

National Institute for Health and Care Excellence

Draft for consultation

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

[B] Evidence review for involving children and young people

NICE guideline TBC

Evidence reviews

August 2021

Draft for consultation

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

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1 Involving children and young people

2 Recommendations supported by this evidence review

3 This evidence review supports recommendations 1.1.2, 1.1.3, 1.1.5 - 1.1.7, 1.1.13, 1.1.15,
4 1.1.20 - 1.1.28, 1.1.32, 1.1.37 - 1.1.41, 1.4.7, 1.4.15, 1.4.16, 1.4.17 and the research
5 recommendation on telehealth and virtual platforms. Other evidence supporting these
6 recommendations can be found in the evidence reviews on Views and experiences of service
7 users (evidence report A), Barriers and facilitators of joined-up care (evidence report K),
8 Views and experiences of service providers (evidence report M).

9 Review question

10 What are the most effective practices (for example, communication and information
11 management) to enable health, social care and education services to work together to
12 involve disabled children and young people with severe complex needs in understanding,
13 planning and reviewing their health, social care and education?

14 Introduction

15 This review aims to identify effective practices to involve disabled children and young people
16 with severe complex needs in understanding, planning and reviewing their health, social care
17 and education.

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

22 Summary of the protocol

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

25 Table 1: Summary of the protocol (PICO table)

Population	Disabled children and young people from birth to 25 years with severe complex needs requiring health, social care and education support.
Intervention	Joint working strategies to involve disabled children and young people in the understanding, planning and reviewing their care and education. For example: <ul style="list-style-type: none">• Individualised communication strategies:<ul style="list-style-type: none">○ Services working together with communication aids and systems (for example interpretive, assistive technology, signing, play therapy)○ Shared care plans and/or records in understandable format○ Shared decision making○ Person centred planning○ Peer support (Ready steady go toolkit)○ Advocate (to empower the child or young person to communicate)○ Self-management○ Patient-initiated appointment systems
Comparison	<ul style="list-style-type: none">• Any other active strategy to involve disabled children and young people• No specific strategy to involve disabled children and young people

Outcome	Critical <ul style="list-style-type: none">• Satisfaction (child or young person) with health, social care and education services (for example as measured by validated scales or assisted communication aids such as talking mats or 'it's all about me')• Understanding of own health, social care and education needs (for example as measured by assisted communication aids such as measured by talking mats, 'it's all about me')• Involvement of child or young person in planning and reviewing health, social care and education (for example reported by child or young person or parent or carer, as recorded in EHC plan, annual review or Ofsted/CQC SEND inspection reports) Important <ul style="list-style-type: none">• Extent to which health, social care and educational needs are met (for example as measured by validated scales or whether EHC plans are met)• Delays in health care, social care and/or education
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1 CQC: Care Quality Commission; EHC: education, health and care; Ofsted: The Office for Standards in Education,
2 Children's Services and Skills; SEND: special educational needs and disability

3 For further details see the review protocol in appendix A.

4 **Methods and processes**

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

8 Declarations of interest were recorded according to [NICE's conflicts of interest policy](#).

9 **Effectiveness evidence**

10 **Included studies**

11 A systematic review of the literature was conducted but no studies were identified which
12 were applicable to this review question.

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

14 **Excluded studies**

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

17 **Summary of studies in the effectiveness evidence**

18 No studies were identified which were applicable to this review question (and so there are no
19 evidence tables in Appendix D). No meta-analysis was undertaken for this review (and so
20 there are no forest plots in Appendix E).

21 No studies were identified which were applicable to this review question (and so there are no
22 GRADE tables in appendix F).

23 **Economic evidence**

24 **Included studies**

25 A systematic review of the economic literature was conducted but no economic studies were
26 identified which were applicable to this review question.

1 A single economic search was undertaken for all topics included in the scope of this
2 guideline. See Supplement B for details.

3 **Excluded studies**

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

6 **Summary of included economic evidence**

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

8 **Economic model**

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

11 **Evidence statements**

12 **Economic**

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

14 **The committee's discussion and interpretation of the evidence**

15 **The outcomes that matter most**

16 Understanding of own health, social care and education needs and involvement of child or
17 young person in planning and reviewing health, social care and education were prioritised as
18 critical outcomes by the committee as identifying how health, social care and education
19 services can work together to enable these factors was the objective of this review question.
20 Child or young person's satisfaction with health, social care and education services was
21 selected as a critical outcome due to the importance of providing person-centred services.

22 The extent to which health, social care and educational needs are met was selected as an
23 important outcome because of the potentially long-term impact on children and young people
24 and their families if needs are not met. Delays in health care, social care and/or education
25 was also selected as an important outcome to investigate the possibility that greater
26 involvement of children and young people could cause delays.

27 No evidence was found for any of the outcomes.

28 **The quality of the evidence**

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

30 **Benefits and harms**

31 There was evidence from the qualitative reviews that using a child/young person centred
32 approach is valued, but that providers are falling short of achieving this (see evidence report
33 M, sub-themes 1.1 and 1.3), that children and young people felt positively and grew in
34 confidence when they were involved (see evidence report A, sub-themes 8.1 and 8.2) and
35 that input from the child or young person was thought to lead to a more accurate reflection of
36 their support needs (see evidence report A, sub-theme 8.3). Therefore, the committee
37 agreed it was important to make a recommendation in support of involving children and
38 young people in discussions and decisions about their care and support [1.1.2]. This was
39 further supported by qualitative evidence about the importance of separating the views of

1 children and young people from the views of their parents [see evidence report M, sub-theme
2 1.5). In the committee's experience, children and young people are not represented at a
3 number of meetings where they should be represented and often if they attend the meeting
4 they are not actively included. The committee acknowledged that attending meetings might
5 be difficult for some children and young people, but that the goal should be that they are
6 actively included and, therefore, made a recommendation in support of this [1.1.2].
7 Recommendations made in the planning and running meetings section of the guideline
8 should improve the experience of attending meetings for children and young people. They
9 also recommended that children and young people are given information in advance about
10 meetings they will be involved in so that they have time to process this information and
11 prepare [REC 1.1.15 consensus]. Based on their experience, the committee agreed it was
12 important to consider which members of the child or young persons' family should be
13 involved to account for situations of family breakdown [1.1.3].

14 The committee agreed, based on their experience, that awareness and understanding of
15 person-centred approaches is variable and subjective. This was supported by qualitative
16 evidence that service providers are falling short of using a child or young person-centred
17 approach (see evidence report M, sub-theme 1.3). The committee were aware of person-
18 centred planning tools that can assist with structuring and conducting meetings in a person-
19 centred way. In their view these tools can be used to ensure that information about the child
20 or young persons' needs and wishes that is unique, relevant and important to them, is
21 elicited at the start of planning. This removes the risk of generic assumptions,
22 misinterpretations and prejudicial attitudes being placed onto the child or young person by
23 practitioners, as a result of their condition. Using these planning tools to facilitate a person-
24 centred approach also focusses on what the child or young person's desired outcomes are
25 and develops a plan to deliver these. In the committee's experience if this is not done a plan
26 can be developed that is easily deliverable within existing service arrangements but will not
27 necessarily deliver the outcomes that are relevant to the individual. Therefore, they
28 recommended that such tools are used as they will reduce variation in practice and ensure
29 the approach used is person-centred. Using a person-centred approach is specified in the
30 SEND code of practice as a way to ensure that children, young people and parents are
31 involved in all aspects of planning and decision-making [1.1.26]. The committee agreed it
32 was also important to check with children and young people if they are satisfied with how
33 they have been involved in decisions and that practitioners look for ways to address
34 concerns if children and you people are not satisfied, so that involvement is beneficial to
35 children and young people and not just tokenistic [1.1.7]. The committee also agreed that it
36 was important to encourage and support children and young people to give their views on
37 their care, education and support and express what they want and need [1.1.5] based on the
38 qualitative evidence outlined above (see evidence report A, sub-themes 8.1, 8.2 and 8.3;
39 evidence report M, sub-themes 1.1 and 1.5) and additional evidence that their views are not
40 always adequately captured in EHC plans (see evidence report M, subtheme 2.2). They also
41 recommended that parents think about how they can support the child or young person to do
42 this and how services can help in light of the qualitative evidence about the importance of
43 separating the views of children and young people from their parent's views [1.1.6].

44 There was evidence from the qualitative reviews (see evidence report A, sub-themes 1.6, 4.2
45 and 6.3 and evidence report K, sub-themes 3.1 and 8.3) that families wanted to be kept up-
46 to-date with the progress of their child or young person's care, including the drafting and
47 progressing of their EHC plan, and providing adequate services and care regimens. Families
48 felt stressed and frustrated by the lack of information around delays, whilst families that were
49 kept informed felt more positively. Therefore, the committee recommended that young
50 people and their families be updated on the progress of their care and support [1.1.15].

51 Helping children and young people to understand their options and to prepare for meetings
52 was thought to help them to communicate their views during meetings, which was supported
53 by evidence from one of the qualitative reviews (see evidence report M, sub-theme 2.4). This
54 was thought to be particularly important for children and young people who use

1 communication aids, as they may prefer to prepare a script in advance of the meeting to
2 enable them to communicate their views more easily. Further, children with cognitive
3 impairments and learning disabilities will benefit from additional lead in time to process
4 information and consider their views. Those with poor literacy will also benefit from having
5 time to prepare for meetings and discussions. Therefore, the committee made a
6 recommendation in support of this [1.1.20]. This aligns with the special educational needs
7 and disability (SEND) Code of Practice (2015) which specifies that “local authorities must
8 ensure children, young people and parents are provided with the information, advice and
9 support necessary to enable them to participate in discussions and decisions about their
10 support... including time to prepare for discussions and meetings”. The committee agreed
11 that parents and carers should be encouraged to discuss meetings in advance with children
12 and young people as this would allow for discussions in the more relaxed home environment
13 and ensure that parents and carers understand the child or young person’s views in advance
14 of the meeting [1.1.20]. This may further benefit the child or young person by reassuring
15 them that they have the agency to participate in meetings. The committee also agreed it was
16 important that parents and carers are provided with support to complete documents ahead of
17 meetings, if required, because the paperwork can be extensive, requires a relatively high
18 level of literacy and may be distressing for families [1.1.20]. Further, in the committee’s
19 experience, if documents are not well completed ahead of meetings, meeting time might be
20 dominated by addressing the paperwork rather than discussion of important issues.

21 The qualitative evidence also highlighted the need to tailor communication to suit the
22 individual and circumstances and the importance of having a flexible approach to collecting
23 views that took into account the child or young person’s age, developmental level and
24 communication skills and the difficulty of capturing the views of children and young people
25 with severe communication difficulties (see evidence report A, sub-theme 3.1; evidence
26 report M, sub-theme 2.4) in addition to the qualitative evidence about the importance of
27 separating the views of children and young people from their parent’s views (see evidence
28 report M, sub-theme 1.5). Further, there was qualitative evidence that children and young
29 people had various levels of ability which affected their level of involvement and
30 understanding and that it can be difficult to understand complicated terminology (see
31 evidence report A, sub-themes 3.2 and 8.4). Therefore, the committee recommended that
32 practitioners find out what communication formats are preferred by each child or young
33 person and use this format to enable them to communicate their views [1.1.13; 1.1.21].
34 Additionally, the committee agreed it was important that the chair reminds everyone involved
35 in the meeting about the child’s or young person’s preferred method of communication during
36 meetings [1.1.27]. These recommendations would be particularly relevant to those with
37 cognitive impairments, communication needs and disorders and sensory impairments. The
38 committee also recommended, based on their experience, that the chair finds out what is
39 important to the child or young person ahead of meetings as the child or young person is
40 likely to be more motivated to participate if the issues being discussed are those that are
41 important to them and this is crucial as decisions made during meetings can be life-altering.
42 They also recommended establishing the age, communication abilities and circumstances of
43 the individual as this information can be used to plan meetings and will be particularly
44 relevant to helping children and young people with communication difficulties, learning
45 disabilities and sensory impairments to meaningfully participate in discussions [1.1.21]. The
46 committee also agreed that it was important to prioritise children and young people’s views
47 when planning meeting agendas, in addition to statutory content and other relevant issues
48 that parents, carers or practitioners need to cover [1.1.22]. This was supported by qualitative
49 evidence that using a child or young person-centred approach is valued and that parents felt
50 positive when given the opportunity to provide their views and negative when their views
51 were ignored (see evidence report A, sub-themes 9.1 and 9.2; evidence report M, sub-theme
52 1.1).

53 The committee agreed, based on their experience, that children and young people are not
54 always given enough time to express their views during meetings. Children and young
55 people may have learning disabilities, cognitive impairments and social and communication

1 needs that impact on the time required to communicate information and they may be asked
2 something unexpected which they will need time to process. Further, children and young
3 people may give very brief answers and require encouragement and additional time to
4 expand upon these. Therefore, the committee made a recommendation supporting giving
5 children and young people plenty of time to communicate [1.1.28].

6 The committee agreed, based on their experience, it was important to consider the child or
7 young person's preferences when structuring meetings to enable them to participate and
8 understand what is happening [1.1.23]. This was supported by qualitative evidence
9 highlighting the need to respect the rights of the child or young person, including their right to
10 privacy and to make their own decisions, and that meetings can be intimidating for service
11 users (see evidence report M, sub-themes 1.6 and 4.5). Specifically, in the committee's
12 experience meetings are scheduled to be convenient for the professionals attending, which
13 may not be the same as what is preferred or convenient for the child or young person.
14 Meetings may clash with activities that the child or young person enjoys or take place in
15 environments that they are less comfortable in, due to lack of familiarity or sensory
16 processing needs. Further, children and young people may experience difficulty with sleeping
17 and fatigue due to their conditions which will impact their ability to efficiently participate in
18 meetings. The committee recommended that meetings are scheduled outside of school time
19 where needed, as regularly missing school will impact negatively on educational progress
20 and may lead children or young people to feel excluded or the focus of unwanted attention
21 [1.1.23]. The committee were also aware, based on evidence from one of the qualitative
22 reviews (see evidence report M, sub-theme 5.2) that it may be easiest for children, young
23 people and their families to discuss sensitive information one-to-one with practitioners they
24 feel comfortable with, so made a recommendation in support of this [1.1.23]. Finally, the
25 committee made a recommendation supporting the need for breaks during long meetings
26 [1.1.23]. The committee agreed it was important to consider that children and young people
27 might need more frequent and/or longer breaks than may usually occur during meetings and
28 that this may be impacted by the format of the meeting and their individual care needs.

29 There was moderate quality evidence from one of the qualitative reviews (see evidence
30 report K, sub-theme 1.2) that practitioners were often failing to take responsibility to be
31 effectively involved in collaborative working, including not attending interagency meetings, or
32 preparing for meetings in advance. The committee agreed that it was crucial education,
33 health and social care practitioners who know the child and are involved in their care, along
34 with key additional people relevant to the meeting in question, make all reasonable efforts to
35 attend meetings to enable effective joint planning to meet the needs of disabled children and
36 young people [1.1.24]. However, they acknowledged that it may not always be possible to
37 attend. In these instances, the committee agreed that ideally a briefed delegate, or
38 alternatively a written update or report, should be sent in their place [1.1.32].

39 The Mental Capacity Act (2005) outlines the principles for involving young people aged 16 or
40 over in decision making. However, the committee were aware that there are inconsistencies
41 in both the interpretation and the implementation of the Mental Capacity Act in children who
42 have a cognitive impairment, and so agreed it was important to highlight these principles to
43 help standardise practice [1.1.41].

44 The SEND Code of Practice (2015) specifies that the views of parents must not be used as a
45 proxy for young people's views and that where there are disagreements between young
46 people and their parents, practitioners should work impartially with both the young person
47 and their parents. However, the committee agreed that this is not consistently done in
48 practice, partly due to the significant resources required to independently hold discussions
49 with both parties. It was also the experience of lay members on the committee that
50 sometimes they are ignored, with practitioners primarily addressing parents, as it is assumed
51 that they do not understand the discussion. Therefore, the committee made a
52 recommendation in support of working impartially with both parties when there are
53 disagreements [1.1.38]. Additionally, the committee agreed to emphasise the SEND Code of

1 Practice and Mental Capacity Act guidance that the young person’s views must be upheld if
2 they are over 16, are cognitively able to make the decision in question, and if disagreements
3 with parents cannot be resolved [1.1.40], as some professionals, especially those less
4 familiar with the Mental Capacity Act, may assume that parent’s views are paramount until
5 the young person turns 18. In contrast, where disagreements cannot be resolved and the
6 child is under 16, the views of the parents, or those with parental responsibility, should be
7 taken into account, but practitioners need to remember that the child’s needs are paramount
8 and that children under 16 can give their own consent if it is clear that they have enough
9 intelligence, competence and understanding to fully appreciate what is involved [1.1.39]. This
10 was supported by qualitative evidence that parents felt positive when given the opportunity to
11 provide their views and negative when their views were ignored (see evidence report A, sub-
12 themes 9.1 and 9.2). The committee agreed that there may be circumstances where children
13 are unable to formulate a view. They agreed that, in these circumstances, practitioners
14 should think about whether their preferences can be identified through other methods, such
15 as observation or play [1.1.37].

16 The committee agreed, based on their experience, that services should coordinate with each
17 other to agree the content of EHC plans and read the sections produced by other
18 practitioners to make sure that the plan works as a whole, as services often complete their
19 sections of the plan independently and this can lead to a lack of alignment across sections
20 and an EHC plan that is not practical to implement [1.4.7]. This was further supported by
21 qualitative evidence that additional assessments from services can cause delays in
22 implementing EHC plans (see evidence report K, sub-theme 8.4). There was some evidence
23 from the qualitative reviews that it can be difficult to understand complicated terminology and
24 using accessible language in EHC plans would increase the involvement of children and
25 young people and improve accountability (see evidence report A, sub-theme 3.2; evidence
26 report M, sub-theme 2.5). The committee noted that certain sections of the plan would need
27 to be written in technical language (for example information about health), but recommended
28 that the outcomes and support provision sections should be written in a clear language that,
29 where possible, can be understood by the child or young person (which would be particularly
30 relevant for those with communication difficulties and poor literacy) [1.4.15]. This aligns with
31 the SEND Code of Practice (2015) which states that “EHC plans should be clear, concise,
32 understandable and accessible to parents, children, young people, providers and
33 practitioners.” Further, the committee recommended that practitioners check with the child or
34 young person if the plan makes sense to them, that they can understand the plan outcomes
35 and that they agree with the content [1.4.16]. This would be particularly relevant to those with
36 cognitive impairments, communication difficulties and learning disabilities. The committee
37 acknowledged that it may be difficult to do this for some children and young people but
38 recommended that this is done to the extent that is possible. Finally, the committee agreed it
39 was important to emphasise the SEND Code of Practice guidance that children or young
40 people must be sent the draft EHC plan, have time to propose changes to the plan and be
41 able to meet with local authority officers [1.4.17] as it was the committee’s experience that
42 some families are aware of their rights and may have access to support groups that provide
43 this information, whereas others may be isolated, have English as a second language or
44 have other barriers to accessing information. Therefore, highlighting this requirement should
45 help to reduce inequalities. This was supported by qualitative evidence that there is a lack of
46 transparency about processes for appeals of complaints in relation to EHC plans (see
47 evidence report K, sub-theme 9.8).

48 There was no evidence about the effectiveness of telehealth and virtual platforms for
49 delivering interventions and meeting the needs of the population of children and young
50 people with severe complex needs; therefore, the committee made a recommendation for
51 research in this area.

1 Cost effectiveness and resource use

2 There was no published economic evidence for this review and no economic modelling was
3 undertaken.

4 The committee considered the recommendation to use person-centred planning tools to
5 structure and conduct meetings. They agreed that the use of such tools would be best
6 practice but is not always done as using these tools effectively requires both preparation time
7 and time to use the tool itself. As a result, compliance with statutory timescales is often
8 prioritised over a truly person-centred approach. Where person-centred planning tools are
9 not currently being used, no new staff will be required for this to happen but existing staff will
10 have to work differently in order to free up the time needed to use the tools. As a result of
11 using person-centred planning tools, the support specified for children and young people is
12 likely to be fit for purpose and help individuals progress towards their agreed outcomes.
13 Consequently, there are likely to be fewer problems that need to be resolved and fewer
14 complaints/tribunals resulting from dissatisfaction with the support provided which will save
15 both time and money later in the process. Also children and young person and their families
16 will be more likely to engage with the specified support, resulting in less money being spent
17 on support that doesn't get used.

18 The committee explained that review meetings are normally held during the school day as
19 schools have responsibility for organising the meeting and teachers are required to attend.
20 The recommendations mean there will need to be more flexibility about when review
21 meetings are held which could have some resource implications. However, the committee
22 agreed that only a subset of children and young people with an EHC plan will need review
23 meetings to be held outside of the school day. In these instances, health and social care staff
24 should be able to work alternative hours to minimise any resource impact. Education staff will
25 not have this flexibility so schools will need to negotiate patterns of annual directed time
26 flexibly including allowing teachers to use their planning, preparation and assessment time if
27 meetings have to be held outside of the school day. Therefore, any resource implications
28 should not be significant.

29 The recommendations imply longer meetings with more breaks therefore potentially taking
30 more time. Similarly, listening to parents views in addition to those of the child or young
31 person will require more professionals time, as will resolving disagreements between
32 children and young people and their parents/carers. However, the committee explained that
33 the participation of children and young people is essential to their care/engagement with
34 care, and the committee justified the recommendations because of this. Engagement with
35 care will positively impact their care, quality of life, and general well-being, outweighing any
36 additional costs. The committee also referred to person-centred care, which informs service
37 planning. If this is not done correctly, it may impact decision-making and end up in a
38 provision that does not meet children and young people's needs, low satisfaction, and
39 complaints. All of which may cost services much more further down the line.

40 The committee noted that there is a widespread professional expectation that services work
41 together to agree the content of EHC plans so that they align. However, as case-loads have
42 increased there is less time for practitioners to develop each plan and this can result in
43 discrepancies, particularly when the opinions of practitioners are different. The
44 recommendation is unlikely to have significant resource implications as the additional time
45 spent on agreeing the content of EHC plans will be offset by a reduced amount of time being
46 needed later in the process to fix problems

47 The committee explained that all other recommendations reinforce existing good practices
48 across services. However, there might be some resource implications for services that
49 provide sub-optimal care or have a different interpretation of the SEND Code of Practice
50 (2015).

1 Recommendations supported by this evidence review

2 This evidence review supports recommendations 1.1.2, 1.1.3, 1.1.5 - 1.1.7, 1.1.13, 1.1.15,
3 1.1.20 - 1.1.28, 1.1.32, 1.1.37 - 1.1.41, 1.4.7, 1.4.15, 1.4.16, 1.4.17 and the research
4 recommendation on telehealth and virtual platforms. Other evidence supporting these
5 recommendations can be found in the evidence reviews on Views and experiences of service
6 users (evidence report A), Barriers and facilitators of joined-up care (evidence report K),
7 Views and experiences of service providers (evidence report M).

8 References – included studies

9 Effectiveness

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

11 Other

12 Department for Education and Department for Health 2015

13 Department for Education and Department for Health, Special educational needs and
14 disability code of practice: 0 to 25 years. Statutory guidance for organisations which work
15 with and support children and young people who have special educational needs or
16 disabilities. Available at:
17 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND Code of Practice January 2015.pdf](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]
18

19 Mental Capacity Act 2005

20 Mental Capacity Act, 2005. Available at: <http://www.legislation.gov.uk/ukpga/2005/9/contents>
21 [Accessed 23/02/2021]

22 NICE 2018

23 National Institute for Health and Care Excellence, Evidence standards framework for digital
24 health technologies, Corporate document [ECD7], 2018. Available at:
25 <https://www.nice.org.uk/corporate/ecd7/chapter/section-a-evidence-for-effectiveness-standards>
26 [Accessed 29/06/2021]

1 Appendices

2 Appendix A – Review protocol

3 **Review protocol for review question: What are the most effective practices (for example, communication and information**
 4 **management) to enable health, social care and education services to work together to involve disabled children and**
 5 **young people with severe complex needs in understanding, planning and reviewing their health, social care and**
 6 **education?**

7 **Table 2: Review protocol**

ID	Field	Content
0.	PROSPERO registration number	CRD42020164795
1.	Review title	What are the most effective practices (for example, communication and information management) to enable health, social care and education services to work together to involve disabled children and young people with severe complex needs in understanding, planning and reviewing their health, social care and education?
2.	Review question	What are the most effective practices (for example, communication and information management) to enable health, social care and education services to work together to involve disabled children and young people with severe complex needs in understanding, planning and reviewing their health, social care and education?
3.	Objective	To identify effective practices to involve disabled children and young people with severe complex needs in understanding, planning and reviewing their health, social care and education?
4.	Searches	The following databases will be searched: <ul style="list-style-type: none"> • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • Health Technology Assessment (HTA) • Database of Abstracts of Reviews of Effects (DARE) • British Education Index (BEI) • Educational Information Resources Center (ERIC) • Health Management Information Consortium (HMIC) • Applied Social Science Index and Abstracts (ASSIA) • Social Care Online • Social Policy and Practice

ID	Field	Content
		<ul style="list-style-type: none"> • Social Science Citation Index • Social Services Abstracts • Sociological Abstracts • PsycINFO • CINAHL • Emcare <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> • Date: 2000 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) • National Audit Office • Audit Commission • Open Grey (if insufficient studies are found from other sources) <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	<p>Inclusion: Disabled children and young people from birth to 25 years with severe complex needs who require health, social care and education support (as identified by parent/carer, health, social care or education professional).</p> <p>Exclusion: Children and young people who do not have needs in all three areas of health, social care and education.</p>
7.	Intervention/Exposure/Test	<p>Joint working strategies to involve disabled children and young people in the understanding, planning and reviewing their care and education, for example:</p> <ul style="list-style-type: none"> • Individualised communication strategies: <ul style="list-style-type: none"> ○ Services working together with communication aids & systems (for example interpretive, assistive technology, signing, play therapy) ○ Shared care plans and/or records in understandable format

ID	Field	Content
		<ul style="list-style-type: none"> ○ Shared decision making ○ Person centred planning ○ Peer support (Ready steady go toolkit) ○ Advocate (to empower the child or young person to communicate) ○ Self-management ○ Patient-initiated appointment systems
8.	Comparator/Reference standard/Confounding factors	<ul style="list-style-type: none"> ● Any other active strategy to involve disabled children and young people ● No specific strategy to involve disabled children and young people
9.	Types of study to be included	<p>Systematic reviews of RCTs or non-randomised comparative studies (including cohort studies, before and after studies and interrupted time series), and RCTS will be included. Non-randomised studies will be included in the absence of RCTs. Service evaluations and audits will be included in the absence of comparative non-randomised studies.</p> <p>Conference abstracts will not be included.</p> <p>Non-randomised studies should adjust for confounders in their analysis such as: dominant provision (for example primarily autism, primarily physical disability), definitions of eligibility for service (for example for primary SEN), socioeconomic status. Studies will be downgraded for risk of bias if important confounding factors are not adequately adjusted for but will not be excluded for this reason.</p>
10.	Other exclusion criteria	<p>Studies will not be included for the following reasons:</p> <ul style="list-style-type: none"> ● Published prior to 2000 ● Not published in the English language ● Non Organisation for Economic Co-operation and Development (OCED) country (https://www.oecd.org/about/members-and-partners/) <p>Studies published prior to 2000 will not be considered due to legislative changes, specifically the Children and Families Care Act 2014, and the Aiming High for Disabled Children (AHDC) programme 2007.</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 non OCED countries will not be considered due to differences in health, social care and education services to those implemented in the UK.</p>
11.	Context	<p>All settings will be considered where health, social care and education is provided for disabled children and young people from birth to 25 years with severe complex needs.</p>
12.	Primary outcomes (critical outcomes)	<p>Critical Outcomes:</p> <ul style="list-style-type: none"> ● Person focused: <ul style="list-style-type: none"> ○ Satisfaction (child or young person) with health, social care and education services (for example as

ID	Field	Content
		<p>measured by validated scales or assisted communication aids such as talking mats or 'it's all about me')</p> <ul style="list-style-type: none"> ○ Understanding of own health, social care and education needs (for example as measured by assisted communication aids such as measured by talking mats, 'it's all about me') ○ Involvement of child or young person in planning and reviewing health, social care and education (for example reported by child or young person or parent or carer, as recorded in EHC plan, annual review or Ofsted/CQC SEND inspection reports)
13.	Secondary outcomes (important outcomes)	<p>Important Outcomes:</p> <ul style="list-style-type: none"> ● Service focused: <ul style="list-style-type: none"> ○ Extent to which health, social care and educational needs are met (for example as measured by validated scales or whether EHC plans are met) ○ Delays in health care, social care and/or education
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.</p> <p>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>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. The following data will be extracted: study details (reference, country where study was carried out, type and dates), participant characteristics, inclusion and exclusion criteria, details of the interventions, setting and follow-up, relevant outcome data and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.</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"> ● ROBIS tool for systematic reviews ● Cochrane RoB tool v.2 for RCTs and quasi-RCTs ● Cochrane ROBINS-I tool for non-randomised (clinical) controlled trials and cohort studies ● Effective Practice and Organisation of Care (EPOC) RoB Tool for before and after studies ● Effective Practice and Organisation of Care (EPOC) RoB Tool for interrupted time series <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>Intervention review:</p> <p>Depending on the availability of the evidence, the findings will be summarised narratively or quantitatively. Where possible, meta-analyses will be conducted using Cochrane Review Manager software. A fixed effect meta-analysis will be conducted and data will be presented as risk ratios or odds ratios for dichotomous outcomes, and mean differences or standardised mean differences for continuous outcomes. Heterogeneity in</p>

ID	Field	Content														
		<p>the effect estimates of the individual studies will be assessed using the I2 statistic. I2 values of greater than 50% and 80% will be considered as significant and very significant heterogeneity, respectively. Heterogeneity will be explored as appropriate using sensitivity analyses and pre-specified subgroup analyses. If heterogeneity cannot be explained through subgroup analysis then a random effects model will be used for meta-analysis, or the data will not be pooled if the I² statistic is greater than 80%.</p> <p>The confidence in the findings across all available evidence will be evaluated for each outcome using an adaptation of the ‘Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox’ developed by the international GRADE working group: http://www.gradeworkinggroup.org/</p> <p>Minimally important differences:</p> <p>We will check the rehabilitation measures database (www.sralab.org) for published MIDs for scales reported by included studies and use these if available. If not, we will use GRADE default MIDs.</p> <p>For extent to which needs are met and mortality, we will use any statistically significant difference.</p> <p>For all remaining continuous outcomes, we will use GRADE default MID of 0.5 times SD of the control groups at baseline (or at follow-up if the SD is not available a baseline). For all remaining dichotomous outcomes (RRs, ORs and HRs), we will use the GRADE default for RRs of 0.8 and 1.25 for consistency.</p>														
17.	Analysis of sub-groups	<p>No predefined subgroups.</p> <p>In the case of heterogeneity, the following groups may be investigated:</p> <p>Group vs individual intervention</p> <p>Setting (for example co-located vs not)</p> <p>Country</p> <p>Rural vs urban</p> <p>Age group (≥16 years versus <16 years)</p>														
18.	Type and method of review	<table border="1"> <tbody> <tr> <td><input checked="" type="checkbox"/></td> <td>Intervention</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Diagnostic</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Prognostic</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Qualitative</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Epidemiologic</td> </tr> <tr> <td><input checked="" type="checkbox"/></td> <td>Service Delivery</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Other (please specify)</td> </tr> </tbody> </table>	<input checked="" type="checkbox"/>	Intervention	<input type="checkbox"/>	Diagnostic	<input type="checkbox"/>	Prognostic	<input type="checkbox"/>	Qualitative	<input type="checkbox"/>	Epidemiologic	<input checked="" type="checkbox"/>	Service Delivery	<input type="checkbox"/>	Other (please specify)
<input checked="" type="checkbox"/>	Intervention															
<input type="checkbox"/>	Diagnostic															
<input type="checkbox"/>	Prognostic															
<input 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	03/01/20														

ID	Field	Content		
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	<p>5a. Named contact National Guideline Alliance</p> <p>5b Named contact e-mail CYPseverecomplexneeds@nice.org.uk</p> <p>5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</p>		
25.	Review team members	National Guideline Alliance		
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance which receives funding from NICE.		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual . Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10113		

ID	Field	Content
29.	Other registration details	None
30.	Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020164795
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, patient participation
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

1 AHDC: Aiming High for Disabled Children; ASSIA: Applied Social Science Index and Abstracts; BEI: British Education Index; CDSR: Cochrane Database of Systematic
2 Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; CINAHL: Cumulative Index to Nursing & Allied Health; DARE: Database of Abstracts of Reviews of
3 Effects; EHC: education, health and care; EPOC: Effective Practice and Organisation of Care; ERIC: Educational Information Resources Center; ERIC: Educational Information
4 Resources Center; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HMIC: Health Management Information Consortium; HR: hazard ratio;
5 HTA: Health Technology Assessment; MID: minimally important difference; NICE: National Institute for Health and Care Excellence; OECD: Organisation for Economic Co-
6 operation and Development; OR: odds ratio; RCT: randomised controlled trial; RoB: risk of bias; ROBINS-I: risk of bias in non-randomised studies – of interventions; ROBIS:
7 Risk of Bias in Systematic Reviews; RR: risk ratio; SD: standard deviation; SEN: special educational needs

1 Appendix B – Literature search strategies

2 Literature search strategies for review question: What are the most effective
3 practices (for example, communication and information management) to
4 enable health, social care and education services to work together to involve
5 disabled children and young people with severe complex needs in
6 understanding, planning and reviewing their health, social care and education?

7

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

10 Date of last search: 12/03/2020

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

#	Searches
	NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
42	(exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
43	or/40-42
44	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
45	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
46	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
47	or/44-46
48	STATE MEDICINE/og [Organization & Administration]
49	CHILD HEALTH SERVICES/og [Organization & Administration]
50	ADOLESCENT HEALTH SERVICES/og [Organization & Administration]
51	EDUCATION/og [Organization & Administration]
52	exp EDUCATION, SPECIAL/og [Organization & Administration]
53	exp SOCIAL WORK/og [Organization & Administration]
54	or/48-53
55	PATIENT PARTICIPATION/
56	STAKEHOLDER PARTICIPATION/
57	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 (involv\$ or engag\$ or empower\$ or participat\$) adj5 (care or service?)).ti,ab.
58	((individual\$ or personal\$) adj5 (communicat\$ or informat\$)).ti,ab.
59	COMMUNICATION AIDS FOR DISABLED/
60	SPEECH RECOGNITION SOFTWARE/
61	SELF-HELP DEVICES/
62	SIGN LANGUAGE/
63	COMMUNICATION METHODS, TOTAL/
64	LIP READING/
65	MANUAL COMMUNICATION/
66	PLAY THERAPY/
67	(communicat\$ adj3 (aid? or system?)).ti,ab.
68	(augmentative adj3 communicat\$).ti,ab.
69	(speech adj3 (software or synthes\$)).ti,ab.
70	(interpret\$ adj3 (device? or technolog\$)).ti,ab.
71	((selfhelp or self help) adj3 (device? or technolog\$)).ti,ab.
72	(assist\$ adj3 (device? or technolog\$)).ti,ab.
73	sign language?.ti,ab.
74	signing.ti,ab.
75	(lip? adj3 read\$).ti,ab.
76	(lipread\$ or speechread\$).ti,ab.
77	(play adj3 therap\$).ti,ab.
78	*PATIENT CARE PLANNING/
79	*MEDICAL RECORDS/
80	HEALTH RECORDS, PERSONAL/
81	PATIENT PORTALS/
82	MEDICAL RECORDS SYSTEMS, COMPUTERIZED/
83	ELECTRONIC HEALTH RECORDS/
84	HEALTH INFORMATION EXCHANGE/
85	(shar\$ adj5 care adj3 plan?).ti,ab.
86	(shar\$ adj5 record?).ti,ab.
87	(clear\$ adj3 informat\$).ti,ab.
88	(understand\$ adj3 (informat\$ or format\$)).ti,ab.
89	DECISION MAKING/
90	((shar\$ or collaborat\$) adj5 (make or making) adj3 decision?).ti,ab.
91	*PATIENT-CENTERED CARE/
92	((patient? or person) adj3 (center\$ or centre\$) adj3 (care or plan\$)).ti,ab.

#	Searches
93	PEER GROUP/ and SOCIAL SUPPORT/
94	(peer? adj3 support\$).ti,ab.
95	ready steady go.ti,ab.
96	CHILD ADVOCACY/
97	PATIENT ADVOCACY/
98	CONSUMER ADVOCACY/
99	(advocate or advocates).ti,ab.
100	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 advoca\$).ti,ab.
101	(communicat\$ adj5 advoca\$).ti,ab.
102	SELF-MANAGEMENT/
103	*SELF CARE/
104	(self adj3 manag\$).ti,ab.
105	"APPOINTMENTS AND SCHEDULES"/
106	((patient? or child\$ or adolescent? or young person? or young people? or young adult?) adj5 appointment?).ti,ab.
107	(appointment? adj5 system?).ti,ab.
108	or/55-107
109	26 and (39 or 43 or 47 or 54) and 108
110	limit 109 to english language
111	limit 110 to yr="2000 -Current"
112	LETTER/
113	EDITORIAL/
114	NEWS/
115	exp HISTORICAL ARTICLE/
116	ANECDOTES AS TOPIC/
117	COMMENT/
118	CASE REPORT/
119	(letter or comment*).ti.
120	or/112-119
121	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
122	120 not 121
123	ANIMALS/ not HUMANS/
124	exp ANIMALS, LABORATORY/
125	exp ANIMAL EXPERIMENTATION/
126	exp MODELS, ANIMAL/
127	exp RODENTIA/
128	(rat or rats or mouse or mice).ti.
129	or/122-128
130	111 not 129

1

2 Databases: Embase; and Embase Classic

3 Date of last search: 12/03/2020

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric\$.ti,ab.
9	YOUNG ADULT/
10	young\$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSON/
13	exp MENTAL DISEASE/
14	INTELLECTUAL IMPAIRMENT/
15	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$).ti.
16	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/12-17
19	11 and 18
20	HANDICAPPED CHILD/
21	CSHCN.ti,ab.
22	"Education Health and Care plan?".ti,ab.

#	Searches
23	EHC plan?.ti,ab.
24	EHCP?.ti,ab.
25	or/19-24
26	PUBLIC RELATIONS/
27	INTERSECTORAL COLLABORATION/
28	INTEGRATED HEALTH CARE SYSTEM/
29	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
30	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
31	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
32	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
33	(interprovider? or multiprovider? or jointprovider?).ti,ab.
34	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
35	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
36	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
37	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
38	or/26-37
39	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/)
40	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
41	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
42	or/39-41
43	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
44	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
45	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
46	or/43-45
47	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
48	CHILD HEALTH CARE/ and ORGANIZATION/
49	EDUCATION/ and ORGANIZATION/
50	exp SPECIAL EDUCATION/ and ORGANIZATION/
51	SOCIAL WORK/ and ORGANIZATION/
52	or/47-51
53	PATIENT PARTICIPATION/
54	*STAKEHOLDER ENGAGEMENT/
55	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 (involv\$ or engag\$ or empower\$ or participat\$) adj5 (care or service?)).ti,ab.
56	((individual\$ or personal\$) adj3 (communicat\$ or informat\$)).ti,ab.
57	COMMUNICATION AID/
58	AUTOMATIC SPEECH RECOGNITION/
59	SELF HELP DEVICE/
60	ASSISTIVE TECHNOLOGY/
61	*SIGN LANGUAGE/
62	TOTAL COMMUNICATION/
63	*LIP READING/
64	MANUAL COMMUNICATION/
65	PLAY THERAPY/
66	(communicat\$ adj3 (aid? or system?)).ti,ab.
67	(augmentative adj3 communicat\$).ti,ab.

#	Searches
68	(speech adj3 (software or synthes\$)).ti,ab.
69	(interpret\$ adj3 (device? or technolog\$)).ti,ab.
70	((selfhelp or self help) adj3 (device? or technolog\$)).ti,ab.
71	(assist\$ adj3 (device? or technolog\$)).ti,ab.
72	sign language?.ti,ab.
73	signing.ti,ab.
74	(lip? adj3 read\$).ti,ab.
75	(lipread\$ or speechread\$).ti,ab.
76	(play adj3 therap\$).ti,ab.
77	*PATIENT CARE PLANNING/
78	*MEDICAL RECORD/
79	ELECTRONIC MEDICAL RECORD SYSTEM/
80	ELECTRONIC HEALTH RECORD/
81	(shar\$ adj5 care adj3 plan?).ti,ab.
82	(shar\$ adj5 record?).ti,ab.
83	(clear\$ adj3 informat\$).ti,ab.
84	(understand\$ adj3 (informat\$ or format\$)).ti,ab.
85	SHARED DECISION MAKING/
86	*DECISION MAKING/
87	((shar\$ or collaborat\$) adj5 (make or making) adj3 decision?).ti,ab.
88	((patient? or person) adj3 (center\$ or centre\$) adj3 (care or plan\$)).ti,ab.
89	PEER GROUP/ and SOCIAL SUPPORT/
90	(peer? adj3 support\$).ti,ab.
91	ready steady go.ti,ab.
92	CHILD ADVOCACY/
93	*PATIENT ADVOCACY/
94	CONSUMER ADVOCACY/
95	(advocate or advocates).ti.
96	(advocate or advocates).ab. /freq=2
97	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 advoca\$).ti,ab.
98	(communicat\$ adj5 advoca\$).ti,ab.
99	*SELF CARE/
100	(self adj3 manag\$).ti,ab.
101	((patient? or child\$ or adolescent? or young person? or young people? or young adult?) adj5 appointment?).ti,ab.
102	(appointment? adj5 system?).ti,ab.
103	or/53-102
104	25 and (38 or 42 or 46 or 52) and 103
105	limit 104 to english language
106	limit 105 to yr="2000 -Current"
107	letter.pt. or LETTER/
108	note.pt.
109	editorial.pt.
110	CASE REPORT/ or CASE STUDY/
111	(letter or comment*).ti.
112	or/107-111
113	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
114	112 not 113
115	ANIMAL/ not HUMAN/
116	NONHUMAN/
117	exp ANIMAL EXPERIMENT/
118	exp EXPERIMENTAL ANIMAL/
119	ANIMAL MODEL/
120	exp RODENT/
121	(rat or rats or mouse or mice).ti.
122	or/114-121
123	106 not 122

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2 Database: Health Management Information Consortium (HMIC)

3 Date of last search: 12/03/2020

#	Searches
1	exp YOUNG PEOPLE/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
3	exp CHILDREN/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
5	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.

#	Searches
6	exp PAEDIATRICS/
7	p?ediatric\$.ti,ab.
8	YOUNG ADULTS/
9	young\$ adult?.ti,ab.
10	or/1-9
11	DISABLED PEOPLE/
12	exp DISABILITIES/
13	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$).ti.
14	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
15	SHCN.ti,ab.
16	or/11-15
17	10 and 16
18	CSHCN.ti,ab.
19	"Education Health and Care plan?".ti,ab.
20	EHC plan?.ti,ab.
21	EHCP?.ti,ab.
22	or/17-21
23	COLLABORATION/
24	exp INTERAGENCY COLLABORATION/
25	INTERPROFESSIONAL COLLABORATION/
26	COLLABORATIVE CARE/
27	INTEGRATED PROVIDERS/
28	INTEGRATED CARE/
29	INTERDISCIPLINARY SERVICES/
30	JOINT WORKING/
31	HEALTH & SOCIAL SERVICES INTERACTION/
32	COMMUNICATION/
33	HEALTH SERVICE PROVISION/
34	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
35	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
36	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
37	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
38	(interprovider? or multiprovider? or jointprovider?).ti,ab.
39	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
40	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
41	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
42	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
43	or/23-42
44	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SUPPORTIVE SOCIAL WORK/)
45	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
46	(exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SUPPORTIVE SOCIAL WORK/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
47	or/44-46
48	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
49	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
50	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or

#	Searches
	service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
51	or/48-50
52	PATIENT PARTICIPATION/
53	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 (involv\$ or engag\$ or empower\$ or participat\$) adj5 (care or service?)).ti,ab.
54	((individual\$ or personal\$) adj5 (communicat\$ or informat\$)).ti,ab.
55	COMMUNICATION AIDS/
56	ASSISTIVE TECHNOLOGY/
57	SIGN LANGUAGE/
58	LIP READING/
59	PLAY THERAPY/
60	(communicat\$ adj3 (aid? or system?)).ti,ab.
61	(augmentative adj3 communicat\$).ti,ab.
62	(speech adj3 (software or synthes\$)).ti,ab.
63	(interpret\$ adj3 (device? or technolog\$)).ti,ab.
64	((selfhelp or self help) adj3 (device? or technolog\$)).ti,ab.
65	(assist\$ adj3 (device? or technolog\$)).ti,ab.
66	sign language?.ti,ab.
67	signing.ti,ab.
68	(lip? adj3 read\$).ti,ab.
69	(lipread\$ or speechread\$).ti,ab.
70	(play adj3 therap\$).ti,ab.
71	INDIVIDUALISED CARE PLANS/
72	MEDICAL RECORDS/
73	HEALTH RECORDS/
74	PATIENT HELD HEALTH RECORDS/
75	ELECTRONIC PATIENT RECORDS/
76	(shar\$ adj5 care adj3 plan?).ti,ab.
77	(shar\$ adj5 record?).ti,ab.
78	(clear\$ adj3 informat\$).ti,ab.
79	(understand\$ adj3 (informat\$ or format\$)).ti,ab.
80	DECISION MAKING/
81	((shar\$ or collaborat\$) adj5 (make or making) adj3 decision?).ti,ab.
82	PATIENT CENTRED CARE/
83	((patient? or person) adj3 (center\$ or centre\$) adj3 (care or plan\$)).ti,ab.
84	PEER GROUPS/
85	(peer? adj3 support\$).ti,ab.
86	ready steady go.ti,ab.
87	CHILD ADVOCACY/
88	PATIENT ADVOCACY/
89	(advocate or advocates).ti,ab.
90	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 advoca\$).ti,ab.
91	(communicat\$ adj5 advoca\$).ti,ab.
92	SELF MANAGEMENT/
93	SELF CARE OF PATIENT/
94	(self adj3 manag\$).ti,ab.
95	PATIENT APPOINTMENTS/
96	PATIENT APPOINTMENT SYSTEMS/
97	((patient? or child\$ or adolescent? or young person? or young people? or young adult?) adj5 appointment?).ti,ab.
98	(appointment? adj5 system?).ti,ab.
99	or/52-98
100	22 and (43 or 47 or 51) and 99
101	limit 100 to yr="2000 -Current"

1

2 Database: Social Policy and Practice

3 Date of last search: 12/03/2020

#	Searches
1	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
4	p?ediatric\$.ti,ab.
5	young\$ adult?.ti,ab.

#	Searches
6	or/1-5
7	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$.ti.
8	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
9	SHCN.ti,ab.
10	or/7-9
11	6 and 10
12	CSHCN.ti,ab.
13	"Education Health and Care plan?".ti,ab.
14	EHC plan?.ti,ab.
15	EHCP?.ti,ab.
16	or/11-15
17	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
18	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
19	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
20	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
21	(interprovider? or multiprovider? or jointprovider?).ti,ab.
22	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
23	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
24	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
25	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
26	or/17-25
27	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
28	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
29	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
30	or/27-29
31	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 (involv\$ or engag\$ or empower\$ or participat\$) adj5 (care or service?)).ti,ab.
32	((individual\$ or personal\$) adj5 (communicat\$ or informat\$)).ti,ab.
33	(communicat\$ adj3 (aid? or system?)).ti,ab.
34	(augmentative adj3 communicat\$).ti,ab.
35	(speech adj3 (software or synthes\$)).ti,ab.
36	(interpret\$ adj3 (device? or technolog\$)).ti,ab.
37	((selfhelp or self help) adj3 (device? or technolog\$)).ti,ab.
38	(assist\$ adj3 (device? or technolog\$)).ti,ab.
39	sign language?.ti,ab.
40	signing.ti,ab.
41	(lip? adj3 read\$).ti,ab.
42	(lipread\$ or speechread\$).ti,ab.
43	(play adj3 therap\$).ti,ab.
44	(shar\$ adj5 care adj3 plan?).ti,ab.
45	(shar\$ adj5 record?).ti,ab.
46	(clear\$ adj3 informat\$).ti,ab.
47	(understand\$ adj3 (informat\$ or format\$)).ti,ab.
48	((shar\$ or collaborat\$) adj5 (make or making) adj3 decision?).ti,ab.
49	((patient? or person) adj3 (center\$ or centre\$) adj3 (care or plan\$)).ti,ab.
50	(peer? adj3 support\$).ti,ab.
51	ready steady go.ti,ab.
52	(advocate or advocates).ti,ab.
53	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 advoca\$).ti,ab.
54	(communicat\$ adj5 advoca\$).ti,ab.
55	(self adj3 manag\$).ti,ab.
56	((patient? or child\$ or adolescent? or young person? or young people? or young adult?) adj5 appointment?).ti,ab.
57	(appointment? adj5 system?).ti,ab.
58	or/31-57

#	Searches
59	16 and (26 or 30) and 58
60	limit 59 to yr="2000 -Current"

1

2 Database: PsycInfo

3 Date of last search: 12/03/2020

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
4	PEDIATRICS/
5	p?ediatric\$.ti,ab.
6	young\$ adult?.ti,ab.
7	or/1-6
8	DISORDERS/
9	exp DISABILITIES/
10	PHYSICAL DISORDERS/
11	exp SENSE ORGAN DISORDERS/
12	exp MENTAL DISORDERS/
13	exp COMMUNICATION DISORDERS/
14	SPECIAL NEEDS/
15	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$).ti.
16	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/8-17
19	7 and 18
20	CSHCN.ti,ab.
21	"Education Health and Care plan?".ti,ab.
22	EHC plan?.ti,ab.
23	EHCP?.ti,ab.
24	or/19-23
25	INTEGRATED SERVICES/
26	INTERDISCIPLINARY TREATMENT APPROACH/
27	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
28	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
29	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
30	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
31	(interprovider? or multiprovider? or jointprovider?).ti,ab.
32	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
33	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
34	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
35	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
36	or/25-35
37	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/)
38	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
39	(exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
40	or/37-39
41	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language)

#	Searches
	adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
42	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
43	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
44	or/41-43
45	CLIENT PARTICIPATION/
46	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 (involv\$ or engag\$ or empower\$ or participat\$) adj5 (care or service?)).ti,ab.
47	((individual\$ or personal\$) adj5 (communicat\$ or informat\$)).ti,ab.
48	AUGMENTATIVE COMMUNICATION/
49	AUTOMATED SPEECH RECOGNITION/
50	ASSISTIVE TECHNOLOGY/
51	SIGN LANGUAGE/
52	LIPREADING/
53	MANUAL COMMUNICATION/
54	PLAY THERAPY/
55	(communicat\$ adj3 (aid? or system?)).ti,ab.
56	(augmentative adj3 communicat\$).ti,ab.
57	(speech adj3 (software or synthes\$)).ti,ab.
58	(interpret\$ adj3 (device? or technolog\$)).ti,ab.
59	((selfhelp or self help) adj3 (device? or technolog\$)).ti,ab.
60	(assist\$ adj3 (device? or technolog\$)).ti,ab.
61	sign language?.ti,ab.
62	signing.ti,ab.
63	(lip? adj3 read\$).ti,ab.
64	(lipread\$ or speechread\$).ti,ab.
65	(play adj3 therap\$).ti,ab.
66	*TREATMENT PLANNING/
67	MEDICAL RECORDS/
68	ELECTRONIC HEALTH RECORDS/
69	(shar\$ adj5 care adj3 plan?).ti,ab.
70	(shar\$ adj5 record?).ti,ab.
71	(clear\$ adj3 informat\$).ti,ab.
72	(understand\$ adj3 (informat\$ or format\$)).ti,ab.
73	DECISION MAKING/
74	((shar\$ or collaborat\$) adj5 (make or making) adj3 decision?).ti,ab.
75	((patient? or person) adj3 (center\$ or centre\$) adj3 (care or plan\$)).ti,ab.
76	PEERS/ and SOCIAL SUPPORT/
77	(peer? adj3 support\$).ti,ab.
78	ready steady go.ti,ab.
79	ADVOCACY/
80	(advocate or advocates).ti,ab.
81	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 advoca\$).ti,ab.
82	(communicat\$ adj5 advoca\$).ti,ab.
83	SELF-MANAGEMENT/
84	*SELF-CARE SKILLS/
85	(self adj3 manag\$).ti,ab.
86	((patient? or child\$ or adolescent? or young person? or young people? or young adult?) adj5 appointment?).ti,ab.
87	(appointment? adj5 system?).ti,ab.
88	or/45-87
89	24 and (36 or 40 or 44) and 88
90	limit 89 to english language
91	limit 90 to yr="2000 -Current"
92	limit 91 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal")

1 Database: Emcare

2 Date of last search: 12/03/2020

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

#	Searches
45	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
46	or/43-45
47	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
48	CHILD HEALTH CARE/ and ORGANIZATION/
49	EDUCATION/ and ORGANIZATION/
50	exp SPECIAL EDUCATION/ and ORGANIZATION/
51	SOCIAL WORK/ and ORGANIZATION/
52	or/47-51
53	PATIENT PARTICIPATION/
54	*STAKEHOLDER ENGAGEMENT/
55	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 (involv\$ or engag\$ or empower\$ or participat\$) adj5 (care or service?)).ti,ab.
56	((individual\$ or personal\$) adj3 (communicat\$ or informat\$)).ti,ab.
57	COMMUNICATION AID/
58	AUTOMATIC SPEECH RECOGNITION/
59	SELF HELP DEVICE/
60	ASSISTIVE TECHNOLOGY/
61	*SIGN LANGUAGE/
62	TOTAL COMMUNICATION/
63	*LIP READING/
64	MANUAL COMMUNICATION/
65	PLAY THERAPY/
66	(communicat\$ adj3 (aid? or system?)).ti,ab.
67	(augmentative adj3 communicat\$).ti,ab.
68	(speech adj3 (software or synthes\$)).ti,ab.
69	(interpret\$ adj3 (device? or technolog\$)).ti,ab.
70	((selfhelp or self help) adj3 (device? or technolog\$)).ti,ab.
71	(assist\$ adj3 (device? or technolog\$)).ti,ab.
72	sign language?.ti,ab.
73	signing.ti,ab.
74	(lip? adj3 read\$).ti,ab.
75	(lipread\$ or speechread\$).ti,ab.
76	(play adj3 therap\$).ti,ab.
77	*PATIENT CARE PLANNING/
78	*MEDICAL RECORD/
79	ELECTRONIC MEDICAL RECORD SYSTEM/
80	ELECTRONIC HEALTH RECORD/
81	(shar\$ adj5 care adj3 plan?).ti,ab.
82	(shar\$ adj5 record?).ti,ab.
83	(clear\$ adj3 informat\$).ti,ab.
84	(understand\$ adj3 (informat\$ or format\$)).ti,ab.
85	SHARED DECISION MAKING/
86	*DECISION MAKING/
87	((shar\$ or collaborat\$) adj5 (make or making) adj3 decision?).ti,ab.
88	((patient? or person) adj3 (center\$ or centre\$) adj3 (care or plan\$)).ti,ab.
89	PEER GROUP/ and SOCIAL SUPPORT/
90	(peer? adj3 support\$).ti,ab.
91	ready steady go.ti,ab.
92	CHILD ADVOCACY/
93	*PATIENT ADVOCACY/
94	CONSUMER ADVOCACY/
95	(advocate or advocates).ti.
96	(advocate or advocates).ab. /freq=2
97	((child\$ or adolescent? or young person? or young people? or young adult?) adj5 advoca\$).ti,ab.
98	(communicat\$ adj5 advoca\$).ti,ab.
99	*SELF CARE/
100	(self adj3 manag\$).ti,ab.
101	((patient? or child\$ or adolescent? or young person? or young people? or young adult?) adj5 appointment?).ti,ab.
102	(appointment? adj5 system?).ti,ab.
103	or/53-102
104	25 and (38 or 42 or 46 or 52) and 103
105	limit 104 to english language
106	limit 105 to yr="2000 -Current"
107	letter.pt. or LETTER/
108	note.pt.
109	editorial.pt.
110	CASE REPORT/ or CASE STUDY/

#	Searches
111	(letter or comment*).ti.
112	or/107-111
113	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
114	112 not 113
115	ANIMAL/ not HUMAN/
116	NONHUMAN/
117	exp ANIMAL EXPERIMENT/
118	exp EXPERIMENTAL ANIMAL/
119	ANIMAL MODEL/
120	exp RODENT/
121	(rat or rats or mouse or mice).ti.
122	or/114-121
123	106 not 122

1

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

4 Date of last search: 12/03/2020

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

DRAFT FOR CONSULTATION
Involving children and young people

#	Searches
	SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"] and ([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"])
#42	([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh ^"EDUCATION"] or [mh "EDUCATION, SPECIAL"] or [mh ^"SCHOOLS"] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^"UNIVERSITIES"] or [mh ^"TEACHING"] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#43	([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"]) and ([mh ^"EDUCATION"] or [mh "EDUCATION, SPECIAL"] or [mh ^"SCHOOLS"] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERIES] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^"UNIVERSITIES"] or [mh ^"TEACHING"] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#44	#41 or #42 or #43
#45	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs near/5 social* near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#46	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#47	(social* near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#48	#45 or #46 or #47
#49	[mh ^"STATE MEDICINE"/og]
#50	[mh ^"CHILD HEALTH SERVICES"/og]
#51	[mh ^"ADOLESCENT HEALTH SERVICES"/og]
#52	[mh ^"EDUCATION"/og]
#53	[mh "EDUCATION, SPECIAL"/og]
#54	[mh "SOCIAL WORK"/og]
#55	#49 or #50 or #51 or #52 or #53 or #54
#56	[mh ^"PATIENT PARTICIPATION"]
#57	[mh ^"STAKEHOLDER PARTICIPATION"]
#58	((child* or adolescent* or "young person*" or "young people*" or "young adult*") near/5 (involv* or engag* or empower* or participat*) near/5 (care or service*)):ti,ab
#59	((individual* or personal*) near/5 (communicat* or informat*)):ti,ab
#60	[mh ^"COMMUNICATION AIDS FOR DISABLED"]
#61	[mh ^"SPEECH RECOGNITION SOFTWARE"]
#62	[mh ^"SELF-HELP DEVICES"]
#63	[mh ^"SIGN LANGUAGE"]
#64	[mh ^"COMMUNICATION METHODS, TOTAL"]
#65	[mh ^"LIP READING"]
#66	[mh ^"MANUAL COMMUNICATION"]
#67	[mh ^"PLAY THERAPY"]
#68	(communicat* near/3 (aid* or system*)):ti,ab
#69	(augmentative near/3 communicat*):ti,ab
#70	(speech near/3 (software or synthes*)):ti,ab
#71	(interpret* near/3 (device* or technolog*)):ti,ab
#72	((selfhelp or "self help") near/3 (device* or technolog*)):ti,ab
#73	(assist* near/3 (device* or technolog*)):ti,ab
#74	"sign language*":ti,ab
#75	signing:ti,ab
#76	(lip* near/3 read*):ti,ab
#77	(lipread* or speechread*):ti,ab
#78	(play near/3 therap*):ti,ab
#79	[mh ^"PATIENT CARE PLANNING"]
#80	[mh ^"MEDICAL RECORDS"]
#81	[mh ^"HEALTH RECORDS, PERSONAL"]
#82	[mh ^"PATIENT PORTALS"]
#83	[mh ^"MEDICAL RECORDS SYSTEMS, COMPUTERIZED"]

#	Searches
#84	[mh ^"ELECTRONIC HEALTH RECORDS"]
#85	[mh ^"HEALTH INFORMATION EXCHANGE"]
#86	(shar* near/5 care near/3 plan*):ti,ab
#87	(shar* near/5 record*):ti,ab
#88	(clear* near/3 informat*):ti,ab
#89	(understand* near/3 (informat* or format*)):ti,ab
#90	[mh ^"DECISION MAKING"]
#91	((shar* or collaborat*) near/5 (make or making) near/3 decision*):ti,ab
#92	[mh ^"PATIENT-CENTERED CARE"]
#93	((patient* or person) near/3 (center* or centre*) near/3 (care or plan*)):ti,ab
#94	[mh ^"PEER GROUP"] and [mh ^"SOCIAL SUPPORT"]
#95	(peer* near/3 support*):ti,ab
#96	"ready steady go":ti,ab
#97	[mh ^"CHILD ADVOCACY"]
#98	[mh ^"PATIENT ADVOCACY"]
#99	[mh ^"CONSUMER ADVOCACY"]
#100	(advocate or advocates):ti,ab
#101	((child* or adolescent* or "young person*" or "young people*" or "young adult*") near/5 advoca*):ti,ab
#102	(communicat* near/5 advoca*):ti,ab
#103	[mh ^"SELF-MANAGEMENT"]
#104	[mh ^"SELF CARE"]
#105	(self near/3 manag*):ti,ab
#106	[mh ^"APPOINTMENTS AND SCHEDULES"]
#107	((patient* or child* or adolescent* or "young person*" or "young people*" or "young adult*") near/5 appointment*):ti,ab
#108	(appointment* near/5 system*):ti,ab
#109	#56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76 or #77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
#110	#27 and #40 and #109
#111	#27 and #44 and #109
#112	#27 and #48 and #109
#113	#27 and #55 and #109
#114	#110 or #111 or #112 or #113
#115	#110 or #111 or #112 or #113 with Cochrane Library publication date Between Jan 2000 and Mar 2020, in Cochrane Reviews
#116	#110 or #111 or #112 or #113 with Publication Year from 2000 to 2020, in Trials

1

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

3 Date of last search: 12/03/2020

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

#	Searches
19	#13 OR #14 OR #15 OR #16 OR #17 OR #18
20	#12 AND #19
21	MeSH DESCRIPTOR DISABLED CHILDREN IN DARE
22	((CSHCN)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
23	((("Education Health" adj2 "Care plan*"))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
24	((("EHC plan*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
25	((EHCP*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
26	#20 OR #21 OR #22 OR #23 OR #24 OR #25
27	((("communication aid*" or "communication system*" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan*" or "ready steady go toolkit*" or advocate or advocates or "patient-initiated appointment system*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
28	((((augmentativ* or alternativ*) adj3 communicat*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
29	((((shar* adj3 decision* adj3 mak*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
30	((((person* or patient*) adj3 (centre* or center*) adj3 (plan* or care*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
31	((((peer* adj3 support*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
32	((((self adj3 manag*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
33	#27 OR #28 OR #29 OR #30 OR #31 OR #32
34	#26 AND #33

1

2 Database: Health Technology Abstracts (HTA)

3 Date of last search: 12/03/2020

#	Searches
1	MeSH DESCRIPTOR ADOLESCENT IN HTA
2	MeSH DESCRIPTOR MINORS IN HTA
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*) IN HTA
4	MeSH DESCRIPTOR CHILD EXPLODE ALL TREES IN HTA
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*) IN HTA
6	MeSH DESCRIPTOR INFANT EXPLODE ALL TREES IN HTA
7	(infan* or neonat* or newborn* or baby or babies) IN HTA
8	MeSH DESCRIPTOR PEDIATRICS EXPLODE ALL TREES IN HTA
9	(pediatric* or paediatric*) IN HTA
10	MeSH DESCRIPTOR YOUNG ADULT IN HTA
11	("young* adult*") IN HTA
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
13	MeSH DESCRIPTOR DISABLED PERSONS EXPLODE ALL TREES IN HTA
14	MeSH DESCRIPTOR MENTAL DISORDERS EXPLODE ALL TREES IN HTA
15	MeSH DESCRIPTOR COMMUNICATION DISORDERS EXPLODE ALL TREES IN HTA
16	MeSH DESCRIPTOR INTELLECTUAL DISABILITY EXPLODE ALL TREES IN HTA
17	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):TI IN HTA
18	((((sever* or complex* or special or high) adj3 need*))) IN HTA
19	#13 OR #14 OR #15 OR #16 OR #17 OR #18
20	#12 AND #19
21	MeSH DESCRIPTOR DISABLED CHILDREN IN HTA
22	(CSHCN) IN HTA
23	((("Education Health" adj2 "Care plan*"))) IN HTA
24	((("EHC plan*")) IN HTA
25	(EHCP*) IN HTA
26	#20 OR #21 OR #22 OR #23 OR #24 OR #25
27	((("communication aid*" or "communication system*" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan*" or "ready steady go toolkit*" or advocate or advocates or "patient-initiated appointment system*")) IN HTA
28	((((augmentativ* or alternativ*) adj3 communicat*)) IN HTA
29	((((shar* adj3 decision* adj3 mak*))) IN HTA
30	((((person* or patient*) adj3 (centre* or center*) adj3 (plan* or care*))) IN HTA
31	((((peer* adj3 support*)) IN HTA
32	((((self adj3 manag*)) IN HTA
33	#27 OR #28 OR #29 OR #30 OR #31 OR #32
34	#26 AND #33

1

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

5 **Date of last search: 12/03/2020**

#	Searches
1	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?")
2	TI(disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR ((sever* OR complex* OR special OR high) NEAR/3 need?) OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?)
3	AB, TI((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?))
4	TI(interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "coordinat* care" OR partnership? OR partnering OR network*)
5	TI(((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))
6	AB, TI("communication aid?" or "augmentative and alternative communication" or "communication system?" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan?" or "shared decision? making" or "person centred plan*" or "peer support" or "ready steady go toolkit?" or advocate or advocates or "self manag*" or "patient-initiated appointment system?")
7	1 AND 2 AND 3 AND 6 Additional limits - Date: From January 2000 to March 2020
8	1 AND 2 AND 4 AND 6 Additional limits - Date: From January 2000 to March 2020
9	1 AND 2 AND 5 AND 6 Additional limits - Date: From January 2000 to March 2020
10	7 OR 8 OR 9

6

7 **Database: British Education Index**

8 **Date of last search: 12/03/2020**

#	Searches
1	TX ("communication aid?" or "augmentative and alternative communication" or "communication system?" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan?" or "shared decision? making" or "person centred plan*" or "peer support" or "ready steady go toolkit?" or advocate or advocates or "self manag*" or "patient-initiated appointment system?") 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 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 TX (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "care co-ordinat*" OR "coordinat* care" OR "coordinat* care" OR partnership? OR partnering OR network*) Limiters - Publication Date: 20000101-20200331
2	TX ("communication aid?" or "augmentative and alternative communication" or "communication system?" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan?" or "shared decision? making" or "person centred plan*" or "peer support" or "ready steady go toolkit?" or advocate or advocates or "self manag*" or "patient-initiated appointment system?") 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 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 TX (((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?"

#	Searches
	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: 20000101-20200331
3	1 or 2

1

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

4 Date of last search: 12/03/2020

#	Searches
1	TX ("communication aid?" or "augmentative and alternative communication" or "communication system?" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan?" or "shared decision? making" or "person centred plan*" or "peer support" or "ready steady go toolkit?" or advocate or advocates or "self manag*" or "patient-initiated appointment system?") 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 multiseector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "care co-ordinat*" OR "coordinat* care" OR "coordinat* care" OR partnership? OR partnering OR network*) Limiters - Publication Date: 2000- 2020
2	TX ("communication aid?" or "augmentative and alternative communication" or "communication system?" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan?" or "shared decision? making" or "person centred plan*" or "peer support" or "ready steady go toolkit?" or advocate or advocates or "self manag*" or "patient-initiated appointment system?") AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunct* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))) Limiters - Publication Date: 2000- 2020
3	1 or 2

5

6 Database: Social Sciences Citation Index (SSCI)

7 Date of last search: 12/03/2020

#	Searches
# 1	TOPIC: ((adolescen* or teen* or youth* or young or juvenile\$ or minors or highschool*)) Indexes=SSCI Timespan=2000-2020
# 2	TOPIC: ((child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid\$ or kindergar* or boy\$ or girl\$)) Indexes=SSCI Timespan=2000-2020
# 3	TOPIC: ((infan* or neonat* or newborn* or baby or babies)) Indexes=SSCI Timespan=2000-2020
# 4	TOPIC: (p#ediatric*) Indexes=SSCI Timespan=2000-2020
# 5	TOPIC: ("young* adult\$") Indexes=SSCI Timespan=2000-2020
# 6	#5 OR #4 OR #3 OR #2 OR #1 Indexes=SSCI Timespan=2000-2020
# 7	TITLE: ((disable\$ or disabilit* or handicap* or retard* or disorder\$ or impair* or condition\$ or difficulty or difficulties or deficit\$ or dysfunct*)) Indexes=SSCI Timespan=2000-2020
# 8	TOPIC: (((sever* or complex* or special or high) near/3 need\$)) Indexes=SSCI Timespan=2000-2020
# 9	TOPIC: (SHCN) Indexes=SSCI Timespan=2000-2020
# 10	#9 OR #8 OR #7 Indexes=SSCI Timespan=2000-2020
# 11	#10 AND #6 Indexes=SSCI Timespan=2000-2020
# 12	TOPIC: (CSHCN) Indexes=SSCI Timespan=2000-2020

#	Searches
# 13	TOPIC: ("Education Health and Care plan\$") Indexes=SSCI Timespan=2000-2020
# 14	TOPIC: ("EHC plan\$") Indexes=SSCI Timespan=2000-2020
# 15	TOPIC: (EHCP\$) Indexes=SSCI Timespan=2000-2020
# 16	#15 OR #14 OR #13 OR #12 OR #11 Indexes=SSCI Timespan=2000-2020
# 17	TOPIC: (((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/5 social)) Indexes=SSCI Timespan=2000-2020
# 18	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)) Indexes=SSCI Timespan=2000-2020
# 19	TOPIC: (((social near/5 (education or educating or educator or educators or school or schools or teach or teaching or teachers))) Indexes=SSCI Timespan=2000-2020
# 20	#19 OR #18 OR #17 Indexes=SSCI Timespan=2000-2020
# 21	TOPIC: (((inter* OR multi* OR collaborat* OR coordinat* OR co-ordinat* OR cooperat* OR co-operat* OR integrat* OR partner* OR service OR practice OR care) NEAR/3 model\$)) Indexes=SSCI Timespan=2000-2020
# 22	TOPIC: ("communication aid\$" or "augmentative and alternative communication" or "communication system\$" or "interpretive technolog*" or "assistive technolog*" or signing or "play therapy" or "shared care plan\$" or "shared decision\$ making" or "person centred plan*" or "peer support" or "ready steady go toolkit\$" or advocate or advocates or "self manag*" or "patient-initiated appointment system\$") Indexes=SSCI Timespan=2000-2020
# 23	#22 OR #21 Indexes=SSCI Timespan=2000-2020
# 24	#23 AND #22 AND #16 Indexes=SSCI Timespan=2000-2020

1

2 Database: Social Care Online

3 Date of last search: 12/03/2020

#	Searches
	AND All fields:'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 All fields:'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 All fields: "communication aid" or "augmentative and alternative communication" or "communication system" or "interpretive technology" or "assistive technology" or signing or "play therapy" or "shared care plan" or "shared decision making" or "person centred planning" or "peer support" or "ready steady go toolkit" or advocate or "self manage" or "patient-initiated appointment systems"
	AND PublicationYear:'2000 2020'

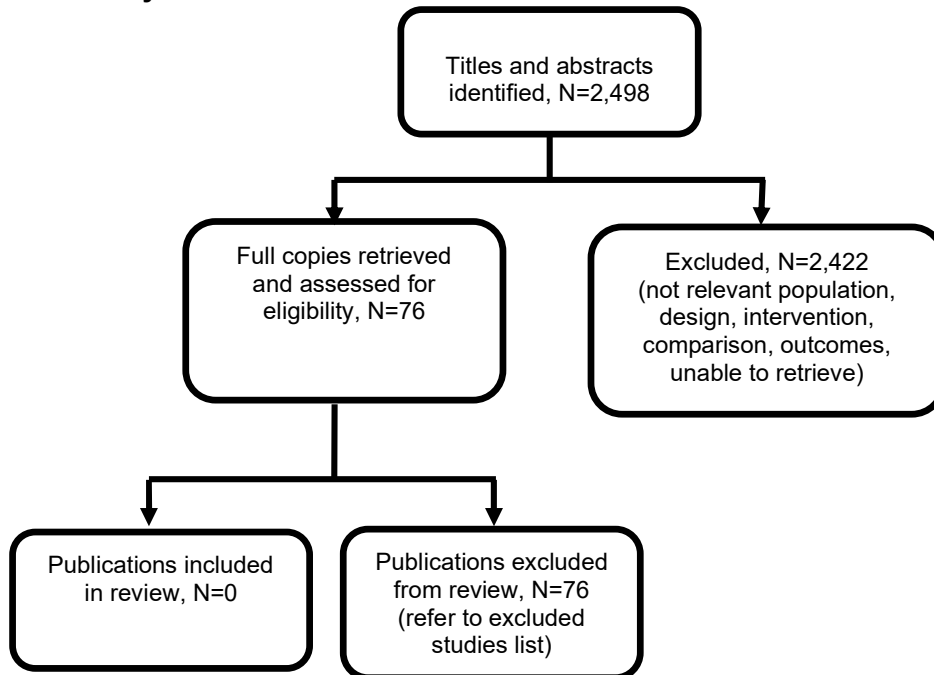
4

5

1 Appendix C – Effectiveness evidence study selection

2 Study selection for review question: What are the most effective practices (for
3 example, communication and information management) to enable health,
4 social care and education services to work together to involve disabled
5 children and young people with severe complex needs in understanding,
6 planning and reviewing their health, social care and education?

7 Figure 1: Study selection flow chart



8

9

10

1 **Appendix D –Effectiveness evidence**

2 **Evidence tables for review question: What are the most effective practices (for example, communication and information**
3 **management) to enable health, social care and education services to work together to involve disabled children and**
4 **young people with severe complex needs in understanding, planning and reviewing their health, social care and**
5 **education?**

6 No evidence was identified which was applicable to this review question.
7

8 **Appendix E – Forest plots**

- 9 **Forest plots for review question: What are the most effective practices (for**
10 **example, communication and information management) to enable health,**
11 **social care and education services to work together to involve disabled**
12 **children and young people with severe complex needs in understanding,**
13 **planning and reviewing their health, social care and education?**
- 14 No evidence was identified which was applicable to this review question.

1 **Appendix F – GRADE tables**

- 2 **GRADE tables for review question: What are the most effective practices (for example, communication and information**
- 3 **management) to enable health, social care and education services to work together to involve disabled children and**
- 4 **young people with severe complex needs in understanding, planning and reviewing their health, social care and**
- 5 **education?**
- 6 No evidence was identified which was applicable to this review question.

1 **Appendix G – Economic evidence study selection**

- 2 **Economic evidence study selection for review question: What are the most**
- 3 **effective practices (for example, communication and information management)**
- 4 **to enable health, social care and education services to work together to involve**
- 5 **disabled children and young people with severe complex needs in**
- 6 **understanding, planning and reviewing their health, social care and education?**
- 7 One global search was undertaken – please see Supplement B for details on study selection.

1 **Appendix H – Economic evidence tables**

2 **Economic evidence tables for review question: What are the most effective**
3 **practices (for example, communication and information management) to**
4 **enable health, social care and education services to work together to involve**
5 **disabled children and young people with severe complex needs in**
6 **understanding, planning and reviewing their health, social care and education?**

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

8

9 **Appendix I – Economic model**

10 **Economic model for review question: What are the most effective practices (for**
11 **example, communication and information management) to enable health,**
12 **social care and education services to work together to involve disabled**
13 **children and young people with severe complex needs in understanding,**
14 **planning and reviewing their health, social care and education?**

15 No economic analysis was conducted for this review question.

16

1 Appendix J – Excluded studies

2 **Excluded studies for review question: What are the most effective practices (for**
 3 **example, communication and information management) to enable health,**
 4 **social care and education services to work together to involve disabled**
 5 **children and young people with severe complex needs in understanding,**
 6 **planning and reviewing their health, social care and education?**

7 Effectiveness studies

8 **Table 3: Excluded studies and reasons for their exclusion**

Study	Reason for Exclusion
Aldiss, S., Baggott, C., Gibson, F., Mobbs, S., Taylor, R. M., A Critical Review of the Use of Technology to Provide Psychosocial Support for Children and Young People with Long-Term Conditions, <i>Journal of Pediatric Nursing-Nursing Care of Children & Families</i> , 30, 87-101, 2015	Population: Children and adolescents with long-term conditions. Primarily health conditions that are unlikely to have needs in all three areas (for example asthma)
Alwell, M., Cobb, B., Social/communicative interventions and transition outcomes for youth with disabilities: a systematic review, 1-58, 2007	Publication type: Abstract only
Alzrayer, Nouf M., Banda, Devender R., Koul, Rajinder K., The Effects of Systematic Instruction in Teaching Multistep Social-Communication Skills to Children with Autism Spectrum Disorder Using an iPad, <i>Developmental Neurorehabilitation</i> , 22, 415-429, 2019	Study design: Single-subject experimental design
Bee, Penny, Pedley, Rebecca, Rithalia, Amber, Richardson, Gerry, Prymachuk, Steven, Kirk, Susan, Bower, Peter, Self-care support for children and adolescents with long-term conditions : the REFOCUS evidence synthesis, <i>Health Services and Delivery Research</i> , 6, 2018	Population: Children and adolescents with long-term conditions. Primarily health conditions that are unlikely to have needs in all three areas (for example asthma)
Biggs, E. E., Carter, E. W., Gilson, C. B., Systematic Review of Interventions Involving Aided AAC Modeling for Children With Complex Communication Needs, <i>Ajidd-American Journal on Intellectual and Developmental Disabilities</i> , 123, 443-473, 2018	Study design and outcomes: Mainly non-comparative studies and lack of relevant outcomes reported
Brown Helen, et al., What works in the delivery of independent support? Final report from the national evaluation of the Independent Support Programme 2014 - 2016, 93, 2017	Study design and outcomes: Mainly qualitative results presented. No comparative quantitative data
Bruce, Susan M., Bashinski, Susan M., The Trifocus Framework and Interprofessional Collaborative Practice in Severe Disabilities, <i>American Journal of Speech-Language Pathology</i> , 26, 162-180, 2017	Publication type: Narrative review
Bruns, Eric J., Hook, Alyssa N., Parker, Elizabeth M., Esposito, Isabella, Sather, April, Parigoris, Ryan M., Lyon, Aaron R., Hyde, Kelly L., Accurso, Attkisson Bangor Bardach Boonstra Brooke Bruns Cellucci Chafouleas Chase Chaudhry Cherry Chiu Chorpita Cifuentes	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
Cohen Cook Cowie Curran Dorsey Elias Fleming Fortney Francis Goodman Hanson Holroyd-Leduc Horvath Hsiao Jensen Jensen-Doss King Kobus Larrison Lau Lawlor Lowes Lutterman Lyon Martens Matiz Matthews McGeorge McGregor Mohr Nguyen Ose Peres Persons Powell Pullmann Raudenbush Reimers Ruud Sakata Sather Sauro Schurer Coldiron Ser Strating Walker Weiskopf, Impact of a web-based electronic health record on behavioral health service delivery for children and adolescents: Randomized controlled trial, Journal of Medical Internet Research, 20, 2018	
Carlson, Barbara Lepidus, Foster, Leslie, Dale, Stacy B., Brown, Randall, Effects of Cash and Counseling on personal care and well-being, Health services research, 42, 467-87, 2007	Insufficient presentation of results
Carr, M. E., Self-management of Challenging Behaviours Associated with Autism Spectrum Disorder: A Meta-Analysis, Australian Psychologist, 51, 316-333, 2016	Study design and outcomes: Includes single-subject studies only. Effectiveness data not synthesised across studies
Croke, Erin E., Thompson, Ashleigh B., Person centered planning in a transition program for Bronx youth with disabilities, Children and Youth Services Review, 33, 810-819, 2011	Study design and outcomes: No relevant comparative data reported
Dale, Stacy B., Brown, Randall S., How does Cash and Counseling affect costs?, Health Services Research, 42, 488-509, 2007	Outcomes: No relevant outcomes reported
de Bruin, C. L., Deppeler, J. M., Moore, D. W., Diamond, N. T., Public School-Based Interventions for Adolescents and Young Adults With an Autism Spectrum Disorder: A Meta-Analysis, Review of Educational Research, 83, 521-550, 2013	Outcomes and intervention: No relevant outcomes reported and interventions delivered within education setting only
Doty, Pamela, Mahoney, Kevin J., Simon-Rusinowitz, Lori, Designing the Cash and Counseling Demonstration and Evaluation, Health Services Research, 42, 378-96, 2007	Publication type: Overview of service delivery model development and evaluation. No data on effectiveness
Drager, K., Light, J., McNaughton, D., Effects of AAC interventions on communication and language for young children with complex communication needs, Journal of Pediatric Rehabilitation Medicine, 3, 303-310, 2010	Publication type: Narrative review
Fernandez, Herminia Guimaraes Couto, Moreira, Martha Cristina Nunes, Gomes, Romeu, Making decisions on health care for children / adolescents with complex chronic conditions: a review of the literature, Tomando decisoes na atencao a saude de criancas/adolescentes com condicoes cronicas complexas: uma revisao da literatura., 24, 2279-2292, 2019	Study design and outcomes: Primarily qualitative studies included. No effectiveness data is presented
Ganz, J. B., Earles-Vollrath, T. L., Heath, A. K., Parker, R. I., Rispoli, M. J., Duran, J. B., A meta-analysis of single case research studies on aided augmentative and alternative communication systems with individuals with	Outcomes: No relevant outcomes reported

Study	Reason for Exclusion
autism spectrum disorders, <i>Journal of Autism and Developmental Disorders</i> , 42, 60-74, 2012	
Gaona, Carolina, Castro, Susana, Palikara, Olympia, The views and aspirations of young people with autism spectrum disorders and their provision in the new Education Health and Care plans in England, <i>Disability and Rehabilitation</i> , 1-12, 2019	Study design: Qualitative
Garboden, Molly, We've got a plan, <i>COMMUNITY CARE</i> , 22-23, 2009	Publication type: Magazine article
Gibson, Barbara E., King, Gillian, Teachman, Gail, Mistry, Bhavnita, Hamdani, Yani, Assembling activity/setting participation with disabled young people, <i>Sociology of health & illness</i> , 39, 497-512, 2017	Study design: Qualitative
Gilroy, S. P., McCleery, J. P., Leader, G., Systematic Review of Methods for Teaching Social and Communicative Behavior with High-Tech Augmentative and Alternative Communication Modalities, <i>Review Journal of Autism and Developmental Disorders</i> , 4, 307-320, 2017	Outcomes: No relevant outcomes reported
Gomaa, W., Robaey, P., Pajer, K., Gardner, W., McCann, M., Mental health integration in primary care: Preliminary results from an ADHD programme in a family health team, <i>ADHD Attention Deficit and Hyperactivity Disorders</i> , 9, S36-S37, 2017	Publication type: Conference abstract
Great Britain Department of Health, Person centred planning: advice for using person-centred thinking, planning and reviews in schools and transition, 33p., 2010	Publication type: Guidance and examples of good practice. No data on effectiveness
Great Britain Office for Disability Issues, How independent advocates can help disabled people: easy read summary, 15p., 2011	Publication type: Easy read summary of advocacy research. No data on effectiveness
Hackett, Janine, et, al, Friends united: an evaluation of an innovative residential self-management programme in adolescent rheumatology, <i>British Journal of Occupational Therapy</i> , 68, 567-573, 2005	Outcomes: No relevant outcomes reported
Hamshire, C., Phillips, J., Palin, H., Hewitt, A., Whittle, H., Bridging the digital divide: Empowering learning and communication with iPads, <i>Physiotherapy (United Kingdom)</i> , 101, eS516-eS517, 2015	Publication type: Conference abstract
Harris, Nicola, Beringer, Antonia, Fletcher, Margaret, Families' priorities in life-limiting illness: improving quality with online empowerment, <i>Archives of disease in childhood</i> , 101, 247-52, 2016	Intervention: Tool used by parents/carers of CYP, not CYP themselves
Hewson, S., Mecija, M., Cordeiro, D., Nagy, L., A multidisciplinary approach to the transition of adolescents with a urea cycle disorder from a paediatric to an adult health care centre, <i>Journal of Inherited Metabolic Disease</i> , 36, S139, 2013	Publication type: Conference abstract
Hooton, Julie, Westaway, Anna, Booth, Clark	Study design and outcomes: Non-comparative.

Study	Reason for Exclusion
Kirkbride Mitchell Morris Murphy Rabiee, The voice of the child with Down syndrome, Down Syndrome: Research & Practice, 12, 179-183, 2009	No data on effectiveness
In, Control, Report on the use of the Personal Outcomes Evaluation Tool (POET) for children with education health and care plans, 82, 2016	Study design and outcomes: Survey with limited comparative data. Comparative data of interest is not reported in sufficient detail for analysis
Jager, Margot, Reijneveld, Sijmen A., Almansa, Josue, Metselaar, Janneke, Knorth, Erik J., De Winter, Andrea F., Less reduction of psychosocial problems among adolescents with unmet communication needs, European Child & Adolescent Psychiatry, 26, 403-412, 2017	Population: Adolescents with emotional and behavioural problems receiving social or mental health care. Unclear if they have needs in all three areas
Jarvikoski, Aila, Martin, Marjatta, Autti-Ramo, Ilona, Harkapaa, Kristiina, Shared agency and collaboration between the family and professionals in medical rehabilitation of children with severe disabilities, International journal of rehabilitation research. Internationale Zeitschrift fur Rehabilitationsforschung. Revue internationale de recherches de readaptation, 36, 30-7, 2013	Study design and outcomes: No relevant comparative data reported
Kaehne, A., Beyer, S., Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability, Journal of Intellectual Disability Research, 58, 603-13, 2014	Study design: Non-comparative
Kids., Communicating with disabled children and young people: PIP briefing, 12p., 2011	Publication type: Overview of barriers to communication and approaches to support communication. No data on effectiveness
Kirk,S., Beatty,S., Callery,P., Gellatly,J., Milnes,L., Prymachuk,S., The effectiveness of self-care support interventions for children and young people with long-term conditions: a systematic review, Child: Care, Health and Development, 39, 305-324, 2013	Population: Children and adolescents with long-term conditions. Primarily health conditions that are unlikely to have needs in all three areas (for example asthma)
Koyama, Takanori, Wang, Hui-Ting, Use of Activity Schedule to Promote Independent Performance of Individuals with Autism and Other Intellectual Disabilities: A Review, Research in Developmental Disabilities: A Multidisciplinary Journal, 32, 2235-2242, 2011	Analysis: No synthesis of effectiveness data
Kranz, Ashley M., Dalton, Sarah, Damberg, Cheryl, Timbie, Justin W., Using Health IT to Coordinate Care and Improve Quality in Safety-Net Clinics, Joint Commission Journal on Quality and Patient Safety, 44, 731-740, 2018	Study design and outcomes: No relevant comparative data
Krause, Christina M., Jones, Christopher S., Joyce, Stephen, Kuhn, Maria E. J., Curtin, Karen, Murphy, Lee P., Krause, Chad M. J., Boan, Brandi, Lucas, Donald R., The impact of a multidisciplinary, integrated approach on improving the health and quality of care for individuals dealing with multiple chronic conditions, The American journal of orthopsychiatry, 76, 109-14, 2006	Population: Adults with chronic illnesses (mean age 52)
Kreider, C. M., Medina, S., Lan, M. F., Wu, C.	Population: Young adults with learning

Study	Reason for Exclusion
Y., Percival, S. S., Byrd, C. E., Delislie, A., Schoenfelder, D., Mann, W. C., Beyond Academics: A Model for Simultaneously Advancing Campus-Based Supports for Learning Disabilities, STEM Students' Skills for Self-Regulation, and Mentors' Knowledge for Co-regulating and Guiding, <i>Frontiers in Psychology</i> , 9, 2018	difficulties – not severe complex needs
Krupa, Terry, Carter, Glenda, Enabling careers, autonomy, and prosperity: using community organizing and building approaches to improve the educational outcomes of people with mental illness, <i>Work (Reading, Mass.)</i> , 43, 105-12, 2012	Publication type: Overview of project. No data on effectiveness
Lee, H., Schepp, K. G., Lessons learned from research with adolescents with schizophrenia and their families, <i>Archives of Psychiatric Nursing</i> , 27, 198-203, 2013	Outcomes: Lessons learnt and implications for future research. No data on effectiveness
Lee, S. H., Simpson, R. L., Shogren, K. A., Effects and implications of self-management for students with autism: a meta-analysis, <i>Focus on Autism and Other Developmental Disabilities</i> , 22, 2-13, 2007	Outcomes and analysis: Limited relevant outcomes reported and synthesis of effectiveness data is not sufficient for analysis
Lennox, N. G., Rey-Conde, T. F., Faint, S. L., A pilot of interventions to improve health care in adolescents with intellectual disability, <i>Journal of Applied Research in Intellectual Disabilities</i> , 21, 484-489, 2008	Study design: Non-comparative
Lennox, Nicholas, Ware, Robert, Carrington, Suzanne, O'Callaghan, Michael, Williams, Gail, McPherson, Lyn, Bain, Chris, Ask: a health advocacy program for adolescents with an intellectual disability: a cluster randomised controlled trial, <i>BMC public health</i> , 12, 750, 2012	Publication type and outcomes: Overview of study design, adherence and response rates. No data on effectiveness
Leo, F., Cocchi, E., Brayda, L., The Effect of Programmable Tactile Displays on Spatial Learning Skills in Children and Adolescents of Different Visual Disability, <i>Ieee Transactions on Neural Systems and Rehabilitation Engineering</i> , 25, 861-872, 2017	Population: CYP with visual impairment only
Liao, Y. T., Hwang, A. W., Liao, H. F., Granlund, M., Kang, L. J., Understanding the Participation in Home, School, and Community Activities Reported by Children with Disabilities and Their Parents: A Pilot Study, <i>International Journal of Environmental Research and Public Health</i> , 16, 2019	Non-OECD country: Taiwan
Lindsay, S., Kingsnorth, S., McDougall, C., Keating, H., A systematic review of self-management interventions for children and youth with physical disabilities, <i>Disability and Rehabilitation</i> , 36, 276-288, 2014	Analysis: No synthesis of effectiveness data
Malone, Helen, Biggar, Susan, Javadpour, Sheila, Edworthy, Zai, Sheaf, Greg, Coyne, Imelda, Interventions for promoting participation in shared decision-making for children and adolescents with cystic fibrosis, <i>The Cochrane</i>	Outcomes: Review did not identify any studies for inclusion

Study	Reason for Exclusion
database of systematic reviews, 5, CD012578, 2019	
McAllister, J. W., Keehn, R. M., Rodgers, R., Mpofu, P. B., Monahan, P. O., Lock, T. M., Effects of a care coordination intervention with children with neurodevelopmental disabilities and their families, <i>Journal of Developmental and Behavioral Pediatrics</i> , 39, 471-480, 2018	Intervention: Intervention appears to be targeting the families of CYP, not CYP themselves
McAllister, Jeanne Walker, Keehn, Rebecca McNally, Rodgers, Rylin, Lock, Thomas M., Care Coordination Using a Shared Plan of Care Approach: From Model to Practice, <i>Journal of pediatric nursing</i> , 43, 88-96, 2018	Intervention and outcomes: Intervention appears to be targeting the families of CYP, not CYP themselves. No data on effectiveness
McNeilly, Patricia, Macdonald, Geraldine, Kelly, Berni, Alderson, Alderson Allen Archard Avis Badger Bazeley Bennett Burstein Cavet Clark Connors Coyne Dahlberg Deatrick Fielding Fitzgerald Foley Fortin Franklin Fraser Gallagher Garth Graham Greco Hart Haydon Honneth Huang Hyde Kelly Kilkelly Kirby Lansdown Lawrence Lewis Lundy MacArthur Mannion Martin McLaughlin McNeish Mitchell Moore Murray Parkes Pilnick Price Rabiee Read Redmond Resch Saldana Shier Singh Slade Taylor Thomas Treseder Turner Winter Woolfson Wright, The participation of disabled children and young people: A social justice perspective, <i>Special Issue: Valuing Disabled Children: Participation and Inclusion.</i> , 21, 266-286, 2015	Study design and outcomes: Mainly qualitative results presented. No comparative quantitative data
Murray, R., Sixth Sense: The Disabled Children and Young People's Participation Project, <i>Children and Society</i> , 26, 262-267, 2012	Publication type: Overview of project. No data on effectiveness
Murray, Rosemary, Carpenter, Duffy Franklin Hart Kelly Leeson Murray Wright, "Yes they are listening but do they hear us?" Reflections on the journey of the Barnardo's Participation Project, <i>Child Care in Practice</i> , 21, 78-90, 2015	Publication type: Overview of project and benefits and challenges of involving disabled CYP
Niemi, A. K., Cox, R., Platt, J., Wayman, K., Mark, J., Enns, G. M., Mitochondrial complex care clinic model-empowering families as part of the care team, <i>Molecular Genetics and Metabolism</i> , 111, 254, 2014	Publication type: Conference abstract
Nightingale, Ruth, McHugh, Gretl, Kirk, Susan, Swallow, Veronica, Supporting children and young people to assume responsibility from their parents for the self-management of their long-term condition: An integrative review, <i>Child: care, health and development</i> , 45, 175-188, 2019	Study design and population: Primarily qualitative studies included and health conditions that are unlikely to have needs in all three areas (for example asthma)
Pearlman, Sara, Michaels, Dina, Hearing the voice of children and young people with a learning disability during the Educational Health Care Plan (EHCP), <i>Support for Learning</i> , 34, 148-161, 2019	Study design: Non-comparative
Potvin, M. C., Prelock, P. A., Savard, L., Supporting Children with Autism and Their	Publication type: Overview of model and case examples

Study	Reason for Exclusion
Families: A Culturally Responsive Family-Driven Interprofessional Process, Pediatric Clinics of North America, 65, 47-57, 2018	
Reed, Mary E., Huang, Jie, Millman, Andrea, Graetz, Ilana, Hsu, John, Brand, Richard, Ballard, Dustin W., Grant, Richard, Portal Use Among Patients With Chronic Conditions: Patient-reported Care Experiences, Medical Care, 57, 809-814, 2019	Population: Adults with chronic conditions
Sandjojo, Janice, Zedlitz, Aglaia M. E. E., Gebhardt, Winifred A., Hoekman, Joop, Haan, Jeanet A., Evers, Andrea W. M., Effects of a self management training for people with intellectual disabilities, Journal of Applied Research in Intellectual Disabilities, 32, 390-400, 2019	Population: Adults with intellectual disabilities (mean age 36)
Sattoe, J. N. T., Bal, M. I., Roelofs, Pddm, Bal, R., Miedema, H. S., van Staa, A., Self-management interventions for young people with chronic conditions: A systematic overview, Patient Education and Counseling, 98, 704-715, 2015	Population: Young people with chronic conditions. Primarily health conditions that are unlikely to have needs in all three areas (for example asthma)
Saturno, C. E., Ramirez, A. R. G., Conte, M. J., Farhat, M., Piucco, E. C., An augmentative and alternative communication tool for children and adolescents with cerebral palsy, Behaviour and Information Technology, 34, 632-645, 2015	Publication type/study design: Narrative review, tool development and single-subject experimental design
Saxby, N., Beggs, S., Battersby, M., Lawn, S., What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A systematic review, Patient Education and Counseling, 102, 607-622, 2019	Analysis and population: No quantitative synthesis of effectiveness data. Includes conditions that are unlikely to have needs in all three areas (for example asthma)
Schore, Jennifer, Foster, Leslie, Phillips, Barbara, Consumer enrollment and experiences in the Cash and Counseling program, Health services research, 42, 446-66, 2007	Study design: Non-comparative
Siller, Michael, Reyes, Nuri, Hotez, Emily, Hutman, Ted, Sigman, Marian, Longitudinal change in the use of services in autism spectrum disorder: Understanding the role of child characteristics, family demographics, and parent cognitions, Autism: The International Journal of Research & Practice, 18, 433-446, 2014	Intervention: Intends to promote parents' ability to participate in planning, not CYP involvement
Sloper, P., Lightfoot, J., Involving disabled and chronically ill children and young people in health service development, Child: Care, Health & Development, 29, 15-20, 2003	Publication type and outcomes: Overview of initiatives to involve CYP in service development. No relevant outcomes reported
Social Policy Research, Unit, Care coordination and key worker services for disabled children in the UK, 4p., 2004	Study design and outcomes: Survey with no comparative data
Southall, Candice M., Gast, David L., Agran, Agran Apple Barry Billingsly Campbell Cole Cooper Coyle Delano Embregts Ferguson Ganz Gast Happe Heflin Hughes Kanner Kern Koegel	Analysis: No synthesis of effectiveness data

Study	Reason for Exclusion
Lee Loftin Macintosh Mancina Morrison Mruzek Myles Newman Ozonoff Palmen Pierce Prater Reinecke Rimland Scheuermann Shabani Shapiro Strain Thede Todd Volkmar Wehmeyer Wilkinson Wing Witwer Wolery Wolf, Self-management procedures: A comparison across the autism spectrum, Education and Training in Autism and Developmental Disabilities, 46, 155-171, 2011	
Stille, Christopher J., Communication, comanagement, and collaborative care for children and youth with special healthcare needs, Pediatric annals, 38, 498-504, 2009	Publication type: Overview of models of communication, comanagement and collaborative care. No data on effectiveness
Taylor, Julie Lounds, Hodapp, Robert M., Burke, Meghan M., Waitz-kudla, Sydney N., Rabideau, Carol, Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial, Journal of Autism and Developmental Disorders, 47, 846-857, 2017	Interventions and outcomes: Intervention is aimed at parents, not CYP and outcomes reported are parental knowledge and empowerment
Trowbridge, Kelly, Mische-Lawson, Lisa, Families With Children With Medical Complexity and Self-Management of Care: A Systematic Review of the Literature, Social Work in Health Care, 53, 640-658, 2014	Interventions: Interventions are targeted at parents and health care system processes, not CYP
Van Dam, L., Neels, S., De Winter, M., Branje, S., Wijsbroek, S., Hutschemaekers, G., Dekker, A., Sekreve, A., Zwaanswijk, M., Wissink, I., Stams, G. J., Youth Initiated Mentors: Do They Offer an Alternative for Out-of-Home Placement in Youth Care?, British Journal of Social Work, 47, 1764-1780, 2017	Population and outcomes: Most common problems in youth were related to family and child rearing, most did not have problems with physical health, competences and cognitive development. No relevant outcomes reported
Vlaskamp, Carla, van der Putten, Annette, Focus on interaction: the use of an Individualized Support Program for persons with profound intellectual and multiple disabilities, Research in Developmental Disabilities, 30, 873-883, 2009	Population: People with profound intellectual and multiple disabilities aged 15 to 58 (mean age 37)
Watson, D., Abbott, D., Townsley, R., Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services, Child: care, health and development, 33, 90-5, 2007	Study design: Qualitative
Watson, Debbie, Tarleton, Beth, Feiler, Anthony, Participation in education (PIE): full report on the findings from research on the involvement of children with little or no verbal communication, 24p., 2006	Study design and outcomes: Descriptive survey. No comparative or effectiveness data
Wehmeyer, Michael L., et, al, Promoting self-determination and self-directed employment planning for young women with disabilities, Journal of Social Work in Disability and Rehabilitation, 8, 117-131, 2009	Publication type and outcomes: Overview of model and limited evaluation. No data on effectiveness
Wright, Amy Conley, Taylor, Sarah, Alper, Altshuler Babbie Bailey Balcazar Bandura Bennett Berlin Black Carr Coats Dempsey Dunst	Study design and outcomes: Survey with no comparative data

Study	Reason for Exclusion
Duquette Dye Glascoe Gupta Harry Hasenfeld Hess Kalyanpur Koren Lareau Leung Levine Linan-Thompson Lock Luthar Madden McCammon Miles Mlawer Murphey Nachshen Olsson Parish Rayner Resch Rivera Rosenberg Shevell Sices Singer Tervo Trainor Turnbull Vincent Wang Weimiao Weiss Zaretsky, Advocacy by parents of young children with special needs: Activities, processes, and perceived effectiveness, Journal of Social Service Research, 40, 591-605, 2014	

1 ADHD: attention deficit hyperactivity disorder; CYP: child or young person; OECD: Organisation for Economic Co-
2 operation and Development

3 Economic studies

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

1 Appendix K – Research recommendations – full details

2 **Research recommendations for review question: What are the most effective**
 3 **practices (for example, communication and information management) to**
 4 **enable health, social care and education services to work together to involve**
 5 **disabled children and young people with severe complex needs in**
 6 **understanding, planning and reviewing their health, social care and education?**

7 **Research recommendation**

8 What is the effectiveness of telehealth and virtual platforms for communication with disabled
 9 children and young people with severe complex needs and providing education, health and
 10 social care interventions?

11 **Why this is important**

12 There is a lack of evidence for the effectiveness of virtual platforms to facilitate participation
 13 of children and young people with severe complex needs in their care. Further research can
 14 inform healthcare, education and social care professionals in planning their use of face-to-
 15 face and virtual interventions.

16 **Rationale for research recommendation**

17 **Table 4: Research recommendation rationale**

Importance to the population	Access to face-to-face interventions between children and young people with severe complex needs and professionals can be compromised by a number of factors such as geographical distance or the recent COVID 19 pandemic. Telehealth and the use of virtual platforms is increasingly used for meetings and delivery of interventions. This research will inform planning and resourcing for local authorities (LAs) and Clinical commissioning groups (CCGs).
Relevance to NICE guidance	This evidence would be essential to inform future updates of recommendations in the current guideline to enable evidence-based recommendations and guidance about modes of intervention for children and young people aged 0 to 25 years with severe complex needs and SEND. Evidence-based recommendations would reduce variation in practice between local areas and potentially reduce inequalities in access to services. However, there may be inequalities in terms of access to technology so this should be measured.
Relevance to the NHS and education and social care services	This research would enable commissioners and health services to plan for high quality, value for money, outcome-focussed services that meet the needs of their population. It would provide an evidence-base around telehealth and virtual platforms to inform local planning and commissioning decisions in accordance with legislation.
National priorities	The NHS Long Term Plan aims to increase the range of digital health tools and services provided to give people more control over their own health

	and care and give people secure access to their own records and allow patients to book appointments online. There are a number of other areas in the NHS Long Term Plan that are applicable to children and young people with severe complex needs and special educational needs and disabilities, including personalised care. Telehealth and virtual platforms are ways in which care can be personalised.
Current evidence base	There was no evidence base about the effectiveness of telehealth and virtual platforms for delivering interventions and meeting the needs of the population of children and young people with severe complex needs.
Equality considerations	Age and disability are relevant to this population and are two of the protected characteristics covered by the Equality Act (2010). Telehealth and virtual platforms have the potential to reduce inequalities in access for those who may find it difficult to attend face-to-face appointments but there is also the potential for inequalities related to access to technology.

1 CCG: clinical commissioning group, LA: Local Authority; SEND: Special Education Needs and Disabilities

2 Modified PICO table

3 **Table 5: Research recommendation modified PICO table**

Population	Children and young people aged 0 to 25 years in England with severe complex needs and SEND
Intervention	Any telehealth or virtual platforms, such as: <ul style="list-style-type: none"> • Secure NHS platforms (e.g. Attend Anywhere or AccuRX) • Commercially available platforms (e.g. Microsoft TEAMS, Google Meet, Skype or Zoom)
Comparator	Traditional face-to-face delivery of meetings and interventions
Outcomes	<ul style="list-style-type: none"> • Satisfaction (child or young person) • Quality of life • Understanding of own health, social care and education needs • Involvement in planning and reviewing health, social care and education • Extent to which health, social care and educational needs are met • Timeliness of updates to assessment information and provision arrangements in EHC plans • Access to services: <ul style="list-style-type: none"> ○ Local availability (e.g., time/distance travelled to access services) ○ Waiting times for services ○ Access to technology and broadband ○ Availability of other professionals for multi-disciplinary meetings • Extent to which virtual platforms meet minimum and best practice standards (see the

	NICE (2018) evidence standards framework for digital health technologies <ul style="list-style-type: none"> • Integrated pathways and models of care • Cost-effectiveness/value for money
Study design	Retrospective or prospective trials, audits or service evaluations.
Timeframe	The NHS is currently funding digital transformation review/evaluations as a result of the increased application of digital platforms during the pandemic. Therefore, research should be conducted as soon as possible to inform this.
Additional information	None.

1
 2 EHC: education, health and care; NHS: National Health Service; PICO: population, intervention, comparison, outcome; SEND: Special Educational Needs and Disability