consisted of semi structured questions covering the following themes: Description and/or experience of certification and registration processes; Attitudes to and meaning of certification and registration; Role and relationships with relevant stakeholders (health, education, social services); and Improving experiences and systems. Data analysis Interview data were analysed thematically A list of deductive codes	Themes Original theme: How to ensure early and consistent support Multidisciplinary team <ul style="list-style-type: none"> • Service provider knowledge and training <ul style="list-style-type: none"> ○ Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build expertise 	Limitations Q1 Was there a clear statement of the aims of the research? Yes Q2 Was a qualitative methodology appropriate? Yes Q3 Was the research design appropriate to address the aims of the research? Yes: No discussion on how they decided which method to use Q4 Was the recruitment strategy appropriate to the aims of the research? No: Participants were purposely selected from areas to provide examples of excellent, ordinary and common practice leading to recruitment bias Q5: Were the data collected in a way that addressed the research issue? Can't tell: The setting for interviews was not justified Q6: Has the relationship between researcher and participants been adequately considered? Yes: The researcher was experienced in the topic and with the interview

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>out UK (England) Study type Primary qualitative Study dates Interviews were completed between March and July 2014.</p>	<p>n=3 Administrators n=1 Social worker</p> <p><i>Parents: n=26</i> n=26 Parents with 28 children n=22 Severely sight impaired, 6 sight impaired n=7 Infants and children with complex needs n=18 Diagnosed under age 1 n=10 Certified under age 1 Ethnicity (children): 26 white, 2 Asian Ethnicity (parents): 2 Asian (8%) (other ethnicities not reported) Gender (children): 12 Girls, 16 boys Income (parents) below £15 000/annum: 27% of parents (n=7)</p> <p>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</p> <p>Exclusion criteria NR</p>	<p>was initially created and inductive codes emerged during the second level of the thematic analysis</p>		<p>population</p> <p>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</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes: Limited detail provided on data analysis</p> <p>Q9: Is there a clear statement of findings? Yes</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes</p> <p>Source of funding The Royal National Institute of Blind People</p> <p>Other information</p>
<p>Full citation Children's Commissioner</p>	<p>Characteristics <i>Face to face focus groups</i> n=99 young people (aged 14-</p>	<p>Setting Focus groups</p> <p>Data collection</p>	<p>Themes Original theme: Young person's participation in their social care</p>	<p>Limitations Q1 Was there a clear statement of the aims of the research?</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>for Wales, 'Don't hold back': transitions to adulthood for young people with learning disabilities, 40, 2018</p> <p>Ref ID 1105580</p> <p>Country/ies where study was carried out UK (Wales)</p> <p>Study type Report including an Evidence Review and Qualitative focus groups</p> <p>Study dates NR</p>	<p>26 years)</p> <p>Speaking welsh: n=17%, Speaking some Welsh: n=25%</p> <p>Black or minority ethnic background: n=5%</p> <p><i>Online questionnaire</i> n=187 parents of children and young people with learning disabilities (nearly all aged 14-25 years)</p> <p><i>Focus groups</i> n=43 professionals from education, social care, health and voluntary services</p> <p><i>Written submissions</i> n=6 6 national voluntary organisations</p> <p>Inclusion criteria young people with learning disabilities (reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life)</p> <p>adults who care for young people with learning disabilities</p> <p>adults who work with young people with learning disabilities</p> <p>Exclusion criteria NR</p>	<p>NR</p> <p>Data analysis NR</p>	<ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ People making decisions are out of touch with the needs of the child/young person • Child/young person centred approach <ul style="list-style-type: none"> ○ Service providers are falling short of using a child/young person centred approach <p>Original theme: Young people's views on the role of parents</p> <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Recognising the child or young person's potential and supporting them to reach it 	<p>Yes: Not explicitly described</p> <p>Q2 Was a qualitative methodology appropriate? Yes</p> <p>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</p> <p>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</p> <p>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</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? No: The relationship between researcher and participants has not been adequately considered</p> <p>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</p> <p>Q8: Was the data analysis sufficiently rigorous? No: No description of analysis process, unclear how themes were</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				<p>derived from the data or selected from the original sample</p> <p>Q9: Is there a clear statement of findings? Yes: No discussion on the credibility of findings</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes: No integration with existing research</p> <p>Source of funding NR</p> <p>Other information https://www.edgehill.ac.uk/eprc/files/2018/07/CCfW-final-report-04072018.pdf</p>
<p>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</p> <p>Ref ID</p>	<p>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</p>	<p>Setting Interviews were conducted via the phone with the exception of one parent and two professionals who were interviewed in person</p> <p>Data collection Semi structured interviews with topic guides Interviews were transcribed verbatim Information from several other contributors was gathered by email</p> <p>Data analysis Thematically analysis using the Framework approach.</p>	<p>Themes Original theme: Sharing information and professional opinions</p> <ul style="list-style-type: none"> • Service provider knowledge and training <ul style="list-style-type: none"> ○ Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build expertise <p>Original theme: Parental engagement with services and community resources</p> <ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Meetings with professionals can 	<p>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 interviewees were disseminated through adoption and disability related networks</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>1105592</p> <p>Country/ies where study was carried out UK (England)</p> <p>Study type Primary qualitative</p> <p>Study dates NR</p>	<p>including heart problems, developmental delay, developmental trauma, developmental coordination disorder (dyspraxia), foetal alcohol spectrum disorders, foetal alcohol syndrome, genetic condition, hearing loss, learning difficulties, sensory processing disorder or sensory issues. (some of the needs were not formally diagnosed)</p> <p>Symptoms and behaviours also included: anxiety, violence and toileting issues</p> <p>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</p> <p>Inclusion criteria Parent and profession interviewees with experience of parenting or supporting children: who had been placed for adoption or entered early permanence placements since 2010 (later extended to 2009)</p>		<p>be intimidating for service users</p>	<p>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</p> <p>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</p> <p>Q7: Have ethical issues been taken into consideration? No: No mention of consent or ethics, or how the research was explained to participants</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited detail provided on data analysis</p> <p>Q9: Is there a clear statement of findings? Can't tell: Limited participant quotes</p> <p>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</p> <p>Source of funding National Institute for Health Research (NIHR) Children's Policy Research Unit</p> <p>Other information</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
	<p>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.</p> <p>Exclusion criteria NR</p>			
<p>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</p>	<p>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</p>	<p>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</p>	<p>Themes Original theme: Barriers</p> <ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Managing parents' expectations • Involvement of families and carers <ul style="list-style-type: none"> ○ Families as providers of care • Relationships between service providers and service users <ul style="list-style-type: none"> ○ People making decisions are out of touch with the needs of the child/young person 	<p>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</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>Country/ies where study was carried out UK (Wales)</p> <p>Study type Mixed methods - including qualitative workshops (focus group discussions)</p> <p>Study dates September 2015</p>	<p>South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists) staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist) parents of primary school children diagnosed with ASD</p> <p>Participants were aged over 18 years of age and able to provide written informed consent</p> <p>Exclusion criteria NR</p>	<p>group.</p> <p>The construction of the initial coding template was based upon the research topic and the themes that emerged from reading the first few transcripts.</p> <p>An iterative approach was used</p> <p>The transcripts were read by all the authors and the initial identification and coding of the themes was conducted by two authors</p> <p>Three types of triangulation were employed – data, method and investigator</p>		<p>size and demographic information of participants not provided.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Yes</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? No: The relationship between the researchers and participants has not been adequately considered</p> <p>Q7: Have ethical issues been taken into consideration? Yes</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes</p> <p>Q9: Is there a clear statement of findings? Yes</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes</p> <p>Source of funding NR</p> <p>Other information</p>
<p>Full citation McConkey, Roy, Gent, Clare, Scowcroft, Emma, Perceptions of effective</p>	<p>Characteristics Family member: n=14 (11 mothers, 6 fathers) Key workers: n=17 Referrers: n=17 (social workers, psychologists and community nurses)</p> <p>Inclusion criteria</p>	<p>Setting Families and practitioners/providers were recruited from Action for Children in Glasgow, Edinburgh and Cardiff, who provide intensive support services for children with</p>	<p>Themes Original theme: Negotiation: Amount of service provided</p> <ul style="list-style-type: none"> • Short breaks and respite breaks provide benefit <ul style="list-style-type: none"> ○ The amount of respite provided should be balanced and 	<p>Limitations Q1 Was there a clear statement of the aims of the research? Yes</p> <p>Q2 Was a qualitative methodology appropriate? Yes: Intending to capture perceptions.</p> <p>Q3 Was the research design appropriate</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>support 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</p> <p>Ref ID 914709</p> <p>Country/ies where study was carried out UK</p> <p>Study type Qualitative</p> <p>Study dates 2008-2010</p>	<p>Families, key workers and referrers of children currently receiving services from Action for Children, or had received services in the past 2 years.</p> <p>Exclusion criteria No additional criteria reported.</p>	<p>developmental disabilities and severely challenging behaviours (aged up to 19 years old).</p> <p>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.</p> <p>Data analysis Thematic analysis was undertaken to identify main themes and subthemes. Limited information is provided about the process of developing themes, and who was responsible for this. The authors report that findings were validated by the team of interviewers who collected the data, but it is not clear if this was done independently or as a group. Findings were then validated by steering groups comprising staff,</p>	<p>responsive to families' needs</p> <p>Original theme: Relationships: Relationships with families and young people</p> <ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Individuals or services going above and beyond to deliver a good service • Child/young person centred approach <ul style="list-style-type: none"> ○ Children and young people benefit from using a consistent approach <p>Original theme: Benefits: Benefits to siblings</p> <ul style="list-style-type: none"> • Short breaks and respite breaks provide benefit <ul style="list-style-type: none"> ○ Short breaks benefit whole family 	<p>to address the aims of the research? Can't tell: There is limited discussion of justification for research design.</p> <p>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.</p> <p>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.</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? Yes: Authors report that researchers were independent of services.</p> <p>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.</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited information is provided about how themes were developed.</p> <p>Q9: Is there a clear statement of findings? Yes: Findings are clearly presented and process for validation of findings is described.</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		parents and referrers (which included some of those interviewed), and the national steering group for the evaluation.		b. Transferability) Yes: Contribution to the literature and directions for future research are discussed. Source of funding Not industry funded Other information
Full citation Molteni, Paola, Guldberg, Karen, Logan, Nick, Bondy, Kasari Mesibov O'Neill Parsons Prizant Prizant Reid Seligman Smith Smith Stake Strom Wittemeyer, Autism and multidisciplinary teamwork through the SCERTS model, BRITISH JOURNAL OF SPECIAL EDUCATION, 40, 137-145, 2013 Ref ID 1103529 Country/ies where study	Characteristics Profession: Teacher: n=5 Teaching assistant: n=4 Care staff: n=7 Therapist: n=4 Head of department (Education and Psychology): n=2 Sex: Female: n=16 Male: n=6 Age range: 23 to 64 Educated to degree level: n=15 Years' experience working with people with autism: 1-5: n=7 6-10: n=4 11-15: n=6 15-20: n=3 >20: n=2 Inclusion criteria Teams of professionals	Setting Teams were recruited from Sunfield, a 52-week independent residential special school which educates students with severe learning difficulties. The majority of students were residential and also had autistic spectrum disorders. The SCERTS model was implemented in 2011. Data collection Qualitative data was collected through focus groups (of the assessment process), semi-structured interviews and one open-ended question on a questionnaire. Focus groups lasted between 1 and 3 hours, and the researchers took an active part in the group. Individuals for interview (n=5) were identified during the focus groups based on	Themes Original theme: Positive aspects of using the SCERTS Model: Working with the child <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Using a child/young person centred approach is valued Original theme: The Team Around the Child as a way of working together: Multidisciplinary work <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Children and young people benefit from using a consistent approach Original theme: The Team Around the Child as a way of working together: Learning from each other <ul style="list-style-type: none"> • Service provider knowledge and training <ul style="list-style-type: none"> ○ Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build 	Limitations Q1 Was there a clear statement of the aims of the research? Yes Q2 Was a qualitative methodology appropriate? Yes: Intending to capture perspectives/experiences. Q3 Was the research design appropriate to address the aims of the research? Yes: Justification for research design clearly explained. Q4 Was the recruitment strategy appropriate to the aims of the research? Can't tell: Recruitment of overall participants was appropriate and authors provide rationale for why specific teams were selected to represent children with differing levels of communication. However, selecting participants for interviews based on involvement in focus groups may not result in a representative sample. Q5: Were the data collected in a way that addressed the research issue? Can't tell: Limited information is provided about the interview guide and data saturation is not discussed.

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>was carried out UK Study type Multi-methods approach involving questionnaire s, observations, focus groups and interviews Study dates 2011</p>	<p>involved in implementing the SCERTS (Social Communication, Emotional Regulation, Transactional Support) model. Exclusion criteria No additional criteria reported.</p>	<p>their participation during the group. Semi-structured interviews were conducted using an interview schedule as a guide and both focus groups and interviews were recorded. A questionnaire was administered to all participants at the end of the assessment process which contained an open-ended question about personal opinions of SCERTS. Data analysis Interpretative Phenomenological Analysis (IPA) was used to analyse data collected from the focus groups and interviews. One research read and re-read the transcripts, identified key themes and connections between themes. The authors also report IPA was used to analyse quantitative data from the questionnaires but no further details are provided about this.</p>	<p>expertise</p>	<p>Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: The authors clearly describe the collaboration between the researcher and key members of staff at the school, discuss the researchers involvement in the focus groups and discuss potential benefits of this, but whether this approach may have led to any biases is not discussed. Q7: Have ethical issues been taken into consideration? Yes: Ethical approval and informed consent obtained. Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited information is provided about analysis. Q9: Is there a clear statement of findings? Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Can't tell: The impact of the findings are clearly discussed, as are some directions for future research, but generalisability of the findings to other settings/approaches may be limited. Source of funding No sources of funding reported.</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				Other information
<p>Full citation Palikara, O., Castro, S., Gaona, C., Eirinaki, V., Professionals' views on the new policy for special educational needs in England: ideology versus implementation, European Journal of Special Needs Education, 34, 83-97, 2019</p> <p>Ref ID 1065416</p> <p>Country/ies where study was carried out UK</p> <p>Study type Survey</p> <p>Study dates Not reported</p>	<p>Characteristics Profession: Educational psychologist: n=90 Speech and language therapist: n=24 Special educational needs co-ordinator: n=154 Headteacher: n=13 Teacher: n=12 Other: n=54</p> <p>Sex: Female: n=307 Male: n=32</p> <p>Educated to degree level: n=348</p> <p>Years of experience: <1: n=4 1-4: n=18 5-10: n=64 11-20: n=131 >20: n=157</p> <p>Inclusion criteria Professional groups working in special education.</p> <p>Exclusion criteria No additional criteria reported.</p>	<p>Setting The survey was distributed to schools/education establishments, educational psychology services, language services and other relevant professional organisations through a research network.</p> <p>Data collection The survey took 15-20 minutes to complete, was semi-structured and had three sections: participant characteristics and work experience, training received in relation to SEND reforms, opinion of main changes introduced by the Children and Families Act 2014 and the SEND Code of Practice. Three reminders were sent to complete the survey before it closed.</p> <p>Responses to the survey were anonymised.</p> <p>Data analysis Qualitative responses were analysed using inductive thematic analysis - no further information reported. Quantitative</p>	<p>Themes Original theme: Extension of age range for service provision (0-25)</p> <ul style="list-style-type: none"> Improved transition <ul style="list-style-type: none"> Extending service provision to 25 has (or should) improve transitions <p>Original theme: Replacement of statements of SEN with EHCPs</p> <ul style="list-style-type: none"> Child/young person centred approach <ul style="list-style-type: none"> Using a child/young person centred approach is valued Involvement of families and carers <ul style="list-style-type: none"> Involvement of families is valued and improves relevancy, accuracy and usefulness of EHC plans Experience of EHC plans <ul style="list-style-type: none"> Introduction of EHC plans has reduced the impact of service provider bias on access to assessment 	<p>Limitations</p> <p>Q1 Was there a clear statement of the aims of the research? Yes</p> <p>Q2 Was a qualitative methodology appropriate? Yes: Intending to capture views/perspectives.</p> <p>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.</p> <p>Q4 Was the recruitment strategy appropriate to the aims of the research? Can't tell: The survey appears to have been sent to a representative sample of professionals but those self-selecting to respond to a survey may give a biased sample.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Can't tell: Open-ended questions in the online consultation form provided the qualitative data, may not provide the necessary richness to address the research question.</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: No information is reported.</p> <p>Q7: Have ethical issues been taken into consideration? Yes: Ethical approval was obtained, participation was voluntary and</p>

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		<p>ratings were analysed using descriptive statistics and ratings between professional groups were compared using one way ANOVAs.</p>		<p>responses were anonymised. Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited information is provided about analysis. Q9: Is there a clear statement of findings? Can't tell: Findings are clearly presented but there is limited discussion of evidence for and against the researchers' arguments or credibility of findings. Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes: Contribution to the literature is clearly discussed and directions for future work are highlighted. Source of funding Not industry funded Other information</p>
<p>Full citation RIP STARS, et al.,, Defining quality and rights-based Education, Health and Care Plans (EHCPs) for disabled children and young people, 36, 2018 Ref ID</p>	<p>Characteristics Young people Age: 13-25 Sex: n=9 female; n=6 male Parent/carers: n=9 mothers n=1 father Professionals: n=17; included SEN (head)teachers, SEND/Autism lead, SEN co-ordinator, educational</p>	<p>Setting Setting/method of recruitment is not reported. Data collection Data collected through interviews and group discussion that were facilitated by one disabled young researcher and one researcher from Coventry University. No information reported about content or structure of interviews/group</p>	<p>Themes Original theme: Accessible information for disabled children and young people about EHCPs</p> <ul style="list-style-type: none"> • Information and support <ul style="list-style-type: none"> ○ Service users should be given more information and support throughout the EHC plan process • Involvement of children and young people <ul style="list-style-type: none"> ○ Using accessible language in EHC plans would help enable 	<p>Limitations Q1 Was there a clear statement of the aims of the research? Yes Q2 Was a qualitative methodology appropriate? Yes: Intending to capture views. Q3 Was the research design appropriate to address the aims of the research? Can't tell: There is limited discussion of justification for research design. Q4 Was the recruitment strategy appropriate to the aims of the research? Can't tell: Recruitment strategy is not</p>

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<p>1105868</p> <p>Country/ies where study was carried out UK</p> <p>Study type Qualitative</p> <p>Study dates Not reported</p>	<p>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</p> <p>Inclusion criteria Not reported.</p> <p>Exclusion criteria Not reported.</p>	<p>discussions.</p> <p>Data analysis Disabled young researchers and researchers from Coventry University worked together to analyse the data thematically. No further information reported.</p>	<p>children and young people to be involved and improve accountability</p> <p>Original theme: Involvement of disabled children and young people in their EHCP</p> <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Service providers are falling short of using a child/young person centred approach ○ Importance of separating the views of the child or young person from the views of parents • Involvement of children and young people <ul style="list-style-type: none"> ○ Supporting children and young people to prepare for meetings and communicate their views • Involvement of families and carers <ul style="list-style-type: none"> ○ Involvement of families can be limited and depends on individual service providers <p>Original theme: A quality "About Me" Section</p> <ul style="list-style-type: none"> • Involvement of children and young people <ul style="list-style-type: none"> ○ Importance of accurately capturing the views of the child/young person <p>Original theme: Accessible EHCPs for disabled children and young people</p>	<p>reported.</p> <p>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.</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: No information is reported.</p> <p>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 confidentiality were explained.</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited information reported about data analysis.</p> <p>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.</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes: Contribution to the literature is</p>

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			<ul style="list-style-type: none"> • Involvement of children and young people <ul style="list-style-type: none"> ○ Using accessible language in EHC plans would help enable children and young people to be involved and improve accountability <p>Original theme: Recognising children and young people's ambitions and strengths</p> <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Recognising the child or young person's potential and supporting them to reach it <p>Original theme: Health</p> <ul style="list-style-type: none"> • Experience of EHC plans <ul style="list-style-type: none"> ○ Information in EHC plans is not always accurate • Child/young person centred approach <ul style="list-style-type: none"> ○ Using a child/young person centred approach is valued <p>Original theme: Respecting the rights of disabled children and young people</p> <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Respecting the rights of the child or young person 	<p>clearly discussed</p> <p>Source of funding Not industry funded</p> <p>Other information</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>Full citation Rodriguez, Alison, King, Nigel, Sharing the care: the key-working experiences of professionals and the parents of life-limited children, International Journal of Palliative Nursing, 20, 165-172, 2014</p> <p>Ref ID 344954</p> <p>Country/ies where study was carried out UK</p> <p>Study type Qualitative</p> <p>Study dates Not reported</p>	<p>Characteristics Professionals: n=21 Parents: n=20 (mothers: n=18; fathers: n=2) Characteristics of the children: Cancer: n=4 Cerebral palsy: n=3 Muscular dystrophy: n=1 Congenital disorder: n=1 Neurological disorder: n=1 Genetic disorder: n=10</p> <p>Inclusion criteria Professionals working in paediatric care; parents of children with life limiting conditions.</p> <p>Exclusion criteria Parents who might find the research process too distressing (based on the opinion of link professionals).</p>	<p>Setting Participants were recruited from 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.</p> <p>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.</p> <p>Data analysis Data was analysed using inductive thematic analysis. An iterative approach was used, re-reading transcripts to identify themes.</p>	<p>Themes</p> <p>Original theme: Great expectations—and disappointments</p> <ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Individuals or services going above and beyond to deliver a good service • Information and support <ul style="list-style-type: none"> ○ Sharing information reduces distress for service users and makes the best use of resources <p>Original theme: The right help from the right person</p> <ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Families are less accepting of key workers who have not had much involvement with the family ○ Individuals or services going above and beyond to deliver a good service <p>Original theme: Changing faces</p> <ul style="list-style-type: none"> • Involvement of families and carers <ul style="list-style-type: none"> ○ Families as providers of care • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Individuals or services going above and beyond to deliver a 	<p>Limitations</p> <p>Q1 Was there a clear statement of the aims of the research? Yes</p> <p>Q2 Was a qualitative methodology appropriate? Yes: Intending to capture experiences.</p> <p>Q3 Was the research design appropriate to address the aims of the research? Yes: Justification for research design clearly explained.</p> <p>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.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Can't tell: Interviews were semi-structured and audio recorded but authors do not report whether they were conducted face-to-face or by telephone and no information is provided about content of topic guide.</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: No information is reported.</p> <p>Q7: Have ethical issues been taken into consideration? Yes: Ethical approval was obtained,</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
			good service	<p>participation was voluntary and informed consent was obtained.</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited information reported about data analysis.</p> <p>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.</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) No: There is limited discussion of implication for practice and authors note that data is not generalisable due to methods of recruitment and lack of diversity in parent sample.</p> <p>Source of funding Authors report there was no external funding.</p> <p>Other information</p>
<p>Full citation Sales, Niaomi, Vincent, Kerry, Strengths and Limitations of the Education, Health and Care Plan Process from a Range of</p>	<p>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</p>	<p>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</p>	<p>Themes Original theme: Involving and valuing parents</p> <ul style="list-style-type: none"> • Involvement of families and carers <ul style="list-style-type: none"> ○ Involvement of families can be limited and depends on individual service providers <p>Original theme: Multi-agency working</p>	<p>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?</p>

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<p>Professional and Family Perspectives, BRITISH JOURNAL OF SPECIAL EDUCATION, 45, 61-80, 2018 Ref ID 1105883 Country/ies where study was carried out UK Study type Qualitative Study dates June 2016- August 2016</p>	<p>Inclusion criteria Not reported Exclusion criteria Not reported</p>	<p>children and young people is not reported. Data collection Qualitative data from 11 of the parents and professionals was collected through face-to-face interviews conducted either at work or at home. The interviews ranged from 30 minutes to three hours (most completed within one hour) and were audio recorded and transcribed. The interviews covered understanding and experience of the EHC assessment process, including its strengths and limitations and the extent to which it changes ways of working between professionals and families. The views of 5 further parents were collected through a focus group which used the same questions as the interviews. Data was collected in the 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</p>	<ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Using a child/young person centred approach is valued <p>Original theme: Ascertaining the views of children and young people</p> <ul style="list-style-type: none"> • Involvement of children and young people <ul style="list-style-type: none"> ○ EHC plans have increased focus on views of child/young person ○ Supporting children and young people to prepare for meetings and communicate their views • Involvement of families and carers <ul style="list-style-type: none"> ○ Involvement of families can be limited and depends on individual service providers <p>Original theme: Extending the age range to 25 years</p> <ul style="list-style-type: none"> • Improved transition <ul style="list-style-type: none"> ○ Extending service provision to 25 has (or should) improve transitions 	<p>Yes: The research design was justified in the text (in order to capture a holistic view of the all those involved in the new assessment process). Q4 Was the recruitment strategy appropriate to the aims of the research? Yes/Can't tell: Recruitment strategy appears to be appropriate for parents and professionals but is not reported for children and young people. Q5: Were the data collected in a way that addressed the research issue? Yes: Content of interviews/focus groups/questionnaires appear to be appropriate to the aims of the research and data was audio recorded and/or written down. Questionnaires for children and young people were adapted to the individual to be accessible and non-threatening. Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: No information is reported. Q7: Have ethical issues been taken into consideration? Yes: Authors report that ethical guidelines regarding informed consent, anonymity, the right to withdraw and storage of data were followed. Written consent to seek the views of children and young people was obtained from parents and verbal consent was obtained from the children and young people themselves. Q8: Was the data analysis sufficiently</p>

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		<p>tailored questionnaires administered in the home setting and completed either with the assistance of the first author (n=1) or a parent (n=3). The questionnaires aimed to capture children's and young people's understanding of EHC plans, if and how they had helped them, whether they were involved in meetings and whether they had support to communicate their views.</p> <p>Data analysis Data was analysed through thematic analysis and was guided by the key interview questions. No further information reported.</p>		<p>rigorous? Can't tell: Limited information reported about data analysis.</p> <p>Q9: Is there a clear statement of findings? Can't tell: Findings are clearly presented but there is limited discussion of credibility of findings.</p> <p>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.</p> <p>Source of funding No sources of funding reported.</p> <p>Other information</p>
<p>Full citation Spivack Rhian, Craston Meera, Redman Rachel, Evaluation of the Special Educational Needs and Disability Pathfinder Programme:</p>	<p>Characteristics Not reported.</p> <p>Inclusion criteria Lead professionals involved in collaborative working with social care.</p> <p>Exclusion criteria No additional criteria reported.</p>	<p>Setting Data was collected from five pathfinder areas. These areas were selected, through discussions with Department for Education and the Pathfinder Support Team, because they had reported strong social care engagement, covered a mix of geographical regions, rural and urban</p>	<p>Themes Original theme: Operational mechanisms to support collaborative working</p> <ul style="list-style-type: none"> • Child/young person centred approach <ul style="list-style-type: none"> ○ Using a child/young person centred approach is valued 	<p>Limitations Q1 Was there a clear statement of the aims of the research? No: The aim stated is to review collaborative working arrangements with social care, but the aim does not state whether the intention was to capture subjective experiences of this.</p> <p>Q2 Was a qualitative methodology appropriate? Can't tell: Unclear statement of aims.</p> <p>Q3 Was the research design appropriate</p>

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thematic report: collaborative working with social care: research report, 2014 Ref ID 1082106 Country/ies where study was carried out UK Study type Qualitative Study dates March 2014-April 2014		areas, and large and small areas, and each area had at least one pathfinder champion. Data was collected from the following professionals: pathfinder leads/manager, leads for children's and adult's social care services, strategic and operational social care professionals/providers, the lead for specialist health and SED, and lead representative from the Association of Directors of Children's Services. Data collection Qualitative data was collected through semi-structured interviews covering the following areas: the role of social care in meeting the SEND reforms, models of engagement and collaborative working, challenges in collaborative working, system changes/outcomes as a result of collaborative working with social care. Interviews lasted 1 to 2 hours and were conducted face-to-face where possible. Face-to-face interviews were recorded		to address the aims of the research? Can't tell: Unclear statement of aims and limited discussion of justification for research design. Q4 Was the recruitment strategy appropriate to the aims of the research? Can't tell: Selection of pathfinder areas with strong social care engagement may have biased sample towards those with more positive experiences. Q5: Were the data collected in a way that addressed the research issue? Can't tell: Limited information is provided about the interview guide, data saturation is not discussed and it is unclear how data from telephone interviews was captured. Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: No information is reported. Q7: Have ethical issues been taken into consideration? Can't tell: No information is reported. Q8: Was the data analysis sufficiently rigorous? Can't tell: Themes were identified a-priori but methods for identifying these themes are not reported. Limited information is reported about data analysis. Q9: Is there a clear statement of findings? No: There is limited reporting of quotes supporting themes. Q10: Is the research valuable for the

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		<p>but it is unclear how data was captured from telephone interviews.</p> <p>Data analysis Data for each pathfinder area was written up under the themes included in the topic guide. Following this, the research team looked across the data from different areas to identify commonalities and differences.</p>		<p>UK? (a. Contribution to literature and b. Transferability) Can't tell: Some implications for practice are discussed but there is limited discussion of the contribution of the evidence to the literature and evidence may be more representative of positive practice/collaboration than typical practice/collaboration.</p> <p>Source of funding No sources of funding reported.</p> <p>Other information Evaluation of the Special Educational Needs and Disability Pathfinder Programme (also reported by Smith 2014, Thom 2014 and Thom 2015)</p>
<p>Full citation Taylor Julie, et al., Disabled children and child protection in Scotland: an investigation into the relationship between professional practice, child protection and disability, 91, 2014</p> <p>Ref ID 1103829</p> <p>Country/ies where study</p>	<p>Characteristics Professionals: n=61 (including social work, education, police, voluntary organisations, health, child protection committee members)</p> <p>Inclusion criteria Experience of responding to at least two child protection cases involving a disabled child.</p> <p>Exclusion criteria No additional criteria reported.</p>	<p>Setting Six local authority areas were selected (from local authority and child protection register data) to cover a range of urban/rural and small/large areas and number of disabled children on child protection registers. In each local authority area, potential participants from social work, education, police, voluntary organisations and health were contacted by the researchers and asked to participate. Potential participants were identified</p>	<p>Themes Original theme: Training experience and workload</p> <ul style="list-style-type: none"> • Service provider knowledge and training <ul style="list-style-type: none"> ○ More training and multi-agency work is needed to communicate effectively with children/young people <p>Original themes: Children's disability teams; Interagency working; Benefits of interagency working</p> <ul style="list-style-type: none"> • Service provider knowledge and training <ul style="list-style-type: none"> ○ Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build 	<p>Limitations Q1 Was there a clear statement of the aims of the research? No: The questions the study intended to address are clearly presented, but the aim does not state whether the intention was to capture subjective experiences.</p> <p>Q2 Was a qualitative methodology appropriate? Can't tell: Unclear statement of aims.</p> <p>Q3 Was the research design appropriate to address the aims of the research? Can't tell: Justification for research design is clearly explained but statement of aims is unclear.</p> <p>Q4 Was the recruitment strategy appropriate to the aims of the research? Can't tell: Local authority areas were</p>

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<p>was carried out UK</p> <p>Study type Mixed methods, including interviews and focus groups</p> <p>Study dates Not reported</p>		<p>through contacting services directly and with the assistance of the Child Protection Committee Coordinator at WithScotland, key researchers and practitioners in the Scottish Sensory Centre and CALL Scotland Centre, and a member of Scottish Government (who also helped recruit Child Protection Committees). Authors do not report whether all eligible participants were contacted or, if not, how they were selected.</p> <p>Data collection Data from professionals, excluding Child Protection Committees, were collected via telephone interviews lasting roughly an hour, which were digitally recorded. Interviews covered areas identified by previous research, but the authors do not report what these areas were. Participants were also asked to give an example of good practice and an example where there were issues in identifying harm,</p>	<p>expertise</p> <p>Original theme: Information sharing and communication</p> <ul style="list-style-type: none"> • Relationships between service providers and service users <ul style="list-style-type: none"> ○ Meetings with professionals can be intimidating for service users • Information and support <ul style="list-style-type: none"> ○ Sharing information reduces distress for service users and makes the best use of resources • Involvement of children and young people <ul style="list-style-type: none"> ○ Involvement of the child/young person should depend on their understanding 	<p>selected to represent a range of areas with differing levels of disabled children on child protection registers, but it is unclear if method of selecting participants from these areas was appropriate.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Can't tell: Limited information provided about content/structure of interviews or focus groups.</p> <p>Q6: Has the relationship between researcher and participants been adequately considered? Can't tell: No information is reported.</p> <p>Q7: Have ethical issues been taken into consideration? Yes: Ethical approval and informed consent were obtained. Identifying information was removed from transcripts and incidents were only used as case studies if confidentiality/anonymity could be maintained. There was also a mechanism in place for disclosing any information that arose from interviews that was not already known to relevant authorities.</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell: No information is reported.</p> <p>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.</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
		<p>provision or uptake of interventions,, or interagency working, and how these issues were resolved. Data from Child Protection Committees were collected through focus groups and covered key themes and issues in responding to and supporting disabled children who may be at risk of harm, and interagency working. It is not clear if a topic guide was used. Two members of the research team took notes during the focus groups.</p> <p>Data analysis No information reported.</p>		<p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes: Recommendations for practice and policy are clearly discussed.</p> <p>Source of funding Not industry funded.</p> <p>Other information</p>
<p>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-</p>	<p>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</p>	<p>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.</p> <p>Data collection Qualitative data was collected via semi-structured interviews or focus groups depending on the preference of the participant. All young</p>	<p>Themes Original theme: Training experience and workload</p> <ul style="list-style-type: none"> • Service provider knowledge and training <ul style="list-style-type: none"> ○ More training and multi-agency work is needed to communicate effectively with children/young people <p>Original themes: Children's disability teams; Interagency working; Benefits of interagency working</p> <ul style="list-style-type: none"> • Service provider knowledge and training 	<p>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? Yes: All families/staff working in the</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
<p>limiting conditions, Children and Youth Services Review, 86, 142-150, 2018</p> <p>Ref ID 1105987</p> <p>Country/ies where study was carried out UK</p> <p>Study type Qualitative</p> <p>Study dates Not reported</p>	<p>conditions and were able to communicate their views (verbally or non-verbally); parents/carers of young adults registered with the service; health or social-care staff working with the service</p> <p>Exclusion criteria No additional criteria reported</p>	<p>people and parents were interviewed individually; three professionals were interviewed individually and the rest participated in focus groups.</p> <p>Interview/focus groups followed a topic guide, were digitally recorded and transcribed.</p> <p>Data analysis Data was analysed thematically using the framework technique. This allows for abstracting data into themes without losing the original raw data.</p>	<ul style="list-style-type: none"> ○ Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build expertise <p>Original theme: Information sharing and communication</p> <ul style="list-style-type: none"> ● Relationships between service providers and service users <ul style="list-style-type: none"> ○ Meetings with professionals can be intimidating for service users ● Information and support <ul style="list-style-type: none"> ○ Sharing information reduces distress for service users and makes the best use of resources ● Involvement of children and young people <ul style="list-style-type: none"> ○ Involvement of the child/young person should depend on their understanding 	<p>service were offered the opportunity to take part. However, the sample is self-selecting which may introduce biases.</p> <p>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.</p> <p>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</p> <p>Q7: Have ethical issues been taken into consideration? Yes: Ethical approval was obtained, written/verbal information was presented in an appropriate way for the participants' level of understanding, written consent was obtained for everyone apart from the young adults, who gave verbal consent and witnessed an advocate of their choice give written consent. All data was anonymised and kept</p>

Study details	Participants	Methods	Themes (information in bullet points are theme(s) applied after thematic synthesis)	Quality assessment
				<p>securely. Efforts were made to minimise the potential for any harm, including psychological exploitation and intrusion into families lives.</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell: Limited information is provided about data analysis.</p> <p>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.</p> <p>Q10: Is the research valuable for the UK? (a. Contribution to literature and b. Transferability) Yes: Contribution to the literature is clearly discussed.</p> <p>Source of funding Not industry funded.</p> <p>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.</p>

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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; ECLLO: eye clinic liaison officer; EHC: education, health and care; IPA: interpretative phenomenological analysis; M: Mean; NHS: National Health Service; NIHR: National Institute for Health Research; NR: not reported; 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; SD: standard deviation

Appendix E – Forest plots

Forest plots for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

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

Appendix F – GRADE CERQual tables

GRADE CERQual tables for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

Table 5: Evidence profile: Theme 1. Child/young person centred approach

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 1.1: Using a child/young person centred approach is valued					
7 (Boesley 2018; Molteni 2013; Palikara 2019; RIP STARS 2018; Sales 2018; Spivack 2014; Young 2018)	2 qualitative studies using semi-structured interviews; 1 qualitative study using semi-structured interviews and focus groups; 1 qualitative study using interviews and focus groups; 1 mixed methods survey using open-ended questions; 1 mixed methods study using semi-structured interviews, focus groups and open-ended question on questionnaire	<p>Service providers valued a child or young person centred approach that encouraged a multidisciplinary team working around the child or young person to identify and meet their needs. They also perceived that this was valued by parents. Service providers reported that EHC plans were more child or young person centred than previous approaches, and that some services were better equipped than others to use a child or young person centred approach.</p> <p>“If you are a young person with epilepsy you need to feel safe at school, you need to understand that somebody meets your needs but also you need to make sure that just because you’ve got label of epilepsy someone is not saying oh that means they can never go out or go on school trips, we can’t do that etc. So for me it’s health from the child’s point of view in terms of what matters.” (RIP STARS 2018)</p>	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.2: Children and young people benefit from using a consistent approach					

Study information		Description of theme or finding	CERQual assessment of the evidence		
2 (McConkey 2013; Molteni 2013)	1 qualitative study using semi-structured interviews; 1 mixed methods study using semi-structured interviews, focus groups and open-ended question on questionnaire	Service providers reported that using a consistent approach was important for multi-agency work and building relationships with families and was beneficial for children and young people as it is more predictable and helps them to generalise. “One of the main benefits is that they are very consistent; consistent with the staff and also consistent with their approach and that helps because it makes it more predictable for N. Other agencies wouldn’t be as skilled...so they offer a more in-depth service.” (McConkey 2013)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 1.3: Service providers are falling short of using a child/young person centred approach					
2 (Children’s Commissioner for Wales; RIP STARS 2018)	1 qualitative study using focus groups; 1 qualitative study using interviews and focus groups	Service providers reported that some professionals do not have a good understanding of what a child or young person centred approach is and that they do not adequately capture the child or young person’s perspective. “I also think that somewhere in that process needs to be... That one to one contact, and what is difficult about that is we don’t have very many resources so we develop processes that meet the outcome of a plan but actually the process can almost appear as if we are not really engaging with the child or young person at the centre of the plan and we need to get better at doing that.” (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.4: Recognising the child/young person’s potential and supporting them to reach it					
3 (Boesley 2018; Children’s Commissioner for Wales 2018; RIP STARS 2018)	1 qualitative study using semi-structured interviews; 1 qualitative	Service providers reported that the potential of children and young people may be underestimated and that good EHC plans should recognise children and young people’s ambitions and help them think about long term options. Some children and young people could exceed expectations if they were given more support. More help is also needed for parents to support their children with	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
	study using focus groups; 1 qualitative study using interviews and focus groups	becoming independent. “...because a lot of my children with autism are managing fairly well in their academic status, they’re able to reach expected level, when they could actually achieve a lot more – not just, ‘just below expected’ or ‘just making expected’ but actually, they could be “exceeding expected” – that’s not really ever considered” (Boesley 2018)		qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.5: Importance of separating the views of the child or young person from the views of parents					
2 (RIP STARS 2018; Young 2018)	1 qualitative study using semi-structured interviews and focus groups; 1 qualitative study using interviews and focus groups	Service providers reported that it is important to keep the focus on the views of the child or young person, as opposed to the parents and questioned whether parents are appropriate advocates or if someone independent is needed. Service providers also highlighted the difficulty of capturing the views of children with severe communication difficulties. “I think sometimes, particularly with some young people, we allow their parents to advocate for them and I think often the parents are advocating their needs rather than the child’s needs, so I think there’s probably more to be done to balance that out.” (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.6: Respecting the rights of the child or young person					
2 (RIP STARS 2018; Young 2018)	1 qualitative study using semi-structured interviews and focus groups; 1 qualitative study using interviews and focus groups	Service providers agreed that the rights of the child or young person should be respected and captured within EHC plans. The right to privacy and allowing young adults to make their own decisions were highlighted. “I think privacy and involvement in decision-making are really important because I think one of the problems with the system is that you can become a number on a form and you stop having the right to be private.” (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

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

Table 6: Evidence profile: Theme 2. Involvement of children and young people

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 2.1: EHC plans have increased focus on views of child/young person					
1 (Sales 2018)	1 qualitative study using semi-structured interviews	Service providers reported that EHC plans gave more weight to the views of the child or young person than previous approaches. “...without a doubt, there’s more weight on the young person’s views.” (Sales 2018)	Methodological limitations	Moderate 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	None or very minor concerns	
Sub-theme 2.2: Importance of accurately capturing the views of the child/young person					
1 (RIP STARS 2018)	1 qualitative study using interviews and focus groups	Service providers reported that EHC plans were considered inadequate if they did not have a well completed ‘about me’ section that captured the views of the child or young person. They also reported it was important to make sure that the views of the child or young person are accurately captured and that they are not rewritten in a way that changes the meaning. “The complications come when you’ve somebody who listens to the young person and then perhaps rewrites what they’re saying in a different way not because they want to change something on purpose but they might change the grammar or something which changes the meaning...” (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 2.3: Involvement of the child/young person should depend on their understanding					
1 (Taylor 2014)	1 qualitative study using	Service providers reported that it was important to consider the level of understanding of the child or young person when deciding if it was appropriate	Methodological limitations	Major concerns about	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
	interviews	for them to attend case conferences. “[What considerations do you think need to be taken into account if a disabled child is invited to a case conference?] I think you need to look at their level of understanding. I think you need to look at whether it's appropriate for the young person to be there or not and whether they understand anything that's going on, and albeit some young people might be twelve or thirteen, they may have the ability of a three year old and I think that needs to be taken into consideration. You wouldn't take a three year old and ask them loads of questions, because they just wouldn't be able to answer them [Interview 10].” (Taylor 2014)		methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 2.4: Supporting children and young people to prepare for meetings and communicate their views					
2 (RIP STARS 2018; Sales 2018)	1 qualitative study using interviews and focus groups; 1 qualitative study using semi-structured interviews	Service providers reported that children and young people should be supported to prepare for meetings and to communicate their views. This involved making sure children were aware of their options and having a flexible approach to collecting views that took into account age, developmental level and communication skills. “...there should be different ages and just be a variety [of formats] to choose from.” (Sales 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Studies together offered some rich data	
Sub-theme 2.5: Using accessible language in EHC plans would enable children and young people to be involved and improve accountability					
1 (RIP STARS 2018)	1 qualitative study using interviews and focus groups	Service providers reported that it is important that children and young people can read EHC plans and recognise that it is a reflection of them and that they are happy with the way they have been involved. One way to do this might be having a simplified, young person friendly version. They also believed that using language that is accessible to the child or young person would also improve accountability.	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
		"I personally believe that all Education, Health and Care Plans should be written in language that is accessible to the young person wherever possible and to be honest, if it's accessible to the young person it means it's harder for people to get out of not doing stuff because if it's clear then it's clear to everyone who should be doing what, but also, it should be made so that everyone knows who's responsible for delivering what parts of the plan." (RIP STARS 2018)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

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

Table 7: Evidence profile: Theme 3. Involvement of families and carers

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 3.1: Involvement of families is valued and improves relevance, accuracy and usefulness of EHC plans					
2 (Boesley 2018; Palikara 2019)	1 qualitative study using semi-structured interviews; 1 mixed methods survey using open-ended questions	Parenteral involvement in EHC plans was considered a strength of EHC plans and service providers reported that it improved the relevance, accuracy and usefulness of EHC plans. "EHCPs are dynamic active documents with parental co-production and therefore more likely to be relevant and up to date, and useful to providers. (P261, Education Consultant)" (Palikara 2019)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Studies together offered moderately rich data	
Sub-theme 3.2: Involvement of families can be limited and depends on individuals service providers					
2 (RIP STARS 2018; Sales 2018)	1 qualitative study using interviews and focus groups; 1 qualitative study using semi-	Service providers reported that sometimes families are only involved in a cursory, tokenistic way and that this depends on individual providers. Service providers described that sometimes parents are consulted through an exchange of paperwork but that there can be limited face-to-face discussions. They also believed that some service providers did not pay attention to the views of parents once they had been captured, but others were committed to	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
	structured interviews	involving parents. “It’s very much down to the professionals and whether they then pay attention to it. I have felt at times it’s like “yeah we have got their views but actually we’re not going to pay any attention to it”. And you know, with other people, they really will pay attention to it. So it is very much down to the individual.” (Sales 2018)		checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 3.3: Families as providers of care					
2 (Hurt 2019; Rodriguez 2014)	2 qualitative studies using focus groups	Some service providers reported that they were surprised with the level of skilled nursing care that parents could provide. However, other service providers reported that families could probably provide more care and be less reliant on services but that they needed more support with this. “I can remember when I came into this role I was adamant that we needed to be finding trained nurses to help these kids that were needing a lot of technology, [but] over the years it has not failed to surprise me how many parents can just get on with it and really they end up doing a lot that we would consider skilled nursing care. (Paediatrician)” (Rodriguez 2014)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	Moderate concerns Most evidence is ambiguous or contradictory without a credible explanation for differences	
			Adequacy	None or very minor concerns	

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

Table 8: Evidence profile: Theme 4. Relationships between service providers and service users

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: Managing parents’ expectations					
2 (Boesley 2018;	1 qualitative	Service providers reported that sometimes they had to manage parents’	Methodological	None or very	High

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Study information		Description of theme or finding	CERQual assessment of the evidence		
Hurt 2019)	study using semi-structured interviews; 1 qualitative study using focus groups	<p>expectations regarding whether or not children or young people had a diagnosis and were eligible for EHC plans. They also had to explain to parents that applications were not always successful and that, if granted, EHC plans would not solve everything.</p> <p>“...you have to quite often explain to parents that it’s not a magic wand – it’s just an increased level of support, but it’s not going to be an immediate solution ... I think there’s frustration afterwards that it hasn’t solved everything.” (Boesley 2018)</p>	limitations	minor concerns	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 4.2: Individuals of services going above and beyond to deliver a good service					
2 (McConkey 2013; Rodriguez 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using focus groups	<p>Service providers reported that they, or other service providers, went above and beyond to deliver a good service. This involved attending meetings when they weren’t working and co-ordinating services on behalf of families.</p> <p>“About 90% of the staff team go above and beyond (their hours) in that we go to meetings when we are off; there isn’t an expectation to do that – you could say: I can’t do that and send your apologies but rarely does that happen. K33” (McConkey 2013)</p>	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 4.3: Families are less accepting of key workers who have not have much involvement with the family					
1 (Rodriguez 2014)	1 qualitative study using focus groups	<p>Service providers reported that sometimes families are given key workers who have not had as much involvement with them as other professionals who they had built stronger relationships with and that some families are only accepting of one professional.</p> <p>“Some families will only accept one person that they get on with ... I think you need that ... but to perhaps also have someone else who can help out, also if there are problems that arise. (Community paediatric nurse)” (Rodriguez 2014)</p>	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Very low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns The study did	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				not offer rich data	
Sub-theme 4.4: People making decisions are out of touch with the needs of the child/young person					
2 (Children's Commissioner for Wales 2018; Hurt 2019)	2 qualitative studies using focus groups	Service providers expressed frustrations that care is meant to be centred on the child or young person but people making decisions are not dealing with children and young people on a daily basis and in some cases have not even met them. "I do have frustrations that people are making very life-changing decisions, and they're sat in a room, having a cup of tea. They're not sat in the classroom dealing with some of the behaviours and the issues that we are dealing with [...] on a day to day basis." (Hurt 2019)	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 4.5: Meetings with professionals can be intimidating for service users					
2 (Council for Disabled Children 2018; Taylor 2014)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews	Service providers reported that the number of professionals involved in services can be overwhelming for service users and that attending meetings and case conferences can be distressing. "For parents, even capable parents who are used to filling out paperwork and all that sort of stuff, it's really difficult navigating the system and the overwhelming number of professionals that get involved, and going into meetings with a whole room of professionals." (Council for Disabled Children 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

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Table 9: Evidence profile: Theme 5. Information and support

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

Study information		Description of theme or finding	CERQual assessment of the evidence		
Sub-theme 5.1: Service users should be given more information and support throughout the EHC plan process					
2 (Boesley 2018; RIP STARS 2018)	1 qualitative study using semi-structured interviews; 1 qualitative study using interviews and focus groups	Service providers reported that service users should be supported throughout, and be given more information about, the EHC plan process, including what the purpose of EHC plans are and what they are meant to achieve, their rights to participate, and the process for review. “There should be information available to disabled children and young people a long way before the planning process so that they understand what the planning process is about and what it’s supposed to achieve...it should set out what the young person’s rights are to participate in the planning process and that their wishes and hopes and desires are central to the planning process.” (RIP STARS 2018)	Methodological limitations	Moderate 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	None or very minor concerns	
Sub-theme 5.2: Sharing information reduces distress for service users and makes the best use of resources					
2 (Rodriguez 2014; Taylor 2014)	1 qualitative study using focus groups; 1 qualitative study using interviews	Service providers reported that needing to repeat information can be difficult for families, especially when discussing sensitive information. They also reported that sharing information would reduce distress for service users, as it would minimise the need to repeat information and they can discuss sensitive information with the professionals that are closest to them, and make the best use of staff time. “The social worker with this child would spend individual time with the child building up a relationship with them and exploring his views of family life. So he was able to bring information back to the core group about some of the discussions that he had with the boy... that seemed to work very well. ... So I think that was good practice that you didn’t have several different adults trying to talk about sensitive information with this child [Interview 1].” (Taylor 2014)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

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

Table 10: Evidence profile: Theme 6. Service provider knowledge and training

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 6.1: Service providers value the different skillsets and knowledge of others and opportunities to learn from each other and build expertise					

Study information		Description of theme or finding	CERQual assessment of the evidence		
4 (Boyce 2015; Council for Disabled Children 2018; Molteni 2013; Taylor 2014)	2 qualitative studies using semi-structured interviews; 1 mixed methods study using semi-structured interviews, focus groups and open-ended question in questionnaire; 1 qualitative study using interviews	<p>Service providers valued working within multi-disciplinary teams, specifically the different perspectives, knowledge and skills that others can bring to the team and how this gave the opportunity to learn from each other, learn how children and young people are in different settings, and build expertise. They also reported that working in multi-disciplinary teams increased the opportunities to identify any concerns about the child or young person.</p> <p>“I think you have to define a system approach that holds in mind both the child’s physical paediatric development health and the child’s mental health [...] trying to bring the advantages of both of those perspectives [...] so it’s kind of complexity of service model I think, and even if you can’t do it as a post in that team, you ought to have colleagues in the team knowing enough about what they don’t know to know that they should try to access that kind of thinking for a small proportion of the assessment or treatment work they’re doing.” (Council for Disabled Children 2018)</p>	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 6.2: More training and multi-agency work is needed to communicate effectively with children/young people					
1 (Taylor 2014)	1 qualitative study using interviews	<p>Service providers reported that more multi-agency work was needed to adapt communication for children and young people and make better use of communication aids. They reported that they lacked training in this area and relied on the multi-agency work with more experienced colleagues to facilitate communication.</p> <p>“I think there is [work being done on adapting communication with disabled children] but it takes time, it takes effort and it takes a multiagency, a multi-disciplinary team to be aware of communication aids and how effective they are and how they’re used and we’re a long way off from multi-agency working in that level [Interview 8].” (Taylor 2014)</p>	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme

Table 11: Evidence profile: Theme 7. Experience of EHC plans

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

Study information		Description of theme or finding	CERQual assessment of the evidence		
Sub-theme 7.1: Information in EHC plans is not always accurate					
1 (RIP STARS 2018)	1 qualitative study using interviews and focus groups	Service providers were concerned that health information reported in EHC plans is not always accurate. “It should be things that are relevant and factually correct, the amount of times that people write wrong things about certain medical conditions is quite high, so it should be correct and understandable.” (RIP STARS 2018)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 7.2: Challenges due to timing of introducing EHC plans					
1 (Boesley 2018)	1 qualitative study using semi-structured interviews	Service providers reported that the timing of introducing EHC plans had impacted their reception due to other changes occurring at a similar time. “I think it’s unfortunate that [EHC plans] have occurred in a landscape in education of things just generally being shook up a lot ... it was like somebody just threw everything up into the air and was just waiting to see where it would fall down.” (Boesley 2018)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Major concerns The study did not offer rich data	
Sub-theme 7.3: Introduction of EHC plans has reduced the impact of service provider bias on access to assessment					
1 (Palikara 2019)	1 mixed methods survey using open-ended questions	Service providers reported that the introduction of EHC plans had reduced teachers’ biases preventing access to assessment for children and young people. “Holistic care. Better child protection. Reduced teacher bias, less chance for prevention of access to assessment, less intimidation, bullying and threats by teachers who ‘just know’ and demand blind trust in place of assessment or threaten and bully to silence. (P339 SEND professional)” (Palikara 2019)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Very low
			Relevance	None or very minor concerns	
			Coherence	None or very	

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Study information		Description of theme or finding	CERQual assessment of the evidence		
			Adequacy	minor concerns Major concerns The study did not offer rich data	

CASP: critical appraisal skills programme; EHC: education, health and care; SEND: special educational needs and disabilities

Table 12: Evidence profile: Theme 8. Improved transition

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 8.1: Extending service provision to 25 has (or should) improve transitions					
2 (Palikara 2019; Sales 2018)	1 mixed methods survey using open-ended questions; 1 qualitative study using semi-structured interviews	Service providers reported that extending the range of service provision to 25 years was an improvement over previous approaches and either already had improved transition or would be likely to, due to clearer pathways and more effective information sharing. "Moving the definition into early adulthood should enable a clearer pathway for parents/carers/students to allow a greater transition. (P355, SENCo)" (Palikara 2019)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

CASP: critical appraisal skills programme; SENCo: special educational needs co-ordinator

Table 13: Evidence profile: Theme 9. Short breaks and respite breaks provide benefit

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 9.1: Short breaks benefit whole family					
1 (McConkey 2013)	1 qualitative study using semi-structured	Service providers reported that short breaks benefitted the whole family as it gave parents time to spend with their other children.	Methodological limitations	Major concerns about methodological limitations of the	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
	interviews	“They have three other children and it’s quite a busy household so taking N out into the community give them time to spend with their other children and do activities with them. when he is in the house it has to be safe and locked up to make it safe so it makes a big difference to the siblings just being able to go out and come in and do activities. K12” (McConkey 2013)		evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 9.2: The amount of respite should be balanced and responsive to families’ needs					
1 (McConkey 2013)	1 qualitative study using semi-structured interviews	Service providers reported that it was important that the amount of respite provided was flexible to changes in families’ circumstances but that it was not too high as this could have a negative impact on family relationships. “I would say (the number of overnights) is right now. I don’t think anymore would be beneficial. I was always wary of it being too high in a sense that N would be out of the family too much and it was important that it wasn’t seen that he was being sent away, that would be very negative. K33” (McConkey 2013)	Methodological limitations	Major concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 9.3: Young adult (short break) services should be offered up to age 30					
1 (Young 2018)	1 qualitative study using semi-structured interviews and focus groups	Service providers reported that they were concerned about what would happen to service users when they were too old to access available services and that young adult services should be offered up to age 30 due to children and young people with life limited conditions living longer. “As some are living longer due to better management, [short break service] places should be offered up to age 30.” (Young 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	

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

CASP: critical appraisal skills programme

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

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

Appendix I – Economic model

Economic model for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

No economic analysis was conducted for this review question.

Appendix J – Excluded studies

Excluded studies for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

1.1.1.13 Qualitative studies

Table 14: 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, <i>Child Care in Practice</i> , 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?, <i>Health & social care in the community</i> , 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, <i>Clinical Child Psychology & Psychiatry</i> , 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, <i>BMC pediatrics</i> , 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, <i>Child: Care, Health and Development</i> , 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, <i>Child & Adolescent Social Work Journal</i> , 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), <i>Research in Developmental Disabilities</i> , 43, 11-20, 2015	Design: Survey with quantitative results only.
Alves, Joao Manuel Nunes de Oliveira, Amendoeira, Jose Joaquim Penedos, Charepe, Zaida Borges, The parental care partnership in the view of parents of children with special	Themes: No views or experiences relevant to joined up care/services.

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Study	Reason for Exclusion
health needs, A parceria de cuidados pelo olhar dos pais de crianças com necessidades especiais de saúde., 38, e2016-70, 2017	
Anderson, Kristy A., Sosnowy, Collette, Kuo, Alice A., Shattuck, Paul T., Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies, Pediatrics, 141, S318-S327, 2018	Study design: Scoping review
Anderson, Lori S., Mothers of children with special health care needs: documenting the experience of their children's care in the school setting, The Journal of school nursing : the official publication of the National Association of School Nurses, 25, 342-51, 2009	Country and publication date: US, pre 2013.
Arcuri, G. G., McMullan, A. E., Murray, A. E., Silver, L. K., Bergthorson, M., Dahan-Oliel, N., Coutinho, F., Perceptions of family-centred services in a paediatric rehabilitation programme: strengths and complexities from multiple stakeholders, Child: Care, Health & Development, 42, 195-202, 2016	Country: Canada.
Barnert, Elizabeth S., Collier, 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 meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis, Health & Social Care in the Community, 27, e143-e157, 2019	International qualitative meta-synthesis. Themes: No relevant qualitative data. References checked for relevant UK papers from 2013 for inclusion.
Boyden, Paul, Muniz, Michelle, Laxton-Kane, Martha, Listening to the Views of Children with Learning Disabilities: An Evaluation of a Learning Disability CAMHS Service, Journal of Intellectual Disabilities, 17, 51-63, 2013	Themes: No qualitative data relevant to the views or experiences of joined-up care/services. Study reports on one learning disability-child and adolescent mental health service only.
Bradshaw, Paul, Hall, Julia, The impact of disability on the lives of young children: analysis of data from the Growing Up in Scotland study, 2013	Study type: Quantitative data only
Bray, L., Shaw, N. J., Snodin, J., Living and managing with the long-term implications of neonatal chronic lung disease: The experiences	Themes: No qualitative data relevant to the views and experiences of joined-up care/services.

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Study	Reason for Exclusion
and perspectives of children and their parents, Heart and Lung: Journal of Acute and Critical Care, 44, 512-516, 2015	
Bristow, Sally, Jackson, Debra, Shields, Linda, Usher, Kim, The rural mother's experience of caring for a child with a chronic health condition: An integrative review, Journal of clinical nursing, 27, 2558-2568, 2018	US and Australia Integrative review. No UK studies included.
Bromley, Jo, Hare, Dougal Julian, Davison, Kerry, Emerson, Eric, Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services, Autism : the international journal of research and practice, 8, 409-23, 2004	Design and publication date: Interview with quantitative data only, pre 2013
Campos, S. R., Soria, E. L., Liz, A. A., PRINCEP program: clinical program for specialized and integrated care of paediatric patients with complex chronic conditions, International Journal of Integrated Care, 16, 2016	Conference abstract
Chapman, M., Lacey, H., Jervis, N., Improving services for people with learning disabilities and dementia: Findings from a service evaluation exploring the perspectives of health and social care professionals, BRITISH JOURNAL OF LEARNING DISABILITIES, 46, 33-44, 2018	Population: Learning disabilities and dementia. Age unclear; study refers to a population aged 25 years plus when dementia screening, takes place.
Collins, Michelle, et, al, A break from caring for a disabled child: parent perceptions of the uses and benefits of short break provision in England, BRITISH JOURNAL OF SOCIAL WORK, 44, 1180-1196, 2014	Themes: No qualitative data relevant to the views or experiences of joined up care/services.
Commission for Social Care Inspection Commission for Healthcare, Audit, Inspection Mental Health Act, Commission, Commissioning services and support for people with learning disabilities and complex needs: National report of joint review, 2009	Design: National report. No qualitative data. Published pre 2013.
Crawford, T., Simonoff, E., Parental views about services for children attending schools for the emotionally and behaviourally disturbed (EBD): a qualitative analysis, Child: Care, Health & Development, 29, 481-91, 2003	Population: Does not meet criteria; emotionally and behaviourally disturbed children without comorbidities. Published pre 2013.
Danvers, Lesley, Freshwater, Dawn, Cheater, Francine, Wilson, Andrew, Providing a seamless service for children with life-limiting illness: experiences and recommendations of professional staff at the Diana Princess of Wales Children's Community Service, Journal of clinical nursing, 12, 351-9, 2003	Publication date: study published pre 2013.
Davies, Karen, Tensions in commissioning : services for children's speech, language and communication needs in one English region, Journal of Health Services, Research and Policy, 17, 2013	Study design and themes: Narrative review of case studies. No relevant qualitative data for extraction.
Dockrell, Julie E., Lindsay, Geoff, Letchford, Becky, Mackie, Clare, Educational provision for children with specific speech and language difficulties: perspectives of speech and language	Population: Does not meet criteria; children with specific speech and language difficulties without severity/complexity or comorbidities. Published pre 2013.

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

Study	Reason for Exclusion
Gallagher, Aoife L., Murphy, Carol-Anne, Conway, Paul, Perry, Alison, Consequential differences in perspectives and practices concerning children with developmental language disorders: an integrative review, <i>International journal of language & communication disorders</i> , 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 post-16 education and employment, <i>British Educational Research Journal</i> , 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, <i>Journal of Intellectual Disability Research</i> , 63, 818, 2019	Conference abstract
Gellasch, Patricia, Developmental Screening in the Primary Care Setting: A Qualitative Integrative Review for Nurses, <i>Journal of Pediatric Nursing</i> , 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, <i>Scandinavian Journal of Caring Sciences</i> , 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, <i>Journal of Psychopharmacology</i> , 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?, <i>International journal of speech-language pathology</i> , 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, <i>Journal of Transcultural Nursing</i> , 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, <i>Tizard Learning Disability Review</i> , 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, <i>International journal of integrated care</i> , 16, 12, 2016	International Systematic Review. Themes: No quantitative data relevant to the views or experiences of joined up care/services. Included list checked for relevant UK studies from 2013.
Hirano, Kara A., Rowe, Dawn, Lindstrom, Lauren, Chan, Paula, Systemic Barriers to	International meta-synthesis. Included studies checked for relevant UK studies from 2013.

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Study	Reason for Exclusion
Family Involvement in Transition Planning for Youth with Disabilities: A Qualitative Metasynthesis, <i>Journal of Child and Family Studies</i> , 27, 3440-3456, 2018	
Hiremath, Girish, Kodroff, Ellyn, Strobel, Mary J., Scott, Melissa, Book, Wendy, Reidy, Cathy, Kyle, Shay, Mack, Denise, Sable, Kathleen, Abonia, Pablo, Spergel, Jonathan, Gupta, Sandeep K., Furuta, T. Glenn, Rothenberg, Marc E., Dellon, Evan S., Individuals affected by eosinophilic gastrointestinal disorders have complex unmet needs and frequently experience unique barriers to care, <i>Clinics and research in hepatology and gastroenterology</i> , 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, <i>Pediatric nursing</i> , 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, <i>Tizard Learning Disability Review</i> , 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, <i>Archives of Disease in Childhood</i> , 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, <i>Journal of Children's Services</i> , 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, <i>Journal of Applied Research in Intellectual Disabilities</i> , 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, <i>International Journal of Integrated Care (IJIC)</i> , 17, 1-2, 2017	Conference abstract
King, Gillian A., Esses, Victoria M., Solomon, Nassisse, Akamatsu, Albright Ali Bailey Barnes Beresford Blacher Blair Blakemore Bronfenbrenner Brookins Bruce Chamba Cho Clarke Conger Crowley Darling Dilworth-Anderson Dilworth-Anderson Eifert Esses Esses Fiene Fong Forsyth Franck Gallegos Gallimore	Publication type: Book chapter

Study	Reason for Exclusion
<p>Gannotti Groce Guendelman Harris Harris Hek Hernandez Ho Huer Ingstad James Jegatheesan Katbamna 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</p>	
<p>Kirk, Susan, Perceptions of effective self-care support for children and young people with long-term conditions, <i>Journal of Clinical Nursing</i>, 21, 2013</p>	<p>Population: Participants with long-term conditions and no mention of severity or complexity.</p>
<p>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, <i>Child: Care, Health & Development</i>, 40, 787-96, 2014</p>	<p>Review. Included list checked for relevant studies, all pre 2013</p>
<p>Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., Rosenbaum, P., Factors affecting family-centred service delivery for children with disabilities, <i>Child: care, health and development</i>, 29, 357-66, 2003</p>	<p>Design: Survey with quantitative data only</p>
<p>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</p>	<p>Themes: No qualitative data relevant to the views or experiences of joined up care/services.</p>
<p>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, <i>International Journal of Language & Communication Disorders</i>, 51, 495-507, 2016</p>	<p>Themes: No qualitative data relevant to the views or experiences of joined up care/services.</p>
<p>Lindsay, S., Child and youth experiences and perspectives of cerebral palsy: A qualitative systematic review, <i>Child: Care, Health and Development</i>, 42, 153-175, 2016</p>	<p>Review. Included list checked for relevant studies, the 3 UK post-2013 papers do not meet inclusion criteria</p>
<p>Lindsay, Sally, Duncanson, Michelle, Niles-Campbell, Nadia, McDougall, Carolyn, Diederichs, Sara, Menna-Dack, Dolly, Applying an ecological framework to understand transition pathways to post-secondary education for youth with physical disabilities, <i>Disability and</i></p>	<p>Country: Canada</p>

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

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

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Views and experiences of service providers

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

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Views and experiences of service providers

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

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

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

1.1.1.14 **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 commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

No research recommendations were made for this review question.

Appendix L – Qualitative thematic maps

Qualitative thematic maps for review question: What is the experience of commissioners, providers and practitioners of joint working of health, social care and education services for disabled children and young people with severe complex needs?

Figure 3: Sub-theme map for child/young person centred approach

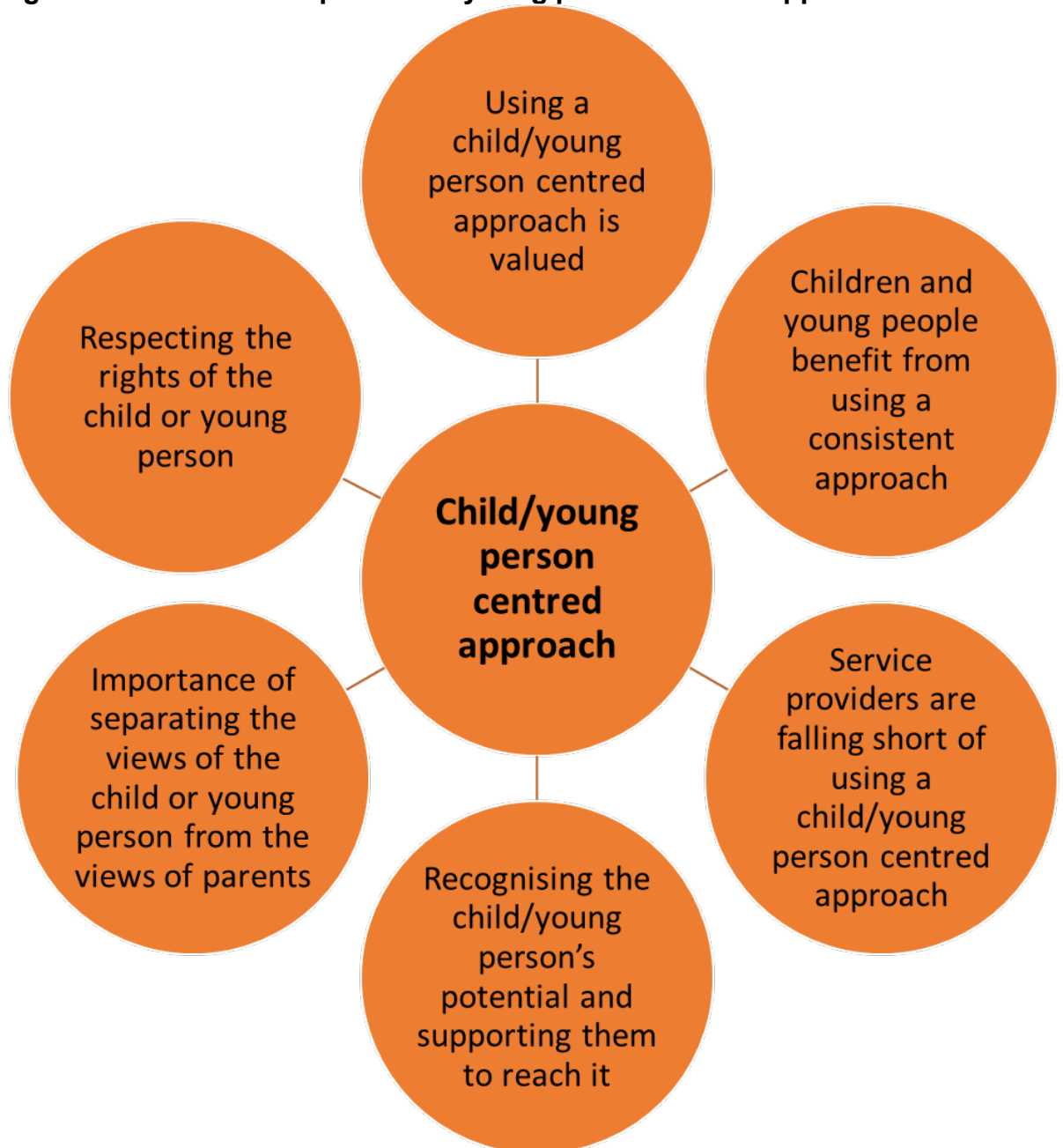


Figure 4: Sub-theme map for involvement of children and young people

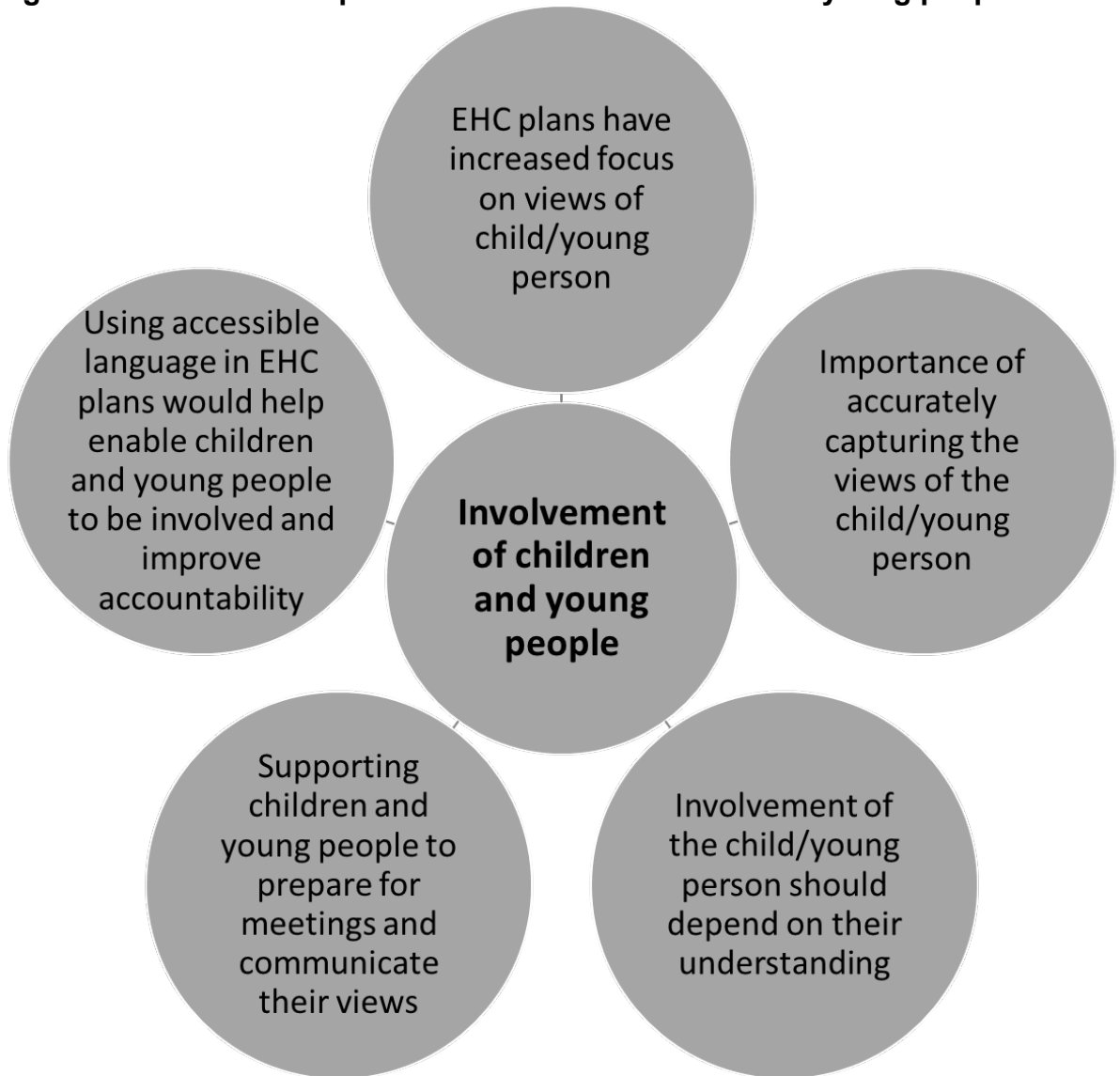


Figure 5: Sub-theme map for involvement of families and carers

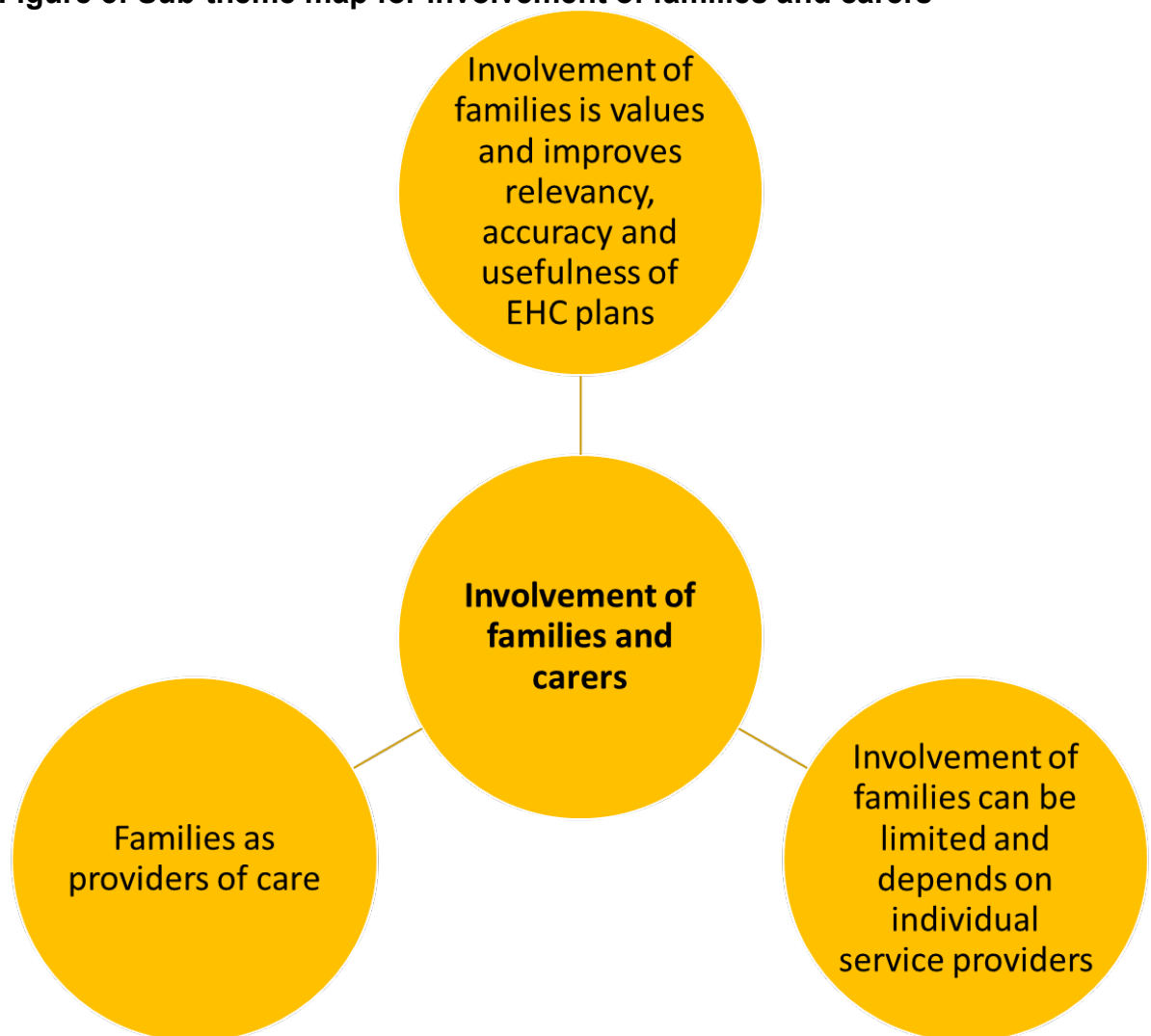


Figure 6: Sub-theme map for relationships between service providers and services users

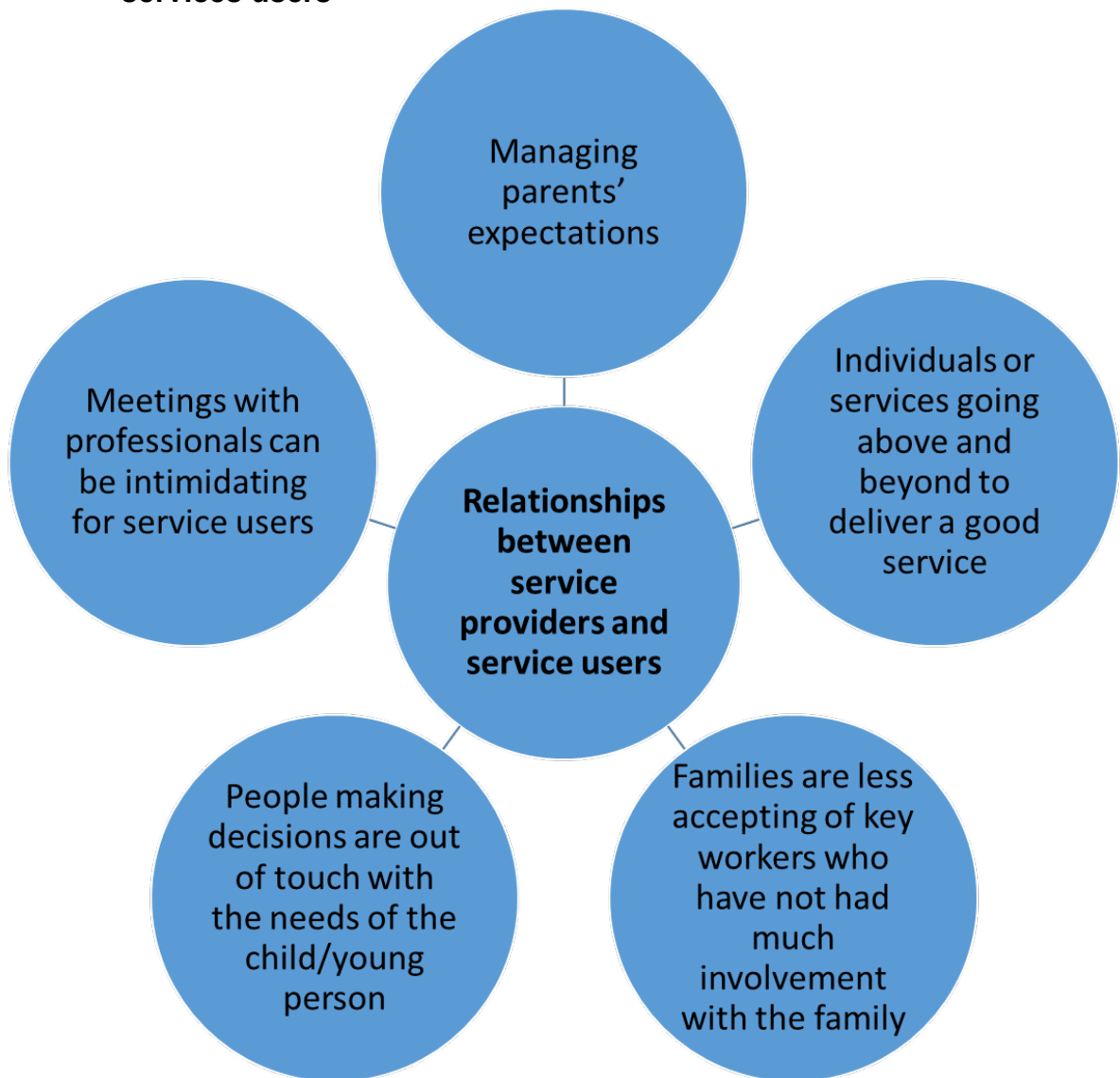


Figure 7: Sub-theme map for information and support

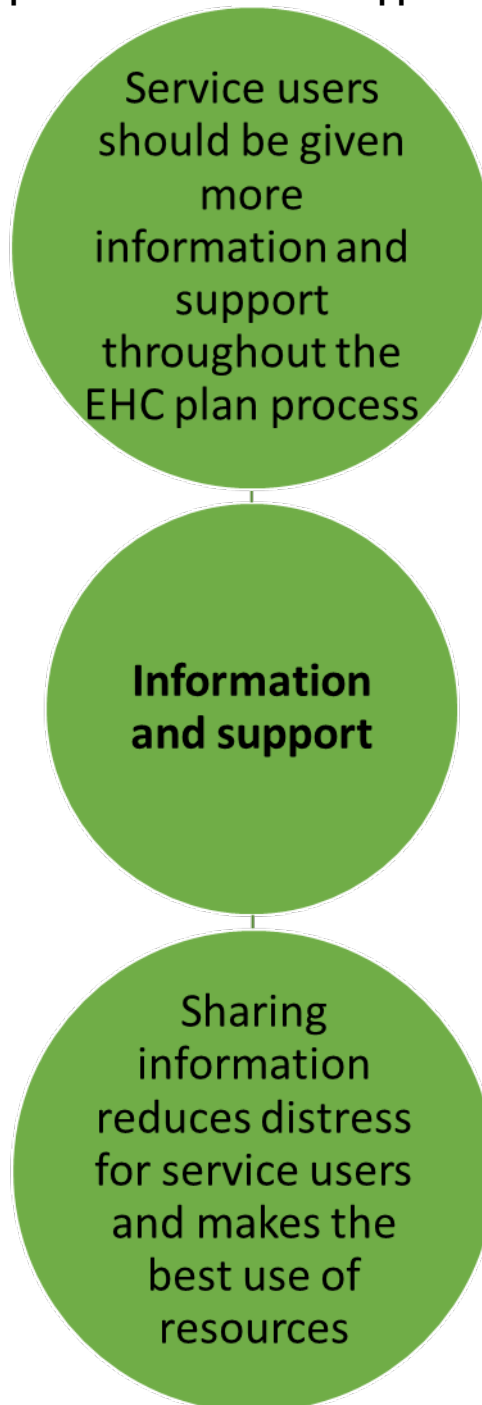


Figure 8: Sub-theme map for service provider knowledge and training

Figure 9: Sub-theme map for experience of EHC plans

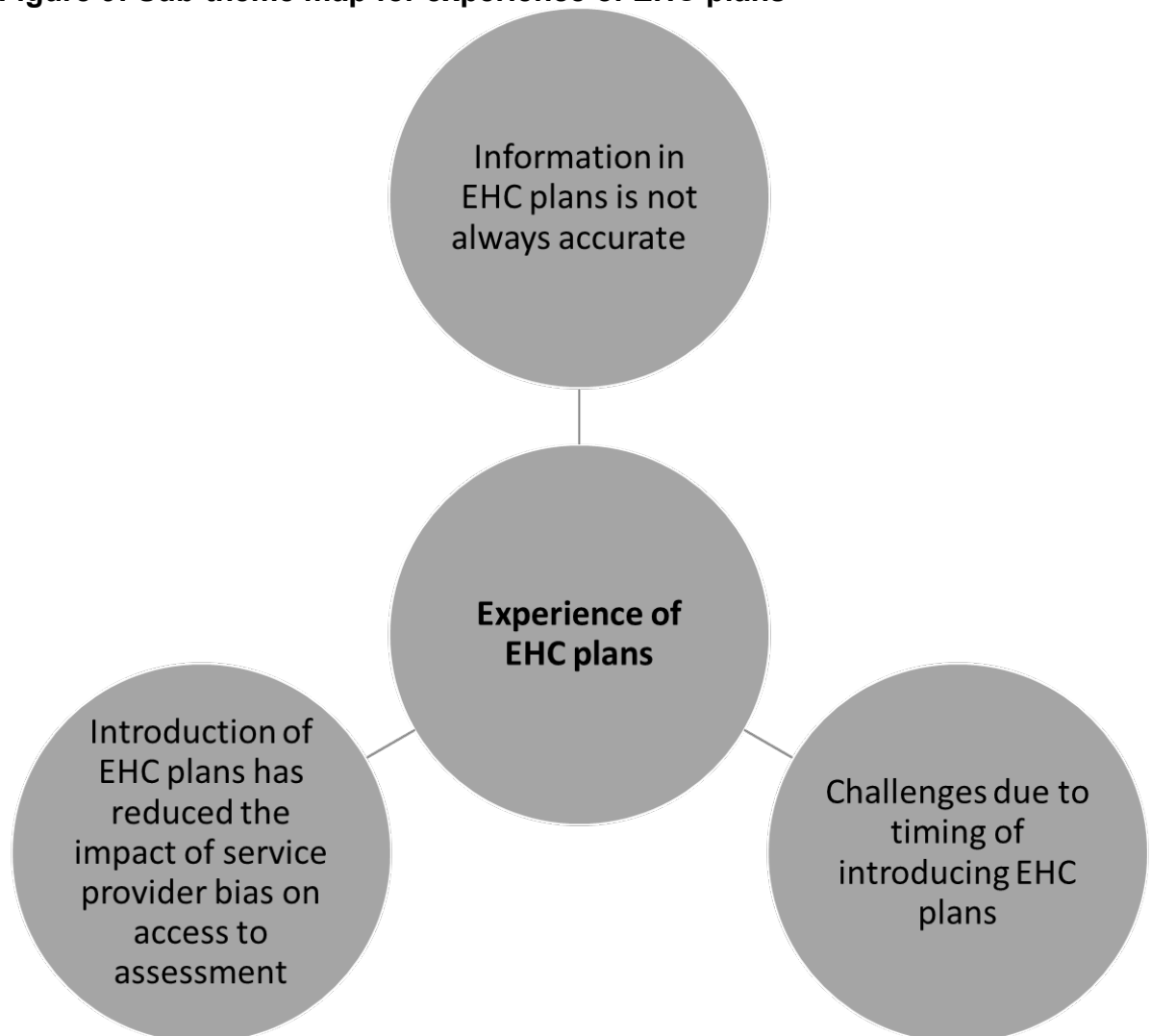


Figure 10: Sub-theme map for improved transition

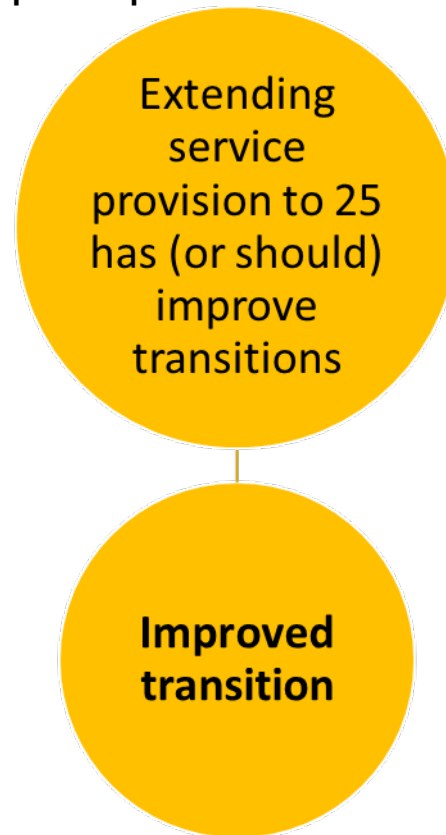


Figure 11: Sub-theme map for short breaks and respite breaks provide benefit

