

EMR keyword search strategies to finding patients with IDD

Diagnostic considerations

Intellectual and developmental disabilities (IDD) refers to various lifelong limitations in intellectual functioning and conceptual, social, or practical skills that emerge in persons before the age of 18 years. These limitations differ in severity and type among people with IDD and can vary during a person’s lifespan. Intellectual and developmental disabilities encompass intellectual disability, developmental disability, and autism spectrum disorder.

A diagnosis of a learning disability (e.g., dyslexia), is not the same as IDD. Presence of “learning disability” might indicate a developmental disability.

You may find a wide range of classifications or wording combinations. For this reason, it is suggested that an EMR search be set up to search multiple fields, with various combinations of search terms. Once your initial search is done, it is important to review this list to remove incorrectly identified individuals (e.g., special education teachers, patients with the last name “Williams”).

Fields or sections where keywords might be recorded:

- ▶ Problem list
- ▶ Past history
- ▶ Personal

Key diagnostic terms to include in an EMR search (syndromes, diseases or disorders):

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| ▶ 22q deletion syndrome, 22q deletion, 22q | ▶ Autism spectrum disorder, ASD, autistic | ▶ Fragile X syndrome, Fragile X | ▶ Prader-Willi, PWS |
| ▶ Angelman syndrome, Angelman | ▶ Cerebral Palsy, CP | ▶ Intellectual, Developmental, Delay, Disability | ▶ Rett syndrome, Rett’s |
| ▶ Asperger syndrome (now classified as autism spectrum disorder) | ▶ Chromosome Congenital | ▶ Learning disability | ▶ Smith-Magenis syndrome, Smith-Magenis |
| ▶ Attention Deficit/Hyperactivity Disorder, ADHD, ADD | ▶ Down syndrome, Down’s | ▶ Mental Retardation, MR | ▶ Syndromes, diseases or disorders: |
| | ▶ Fetal Alcohol Spectrum Disorder, FASD, Fetal Alcohol | ▶ Pervasive developmental disorder, PDD | ▶ Tuberous sclerosis |
| | | ▶ Prader-Willi syndrome, | ▶ William’s, Asperger, Asperger’s |

Severity levels:

- ▶ Borderline intelligence
- ▶ Mild ID
- ▶ Moderate ID
- ▶ Severe ID
- ▶ Profound ID
- ▶ Low functioning
- ▶ High functioning

Service agency names:

Check with the provincial access point for developmental disability services for a list of agencies that support this population (e.g., in Ontario: “Developmental Services Ontario”).

Social alerts:

- ▶ Special education
- ▶ Learning
- ▶ Day program
- ▶ Group home
- ▶ Case worker, case manager