



**Health  
Information  
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An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# **The transition to, and organisation of, adult healthcare services for individuals with severe neurological impairment: protocol for a health technology assessment**

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Reporting to the Minister for Health and engaging with relevant government Ministers and departments, HIQA has responsibility for the following:

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Regulating social care services — The Chief Inspector of Social Services within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.

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## Table of contents

List of tables.....	4
<b>List of abbreviations used in this report .....</b>	<b>5</b>
<b>1 Introduction .....</b>	<b>6</b>
1.1 Background .....	6
1.2 Aims and objectives.....	8
1.3 Establishment of the Expert Advisory Group .....	9
<b>2 Service provision for individuals with SNI.....</b>	<b>10</b>
<b>3 Epidemiology and burden of disease .....</b>	<b>10</b>
<b>4 International overview and clinical effectiveness and safety.....</b>	<b>10</b>
4.1 Inclusion criteria .....	11
4.2 Search strategy and information sources.....	14
4.3 Study selection .....	15
4.4 Data extraction .....	15
4.5 Quality assessment .....	15
4.6 Data synthesis and analysis.....	15
<b>5 Economic evaluation.....</b>	<b>15</b>
<b>6 Organisational considerations .....</b>	<b>16</b>
<b>7 Ethical, legal, patient and social considerations .....</b>	<b>17</b>
<b>8 Dissemination .....</b>	<b>17</b>
<b>References .....</b>	<b>18</b>
<b>Appendix 1: Search strategy.....</b>	<b>20</b>

## List of tables

Table 1 Population, Intervention, Comparator, Outcomes and Study Design (PICOS) eligibility criteria for RQ1 and RQ2. ....	11
Table 2 Population, Intervention, Comparator, Outcomes and Study Design (PICOS) eligibility criteria for RQ3 and RQ4. ....	13
Table 3 Model characteristics for BIA.....	16

## List of abbreviations used in this report

<b>BIA</b>	budget impact analysis
<b>DoH</b>	Department of Health
<b>EAG</b>	expert advisory group
<b>EU</b>	European Union
<b>HIQA</b>	Health Information and Quality Authority
<b>HSE</b>	Health Service Executive (Ireland)
<b>HTA</b>	health technology assessment
<b>OECD</b>	Organisation for Economic Co-operation and Development
<b>PICOS</b>	Population, Intervention, Comparator, Outcomes, Study Design
<b>SNI</b>	severe neurological impairment
<b>WHO</b>	World Health Organization

# 1 Introduction

## 1.1 Background

Neurodisability is an umbrella term for a group of conditions associated with impairment of the brain and or neuromuscular system, leading to functional limitations. Included conditions range in severity and complexity, often affecting multiple areas of functioning.<sup>(1)</sup> Severe neurological impairment (SNI) represents a subset of neurodisability. The internationally developed definition of SNI is:

a group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment, and medical complexity, where much assistance is required with activities of daily living.<sup>(2)</sup>

SNI encompasses a wide range of conditions, many of which are rare and life-limiting and not typically managed in an adult healthcare setting. While most young people with neurodisability may be managed at community and ambulatory care level with sporadic utilisation of clinical specialty care, young people and adults with SNI typically require life-sustaining technology, more frequent clinical specialty care and continuous monitoring throughout their lives.<sup>(3)</sup> As a result, a higher level of coordination is required to meet their more complex and frequent care needs.

There are limited data on the paediatric prevalence of SNI, mainly based on administrative data from the US and Canada, suggesting less than 1% but potentially as low as 0.05%.<sup>(4)</sup> With improvements in treatment and management, children with life-limiting SNI conditions are more frequently surviving to adulthood. This has led to a higher prevalence of young adults presenting to adult healthcare services with complex and lifelong needs.<sup>(5)</sup> Consequently, there is a growing need to manage transition from paediatric to adult care and to facilitate training to support clinical knowledge in primary care settings. Paediatric neurodisability is the subspeciality focused on managing children affected by neurodisability conditions including SNI, although care typically involves input from health professionals across multiple disciplines.<sup>(1)</sup>

Available qualitative evidence suggests that transitions are often associated with negative experiences for young people living with a chronic condition and their caregivers, not only in the Irish healthcare system, but also worldwide.<sup>(6, 7)</sup> These findings are not specific to individuals with SNI. Moreover, the experience of those with SNI is poorly documented with limited research to support an understanding of how the transition process impacts patients' and caregivers' outcomes.<sup>(5)</sup> The current pathways of care for individuals with SNI during transition are not well characterised. There is insufficient knowledge about how these pathways operate in

practice or how they could be redesigned to ensure smoother transitions, and to improve outcomes and experiences.

Once in adult healthcare settings, young adults with SNI may struggle to have their needs met. Issues highlighted included fragmented care, insufficient training in holistic management of young adults with SNI, and systemic challenges (such as long waiting lists, workforce shortages, and geographic disparities in service provision).<sup>(5, 8-10)</sup> This may contribute to a negative impact on young adults' experiences and their health outcomes and increase the burden on their caregivers. Effective transition pathways and defined mechanisms for coordinated care could potentially improve the safety and quality of care, enhance patient outcomes, and support both patients and caregivers.<sup>(11)</sup>

The transition from child to adult healthcare services for young people with SNI is an inherent part of healthcare delivery, reflecting both developmental life stages and the structure of healthcare systems. To ensure a smooth transition process, patients and caregivers should be adequately informed and prepared in a timely manner, and healthcare services appropriately resourced. Preparedness involves raising awareness of how adult healthcare services are organised; this can help reduce anxiety and ultimately lead to the continuity of care.<sup>(12)</sup> Given that transition is intended as a planned, gradual process, it may be divided into key stages for the young person and their family, such as preparation, early transition, active transition, late transition and finally transfer to an adult service, with early transition planning potentially starting from age 12 years.<sup>(13)</sup> However, challenges arise in the context of young people with SNI due to the need for coordinated care across multiple services and specialities. In addition, transition has been identified as a critical point for individuals with chronic life-limiting conditions — particularly those with SNI — because of the increased risk of loss of contact with healthcare services. Loss of contact can lead to an aggravation of the condition and or the associated comorbidities.<sup>(14, 15)</sup> Moreover, the need to optimise planned care of people with neurodevelopmental disabilities — including the trajectories in healthcare — has been recognised as necessary to overcome the challenges these individuals face, and ultimately to avoid poorer quality care and inequalities in health outcomes.

The Health Service Executive (HSE) has developed a framework to guide the transition of children and young people from paediatric to adult healthcare services.<sup>(13)</sup> The framework acknowledges the need to support all young people with chronic conditions transitioning to adult healthcare services to achieve their life goals while remaining engaged within health and social care services and experiencing a positive and well-supported transition process. The framework also sets out standards for best transition practices for young people and caregivers for all

healthcare providers to adhere to.<sup>(13)</sup> While the framework is suitable for young people with chronic conditions that are mostly managed by a specific clinical speciality, individuals with SNI managed through paediatric neurodisability services do not have an equivalent speciality service in adult care. In addition, meeting the substantial care needs of individuals with SNI requires coordination not only across different settings, but also among healthcare professionals within the same setting.

The Department of Health (DoH) requested that HIQA conduct a health technology assessment (HTA) of the transition to, and organisation of, adult healthcare services for individuals with severe neurological impairment. The findings of this HTA will provide evidence-based advice to inform decision-making by the Minister of Health and the HSE.

This protocol outlines the proposed methodology for the HTA. The assessment will be carried out in line with the HIQA quality assurance framework for HTA.

## **1.2 Aims and objectives**

The aim of this HTA is to assess the clinical effectiveness, economic impact and organisational implications of models for the transition to, and organisation of, adult healthcare services for individuals with severe neurological impairment.

Considering specifically the population with SNI, the objectives of this HTA are to:

- describe the epidemiology and burden of disease in adults and in those preparing to transition to adult healthcare services (those aged 12 years and over)
- describe the current organisation of healthcare services, including how individuals transition from paediatric to adult healthcare within the Irish health system
- conduct an international review of national policies and guidelines on care coordination and the transition from paediatric to adult healthcare services
- assess the clinical effectiveness and safety of transition care models and models of care for adult healthcare services
- analyse the budget impact and resource implications of implementing an Irish transition of care model and organisation of care in adult healthcare services
- consider the organisational implications of implementing a transition of care model, and organisation of care for adult healthcare services, within the Irish healthcare system

- consider the ethical and social implications that introducing a transition of care model and coordinated adult healthcare services may have for patients, caregivers, the wider public and the Irish healthcare system
- based on the evidence in this assessment, provide advice to support a decision regarding the transition to and organisation of adult healthcare services for individuals with severe neurological impairment in Ireland.

### **1.3 Establishment of the Expert Advisory Group**

An appropriately represented Expert Advisory Group (EAG) will be convened as a source of expertise to inform the interpretation of the evidence and development of the advice to the HSE.

This group will comprise nominees from a range of stakeholder organisations, including patient representation, healthcare providers, and clinical, public health and methodological experts.

The terms of reference of the Expert Advisory Group (EAG) are to:

- contribute to the provision of high quality and considered advice by HIQA to the Minister for Health and the HSE
- contribute fully to the work, debate and decision-making processes of the group by providing expert guidance, as appropriate
- be prepared to provide expert advice on relevant issues outside of group meetings, as requested
- provide advice to HIQA regarding the scope of the analysis
- support the Evaluation Team led by HIQA during the assessment process by providing expert opinion and access to pertinent data, as appropriate
- review the project plan outline and advise on priorities, as required
- review the draft report from the Evaluation Team and recommend amendments, as appropriate
- contribute to HIQA's development of its approach to HTA by participating in an evaluation of the process on the conclusion of the assessment.

## **2 Service provision for individuals with SNI**

This chapter will describe how care is currently delivered for both young people and adults with SNI in primary and secondary clinical settings. It will also outline the current pathways for transitioning from paediatric to adult healthcare services for individuals with SNI within Ireland's publicly funded healthcare system. This chapter will focus on healthcare services, rather than community or social care services. Healthcare encompasses medical services provided by hospital consultants, specialised clinics, and general practitioners. While HIQA acknowledges that a considerable amount of care is provided in both community and social care settings for patients with SNI, it is beyond the scope of this HTA to consider the transition to, and organisation of, such services.

## **3 Epidemiology and burden of disease**

In this chapter, key definitions in relation to SNI will be provided, clinical characteristics described, and Irish epidemiologic measures will be estimated. An overview of the main conditions within this group will be outlined. The number of individuals transitioning annually and the potential new adult population requiring care within the publicly-funded system in Ireland will be estimated.

Bearing in mind the wide range of conditions that may be associated with SNI, the lifetime burden of disease for individuals will be explored. The burden on caregivers will also be included. This chapter will be informed by a review of both international literature and Irish data sources, where available.

## **4 International overview and clinical effectiveness and safety**

A literature review of international public health policy documents and research publications will be conducted based on a selected list of Organisation for Economic Co-operation and Development (OECD) countries. The transition of care and organisational pathways for delivering care in adult healthcare services to adults with SNI will be reviewed and described. Eight OECD countries (Australia, Canada, England, France, Germany, Scotland, Sweden, and the Netherlands) were selected because they share broadly comparable principles of universal or publicly funded healthcare, multidisciplinary paediatric neurodisability provision, and policy-level attention to transition and adult healthcare service organisation. Other countries may also be considered for inclusion based on the references retrieved during the systematic review of clinical effectiveness and safety.

Four research questions (RQ) have been formulated for the systematic reviews to establish the clinical effectiveness and safety of both models of care for adults with SNI and for those with SNI transitioning from paediatric to adult healthcare services.

- RQ1. What is the effectiveness and safety of interventions designed to improve the transition of individuals with SNI from paediatric to adult healthcare services?
- RQ2. What are the experiences of individuals with SNI, their families and carers of transition interventions from paediatric to adult healthcare services?
- RQ3. What is the effectiveness and safety of models of care for adults with SNI?
- RQ4. For patients and their families and or carers, what is the experience of models of care for adults with SNI?

A mixed-methods review will be conducted with a convergent segregated approach. The convergent segregated approach consists of conducting separate quantitative synthesis and qualitative synthesis, followed by integration of evidence derived from both syntheses.<sup>(16)</sup>

## 4.1 Inclusion criteria

The eligibility criteria for inclusion in the review were formulated according to the Population, Intervention, Comparator, Outcomes and Study Design (PICOS) framework. Table 1 outlines the eligibility criteria for RQ1 and RQ2. Table 2 outlines the eligibility criteria for RQ3 and RQ4.

**Table 1 Population, Intervention, Comparator, Outcomes and Study Design (PICOS) eligibility criteria for RQ1 and RQ2.**

<b>Population</b>	<p><b>Included:</b></p> <ul style="list-style-type: none"> <li>▪ children and young people with SNI using paediatric healthcare services who are preparing for, undergoing, or have completed transition into adults' health care services</li> <li>▪ families and carers of young people who are preparing for, undergoing, or have completed transition.</li> </ul> <p><b>Excluded:</b></p> <ul style="list-style-type: none"> <li>▪ children and young people with SNI who are not using paediatric healthcare services</li> <li>▪ young people entering into adult healthcare services who were not previously using paediatric healthcare services.</li> </ul>
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<b>Intervention</b>	<p><b>Included:</b></p> <ul style="list-style-type: none"> <li>▪ any structured transition model, programme or specific intervention directed at improving the transition between paediatric and adult healthcare services.</li> </ul> <p><b>Excluded:</b></p> <ul style="list-style-type: none"> <li>▪ transition models and interventions not associated with a healthcare element, for example: educational, vocational or housing</li> <li>▪ models and interventions that do not specifically target the transition from paediatric to adult healthcare services</li> <li>▪ studies focusing exclusively on transition between paediatric and adult psychiatry or mental health services.</li> </ul>
<b>Comparators</b>	Any comparator or no comparator
<b>Outcomes</b>	<p>Patient/family/carer outcomes, including*:</p> <ul style="list-style-type: none"> <li>▪ transition readiness (measured by relevant transition readiness scales)</li> <li>▪ functional outcomes</li> <li>▪ continuity of care</li> <li>▪ health-related quality of life</li> <li>▪ condition-specific outcomes</li> <li>▪ safety and adverse outcomes</li> <li>▪ experience of care.</li> </ul> <p>System outcomes:</p> <ul style="list-style-type: none"> <li>▪ healthcare utilisation (planned/unplanned visits, ED attendances, admissions, service duplication).</li> </ul>
<b>Study design</b>	<p><b>Include:</b></p> <p>Empirical evidence (all study designs) primary quantitative or qualitative study designs.</p> <p><b>Exclude:</b></p> <ul style="list-style-type: none"> <li>▪ studies that describe a transition model/programme without providing any quantitative or qualitative outcome data</li> <li>▪ conceptual papers and projections of possible future developments</li> <li>▪ editorials, commentaries or preprints</li> </ul>

	<ul style="list-style-type: none"> <li>▪ reviews</li> <li>▪ conference abstracts, dissertations</li> <li>▪ case studies.</li> </ul>
<b>Location</b>	Include studies from OECD countries only.

**Key:** ED – emergency department; OECD – Organisation for Economic Cooperation and Development; RQ – research question; SNI – severe neurological impairment.

\* Other outcomes may be reported and if relevant, will be extracted.

**Table 2 Population, Intervention, Comparator, Outcomes and Study Design (PICOS) eligibility criteria for RQ3 and RQ4.**

<b>Population</b>	<p><b>Included:</b></p> <ul style="list-style-type: none"> <li>▪ adults (18 years and older) with SNI who are engaged in adult health services</li> <li>▪ families and carers of adults with SNI.</li> </ul> <p><b>Excluded:</b></p> <ul style="list-style-type: none"> <li>▪ adults without SNI</li> <li>▪ studies of paediatric-only populations (covered under RQ1-RQ2)</li> <li>▪ adults with SNI engaged with paediatric services only or paediatric patients with SNI engaged with adult healthcare services.</li> </ul>
<b>Intervention</b>	<p><b>Included:</b></p> <ul style="list-style-type: none"> <li>▪ any model of healthcare delivery designed to coordinate care for adults with SNI</li> <li>▪ models may target healthcare alone, or healthcare in combination with community care.</li> </ul> <p><b>Excluded:</b></p> <ul style="list-style-type: none"> <li>▪ conceptual models without implementation</li> <li>▪ standalone educational, vocational or housing programmes without healthcare involvement</li> <li>▪ studies focusing exclusively on the organisation or delivery of adult psychiatry or mental health services.</li> </ul>
<b>Comparators</b>	<ul style="list-style-type: none"> <li>▪ Any comparator or no comparator.</li> </ul>
<b>Outcomes</b>	<p>Patient outcomes, including*:</p> <ul style="list-style-type: none"> <li>▪ continuity of care</li> <li>▪ health-related quality of life</li> </ul>

	<ul style="list-style-type: none"> <li>▪ functional outcomes</li> <li>▪ condition-specific outcomes</li> <li>▪ safety and adverse outcomes</li> <li>▪ experience of care.</li> </ul> <p>System outcomes:</p> <ul style="list-style-type: none"> <li>▪ healthcare utilisation (planned/unplanned visits, ED attendances, admissions, service duplication).</li> </ul>
<b>Study design</b>	<p><b>Include:</b></p> <ul style="list-style-type: none"> <li>▪ empirical evidence (all study designs) from primary quantitative or qualitative study designs.</li> </ul> <p><b>Exclude:</b></p> <ul style="list-style-type: none"> <li>▪ studies that describe a coordinated or integrated model of care without providing any quantitative or qualitative outcome data</li> <li>▪ conceptual papers and projections of possible future developments</li> <li>▪ reviews</li> <li>▪ editorials, commentaries or preprints</li> <li>▪ conference abstracts, dissertations</li> <li>▪ case studies.</li> </ul>
<b>Location</b>	Include studies from OECD countries only

**Key:** ED – emergency department; OECD – Organisation for Economic Cooperation and Development; RQ – research question; SNI – severe neurological impairment.

\* Other outcomes may be reported and if relevant, will be extracted.

## 4.2 Search strategy and information sources

Two comprehensive searches will be performed in the following databases: Embase (Elsevier), Medline Complete (Ebsci), CINAHL Complete (EBSCOhost), PsycInfo (EBSCOhost), and the Cochrane Library. The search strategies will be developed by a librarian and peer reviewed by a second librarian. Searches will be limited to the period from 2005 to 2025. Forward and backward citation chasing will be conducted and relevant reviews will be cross-checked to identify any additional studies. Draft search strategies are provided in the Appendix.

### **4.3 Study selection**

Titles and abstracts of articles retrieved will be screened independently by two reviewers in Covidence. The full text of potentially eligible articles will be retrieved and independently assessed for eligibility by two reviewers according to the specified criteria. A PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram, outlining the study selection process, will be completed. Disagreements will be resolved through discussion, or if necessary, through involvement of a third reviewer.

### **4.4 Data extraction**

Data extraction will be conducted using a standardised, pre-piloted electronic data extraction form. A second reviewer will independently validate all extracted data. Disagreements in data extraction will be resolved through discussion, or if necessary, a third reviewer.

### **4.5 Quality assessment**

Critical appraisal will be carried out by one reviewer using the Mixed Methods Appraisal Tool (MMAT version 2018).<sup>(17)</sup> A second reviewer will independently verify the appraisal. Disagreements will be resolved through discussion, or if necessary, a third reviewer.

### **4.6 Data synthesis and analysis**

Data will be narratively synthesised. Where possible, data relating to different transition models and different models of care for adults will be analysed and presented separately. The mixed-methods review will be conducted with a convergent segregated approach. This method consists of conducting separate quantitative synthesis and qualitative synthesis, followed by integration of evidence derived from both syntheses.<sup>(18)</sup>

## **5 Economic evaluation**

The possibility of undertaking an economic evaluation consisting of a budget impact analysis (BIA) will depend on whether clear clinical pathways have been identified as part of the review of clinical effectiveness, and whether it is feasible and appropriate to build a coherent reference case and alternative implementation scenarios. The aim of the BIA would be to provide information for decision-makers regarding the potential affordability of proposed clinical pathways for the transition to adult healthcare services for individuals with SNI. However, the execution of BIA may be

subject to the findings of previous chapters and the availability of sufficient, robust data to parameterise the BIA. If the BIA were to proceed, it will describe, quantify and cost the additional resources (such as personnel, equipment and training) for the HSE associated with implementing a clinical pathway for the transition of individuals with SNI to adult healthcare services over an initial five-year time horizon. Potential cost offsets, such as avoided urgent and emergency care costs, and cost offsets related to a reduction in the burden of exacerbations would be considered and included, if appropriate.

If undertaken, the BIA will be reported in terms of the incremental annual cost. In Ireland, the 'reference case' or preferred method in the analysis for HTA is to adopt the perspective of the publicly funded health and social care system, that is, the HSE.<sup>(19)</sup> A summary of the model characteristics for the BIA is presented in Table 3.

**Table 3 Model characteristics for BIA**

Model characteristics	BIA
Perspective	Publicly funded health and social care system (HSE)
Time horizon	Five years
Discount rate	N/A
Outcome	Incremental cost per annum
Sensitivity analysis	Deterministic and probabilistic

**Key:** BIA – budget impact analysis; HSE – Health Service Executive; N/A – not applicable.

The estimated population size with SNI is expected to be subject to a high degree of uncertainty. Therefore, should the BIA proceed, a range of scenario analyses would be required to test the impact of population size on the BIA. For parameters that are unsupported by published literature, input from the EAG will be used to inform plausible values. In addition to the cost of this clinical pathway, changes to organisational processes resulting from the addition of this clinical pathway will be identified and considered as part of the BIA, where applicable.

## 6 Organisational considerations

An assessment of necessary organisational changes arising from the implementation of transition models or programmes will be carried out. Anticipated changes in the

organisation of care for young people and adults with SNI will be described along with the expected impact on existing healthcare activities. Consideration will also be given to the impact on various types of resources (such as human resources, equipment and supplies, and facilities) and any additional associated healthcare interventions (for example, additional patient education and support services) that may be required. This chapter will focus on healthcare services, rather than community or social care services. Healthcare encompasses medical services provided by hospital consultants, specialised clinics, and general practitioners. While HIQA acknowledges that a considerable amount of care is provided in both community and social care settings for patients with SNI, it is beyond the scope of this HTA to consider the transition to, and organisation of, such services.

## **7 Ethical, legal, patient and social considerations**

This chapter will outline the potential ethical, legal, patient and social considerations relating to the provision of transition models/programmes and organisation of adult healthcare services for young people and adults with SNI. The data from the mixed-methods review (section 4) undertaken to identify transition models and or programmes internationally and the organisation of adult healthcare services will be used to inform the section on patient and social considerations. The analysis of this information will be guided by the ethical, legal, and patient and social domains of the EUnetHTA Core Model.<sup>(20)</sup>

## **8 Dissemination**

The evidence gathered, as outlined in sections 2 to 7, will be synthesised in a draft report. The draft report will be published on the HIQA website and will be available for feedback in a public consultation for a period of six weeks. Following the public consultation, the report will be updated as necessary and submitted to the Board of HIQA for approval. The finalised report will be published on the HIQA website and submitted to the Minister for Health and the HSE as advice.

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## Appendix 1: Search strategy

### RESEARCH QUESTION(S)

- RQ1. What is the effectiveness and safety of interventions designed to improve the transition of individuals with SNI from paediatric to adult healthcare services?
- RQ2. What are the experiences of young people with SNI, their families and carers of transition from paediatric to adult healthcare services?

### SEARCH STRATEGIES

Database Name		MEDLINE Complete via Ebsco		
#	Query	Limiters/Expanders	Last Run Via	Results
S19	S17 NOT S18	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	751
S18	S9 AND S12 AND S15	Limiters - Publication Type: Comment, Commentary, Conference, Consensus Development Conference, Consensus Development Conference, NIH, Editorial, Letter Expanders - Apply equivalent	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	10

		subjects Search modes - Proximity		
S17	S9 AND S12 AND S15	Limiters - Publication Date: 20050101-20251231 Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	760
S16	S9 AND S12 AND S15	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	786
S15	S13 OR S14	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	4,822,917
S14	XB (child OR children OR teen* OR adolescen* OR "young adult*" OR "young person*" OR pediatric* OR paediatric* OR youth)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	2,254,694
S13	(MH "Adolescent") OR (MH "Young Adult") OR (MH "Pediatrics+") OR (MH "Child+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	4,133,231
S12	S10 OR S11	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	27,735

S11	XB ( transition* N3 (healthcare or care or model* or progam*) OR XB transition* N1 adult	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	26,430
S10	(MH "Transitional Care") OR (MH "Transition to Adult Care")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	4,037
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	1,006,493
S8	XB ("severe disability" or "complex disability" or "technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or myelomeningocele or hydrocephalus)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	49,227

S7	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	54,139
S6	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	173,833
S5	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or "down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord tumor*" or "spinal cord tumour*")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	138,606

S4	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular or mental) N1 (disabilit* OR impair* OR disorder* or disease or dysfunction))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	402,313
S3	(MH "Cerebral Palsy") OR (MH "Spinal Dysraphism+") OR (MH "Down Syndrome") OR (MH "Spinal Cord Injuries+") OR (MH "Spinal Cord Neoplasms+") OR (MH "Meningomyelocele") OR (MH "Hydrocephalus+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	Display
S2	(MH "Brain Injuries+") OR (MH "Brain Neoplasms+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	Display
S1	(MH "Developmental Disabilities") OR (MH "Persons with Intellectual Disabilities")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	Display

Database Name		CINAHL Complete via Ebsco		
#	Query	Limiters/Expanders	Last Run Via	Results
S36	S28 AND S31 AND S34	Limiters - Publication Date: 20050101-20251231 Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	469
S35	S28 AND S31 AND S34	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	485
S34	S32 OR S33	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,588,826
S33	XB (child OR children OR teen* OR adolescen* OR "young adult*" OR "young person*" OR pediatric* OR paediatric* OR youth)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	859,457
S32	(MH "Adolescence+") OR (MH "Child+") OR (MH "Young Adult") OR (MH "Pediatrics+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,325,939
S31	S29 OR S30	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	14,964

S30	XB ( transition* N3 (healthcare or care or model* or progam*) ) OR XB transition* N1 adult	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	12,722
S29	(MH "Transitional Care")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	5,061
S28	S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	268,287
S27	XB ("severe disability" or "complex disability" or "technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or myelomeningocele or hydrocephalus)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	8,367

S26	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	12,538
S25	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	42,538
S24	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or "down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord tumor*" or "spinal cord tumour*")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	49,082

S23	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular or mental) N1 (disabilit* OR impair* OR disorder* or disease or dysfunction))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	115,106
S22	(MH "Spina Bifida") OR (MH "Cerebral Palsy") OR (MH "Down Syndrome") OR (MH "Spinal Cord Injuries+") OR (MH "Spinal Cord Neoplasms") OR (MH "Hydrocephalus+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	54,175
S21	(MH "Brain Injuries+") OR (MH "Brain Neoplasms+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	54,255
S20	(MH "Developmental Disabilities") OR (MH "Persons with Intellectual Disabilities")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	18,052
S19	S17 NOT S18	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	0
S18	S9 AND S12 AND S15	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	410

S17	S9 AND S12 AND S15	Limiters - Publication Date: 20050101-20251231 Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	399
S16	S9 AND S12 AND S15	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	410
S15	S13 OR S14	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,420,978
S14	XB (child OR children OR teen* OR adolescen* OR "young adult*" OR "young person*" OR pediatric* OR paediatric* OR youth)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	859,457
S13	(MH "Adolescent") OR (MH "Young Adult") OR (MH "Pediatrics+") OR (MH "Child+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,057,641
S12	S10 OR S11	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	12,899
S11	( XB (transition*) N3 (healthcare or care) ) OR XB "transition to adult"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	10,570

S10	(MH "Transitional Care") OR (MH "Transition to Adult Care")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	5,061
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	267,570
S8	XB ("severe disability" or "complex disability" or "technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or myelomeningocele or hydrocephalus)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	8,367
S7	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	12,538

S6	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	42,538
S5	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or "down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord tumor*" or "spinal cord tumour*")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	49,082
S4	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular or mental) N1 (disabilit* OR impair* OR	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	115,106

	disorder* or disease or dysfunction))			
S3	(MH "Cerebral Palsy") OR (MH "Spinal Dysraphism+") OR (MH "Down Syndrome") OR (MH "Spinal Cord Injuries+") OR (MH "Spinal Cord Neoplasms+") OR (MH "Meningomyelocele") OR (MH "Hydrocephalus+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	51,554
S2	(MH "Brain Injuries+") OR (MH "Brain Neoplasms+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	54,255
S1	(MH "Developmental Disabilities") OR (MH "Persons with Intellectual Disabilities")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	18,052

Database Name		APA PsycINFO via Ebsco		
S17	S9 AND S12 AND S15	Limiters - Publication Date: 20050101-20251231 Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	399
S16	S9 AND S12 AND S15	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	446
S15	S13 OR S14	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,061,853
S14	XB (child OR children OR teen* OR adolescen* OR "young adult*" OR "young person*" OR pediatric* OR paediatric* OR youth)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,060,444
S13	DE "Pediatrics"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	37,193
S12	S10 OR S11	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	12,332

S11	( XB (transition*) N3 (healthcare or care or model* or program*) ) OR XB transition* N1 adult	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	9,896
S10	DE "Continuum of Care"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	2,691
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	312,589
S8	XB ("severe disability" or "complex disability" or "technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or myelomeningocele or hydrocephalus)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	3,879

S7	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	19,891
S6	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	40,273
S5	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or "down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord tumor*" or "spinal cord tumour*")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	26,433
S4	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	205,411

	or mental) N1 (disabilit* OR impair* OR disorder* or disease or dysfunction))			
S3	((DE "Cerebral Palsy") OR (DE "Spina Bifida")) OR (DE "Spinal Cord Injuries")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	15,939
S2	DE "Brain Injuries" OR DE "Traumatic Brain Injury"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	28,652
S1	(DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	52,475

Database Name	Embase via Elsevier
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No.	Query	Results
#24	#22 NOT #23	758
#23	#17 AND #20 AND [2005-2025]/py AND ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it OR 'editorial'/it OR 'letter'/it OR 'preprint'/it)	463
#22	#17 AND #20 AND [2005-2025]/py	1221
#21	#17 AND #20	1247
#20	#18 OR #19	5958530
#19	child:ab,ti OR children:ab,ti OR teen*:ab,ti OR adolescen*:ab,ti OR 'young adult*':ab,ti OR 'young person*':ab,ti OR pediatric*:ab,ti OR paediatric*:ab,ti OR youth:ab,ti	3079263
#18	'adolescent'/exp OR 'young adult'/exp OR 'pediatrics'/exp OR 'child'/exp	5269528

#17	#12 AND #16	2220
#16	#13 OR #14 OR #15	28569
#15	(transition* NEAR/1 adult):ab,ti	718
#14	(transition* NEAR/3 (healthcare OR care OR program* OR model*)):ab,ti	34731
#13	'transitional care'/exp OR 'transitional care'	9052
#12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11	1962255
#11	'severe disabilit*':ab,ti OR 'complex disabilit*':ab,ti OR 'technology dependent child*':ab,ti OR 'technology dependent adult*':ab,ti OR pimd:ab,ti OR 'central nervous system congenital abnormalit*':ab,ti OR 'central nervous system congenital malformation*':ab,ti OR 'spine malformation*':ab,ti OR 'neural tube defect*':ab,ti OR myelomeningocele:ab,ti OR hydrocephalus:ab,ti	69966
#10	'spastic diplegia':ab,ti OR 'cerebral palsy':ab,ti OR 'spina bifida':ab,ti OR 'spinal muscular atrophy':ab,ti	68900
#9	neurodisabilit*':ab,ti OR 'neuro disabilit*':ab,ti OR neurodevelopmental:ab,ti OR 'neuro developmental':ab,ti OR polyhandicap*':ab,ti	74784
#8	(brain NEAR/1 (injur* OR impair* OR tumor* OR tumour* OR cancer* OR neoplasm*)):ab,ti	241933
#7	'duchenne muscular dystrophy':ab,ti OR 'downs syndrome':ab,ti OR 'down syndrome':ab,ti OR 'trisomy 21 syndrome':ab,ti	44663
#6	'spinal cord injur*':ab,ti OR 'spinal cord tumor*':ab,ti OR 'spinal cord tumour*':ab,ti	72335
#5	'brain palsy':ab,ti OR 'brain paralysis':ab,ti OR 'central palsy':ab,ti OR 'central paralysis':ab,ti OR 'cerebral paralysis':ab,ti OR 'cerebral paresis':ab,ti OR 'diplegia spastica':ab,ti OR 'encephalopathia infantilis':ab,ti	667
#4	((intellectual OR developmental OR cognitive OR neurologic* OR neuromuscular OR mental) NEAR/1 (disabilit* OR impair* OR disorder* OR disease OR dysfunction)):ab,ti	502026
#3	'cerebral palsy'/exp OR 'spinal dysraphism'/exp OR 'down syndrome'/exp OR 'meningomyelocele'/exp OR 'spinal cord injury'/exp OR 'spinal cord tumor'/exp OR 'hydrocephalus'/exp	306835
#2	'brain injury'/exp OR 'brain tumor'/exp	519557
#1	'intellectual impairment'/exp	753733

Database Name	The Cochrane Library

RESEARCH QUESTION(S)

- RQ3. What is the effectiveness and safety of models of care for adults with severe neurological impairment?
- RQ4. For patients and their families and/or carers, what is the experience of models of care for adults with severe neurological impairment?

Database Name	Embase via Elsevier	
No.	Query	Results
#29	#27 NOT #28	5254
#28	#22 AND #25 AND [2005-2025]/py AND ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it OR 'editorial'/it OR 'preprint'/it)	2995
#27	#22 AND #25 AND [2005-2025]/py	8249
#26	#22 AND #25	8745
#25	#23 OR #24	10623971
#24	effective*:ab,ti OR outcome*:ab,ti OR safety:ab,ti OR 'adverse event*':ab,ti OR 'adverse effect*':ab,ti OR 'quality of life':ab,ti OR qol:ab,ti OR 'caregiver burden':ab,ti OR 'carer burden':ab,ti OR satisfaction:ab,ti OR 'patient impact':ab,ti OR 'patient experience':ab,ti OR 'continuity of care':ab,ti	9301342
#23	'quality of life'/exp OR 'treatment outcome'/exp OR 'patient safety'/exp OR 'patient satisfaction'/exp	4014733

#22	#12 AND #21	13488
#21	#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20	185678
#20	'co-located care':ab,ti OR 'service hub*':ab,ti	72
#19	'shared care':ab,ti OR 'service model*':ab,ti OR 'care program*':ab,ti OR 'care pathway*':ab,ti	46285
#18	((integrated OR community) NEAR/1 (care OR hub* OR pathway*)):ab,ti	23494
#17	'care coordinat*':ab,ti OR keyworker:ab,ti OR 'case manag*':ab,ti OR 'care navigator*':ab,ti OR 'patient navigator*':ab,ti	36962
#16	(mdt NEAR/1 (clinic* OR network* OR service*)):ab,ti	541
#15	(multidisciplinary NEAR/1 (clinic* OR network* OR service* OR team*)):ab,ti	63568
#14	(model* NEAR/1 care):ab,ti	20664
#13	'integrated health care system'/exp OR 'patient care team'/exp	26390
#12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11	1967870
#11	'technology dependent child*':ab,ti OR 'technology dependent adult*':ab,ti OR pimd:ab,ti OR 'central nervous system congenital abnormalit*':ab,ti OR 'central nervous system congenital malformation*':ab,ti OR 'neural tube defect*':ab,ti OR myelomeningocele:ab,ti OR hydrocephalus:ab,ti	59339
#10	'spastic diplegia':ab,ti OR 'cerebral palsy':ab,ti OR 'spina bifida':ab,ti OR 'spinal muscular atrophy':ab,ti	68900
#9	neurodisabilit*:ab,ti OR 'neuro disabilit*':ab,ti OR neurodevelopmental:ab,ti OR 'neuro developmental':ab,ti OR polyhandicap*:ab,ti	74784
#8	(brain NEAR/1 (injur* OR impair* OR tumor* OR tumour* OR cancer* OR neoplasm*)):ab,ti	241933
#7	'duchenne muscular dystrophy':ab,ti OR 'downs syndrome':ab,ti OR 'down syndrome':ab,ti OR 'trisomy 21 syndrome':ab,ti	44663
#6	'spinal cord injur*':ab,ti OR 'spinal cord tumor*':ab,ti OR 'spinal cord tumour*':ab,ti	72335

#5	'brain palsy':ab,ti OR 'brain paralysis':ab,ti OR 'central palsy':ab,ti OR 'central paralysis':ab,ti OR 'cerebral paralysis':ab,ti OR 'cerebral paresis':ab,ti OR 'diplegia spastica':ab,ti OR 'encephalopathia infantilis':ab,ti	667
#4	((intellectual OR developmental OR cognitive OR neurologic* OR neuromuscular OR mental) NEAR/1 (disabilit* OR impair* OR disorder* OR disease OR dysfunction)):ab,ti	502026
#3	'cerebral palsy'/exp OR 'spinal dysraphism'/exp OR 'down syndrome'/exp OR 'meningomyelocele'/exp OR 'spinal cord injury'/exp OR 'spinal cord tumor'/exp OR 'hydrocephalus'/exp	306835
#2	'brain injury'/exp OR 'brain tumor'/exp	519557
#1	'intellectual impairment'/exp	753733

Database Name	MEDLINE Complete via Ebsco
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#	Query	Limiters/Expanders	Last Run Via	Results
S23	S19 AND S22	Limiters - Publication Date: 20051001- Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	2,020
S22	S20 OR S21	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	2,903,440
S21	XB (effective*OR outcome* OR safety OR 'adverse event*' OR 'adverse effect*' OR 'quality of life' OR qol OR 'caregiver burden' OR 'carer	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	1,642,325

	burden' OR satisfaction OR 'patient impact' OR 'patient experience' OR 'continuity of care')			
S20	(MH "Quality of Life+") OR (MH "Treatment Outcome+") OR (MH "Patient Safety") OR (MH "Patient Satisfaction+") OR (MH "Continuity of Patient Care")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	1,739,059
S19	S9 AND S18	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	9,713
S18	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	222,577
S17	XB ('co-located care' OR 'service hub*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	55
S16	XB ('shared care' OR 'service model*' OR 'care program*' OR 'care pathway*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	29,854
S15	XB ((integrated OR community) N1 (care OR hub* OR pathway*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	34,461

S14	XB ('care coordinat*' OR keyworker OR "key worker" OR 'case manag*' OR 'care navigator*' OR 'patient navigator*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	26,525
S13	XB (mdt N1 (clinic* OR network* OR service*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	179
S12	XB (multidisciplinary N1 (clinic* OR network* OR service* OR team*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	40,241
S11	XB model* N1 care	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	29,232
S10	(MH "Delivery of Health Care, Integrated+") OR (MH "Patient Care Team+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	90,008
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	1,002,505
S8	XB ("technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	43,802

	congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or myelomeningocele or hydrocephalus)			
S7	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	54,150
S6	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	173,845
S5	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	138,618

	"down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord tumor*" or "spinal cord tumour*")			
S4	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular or mental) N1 (disabilit* OR impair* OR disorder* or disease or dysfunction))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	402,343
S3	(MH "Cerebral Palsy") OR (MH "Spinal Dysraphism+") OR (MH "Down Syndrome") OR (MH "Spinal Cord Injuries+") OR (MH "Spinal Cord Neoplasms+") OR (MH "Meningomyelocele") OR (MH "Hydrocephalus+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	160,675
S2	(MH "Brain Injuries+") OR (MH "Brain Neoplasms+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	273,181
S1	(MH "Developmental Disabilities") OR (MH	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	27,478

	"Persons with Intellectual Disabilities")			
<b>Database Name</b>		CINAHL Complete via Ebsco		
<b>#</b>	<b>Query</b>	<b>Limiters/Expanders</b>	<b>Last Run Via</b>	<b>Results</b>
S24	S20 AND S23	Limiters - Publication Date: 20051001-20251031 Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,558
S23	S21 OR S22	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,146,314
S22	XB (effective* OR outcome* OR safety OR 'adverse event*' OR 'adverse effect*' OR 'quality of life' OR Qol OR 'caregiver burden' OR 'carer burden'OR satisfaction OR 'patient impact' OR 'patient experience' OR 'continuity of care')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	507,960
S21	(MH "Quality of Life+") OR (MH "Treatment Outcomes+") OR (MH "Patient Safety+") OR (MH "Patient Satisfaction+") OR	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	865,879

	(MH "Continuity of Patient Care+")			
S20	S9 AND S19	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	6,206
S19	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	146,776
S18	XB ('co-located care' OR 'service hub*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	38
S17	XB ('shared care' OR 'service model*' OR 'care program*' OR 'care pathway*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	16,800
S16	XB ((integrated OR community) N1 (care OR hub* OR pathway*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	23,258
S15	XB ('care coordinat*' OR keyworker OR "key worker" OR 'case manag*' OR 'care navigator*' OR 'patient navigator*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	19,724
S14	XB (mdt N1 (clinic* OR network* OR service*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	76

S13	XB (multidisciplinary N1 (clinic* OR network* OR service* OR team*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	17,234
S12	XB model* N1 care	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	19,506
S11	(MH "Multidisciplinary Care Team+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	59,101
S10	(MH "Health Care Delivery, Integrated")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	18,205
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	267,158
S8	XB ("technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	6,585

	myelomeningocele or hydrocephalus)			
S7	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	12,548
S6	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	42,559
S5	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or "down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	49,112

	tumor*" or "spinal cord tumour*")			
S4	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular or mental) N1 (disabilit* OR impair* OR disorder* or disease or dysfunction))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	115,186
S3	(MH "Spina Bifida") OR (MH "Cerebral Palsy") OR (MH "Down Syndrome") OR (MH "Spinal Cord Injuries+") OR (MH "Spinal Cord Neoplasms") OR (MH "Hydrocephalus+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	54,200
S2	(MH "Brain Injuries+") OR (MH "Brain Neoplasms+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	54,282
S1	(MH "Developmental Disabilities") OR (MH "Persons with Intellectual Disabilities")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	18,060

Database Name		APA PsycInfo via Ebsco		
#	Query	Limiters/Expanders	Last Run Via	Results
S22	S9 AND S18 AND S21	Limiters - Publication Date: 20051001-20251031 Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,626
S21	S19 OR S20	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,194,664
S20	XB (effective* OR outcome* OR safety OR 'adverse event*' OR 'adverse effect*' OR 'quality of life' OR QoL OR 'caregiver burden' OR 'carer burden' OR satisfaction OR 'patient impact' OR 'patient experience' OR 'continuity of care')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,151,170
S19	(((((DE "Quality of Life" OR DE "Health Related Quality of Life") OR (DE "Treatment Outcomes" OR DE "Psychotherapeutic Outcomes" OR DE "Side Effects (Treatment)" OR DE "Treatment Compliance" OR DE "Treatment Duration" OR DE	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	168,849

	"Treatment Refusal" OR DE "Treatment Termination" OR DE "Treatment Withholding")) OR (DE "Patient Safety")) OR (DE "Client Satisfaction")) OR (DE "Continuum of Care")			
S18	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	52,728
S17	XB ('co-located care' OR 'service hub*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	26
S16	XB ('shared care' OR 'service model*' OR 'care program*' OR 'care pathway*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	8,493
S15	XB ((integrated OR community) N1 (care OR hub* OR pathway*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	11,882
S14	XB ('care coordinat*' OR keyworker OR "key worker" OR 'case manag*' OR 'care navigator*' OR 'patient navigator*')	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	10,285
S13	XB (mdt N1 (clinic* OR network* OR service*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	9

S12	XB (multidisciplinary N1 (clinic* OR network* OR service* OR team*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	6,425
S11	XB model* N1 care	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	8,818
S10	((DE "Integrated Services") OR DE "Interdisciplinary Treatment Approach")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	14,383
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	312,145
S8	XB ("technology dependent child*" or "technology dependent adult*" or "profound intellectual and multiple disabilities" or PIMD "central nervous system congenital abnormalit*" or "central nervous system congenital malformation*" or "congenital brain and spine malformation*" or "neural tube defect*" or myelomeningocele or hydrocephalus)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	2,852

S7	XB (neurodisabilit* or neuro-disabilit* or neurodevelopmental or neuro-developmental or polyhandicap*)	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	19,927
S6	XB (brain N1 (injur* or impair* or tumor* or tumour* or cancer* or neoplasm*))	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	40,302
S5	XB ('brain palsy' OR 'brain paralysis' OR 'central palsy' OR 'central paralysis' OR 'cerebral paralysis' OR 'cerebral paresis' OR 'diplegia spastica' OR 'encephalopathia infantilis' OR 'spastic diplegia' OR 'cerebral palsy' or "spina bifida" or "Spinal muscular atrophy" Or "Duchenne muscular dystrophy" or "down's syndrome" or "downs syndrome" or "down syndrome" or "trisomy 21 syndrome" or "spinal cord injur*" or "spinal cord tumor*" or "spinal cord tumour*")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	26,457
S4	XB (intellectual or developmental or cognitive or neurologic* or neuromuscular or mental) N1 (disabilit* OR	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	205,576

	impair* OR disorder* or disease or dysfunction))			
S3	((DE "Cerebral Palsy") OR (DE "Spina Bifida")) OR (DE "Spinal Cord Injuries")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	15,948
S2	DE "Brain Injuries" OR DE "Traumatic Brain Injury"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	28,670
S1	(DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	52,504
Database Name		The Cochrane Library		

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