

# Researching non-categorically defined populations

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# Overview of Presentation

1. Background

Conceptual - contextual  
(different kinds of research)

2. My own work

# Background

## Four contrasting kinds of research

1. Clinical research vs. Lab-based or “basic” research
2. Observational research vs. Experimental research
3. Population-based research vs. Research with individuals/small samples of the population
4. Research with Categorically-defined vs. Non-categorically groups and populations

# Clinical research vs. Lab-based (“basic”) research



# Observational research vs. Experimental research



# Population-based research vs. Research with individuals/small samples (of the population)



- ❖ Aims
- ❖ Methods
- ❖ Strengths and Limitations



# Research with Categorically-defined vs. Non-categorically groups and populations

Categorical

Autism

Cerebral palsy

Intellectual disability

Fragile x syndrome

# Research with Categorically-defined vs. Non-categorically groups and populations

## Non-categorical

Children with disabilities

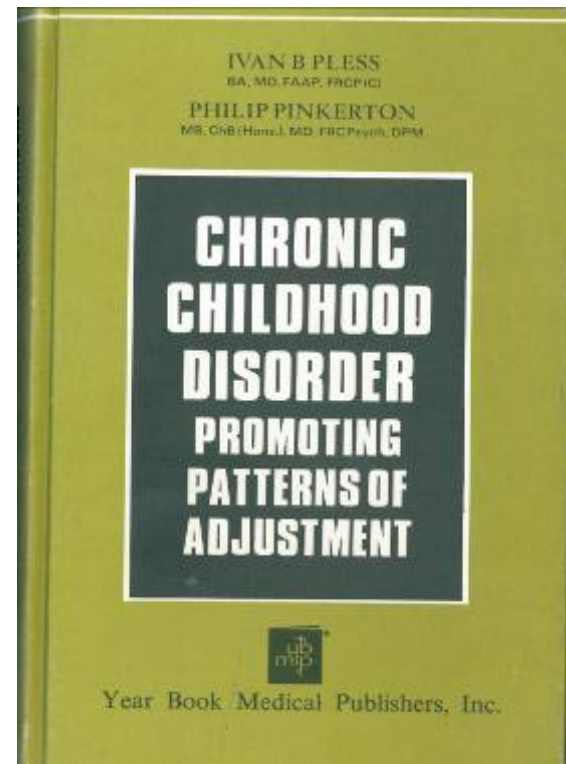
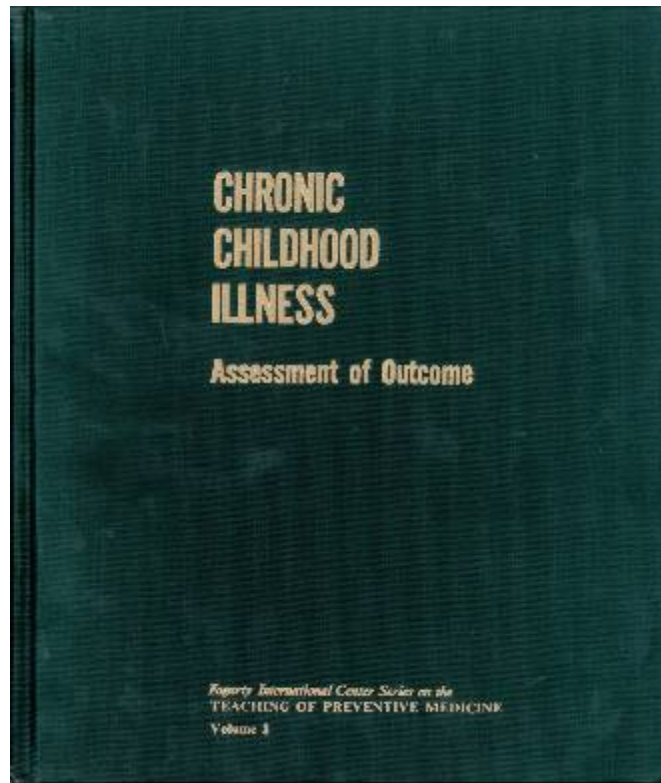
Children and youth with special needs (CYSN)

Children with chronic health conditions

Children with medical complexity



# Origins of non-categorical concept



## LEVEL OF OBSERVATION

## Individuals/Samples

## Whole Population

Observational

## Experimental

## TYPE OF RESEARCH

## LEVEL OF OBSERVATION

Individuals/Samples

Whole Population

Observational

Characteristics/attributes  
including:

- clinical status
- attitudes/experiences
- utilization of services, etc.

Experimental

TYPE OF RESEARCH

## LEVEL OF OBSERVATION

### TYPE OF RESEARCH

	Individuals/Samples	Whole Population
Observational	Characteristics/attributes including: <ul style="list-style-type: none"><li>• clinical status</li><li>• attitudes/experiences</li><li>• utilization of services, etc.</li></ul>	Same
Experimental		

## LEVEL OF OBSERVATION

### TYPE OF RESEARCH

	Individuals/Samples	Whole Population
Observational	Characteristics/attributes including: <ul style="list-style-type: none"><li>• clinical status</li><li>• attitudes/experiences</li><li>• utilization of services, etc.</li></ul>	Same
Experimental	Studies of Treatments / Intervention	

## LEVEL OF OBSERVATION

### TYPE OF RESEARCH

	Individuals/Samples	Whole Population
Descriptive/ Observational	Characteristics/attributes including: <ul style="list-style-type: none"><li>• clinical status</li><li>• attitudes/experiences</li><li>• utilization of services, etc.</li></ul>	Same
Experimental	Studies of Treatments / Intervention	at population level, e.g., public health intervention

# Descriptive / Observational studies

DESCRIPTION/ASCERTAINMENT OF SUBJECTS (PARTICIPANTS)

## LEVEL OF OBSERVATION

	Individuals/Samples	Whole Population
Categorical		
Non-categorical		

# Descriptive / Observational studies

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Categorical	<ul style="list-style-type: none"><li>• Characteristics of children seen in Hearing Loss Clinic</li><li>• Experimental study of children with cerebral palsy</li></ul>	Use of services by children with autism spectrum disorder in BC
Non-categorical		



# Descriptive / Observational studies

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Non-categorical	Perceptions of continuity of care among families of children seen at Sunny Hill	<ul style="list-style-type: none"><li>• Prevalence of children with special health care needs in USA</li><li>• Participation in recreational activities among children with disabilities in Canada</li></ul>

# My work

➤ Observational type research

*at*

➤ Population level

*involving*

➤ Non-categorical populations

# My work

## Two specific projects

1. Identifying and defining children in Canada in terms of “health status groups”
2. Identifying and describing children with Neurodevelopmental Disorders and Disabilities (NDD/D) in the Canadian population

# Project 1. Identifying and defining children in “health status groups”

- Context (“Caregiver Study”)
- Collaborators
- Data Source: National Longitudinal Survey of Children and Youth (NLSCY)

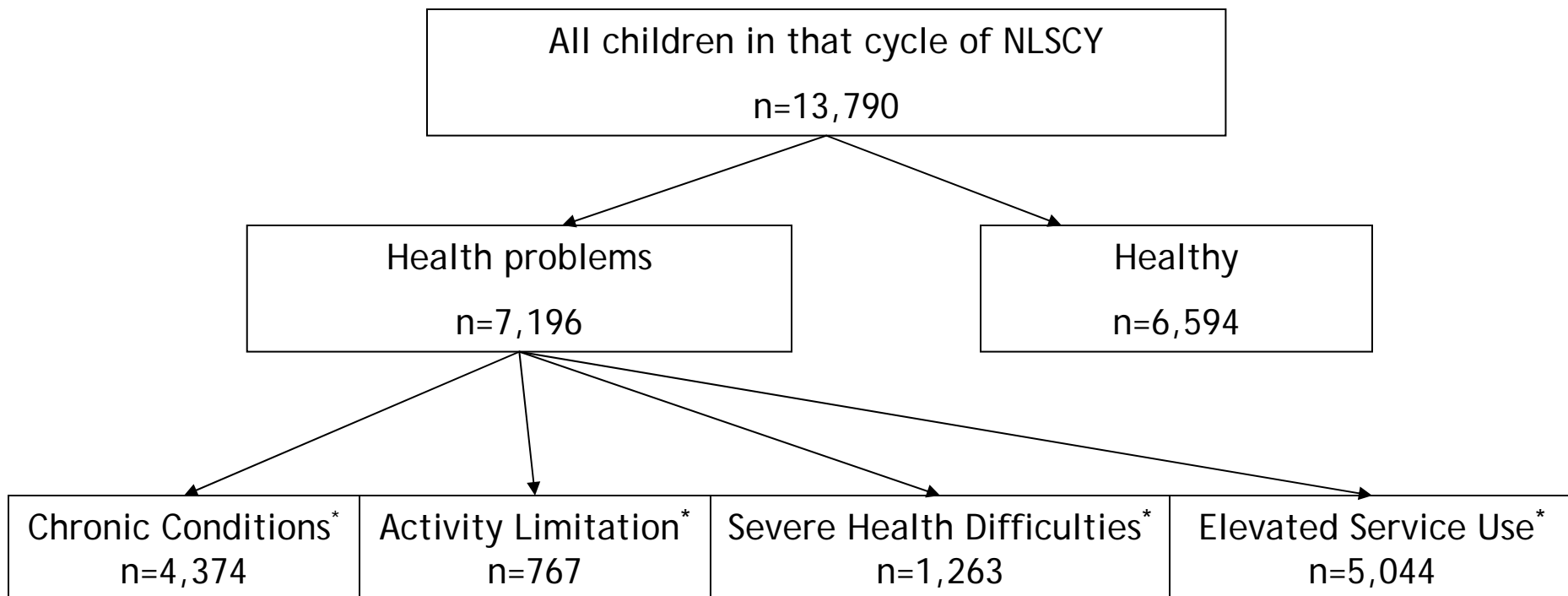
# Project 1. Identifying and defining children in “health status groups” in NLSCY

- Questions, Aims and Challenges
- Methods — use of 4 key health “indicators” of childhood health problems

# Project 1. Identifying and defining children in “health status groups” in NLSCY

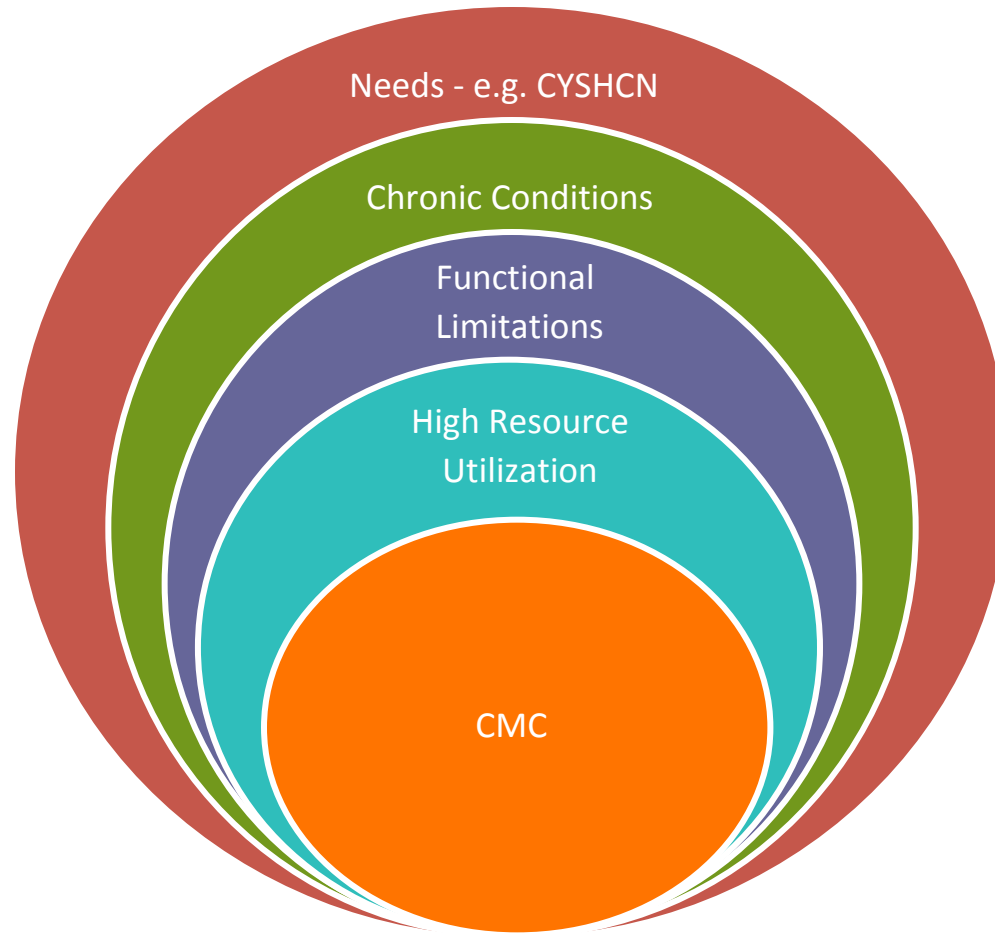
4 key health “indicators” in NLSCY:

- Presence of Chronic Health Conditions
- Presence of Activity Limitations
- ‘Severe Health Difficulties’ (functional limitations on Health Utilities Index)
- Elevated Service Use



\* The four groups are not mutually exclusive.

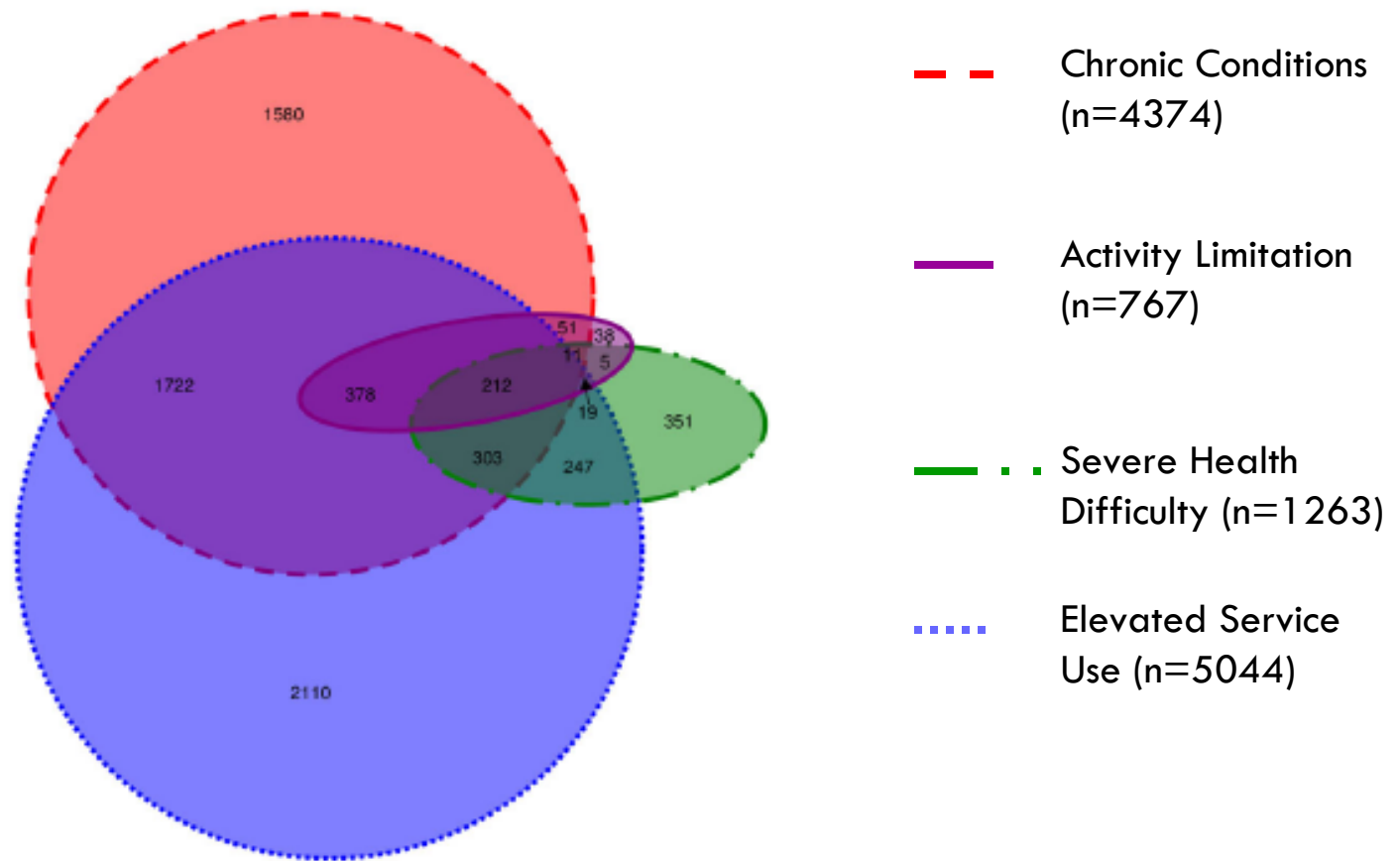
# Children with medical complexity: conceptual framework



Courtesy of Dr Eyal Cohen, Complex Care Program, Hospital for Sick Children, Toronto



# Children with special needs: empirical categories



Conceptualizing childhood health problems using survey data: a comparison of key indicators  
(Kohen, Brehaut, Garner, Miller et al. *BMC Pediatrics* 2007 )

## Project 2. Identifying and describing children with Neurodevelopmental Disorders and Disabilities (NDD/D) in the Canadian population

- Context (“Participation Study”)
- Collaborators
- Data Source: Participation and Activities Limitation Survey (PALS)



*The federally sponsored Canadian Participation and Activity Limitation Survey (PALS) aims to document the participation in society among Canadian adults and children with disabilities (persons whose everyday activities are limited because of a health-related condition or problem)*

# Project 2. Identifying and defining children with NDD/D in PALS

Aim of overarching project

- Participation in activities among children with NDD/D



## Project 2. Identifying and defining children with NDD/D in PALS

- Challenges
- Aims of this part of project:
  - identify children with NDD/D
  - ascertain what kind of NDD/D group each child belongs to
  - describe children with NDD/D in Canada
    - demographic characteristics
    - how distributed across NDD/D groups

# Project 2. Identifying and defining children with NDD/D in PALS

## Emerging issues

- Identifying and ascertaining children with NDD/D
  - based on diagnostic information
  - based on functional limitation information
- Complexity among children with NDD/D

## Additional questions

- how does diagnostic information for each child align with functional information?
- how does complexity present in this population and how prevalent is it?

# Project 2. Identifying and defining children with NDD/D in PALS

## Methods

- Defining and operationalizing our non-categorical population (i.e. children with NDD/D)
- Definitions
  - developmental disabilities
  - intellectual disabilities
  - neurodevelopmental disorders
  - neurodevelopmental disabilities

# Project 2. Identifying and defining children with NDD/D in PALS

## Our definition of NDD/D

Impairment in main domains of child development

- Motor
- speech-language/communication
- intellectual-learning
- reciprocal social interaction

Plus

- sensory impairment
- psychological - emotional- behavioral



# Project 2. Identifying and defining children with NDD/D in PALS

## Operationalizing definition for PALS

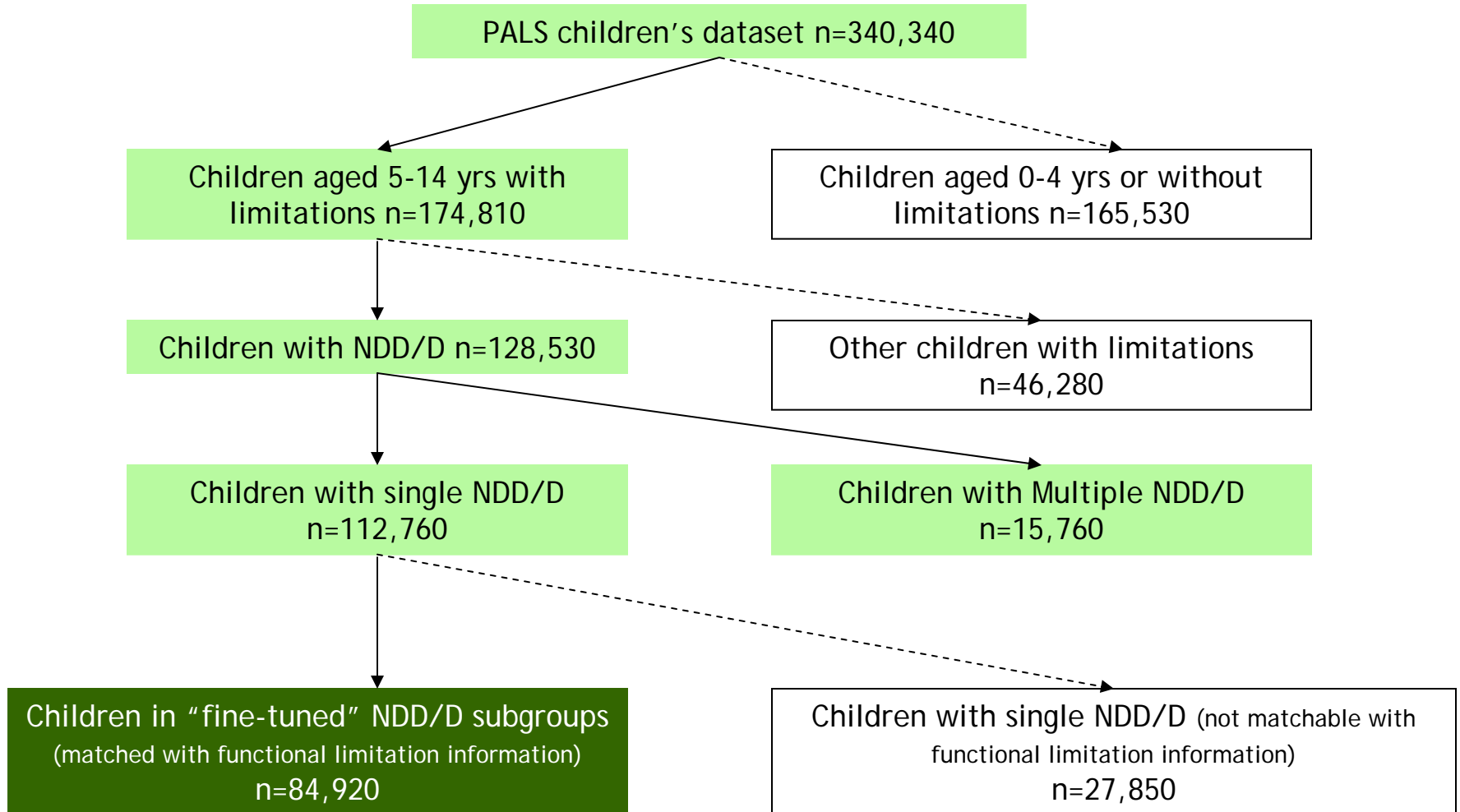
Use of diagnostic information (ICD-10 codes) with some supplementary “fine tuning” using functional information.

## Ascertaining and classifying children in PALS

A multi-step process

1. Review of ICD-10 codes for all children in the dataset.
2. Determine the significance of multiple diagnoses, when present.
3. Use of functional limitations information to “fine tune” a child’s NDD/D subgroup assignment

# Children with NDD/D in PALS



# Children with NDD/D in PALS

	NDD/D subgroups					
	Motor	Speech-language	Learning-cognition	Social	Sensory	Psychological
N	9030 (10.6%)	4380 (5.2%)	24430 (28.8%)	16910 (19.9%)	11310 (13.3%)	18860 (22.2%)
Example of common ICD-10 diagnoses	* (G809) Infantile Cerebral Palsy, Unspecified * (Q059) Spina Bifida, Unspecified	* (R478) Other And Unspecified Speech Disturbances * (R470) Dysphasia And Aphasia	* (F819) Developmental Disorder Of Scholastic Skills, Unspecified * (Q860) Fetal Alcohol Syndrome (Dysmorphic)	* (F840) Childhood Autism * (F845) Asperger's Syndrome	* (H919) Hearing Loss, Unspecified * (H547) Unspecified Visual Loss	* (F900) Disturbance Of Activity And Attention * (F988) Other Specified Behavioural And Emotional Disorders With Onset Usually Occurring In Childhood And Adolescence

# Children with NDD/D in PALS

## Alignment of diagnostic with functional information

Functional impairment information	Diagnosis-based NDD/D group
Simple match	15810 (14.0%)
Match + 1 limitation	18130 (16.1%)
Match + 2 limitations	19660 (17.4%)
Match + 3 limitations	18010 (16.0%)
Match + 4 limitations	11170 (9.9%)
Match + 5 limitations	2140 (1.9%)
Non-match	27840 (24.7%)
Total	112760

# Children with NDD/D in PALS

## Diagnostic Complexity

Number of ICD-10 diagnoses	NDD/D subgroups					
	Motor	Speech-language	Learning-cognition	Social	Sensory	Psychological
1 or no ICD-10 diagnosis	5200 (57.5%)	2880 (65.6%)	12880 (52.7%)	10480 (62.0%)	7840 (69.3%)	10730 (56.9%)
2 or 3 ICD-10 diagnosis	3840 (42.5%)	1510 (34.4%)	11550 (47.3%)	6430 (38.0%)	3470 (30.7%)	8130 (43.1%)
Total	9030	4380	24430	16910	11310	18860

# Children with NDD/D in PALS

## Functional Complexity

Number of functional limitation area reported	NDD/D subgroups					
	Motor	Speech-language	Learning-cognition	Social	Sensory	Psychological
1 or 2	3490 (38.6%)	1960 (44.8%)	11890 (48.6%)	1500 (8.9%)	8030 (71.0%)	7090 (37.6%)
3	1620 (18.0%)	1360 (31.1%)	5780 (23.7%)	3270 (19.4%)	1790 (15.8%)	5830 (30.9%)
4 or 5 or 6	3920 (43.4%)	1060 (24.1%)	6770 (27.7%)	12130 (71.8%)	1500 (13.2%)	5950 (31.6%)
Total	9030	4380	24430	16910	11310	18860

# Concluding Comments

Where this work fits in

- Foundational
- Enabling
- Supporting a research and clinical perspective
- Adding to knowledge