

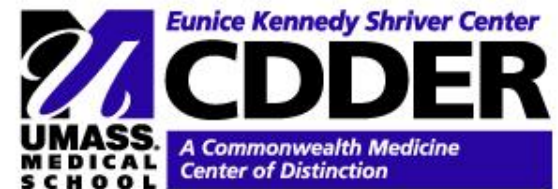
Operational Definition of Intellectual Disability: Getting it right for national health surveillance

Alixé Bonardi

Emily Lauer

University of Massachusetts Medical School, E.K. Shriver Center.
Center for Developmental Disabilities Evaluation and Research

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Team Members

UMMS Center for Developmental Disabilities Evaluation and Research (CDDER)



Alexandra Bonardi, OTR/L, MHA (PI)
Emily Lauer, MPH
Steven Staugaitis, PhD
Courtney Noblett, MPH

Human Services Research Institute (HSRI)



Val Bradley, MA
Sarah Taub, MA
Julie Bershadsky, PhD

Public Health Surveillance and Health Disparities

“We’re invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up.”

Participant – Surgeon General’s Conference on Health Disparities and Mental Retardation 2001

Who are we talking about?

- Eligible for state DD/ID specific services (NCI)
- Self-identify on national health survey (NHIS)
- Receive SSI/SSDI because of an intellectual disability (SSA)
- A diagnosis of a 'related condition' ~ Autism, Down Syndrome... (Medicaid/Medicare or survey)
- People who were identified with 'MR / ID' in school?



WIKIPEDIA
The Free Encyclopedia

Article [Discussion](#)

Intellectual disability

From Wikipedia, the free encyclopedia

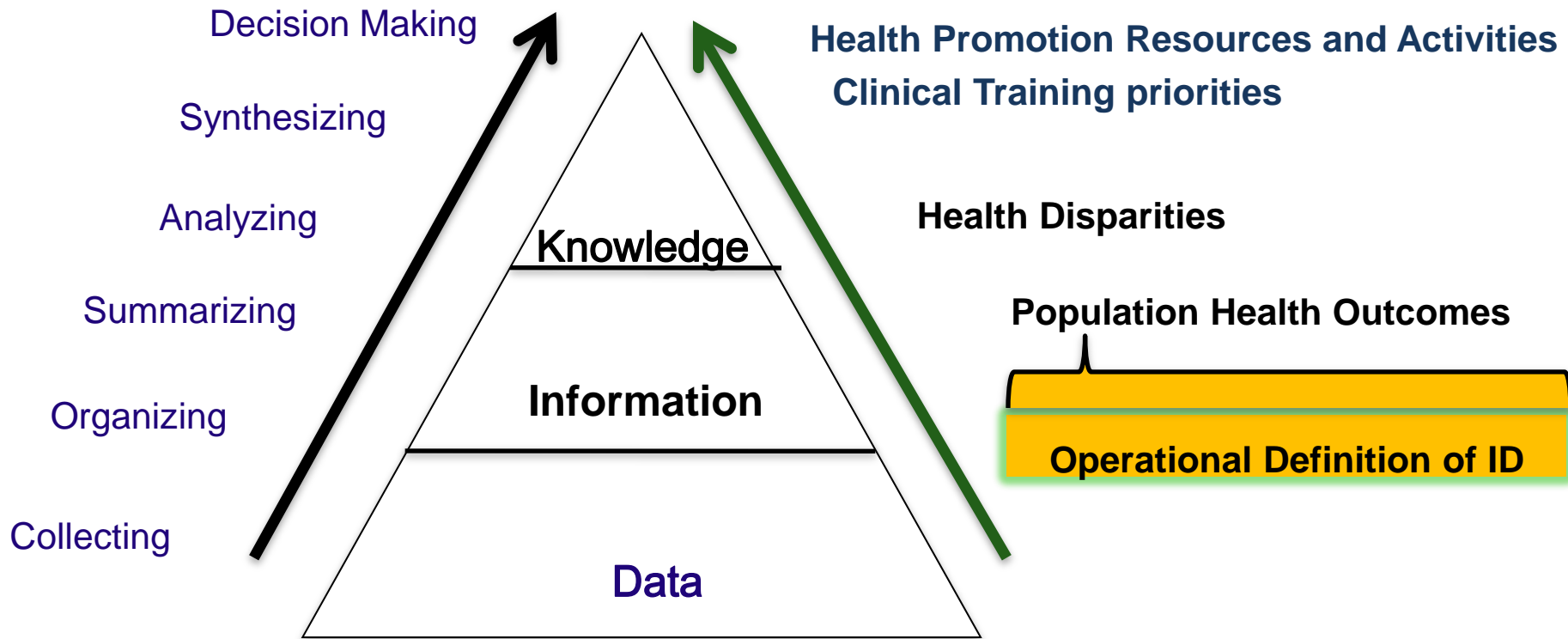
*This article is about the general term relating to disabilities involving the mind.
For the medical condition, see [Mental retardation](#).*

“Intellectual disability is a broad concept encompassing various intellectual deficits, including [mental retardation \(MR\)](#), deficits too mild to properly qualify as MR, various specific conditions (such as [specific learning disability](#)), and problems acquired later in life through [acquired brain injuries](#) or [neurodegenerative diseases like dementia](#). Intellectual disabilities may appear at any age.

Intellectual disability is also increasingly being used as a synonym for the term mental retardation as used in standard medical references.”

(accessed May 12, 2011)

Defining the population for health surveillance



“Surveillance demands uniformity, simplicity,
and brevity”

(MMWR vol. 39/No. RR13)

*“The myriad of **needs** for disability data and a **general lack of consensus regarding an operational definition** of disability leads to data collections that use different questions and combine information in different ways to define the population of people with disabilities”*

(Livermore & She, 2007)

Health Surveillance of Adults with ID

1. **Define ID** (“Who are we talking about?”)
2. **Compile and synthesize a knowledge base** (“What are we talking about?”)
3. **Extend past analyses** of existing data sources that capture health information for people with an ID...
4. **Pilot state or regional demonstrations**
5. **Develop sustainable approaches to expand surveillance**

2010 RTOI: Health Surveillance in Adults with Intellectual Disability

1. Operational Definition of ID
2. Compendium of sources of health data, including a critical review of reliability, validity, and utility,
3. Expand knowledge about the population not included in current sampling frames.

Input and guidance from the Project Advisory Group.

Defining Intellectual Disability for Health Surveillance

To date:

- Review of current definitions
- Summit: Developing an Operational Definition of ID
- Draft definition

We are now in the **comment period**

Identifying the population with Intellectual Disability

ADMINISTRATIVE definitions (used for eligibility / funding)

- AAIDD
- Developmental Disabilities Act (DD Act)
- ICD-9, ICD-10
- DSM-IV, DSM-V
- SSI/SSDI

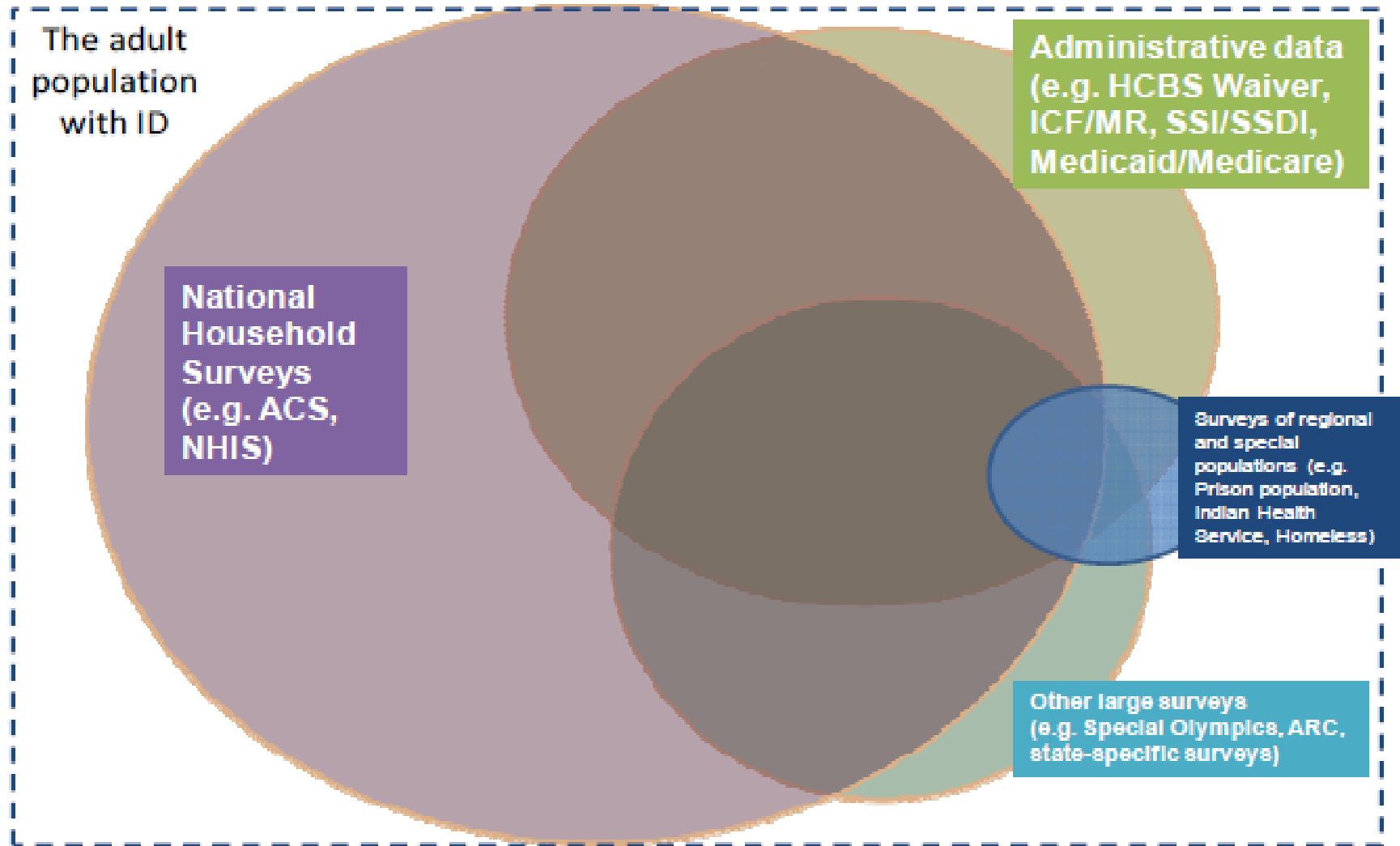
SURVEY (examples)

- Current Population Survey and American Community Survey
- National Health Interview Survey
- Behavioral Risk Factor Surveillance System
- Survey of Income and Program Participation

Additional sample frames

- ICF
- Special Olympics
- Metropolitan Atlanta DD Surveillance program
- Pomona Project (range)

US Health Surveillance Sources



Expert Summit to Define ID

Multi-stakeholder participation:

Self Advocates and family members

Researchers,

State ID/D service providers,

Clinicians

Input from Federal agencies – need more!

- Pre-summit materials (summary of current definitions of ID)
- One day summit to develop draft (4-13-11)
- Summit notes and draft definition

Assumptions

1. Focus on ***adults with intellectual disability***.
2. Focus on ***health surveillance***, recognizing that health is one of many important areas of quality of life.
3. **Intellectual Disability = Mental Retardation**
4. Health surveillance demands a ***representative population***.
5. **Ethical issues** of labeling must be considered.
6. Definition primarily for health surveillance. **Not intended for eligibility.**

Guiding Principles

- ✓ Applicable now and in the future
- ✓ Include a functional component to the inclusion criteria. (Not solely based upon IQ score)
- ✓ Go beyond service eligibility definitions.
- ✓ To the degree possible, identify (neurodevelopmental) cause of ID.
- ✓ Refrain from putting a negative value on people with intellectual disabilities.
- ✓ Definition needs to be mindful of ('fit over') current, ongoing, and any new data collection efforts.

Framing the review of current definitions of ID/DD :

Use of AAIDD Domains

DOMAIN	AAIDD	DD Act	SSI/SSDI	State ID/D Services	ICD-10	DSM-V
1. Intellectual Abilities	✓		✓	☑	✓	✓
2. Adaptive Behavior	✓	✓	✓	☑		✓
3. Health			✓	☑	✓	✓
4. Participation		✓	✓	☑		
5. Context						
Age of onset*	✓	✓	✓	☑		✓
Support needs*	✓	✓				✓

Example

DOMAIN	AAIDD	DD Act	SSI/SSDI	State DD Services	ICD-10	DSM-V
Domain #1 Intellectual Abilities	Limitation assessed 2 SD below mean		Significantly sub-average intellectual function (assessed by IQ)	8 no 17 ID 22 ID+ rel. conditions	Standardized IQ under 70	Generally, IQ under 70

Example

DOMAIN	AAIDD	DD Act	SSI/S SDI	State DD Services	ICD-10	DSM-V
Age of onset*	Before 18	Before 22	Before 22	Varies		Develop- mental pd.
Support needs*	Assumes: With appropriate personalized supports, over a sustained period, the life functioning of the person with intellectual disability generally will improve.	...need for ...services, individualized supports, or other forms of assistance that are of lifelong or extended...				The limitations result in the need for ongoing support at school, work, or independent life.

Working Definition for Health Surveillance

- [#1] **IQ score approximately 70** or below,
OR a clinician has told the person that they have an ID,
OR “**related condition**” with support need
[Intellectual Abilities and related conditions]
- AND [#2] **needs formal or informal support**
[Adaptive behavior]
- AND [#3] diagnosed in the ‘**developmental period**’.
[Age of onset]
- AND [#4] expected to need some help for their entire life
because of intellectual limitations. [Life-long]
- OR [#5] person is eligible for State or Federal public support
programs because of intellectual disability. [Support needs]

Inclusion

Adults with lifelong intellectual limitation and long term support needs in order to function / participate.

(‘Support’ : Formal, Informal, Environmental.)

[Discussed: Severe learning disability (?)]

Exclusion

Cognitive disability that is short term or first manifested after developmental period.

Disability due to mental or emotional conditions with no intellectual limitation.

[Discussed: Autism/DD with no intel. limit. (?)]

Application of the Definition

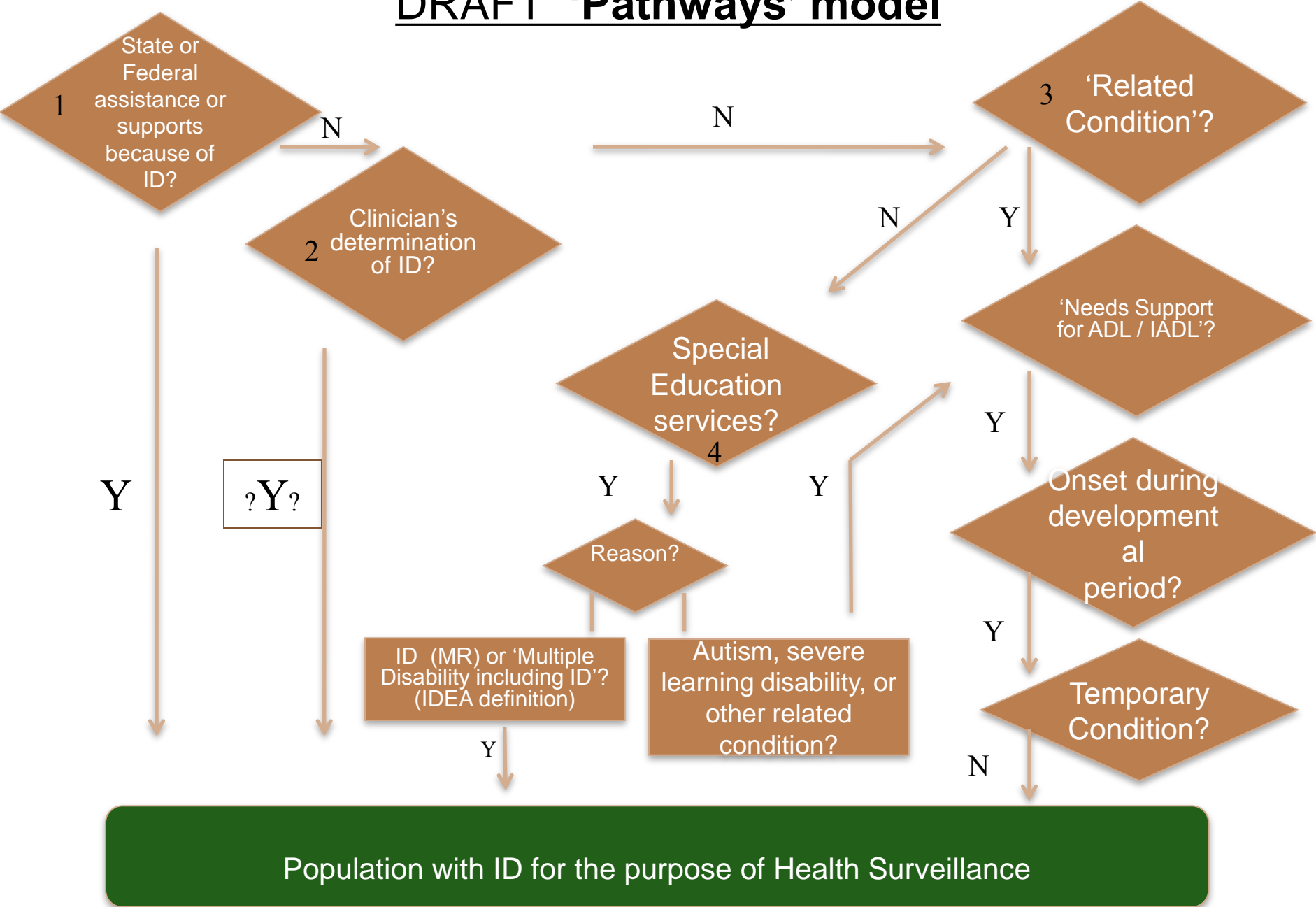
Apply working definition across data sources to identify population by:

- **Mining current administrative or survey data.**
and/or
- **Tweaking current collection** of information (e.g. modification of BRFSS or ACS questions)
and/or
- **New data collection** (e.g. *de novo* survey or longitudinal study)

Pathways to identifying the population with ID

1. Eligible for services because of ID?
2. Test of intelligence, or determination by clinician?
3. Related condition and difficulties in learning?
4. Special education?

DRAFT 'Pathways' model



NHIS-D 'Related Conditions'

Acromegaly

Amino Acid Transport
Disease

Autism

Branched chain amino
acid disturbance

Cerebral palsy

Congenital anomaly

Congenital birth defect

Congenital CMV

Congenital hypothyroidism

Congenital syphilis

Copper metabolic disorder

Deformity of the skull

Down syndrome

Encephalopathy

Epilepsy

Hydrocephalus

Klinefelter's syndrome

Leukodystrophy

Lipodoses

Noxious substance affecting
newborn

Other brain or CNS condition
or deformities

Reduction deformity of
the brain

Sex chromosome
anomaly

Spina bifida

Thalasseмии

Tuberous Sclerosis

Unknown Congenital
or birth injury

(Larson, S., Lakin, C. , Anderson, L et al MR/DD Data Brief April 2000, Vol. 2. No. 1)

Ongoing considerations

- Language is important – MR, learning disability, neurodevelopmental disorder.
- Self-identification, proxy, presumptive ID?
- ID = MR?
- Comparison with other populations
- Comparison within population
- Health outcomes of particular interest

Research methods discussion

Feasibility / recommendations:

- Using existing administrative data
- In surveys
- In new data collection.

Use of model

- to guide development of survey questions / methods?
- to describe the population included / excluded in sample frame?

Contact

Alixé Bonardi

Alexandra.Bonardi@umassmed.edu

Emily Lauer

Lauer.Emily@gmail.com