

Research & Data

An evidence library for disability, safety, autonomy, accessibility, abuse prevention, family support, and systems practice

Evidence-informed • person-centered • rights-respecting • implementation-focused

WHY THIS LIBRARY EXISTS

A statistic without a denominator, population, date, method, or source can mislead. This guide is designed to help readers trace claims back to evidence and understand what the evidence can - and cannot - establish.

1. Evidence hierarchy used by Oklahoma Child Wellbeing

Tier 1 - Authoritative standards and surveillance

Current federal/public-health data, regulations, technical standards, major national surveillance systems, and international public-health reports.

Tier 2 - Systematic reviews and meta-analyses

Evidence syntheses that use explicit search and appraisal methods. Quality still varies; heterogeneity and study limitations matter.

Tier 3 - High-quality primary research

Well-designed cohort, case-control, cross-sectional, qualitative, mixed-method, or intervention studies appropriate to the question.

Tier 4 - Consensus, position, and practice guidance

Useful for implementation, ethics, rights, and professional standards, but not automatically proof of intervention effectiveness.

Tier 5 - Emerging evidence and lived experience

Critical for identifying problems, mechanisms, priorities, and implementation realities; should be labeled accurately rather than overstated.

2. How to read a disability statistic

- Population: children, adults, people with intellectual disability, autistic people, all disabled people, service users, or another group?

- Geography and setting: national, state, institutional, community, school, healthcare, or convenience sample?
- Outcome definition: what exactly counted as abuse, violence, access, autonomy, quality of life, or disability?
- Denominator: percent of whom?
- Timeframe: lifetime, past year, current, or point prevalence?
- Method: self-report, caregiver report, administrative data, clinical record, survey, or interview?
- Uncertainty: confidence interval, sample size, missing data, bias, heterogeneity?
- Comparison: prevalence ratio, odds ratio, risk ratio, or raw percentage? These are not interchangeable.
- Causality: an association does not prove that disability itself caused the outcome.

3. Core evidence snapshot

Topic	What strong evidence says	Important limitation	Primary source
Global disability	WHO estimates about 1.3 billion people - roughly 16% of the world population - experience significant disability.	Global estimate; definitions and measurement vary across countries.	WHO 2022
Health equity	WHO documents substantial avoidable health inequities affecting people with disabilities and identifies health-system and social barriers.	The report synthesizes global evidence; conditions differ by country and disability group.	WHO 2022
Autonomy & decision-making	A 2025 qualitative systematic review found adults with intellectual disability often reported decisions being made for them and autonomy not being prioritized.	15 studies/246 participants; qualitative synthesis, heterogeneous methods.	J Intellect Disabil Res 2025
Everyday decision support	A systematic review of 81 papers found adults with intellectual disability want to make decisions and may need support; SDM is prominent but implementation evidence remains underdeveloped.	Mostly qualitative literature; SDM effectiveness questions remain.	Aston et al. 2023
Family-centered care	A 2024 systematic review identified components including shared decision-making, family education, cultural respect, engagement, social/emotional support, and recognition of family needs.	Only 10 studies met criteria; outcome evidence is not uniform.	Systematic review 2024

Topic	What strong evidence says	Important limitation	Primary source
Interprofessional care	A scoping review found a small, heterogeneous evidence base for team-based primary care for adults with IDD.	Only 20 records; mostly descriptive and North American.	Bobbette et al. 2020
Joint working	A 2023 systematic review found information-sharing important and responsibility confusion a barrier to joint work between acute and disability services.	12 publications; evidence emphasizes provider experience.	Systematic review 2023
Digital accessibility	DOJ's Title II web/mobile rule uses WCAG 2.1 Level AA as the technical standard for covered state/local government web content and apps, with compliance dates extended in 2026.	Legal applicability depends on entity/content and exceptions.	DOJ ADA.gov

4. Evidence appraisal checklist

- ☐ Is the source primary research, a systematic review, surveillance, guidance, or opinion?
- ☐ Is the population the same population being discussed?
- ☐ Is the source current enough for the claim?
- ☐ Are inclusion/exclusion criteria clear?
- ☐ Were measures validated or clearly defined?
- ☐ Is the sample large and representative enough for the conclusion?
- ☐ Are confounding and bias addressed?
- ☐ For meta-analysis: is heterogeneity reported and interpreted?
- ☐ Are absolute numbers provided alongside relative measures when possible?
- ☐ Does the conclusion match the study design?
- ☐ Are limitations visible rather than buried?
- ☐ Can a reader reach the original source?

5. Claim-writing rules

- Write 'associated with' when the design does not establish causation.
- Name the population and timeframe near the statistic.
- Do not generalize a study of intellectual disability to all disabilities without justification.
- Do not turn an odds ratio into 'times more likely' without careful explanation.
- Do not combine unlike prevalence estimates into one headline number.
- When studies are heterogeneous, say so.
- Use the newest high-quality synthesis when it materially changes older estimates.

- Separate legal requirements, ethical principles, and empirical effectiveness claims.

6. Research gaps worth tracking

- Long-term real-world outcomes of supported decision-making.
- Interventions that reduce abuse and exploitation while preserving autonomy.
- Accessible reporting systems and disclosure pathways for people with communication disabilities.
- Cross-system models that demonstrably improve closed-loop follow-up.
- Disability-inclusive measures of safety that include autonomy, dignity, and participation.
- Interventions designed and evaluated with people with disabilities as co-researchers or co-educators.
- Family support models that reduce caregiver burden without increasing control over the disabled person.

7. Citation record template

Field	Record
Full citation	_____
URL/DOI	_____
Publication date	_____
Study type	_____
Population/sample	_____
Setting/geography	_____
Outcome definition	_____
Key finding	_____
Uncertainty/CI	_____
Limitations	_____
What claim this source supports	_____
Date source was checked	_____

References & trusted sources

Source hierarchy: current federal/public-health guidance and rights standards; systematic reviews and evidence syntheses; then supporting peer-reviewed studies. Legal requirements vary by setting and jurisdiction.

1. WHO. Global report on health equity for persons with disabilities (2022). [Source](#)
2. Aston P, et al. Everyday decision-making: systematic review (2023). [Source](#)
3. Perceptions of people with intellectual disabilities on autonomy and decision-making: systematic review (2025). [Source](#)
4. Impact of family-centered care in families with children with intellectual disability: systematic review (2024). [Source](#)
5. Bobbette N, et al. Interprofessional team-based primary health care: scoping review (2020). [Source](#)
6. Joint working between acute and disability services: systematic review (2023). [Source](#)
7. U.S. DOJ. Title II Web and Mobile Accessibility Rule fact sheet, updated for 2026 IFR. [Source](#)

EVIDENCE INTEGRITY

Where evidence is mixed, emerging, or primarily qualitative, this resource says so. Rights-based standards and legal requirements are not presented as randomized-trial findings, and associations are not presented as causation.

Prepared for Oklahoma Child Wellbeing • Disability, Safety & Autonomy

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