

Appendix 2: Search Strategy

A. Database search

The search strategy was developed using subject headings and search terms related to 1) informed consent, 2) intellectual disability, and 3) health care, and were combined using the 'AND' Boolean operator. Synonyms were combined using 'OR'. Truncated search terms were used to search titles and key words to capture all possible relevant studies.

The search strategy was developed with guidance from a Librarian with three consultations, and discussion with the research team for review and input.

Relevant databases were searched, which consisted of: Embase, MEDLINE, PsychINFO, PubMed, SCOPUS, Web of Science, and CINAHL. These databases were chosen as they include healthcare and psychology databases to best capture all relevant literature to this topic, including both medical and nursing literature, as well as social sciences and bioethical databases. The search was limited to studies published from 1990 onwards as the current understanding of consent has changed over time, and literature published prior to 1990 is based on an outdated view of consent and capacity.

1. Embase

1. Intellectual impairment/
2. Learning disorder/
3. Informed consent/
4. Exp health service/
5. Decision making/ or clinical decision making/ or medical decision making/ or patient decision making/ or shared decision making/
6. Mental deficiency/
7. ("Intellectual* disab*" or "Learning disab*" or "Learning difficult*" or "Developmental* disab*" or "Cognitive* disab*" or "Cognitive* impair*" or "Mental* retard*" or "Mental* Handicap*" or "Developmental* Delay*").kw,ti.
8. 1 or 2 or 6 or 7
9. ("decision mak*" or assent or consent* or autonomy).kw,ti.
10. 3 or 5 or 9
11. ("health care" or "healthcare" or "health service" or "clinical practice" or "medical care" or "procedure" or "interven*" or "treat*" or "management").kw,ti.
12. 4 or 11
13. 8 and 10 and 12

Results from search = 2457 results

2. MEDLINE

MEDLINE(R) All including Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R)

1. exp Intellectual Disability/
2. exp Learning Disabilities/
3. exp Informed Consent/
4. Decision Making/
5. Clinical Decision-Making/
6. Decision Making, Shared/
7. Presumed Consent/
8. Personal Autonomy/
9. exp Health Services/
10. exp patient care management/ or exp "delivery of health care"/
11. ("Intellectual* disab*" or "Learning disab*" or "Learning difficult*" or "Developmental* disab*" or "Cognitive* disab*" or "Cognitive* impair*" or "Mental* retard*" or "Mental* Handicap*" or "Developmental* Delay*").kw,ti.
12. ("health care" or "healthcare" or "health service" or "clinical practice" or "medical care" or "procedure" or "interven*" or "treat*" or "management").kw,ti.
13. 9 or 10 or 12
14. Developmental Disabilities/
15. 1 or 2 or 11 or 14
16. ("decision mak*" or assent or consent* or autonomy).kw,ti.
17. 3 or 4 or 5 or 6 or 7 or 8 or 16
18. 13 and 15 and 17

Results from search = 1112 results

3. PsychInfo:

1. Exp intellectual development disorder/
2. Exp learning disorders/
3. Exp developmental disabilities/
4. Exp cognitive impairment/
5. Informed consent/ or client rights/ or duty to warn/ or involuntary treatment/ or treatment compliance/ or treatment refusal/ or treatment withholding/

6. Exp decision making/
7. Exp volition/ or agency/ or choic ebehaviour/ or decision making/ or determinism/ or freedom/ or self-determination/
8. Competence/
9. Exp autonomy/
10. Exp Health/ or exp Health Care Services/ or exp Primary Health Care/ or exp Mental Health/ or exp Mental Health Services/ or exp Clinical Practice/ or exp Health Care Delivery/
11. Exp "Medical treatment (General)"/ or exp Drug Therapy/
12. ("Intellectual* disab*" or "Learning disab*" or "Learning difficult*" or "Developmental* disab*" or "Cognitive* disab*" or "Cognitive* impair*" or "Mental* retard*" or "Mental* Handicap*" or "Developmental* Delay*").id,ti.
13. ("health care" or "healthcare" or "health service" or "clinical practice" or "medical care" or "procedure" or "interven*" or "treat*" or "management").id,ti.
14. 1 or 2 or 3 or 4 or 12
15. 10 or 11 or 13
16. ("decision mak*" or assent or consent* or autonomy).id,ti.
17. 5 or 6 or 7 or 8 or 9 or 16
18. 14 and 15 and 17

Results from search = 910 results

4. Pubmed

((intellectual disability[MeSH Terms]) OR (learning disabilities[MeSH Terms]) OR (learning disab*[Title]) OR (developmental* disab*[Title]) OR (learning difficult*[Title]) OR (cognitive* disab*[Title]) OR (cognitive* impair*[Title]) OR (mental* retard*[Title]) OR (mental* handicap*[Title]) OR (developmental* delay*[Title]))

AND

("Decision Making"[Mesh:NoExp]) OR ("Informed Consent"[Mesh]) OR ("Clinical Decision-Making"[Mesh]) OR ("Decision Making, Shared"[Mesh]) OR ("Presumed Consent"[Mesh]) Or ("Personal Autonomy"[Mesh]) OR (consent*[Title]) OR (decision making[Title]) OR (assent[Title]) OR (autonomy[Title]))

AND

((health services[MeSH Terms]) OR (patient care management[MeSH Terms]) OR (delivery of health care[MeSH Terms]) OR (health care[Title]) OR (healthcare[Title]) OR (health service[Title]) OR (clinical practice[Title]) OR (medical care[Title]))

Results from search = 208 results

5. SCOPUS

(((TITLE ("intellectual* disab*") OR TITLE ("learning disab*") OR TITLE ("developmental* disab*") OR TITLE ("learning difficult*") OR TITLE ("cognitive* disab*") OR TITLE ("cognitive* impair*") OR TITLE ("mental* retard*") OR TITLE ("mental* handicap*") OR TITLE ("development* delay*"))) OR ((KEY ("intellectual* disab*") OR KEY ("learning disab*") OR KEY ("developmental* disab*") OR KEY ("learning difficult*") OR KEY ("cognitive* disab*") OR KEY ("cognitive* impair*") OR KEY ("mental* retard*") OR KEY ("mental* handicap*") OR KEY ("development* delay*"))))

AND

(((TITLE ("patient care") OR TITLE ("health care") OR TITLE (healthcare) OR TITLE ("health service") OR TITLE ("clinical practice") OR TITLE ("medical care"))) OR ((KEY ("patient care") OR KEY ("health care") OR KEY (healthcare) OR KEY ("health service") OR KEY ("clinical practice") OR KEY ("medical care"))))

AND

(((TITLE ("decision making") OR TITLE (consent*) OR TITLE (autonomy) OR TITLE (assent))) OR ((KEY ("decision making") OR KEY (consent*) OR KEY (autonomy) OR KEY (assent))

Results from search = 1040 results

6. Web of Science

(TI=("intellectual* disab*") OR TI=("learning disab*") OR TI=("developmental* disab*") OR TI=("learning difficult*") OR TI=("cognitive* disab*") OR TI=("cognitive* impair*") OR TI=("mental* retard*") OR TI=("mental* handicap*") OR TI=("development* delay*") OR KP=("intellectual* disab*") OR KP=("learning disab*") OR KP=("developmental* disab*") OR KP=("learning difficult*") OR KP=("cognitive* disab*") OR KP=("cognitive* impair*") OR KP=("mental* retard*") OR KP=("mental* handicap*") OR KP=("development* delay*") OR AK=("intellectual* disab*") OR AK=("learning disab*") OR AK=("developmental* disab*") OR

AK=("learning difficult*") OR AK=("cognitive* disab*") OR AK=("cognitive* impair*") OR
AK=("mental* retard*") OR AK=("mental* handicap*") OR AK=("development* delay*")

AND

(TI=("decision mak*") OR TI=(consent*) OR TI=(autonomy) OR TI=(assent) OR KP=("decision
mak*") OR KP=(consent*) OR KP=(autonomy) OR KP=(assent) OR AK=("decision mak*") OR
AK=(consent*) OR AK=(autonomy) OR AK=(assent))

AND

(TI=("patient care") OR TI=(healthcare) OR TI=("health care") OR TI=("health service") OR
TI=("clinical practice") OR TI=("medical care") OR KP=("patient care") OR KP=(healthcare) OR
KP=("health care") OR KP=("health service") OR KP=("clinical practice") OR KP=("medical care")
OR AK=("patient care") OR AK=(healthcare) OR AK=("health care") OR AK=("health service") OR
AK=("clinical practice") OR AK=("medical care"))

Results from search = 114 results

7. CINAHL

1. (MH "Intellectual Disability") OR (MH "Learning Disorders+") OR (MH "Mentally Disabled Persons") OR (MH "Developmental Disabilities") OR (MH "Health Services for Persons with Disabilities")
2. TI ("Intellectual* disab*" or "Learning disab*" or "Learning difficult*" or "Developmental* disab*" or "Cognitive* disab*" or "Cognitive* impair*" or "Mental* retard*" or "Mental* Handicap*" or "Developmental* Delay*") OR SU ("Intellectual* disab*" or "Learning disab*" or "Learning difficult*" or "Developmental* disab*" or "Cognitive* disab*" or "Cognitive* impair*" or "Mental* retard*" or "Mental* Handicap*" or "Developmental* Delay*")
3. (MH "Decision Making+")
4. (MH "Consent+") OR (MH "Consent (Research)")
5. (MH "Mild Cognitive Impairment")
6. (MH "Autonomy") OR (MH "Patient Autonomy")
7. (MH "Medical Care")
8. (MH "Health Services+")
9. TI ("health care" or "healthcare" or "health service" or "clinical practice" or "medical care" or "procedure" or "interven*" or "treat*" or "management") OR SU ("health care" or

- "healthcare" or "health service" or "clinical practice" or "medical care" or "procedure" or "interven*" or "treat*" or "management")
10. TI ("decision mak*" or assent or consent* or autonomy) OR SU ("decision mak*" or assent or consent* or autonomy)
 11. S1 OR S2 OR S5
 12. S3 OR S4 OR S6 OR S10
 13. S7 OR S8 OR S9
 14. S11 AND S12 AND S13

Results from search = 846 results

B. Hand-search of journals

A hand-search of three journals was completed. All published articles from 1990 January onwards were reviewed.

The most prominent journals were identified by examining all included articles in the systematic literature review and identifying which journals they were published in. The top three journals were included. This was decided after a joint discussion with the research team and review of the proportion of articles published in each journal and limiting the number of hand-searched journals by considering feasibility and time requirements. The chosen journals were:

1. British Journal of Learning Disabilities
2. Journal of Intellectual Disabilities
3. Journal of Intellectual Disability Research.

C. Ancestral search

The reference lists of all included articles were reviewed by two independent researchers to identify any other relevant literature that meets inclusion criteria. These were collated into an Excel spreadsheet and the inclusion criteria were applied.

This identified 24 additional studies which were then screened by abstract and title, and then eligibility criteria were assessed.