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Meaningful Geroscience Outcomes for Intrinsic Capacity in People with Intellectual and/or Developmental Disabilities (IDD)

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Contents

I. Executive Summary

Geroscience aims to understand and modify the biological and social processes of aging to extend "healthspan," the length of life a person spends in good health. However, traditional geroscience outcome measures, which often focus on endpoints specific to disease, laboratory biomarkers, or narrowly defined functional tests, frequently fail to capture what healthy aging means to people with intellectual and/or developmental disabilities (IDD). For many individuals with IDD, healthy aging is not defined by the absence of disease alone, but by sustained energy, comfort, social participation, autonomy, and the ability to continue doing the things they value. As Beard (2025) notes, the outcome of greatest importance to most people is not simply how long they live, but the quality of those years, a distinction that is especially critical when applying geroscience frameworks to populations like people with IDD, whose lived experience of health cannot be captured by disease incidence alone.

This paper operationalizes priorities defined by stakeholders (adults with IDD, family members, clinicians, insurers, researchers, and policymakers) through the IIDDEAL (Individuals with IDD Engaged, Aligned, And Leading) project and translates them into meaningful and measurable geroscience outcomes using the World Health Organization (WHO) Intrinsic Capacity framework. By aligning IIDDEAL's community-defined consensus of what outcomes matter most with a globally recognized aging framework, we provide practical guidance for researchers seeking to design inclusive, rigorous, and equitable geroscience knowledge, and for clinicians seeking to apply geroscience strategies in support of people with IDD.

Key recommendations include:

1. Centering community priorities from the earliest stages of research design;
2. Using standard geroscience measures alongside tools adapted for IDD, rather than replacing accepted measures;
3. Accounting for differences in baseline function and accelerated aging trajectories in IDD populations; and
4. Emphasizing outcomes that reflect social and community participation, autonomy, and quality of life as central indicators of healthy aging.

II. Introduction: Bridging Geroscience and IDD Community Priorities

What is IDD?

IDD encompasses a diverse range of conditions, including autism spectrum disorder, Down syndrome, cerebral palsy, and fragile X syndrome, that are present at birth or develop during childhood. These conditions can result in challenges with cognition, communication, mobility, and daily functioning, though the nature and severity of these challenges vary tremendously from person to person and across different conditions.

A critical aspect that many geroscientists may not recognize is that a person with IDD's capabilities and resilience can vary greatly from day to day based on environmental factors, physical health, emotional state, stress levels, and available supports. What someone can accomplish independently on one day may require significant support on another, and this variability is a normal part of the lived experience rather than a marker of decline. Environmental modifications, such as sensory accommodations, visual schedules, assistive technology, or the presence of a familiar support person, can dramatically influence function and wellbeing. This day-to-day variability means that single-point assessments can be misleading, and longitudinal measurement approaches that capture patterns over time are essential.

Equally important is adopting a strengths-based approach when working with people with IDD. Rather than focusing primarily on deficits or limitations, a strengths-based perspective recognizes and builds upon each person's capabilities, preferences, interests, and resilience. This approach acknowledges that people with IDD possess unique skills, knowledge, and ways of experiencing the world that should be valued and leveraged in research, clinical care, and intervention design. It means asking "What can this person do?" and "What supports would help them thrive?" rather than cataloging what they cannot do. In the context of aging research, this translates to measuring maintenance of valued activities and participation rather than solely focusing on decline, and to recognizing adaptation and compensatory strategies as markers of successful aging rather than indicators of deterioration.

The Intersection of IDD and Aging

The relationship between IDD and aging presents unique patterns that challenge conventional geroscience frameworks. Some individuals with IDD, particularly those with Down syndrome, experience accelerated aging and earlier onset of age-related conditions such as Alzheimer's disease, often appearing in their 40s and 50s rather than later in life. Conversely, other conditions may follow different aging trajectories that don't align with typical patterns observed in the general population. Adults with IDD face higher rates of chronic health conditions including cardiovascular disease, diabetes, epilepsy, and osteoporosis, often presenting earlier and with greater complexity than in non-disability populations (McLean et al., 2025).

Beyond biological aging, the aging experience for people with IDD is shaped profoundly by social and systemic factors. Many aging adults with IDD depend on family caregivers who are themselves aging and facing declining health, creating a dual-aging dynamic rarely captured in traditional geroscience research. Nearly one million households in the United States include adults with IDD supported by an aging caregiver, and as parents and caregivers age, they may become unable to support their adult child to the same extent because of illness or other health concerns (Centers for Medicare & Medicaid Services, n.d.). Research shows that by early old age, parents of individuals with IDD had significantly poorer health and mental health than comparison parents, and that long-term co-residence may take a particular toll on parental psychological functioning. Depression emerges as parents reach old age, as they grapple with their own functional limitations while simultaneously planning for their child's long-term future (Seltzer et al., 2011). Conversely, further research is warranted to identify the potential of increased stress as adults with IDD assume some caregiver roles for their aging parents.

The weathering effect, how chronic exposure to social stressors, healthcare barriers, marginalization, and inadequate support systems accelerates biological aging, may be particularly pronounced in this population. Research consistently highlights that aging and functional deterioration occur prematurely among people with IDD, with some consensus that signs of functional decline can begin as early as age 45, presenting symptoms of aging typically not observed in the general population until ages 65 to 70 (Cuesta Gómez et al., 2023). Identified causes include lifelong lack of prevention and health monitoring programs, reduced access to health services, and low quality social and health care, which cause functional deficits to accumulate over time (Cuesta Gómez et al., 2023). People with IDD experience chronic, lifelong stressors central to the weathering framework: as a group, they meet all established criteria for a health disparity population, having experienced a documented history of institutionalization, marginalization, unmet health care needs, and adverse social determinants of health (Krahn et al., 2015). They face the same conditions, including social exclusion, limited access to education and community life, and structural barriers to care, that have been shown to accelerate biological aging through weathering in other marginalized populations (Krahn et al., 2015). Ensuring that geroscience advances are accessible and equitable, rather than benefiting only wealthy or well-resourced populations, has been identified as a foundational principle for the field moving forward (Whitman & Tan, 2025). Yet the weathering framework has never formally applied to people with IDD. This is a critical gap: among people with intellectual disabilities, 37% of deaths have been identified as avoidable, attributable to factors addressable through quality care, compared to only 13% in the general population (Hatton et al., 2016; Vos et al., 2025), a disparity that may reflect, at least in part, the unmeasured biological toll of a lifetime of chronic social stress. Additionally, cohort effects matter: older adults with IDD today came of age before the deinstitutionalization movement and may have spent formative years in restrictive settings, whereas younger cohorts have grown up with greater access to inclusive education and community living, potentially influencing their aging trajectories.

Social and Healthcare Context: Insights from the Landscape Review

Healthcare System Challenges: Aging adults with IDD typically see multiple clinical specialists, yet care coordination is inconsistent, increasing the risk of conflicting treatments and medication interactions. Medicare and Medicaid policies often limit access to specialized services, with many adults' reporting difficulty obtaining needed care such as memory assessments, mobility support, dental care, or mental health services. Diagnostic overshadowing, where new symptoms are incorrectly attributed to existing IDD or pre-existing co-occurring conditions rather than investigated as possible new, age-related illnesses, has the potential to delayed diagnosis and treatment of conditions like dementia, cardiovascular disease, and mental health disorders, and increase the chance of added stress to both the individual and their support persons. Specialized centers for geriatric care even have clinicians unfamiliar with aging adults with IDD and may make diagnostic and therapeutic errors.

Caregiving Realities: The majority of aging adults with IDD depend on family caregivers who face their own declining health and financial strain without adequate respite services or coordinated support systems (Heller & Caldwell, 2006; O'Dwyer et al., 2018). When these primary caregivers pass away or can no longer provide care, transitions to new living or support arrangements are especially destabilizing, disrupting familiar routines that are essential for wellbeing especially when it occurs suddenly and without warning (Tilley et al., 2023; Egan et al., 2022). Unlike typical elderly adults whose caregivers are usually their adult children, many aging people with IDD have relied on a parent as their primary caregiver for most of their lives, making these transitions particularly profound (Sullivan et al., 2019; Jordan et al., 2023).

Social Determinants and Participation: Mental health challenges, social isolation, and limited access to inclusive recreational programs significantly impact overall wellbeing

(Lough et al., 2020; Mihaila et al., 2024). Transportation barriers restrict access to healthcare, employment, and community activities, with research showing that difficulties accessing and using transport increase the risk of exclusion and loneliness for people with IDD (McCausland et al., 2020; McCausland et al., 2023). Adverse experiences, including trauma, abuse, and discrimination, affect health throughout life and may compound with age (McNally et al., 2021; Keesler & Isbell, 2023). Critically, the ability to maintain meaningful activities, relationships, and roles emerged from community input as a central indicator of healthy aging, yet these participation outcomes are rarely measured in traditional geroscience research (Mihaila et al., 2024; Pham et al., 2024).

Knowledge Gaps in Clinical Care: Healthcare providers and direct support professionals often lack training in recognizing and managing age-related conditions in people with IDD (Kemere et al., 2024). While standardized approaches for essential skills like dementia care adapted for IDD, mobility assessment, pain assessment for individuals with communication differences, and end-of-life planning that honors supported decision-making remain inconsistent across the field, training resources do exist. The challenge is that organizations do not universally require or mandate their use (Centers for Medicare & Medicaid Services, n.d.).

Although significant gaps in formal IDD training persist, it is worth highlighting the growing number of organizations and initiatives that have developed resources to support providers.

- **NICHE (Neurodevelopmental IDD Curriculum in Health Education)** is an interdisciplinary curriculum program developed for medical and dental schools, offering training modules covering IDD health across the lifespan, designed with educators, learners, and self-advocates to address the gap in formal IDD training in health professional education (NICHE, n.d.).
- **The National Task Group on Intellectual Disabilities and Dementia Practices (NTG)** offers training and education specifically focused on ID and dementia, including upcoming webinar series tailored for primary care physicians (National Task Group on Intellectual Disabilities and Dementia Practices, n.d.).
- **The National Down Syndrome Society** provides condition-specific clinical guidance through its CARE program (National Down Syndrome Society, n.d.).
- **Project ECHO (Extension for Community Healthcare Outcomes)**, a telementoring model, has emerged as a promising approach to bridge these gaps. Multiple ECHO programs now offer free, virtual, interprofessional training on IDD care, including aging, dementia, psychiatric care, and primary care topics, with

research demonstrating significant gains in provider knowledge and confidence (Kemere et al., 2024; Clark et al., 2023).

The Challenge

Traditional geroscience research has largely been built around neurotypical populations, with outcomes that emphasize disease prevention, mortality, and narrowly defined functional performance. When applied without adaptation to people with IDD, these outcomes risk misclassifying baseline differences as decline, overlooking meaningful changes, and producing findings that do not translate into improved daily life. As a result, clinicians may find it challenging to apply traditional geroscience findings to people with IDD, may not succeed in supporting a person's health and life goals in doing so, and/or may cause inadvertent harm.

The Opportunity

The IIDDEAL project offers consensus led by the IDD community on what health and healthy aging mean for people with IDD (Pham et al., 2024). Through authentic engagement with over 300 stakeholders, IIDDEAL articulates priorities that reflect lived experience rather than externally imposed clinical norms (Pham et al., 2024).

The Framework

The WHO Intrinsic Capacity framework focuses on the combined physical and mental capacities of an individual and includes cognition, mobility, psychological health, vitality, and sensory functions (Hoogendijk et al., 2023). This framework shifts attention from disease to function, making it well suited for capturing aging trajectories in heterogeneous populations such as people with IDD (Hoogendijk et al., 2023). This framework reflects a broader shift in geroscience thinking away from the traditional disease model and toward a more holistic conception of health, one that Beard (2025) argues may be more effective precisely because it addresses underlying biological processes rather than targeting individual conditions in isolation.

The Purpose

This paper aims to make geroscience research meaningful to people with IDD by translating IIDDEAL priorities into outcomes aligned with intrinsic capacity that are feasible, valid, and relevant across research and clinical contexts.

III. Background: Understanding IIDDEAL and Intrinsic Capacity

IIDDEAL Project Overview

The IIDDEAL project (Individuals with IDD Engaged, Aligned, and Leading), is a multi-phase initiative to develop a consensus approach to measuring quality of care that reflects what good health means for people with intellectual and developmental disabilities. Quality measures are critical levers for improving both clinical care and research, as they determine what is prioritized, measured, and ultimately incentivized.

IIDDEAL used a structured consensus process centered in the community, engaging self-advocates, family members, care partners, clinicians, researchers, and system leaders. Through this process, the project identified nine priority health outcome domains:

- Making healthy choices
- Physical health with reduced pain and improved energy
- Emotional and mental health
- Sexual, reproductive, gender, and parenting health
- Being able to do the things one loves and needs to do
- Caregiver wellness and support
- Improving workforce development
- Payer and regulator needs
- System supports

Across these domains, participants prioritized 29 health care elements that define what high quality care focused on the person looks like for people with IDD (Pham et al., 2024). For example, stakeholders identified access to counselors who understand IDD as one key element supporting emotional and mental health (Pham et al., 2024).

Central to IIDDEAL’s methodology was authentic engagement, valuing lived experience as expertise, accommodating diverse communication preferences, and using plain language to ensure accessibility (Pham et al., 2024).

The resulting domains reflect holistic conceptions of health, including vitality, participation, emotional wellbeing, and the ability to live with dignity and autonomy (Pham et al., 2024).

WHO Intrinsic Capacity Framework

The WHO Intrinsic Capacity framework defines five domains: locomotion, cognition, vitality, sensory capacity, and psychological capacity. Rather than focusing on diagnoses or diseases, intrinsic capacity emphasizes functional ability and change over time in interaction with the environment (World Health Organization, 2020).

Why Adapting Geroscience for IDD Matters

Without intentional translation, geroscience risks producing research that is methodologically rigorous but irrelevant for people with IDD. Aligning IIDDEAL priorities with intrinsic capacity ensures that research outcomes reflect what healthy aging truly means to the community and supports equity in aging research (Pham et al., 2024).

IV. Translating IIDDEAL Priority Domains into Intrinsic Capacity Measures

Domain 1: Vitality – Physical Health, Reduced Pain, and Improved Energy

- **Community Priority Definition**
    - Vitality was consistently described by the IIDDEAL community as having enough energy, comfort, and physical wellbeing to engage in daily life without unmanaged pain or exhaustion (Pham et al., 2024).
- **Mapping to Intrinsic Capacity**
    - This priority aligns most directly with the intrinsic capacity domain of vitality, as well as with locomotion and psychological wellbeing (World Health Organization, 2020).
- **Proposed Measurement Approaches**
    - Use standard vitality measures including endurance or mobility tests alongside tools adapted for IDD, such as the modified ***2-Minute Walk Test*** and the ***Performance-Oriented Mobility Assessment***, which have been validated for use with people with IDD and shown to track physical performance changes associated with aging (Maring et al., 2013).
    - Use pictorial scales of fatigue and energy that can be framed in a positive way and completed with support from caregivers if necessary. For example, the preprint tool ***Autistic Depression Assessment Tool – Adult*** uses a measuring cup with varying levels of "fullness" to pictorially represent internal states, offering a concrete and accessible way to communicate something as abstract as energy levels (Cassidy et al., 2021). Pictorial scales can be more effective for people with IDD because they reduce cognitive and language demands, allowing individuals to express internal experiences without relying on verbal fluency or numerical abstraction (Sheaf et al., 2022).
    - Use pain assessment tools designed for individuals with communication differences. Two validated observational tools include the ***Non-Communicating Adults Pain Checklist (NCAPC)***, an 18-item behavioral scale assessing pain responses in adults with IDD, and the ***Pain and Discomfort Scale (PADS)***, which uses nonverbal behavioral observation rather than self-report (Lotan et al., 2023; Shinde et al., 2014). The ***Wong-Baker FACES Pain Rating***

        Scale is also widely used with individuals who have some communication ability, using facial expression images to rate pain intensity (Wong & Baker, 1988).
        - Use validated administrative screening tools to detect early cognitive changes and monitor for dementia. The ***NTG-Early Detection Screen for Dementia (NTG-EDSD)***, is designed to be completed by family caregivers and direct support staff, recording observations of functional change over time rather than relying on the individual to self-report (National Task Group on Intellectual Disabilities and Dementia Practices, n.d.-b). Adapted from the **Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)**, an instrument developed by Professor Shoumitro Deb and colleagues (2007), the NTG-EDSD has been recognized in clinical guidelines for Down syndrome and validated in studies of mild cognitive impairment, making it a practical first-step screening tool for use across care settings (Deb et al., 2007; Tsou et al. 2020). Its concern-based scoring approach, where two or more concerns suggest possible MCI and three or more suggest progression toward dementia, makes it particularly accessible for non-clinical staff who regularly observe the individual (National Task Group on Intellectual Disabilities and Dementia Practices, n.d.-b; Silverman et al., 2021).
        - Use modified functional tests conducted in community-based settings rather than only in clinics. For example, Maring et al., (2013) modified three standardized performance tools, the ***2-Minute Walk Test*, the *Performance-Oriented Mobility Assessment I*,** and the ***Modified Barthel Index***, specifically for administration with people with IDD in real-world contexts, finding they successfully tracked physical performance changes over time.
    - **Challenges and Adaptations**
        - Accounting for variability from day to day, because people with IDD have good days and harder days.
        - Distinguishing between lifelong baseline differences between a person with IDD and the general populations versus change related to aging.

Domain 2: Preventing Declines Related to Aging in Intrinsic Capacity

- **Community Priority Definition**
    - Preventing decline was framed not as avoiding disability, but as maintaining current abilities and slowing unwanted losses over time (Pham et al., 2024).
- **Mapping to Intrinsic Capacity**
    - This domain cuts across locomotion, cognition, and sensory capacity (Pham et al., 2024).
- **Proposed Measurement Approaches**
    - Longitudinal tracking of functional trajectories rather than cross sectional comparisons to general populations.
    - Mobility and independence measures that allow for the use of assistive technology if that is what the person typically relies on.
    - Tools for measuring cognitive aging that distinguish baseline IDD from neurodegenerative change, or, where such distinction is not yet possible, instruments that can establish an individual's baseline cognitive and communication abilities and daily living skills in order to detect meaningful change over time that may be associated with neurodegeneration (Silverman et al., 2021; NTG, n.d.).
    - Biomarkers specific to a condition where appropriate, such as Alzheimer's disease risk in Down syndrome.
- **Challenges and Adaptations**
    - Building reference ranges specific to different forms of IDD.
    - Accounting for premature or accelerated aging patterns in some conditions associated with IDD.

Domain 3: Being Able to Do the Things I Love and Need to Do

- **Community Priority Definition**
    - Healthy aging was defined by continued participation in meaningful activities, relationships, and roles (Pham et al., 2024).
- **Mapping to Intrinsic Capacity**
    - This domain aligns with psychological capacity and functional integration across all intrinsic capacity domains (Pham et al., 2024).
- **Proposed Measurement Approaches**
    - Goal Attainment Scaling based on priorities focused on the person.
    - Participation measures capturing work, social life, and community engagement.

    - Assessments of autonomy and self-determination, including measures of the degree to which people with IDD are supported to make meaningful choices about their care, daily routines, and future planning (Schalock et al., 2008; Verdugo et al., 2012).
    - Assessments of communication that account for the assistive technology and augmentative and alternative communication (AAC) systems the person typically uses, as restricting access to familiar tools will systematically underestimate communicative competence and may invalidate results (Silverman et al., 2021; NTG, n.d.). For example, if a person with IDD relies on a speech-generating device to communicate, an assessment of communication ability should allow for use of that device.
- **Challenges and Adaptations**
    - Centering on the individual's own definition of independence (Pham et al., 2024).
    - Measuring meaning and participation, not just completion of tasks (Pham et al., 2024).

V. Case Studies: Putting Principles into Practice

The following case studies illustrate how IIDDEAL community priorities can be translated into geroscience outcomes aligned with intrinsic capacity that are meaningful, feasible, and sensitive to lived realities. Each case highlights the importance of understanding baseline functioning, context, and fluctuation over time rather than relying solely on standardized clinical benchmarks.

Marcus (42, Down syndrome): Vitality Domain

Figure 1: Stock photo of a man with Down Syndrome.

Background

Marcus is a 42-year-old man with Down syndrome who works part time at a community garden. This role provides physical movement, social connection, and a strong sense of purpose. He lives with his sister and brother-in-law, who provide daily support, supplemented by a paid direct support professional several afternoons each week. His circle of support includes family members, a primary care clinician, a cardiologist, and an occupational therapist based in the community.

Marcus has a history of congenital heart disease repaired in childhood, hypothyroidism managed with medication, and chronic sleep disruption related to obstructive sleep apnea. Beginning at age 40, he has participated in annual cognitive screening for early detection of Alzheimer's disease. While no clear dementia diagnosis has been made, his family has noticed subtle changes, including increased fatigue and occasional need for reminders for tasks that were previously automatic.

Marcus communicates verbally using short phrases and gestures, and reliably expresses preferences, though he has difficulty describing internal states such as pain or fatigue. His medication regimen includes thyroid replacement therapy, a beta blocker, and intermittent use of medications for sleep. Over the past two years, Marcus has experienced increasing joint pain and fatigue that fluctuate from day to day. Marcus's regimen has grown more complex with age, and the interaction effects of thyroid replacement, beta blockade, and sleep medications, and their combined impact on energy, cognition, and cardiovascular function, have not been systematically reviewed as a unified picture of polypharmacy burden.

For Marcus, good health means having enough energy and comfort to work in the garden, socialize with coworkers, and return home without exhaustion or pain. His baseline functioning has historically included consistent participation in physical activity, but recent changes suggest challenges related to aging rather than long standing limitations.

Research Challenge: Standard vitality measures such as the six minute walk test or assessments of oxygen capacity do not capture Marcus's lived experience of energy, pain, or recovery after activity. Additionally, standard measures do not account for the cumulative effects of polypharmacy on fatigue and vitality.

Adapted Measures

- Pictorial fatigue and energy scales completed with caregiver support
- Modified timed up-and-go assessments conducted at home
- Nonverbal pain checklists validated for adults with communication differences
- Occupational therapy evaluations focused on endurance and task-related fatigue, alongside adapted measures of life satisfaction and emotional health. Validated tools specifically developed for people with IDD include the ***Personal Wellbeing Index – Intellectual Disability (PWI-ID),*** a self-report scale using simplified questions and flexible response formats that has demonstrated acceptable psychometric properties across multiple samples and is recommended for tracking change over time (Cummins & Lau, 2005; McGillivray et al., 2009; Patel et al., 2023). Broader emotional and life quality outcomes can also be assessed using

frameworks derived from the ***Schalock and Verdugo Quality of Life Model**,* which encompasses eight core domains including emotional wellbeing, personal development, and self-determination, and has generated multiple validated instruments for use with IDD populations (Schalock et al., 2008; Verdugo et al., 2012).
- Polypharmacy burden assessments, such as medication reviews using the ***Medication Appropriateness Index (MAI)***, integrated with vitality outcomes to examine whether cumulative drug load correlates with fatigue and reduced activity tolerance (Hanlon et al., 1992).

Beyond currently available functional and behavioral assessments, an emerging biological approach offers promising new possibilities for this population:

Emerging Research Opportunity: Biomarkers for Alzheimer's Disease in DS and IDD

- A significant and growing research opportunity involves the use of blood-based biomarkers, including beta-amyloid and tau proteins, as well as PET imaging, which are expected to soon be recommended and implemented to help confirm Alzheimer's disease diagnoses in people aging with Down syndrome and other IDD (Zhou et al., 2025; Russell et al., 2026). Blood-based biomarkers in particular offer a less invasive and more accessible pathway for early detection in this population, which is especially important given the high rates of early-onset Alzheimer's disease in people with Down syndrome and the diagnostic challenges posed by baseline cognitive differences (Zhou et al., 2025). Recent research has also demonstrated concordance between biological and clinical staging of Alzheimer's disease pathology in Down syndrome, strengthening the case for integrating these tools into standard care (Russell et al., 2026).

Why It Matters: These adapted measures capture whether Marcus can sustain meaningful activity with comfort, preserving the physical, psychological, and social benefits that gardening gives him. Emerging biomarker tools may soon allow for earlier and more precise identification of neurodegenerative change in people like Marcus, enabling more timely and appropriate supports. Polypharmacy review is also relevant here: fatigue and reduced endurance in aging adults with IDD may be partly medication-mediated and therefore modifiable. In particular, sedative-hypnotic medications, including benzodiazepines and non-benzodiazepine sleep aids, warrant careful consideration, as evidence from the general population suggests these medications are associated with pharyngeal muscle relaxation, increased apnea duration, and hypoxia, which can worsen OSA and thereby compound daytime fatigue (Hsu et al., 2021). It is important to note, however, that this evidence is drawn from the general population, and IDD-specific research on the relationship between sleep medications and OSA severity remains notably limited, underscoring the need for clinical caution and individualized review in this population.

Lila (58, Autism, diagnosed late): Cognition and Emotional Regulation Domain

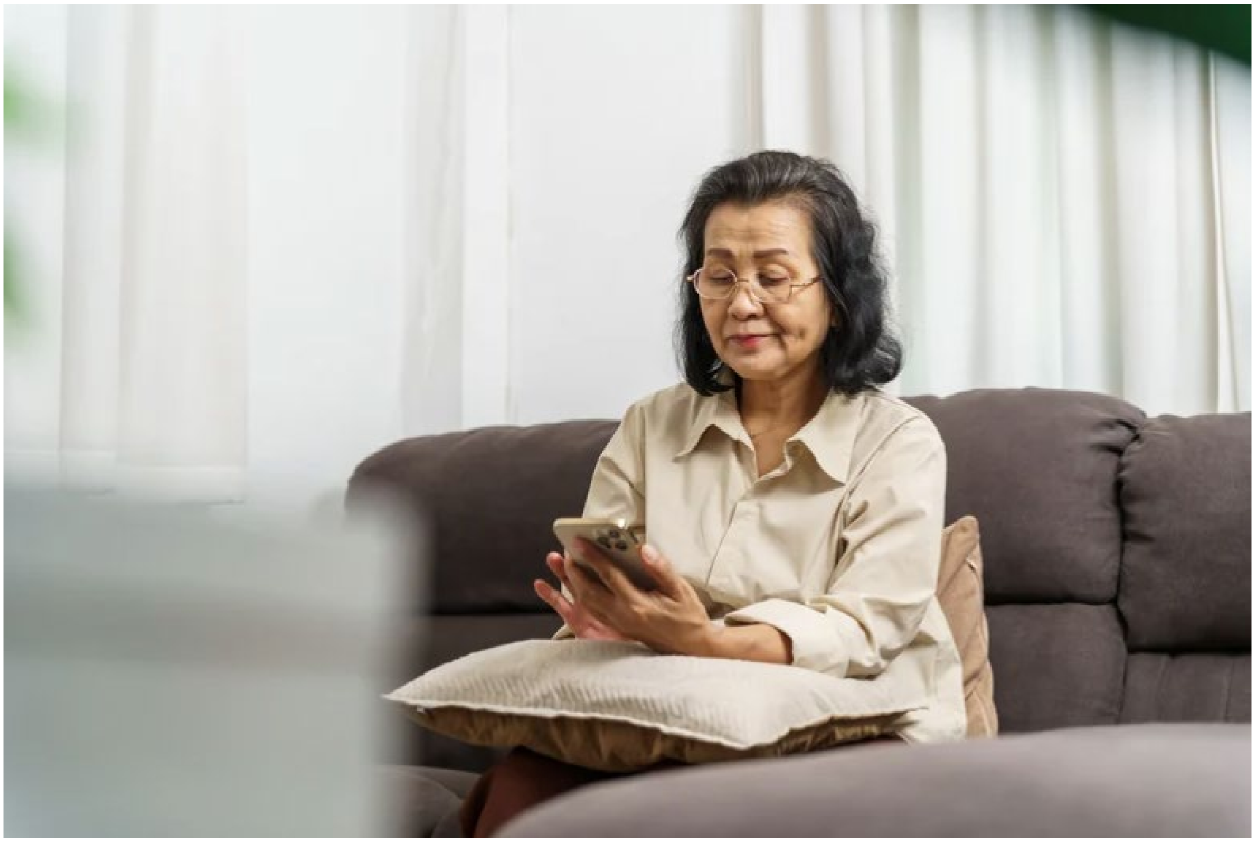

Figure 2: Stock photo of an older woman.

Background
Lila is a 58-year-old autistic woman with an intellectual disability who was diagnosed in midlife after decades of misdiagnosis and inappropriate treatment. She lives in a small group setting with three other adults and consistent staff support. Her support network includes a primary care physician, direct support professionals, a neurologist, a psychiatrist, and a case manager with a long-standing role.

Lila values predictable routines, sensory comfort, and quiet environments. She is minimally verbal and communicates through an augmentative communication device, facial expressions, and behavioral cues. Earlier in adulthood, she was treated with antipsychotic medications for behaviors later understood as expressions of sensory distress and anxiety, a pattern that reflects a well-documented problem in this population, where behaviors rooted in communication differences, sensory processing, and anxiety have historically been misattributed to psychiatric disorders and treated with psychoactive medications without adequate diagnostic clarity (O'Dwyer et al., 2018; Smith et al., 2022). Several of these medications were discontinued after her autism diagnosis, though she continues to need management of a seizure disorder and uses medications for sleep and anxiety.

Lila's history raises an important and underexplored research question: what are the long-term consequences of lifelong or decades-long psychoactive medication exposure on aging in adults with IDD? Antipsychotics are among the most commonly prescribed medications in this population, often initiated in childhood or early adulthood and continued for many years, frequently without a formal psychiatric indication (Yoshida et al., 2025; O'Dwyer et al., 2018). Yet the cumulative physiological effects of this exposure on aging, including metabolic syndrome, cardiovascular risk, extrapyramidal symptoms, bone density loss, and hyperprolactinemia, are poorly understood in the IDD population specifically, and long-term studies in aging adults with IDD remain scarce (Smith et al., 2022; O'Dwyer et al., 2018). Polypharmacy is also common in this group, with autistic adults with IDD showing significantly higher rates of psychotropic medication use and polypharmacy than autistic adults without IDD (Yoshida et al., 2025), compounding these risks as they age. Importantly, the difficulty of deprescribing in this population, due to caregiver concerns, lack of non-pharmacological alternatives, and the absence of IDD-specific prescribing guidelines, means that many individuals like Lila carry decades of medication burden into older age with limited clinical reassessment (Grant et al., 2025; O'Dwyer et al., 2018). Importantly, capturing and measuring this lifetime drug exposure presents its own methodological challenge: medication records are often incomplete, doses and indications have changed across providers and settings, and no standardized instrument exists for quantifying cumulative psychotropic burden in aging adults with IDD.

Lila is post-menopausal and has experienced increased sleep disruption, anxiety, and sensory sensitivity over the past several years. These changes fluctuate in intensity and are often exacerbated by environmental stressors such as staff turnover or changes in routine. Her baseline functioning includes strong pattern recognition skills, independence with familiar tasks, and enjoyment of structured activities.

For Lila, good health means emotional regulation, sensory comfort, predictable routines, and the ability to communicate needs without distress.

Research Challenge: Traditional cognitive and mental health assessments rely heavily on verbal communication and abstract reasoning, which do not accurately reflect Lila's capacities or wellbeing. Existing measures also cannot isolate the contribution of polypharmacy to observed changes, making it difficult to distinguish medication effects from aging or disease progression.

Adapted Measures

- The ***NTG Early Detection Screen for Dementia (NTG-EDSD)***, a structured informant-based screening tool recommended for adults with IDD that tracks cognitive and functional changes over time and can serve as a baseline and longitudinal monitoring instrument in clinical settings, particularly where no off-the-shelf nonverbal cognitive battery currently exists for this population (NTG, n.d.-b.; Silverman et al., 2021)
- Nonverbal cognitive pattern comparison tasks, including tools such as ***Raven's Progressive Matrices*** (Raven, 1998), the ***Leiter International Performance Scale–Third Edition*** (Leiter-3; Roid et al., 2013), and the ***Test of Nonverbal Intelligence–Fourth Edition*** (TONI-4; Brown et al., 2010), which assess fluid reasoning and abstract problem-solving without verbal response requirements, making them particularly suitable for people with IDD who have limited speech, motor impairments, or communication differences.
- Physiological indicators of stress such as heart rate variability
- Visual calmness and distress scales
- Sensory diaries completed with staff support
- Autism-specific tools to measure anxiety, such as the ***Anxiety Scale for Autism-Adults (ASA-A)***, a 20-item self-report measure validated for autistic adults with strong psychometric properties including good internal consistency, test-retest reliability, and a bifactor structure capturing general anxiety, social anxiety, uncertainty, and anxious arousal (Rodgers et al., 2020); and standardized nonverbal cognitive assessment using the Leiter International Performance Scale, Third Edition (Leiter-3), a fully nonverbal measure of fluid intelligence, memory, and processing speed validated across clinical groups including autism spectrum disorder, cognitive delays, and speech and language impairments, with an age range of 3 to 75+ years (Roid et al., 2013; Roid & Koch, 2017)
- Structured lifetime medication exposure inventories, drawing on caregiver records, pharmacy histories, and clinician reports, to quantify cumulative psychotropic burden and support investigation of its relationship to cognitive and physiological aging outcomes.

Why It Matters: These measures prioritize emotional regulation and comfort as core indicators of healthy aging rather than decline based on inappropriate benchmarks. The difficulty of reconstructing and measuring lifelong drug exposure is itself a research problem: without standardized tools for capturing polypharmacy history in this population, the long-term consequences of decades of psychotropic use will remain poorly understood.

Devon (45, Quadriplegic Cerebral Palsy): Participation Domain

Figure 3: Stock photo of a man in a wheelchair.

Background

Devon is a 45-year-old man with quadriplegic cerebral palsy who uses a power wheelchair and an assistive communication device. He lives independently in an accessible apartment with daily personal assistance and works as an accessibility consultant. His circle of support includes personal care attendants, a rehabilitation physician, a urologist, and peers within the disability advocacy community.

Devon has lifelong motor impairments but strong cognitive and communication abilities. He is experiencing changes related to aging, including degenerative spine and joint disease, bladder dysfunction, chronic fatigue, and pain that increase after prolonged workdays. His medication history includes chronic use of antispasmodics, pain management therapies, and bladder medications.

Devon's support circle reflects a pattern common among aging adults with IDD and childhood-onset physical disabilities: he sees multiple specialists but does not have a primary care physician coordinating his overall health. Research on adults aging with cerebral palsy consistently identifies this gap, adults with CP often receive care from a range of specialists without an overarching generalist provider, resulting in fragmented care, limited preventive health monitoring, and poor coordination across conditions (Kramer et al., 2023; Peterson et al., 2021; Sullivan et al., 2011). The absence of a primary care physician means that no single clinician holds a longitudinal view of Devon's health trajectory, monitors for age-related changes across systems, or coordinates his antispasmodic, pain, and bladder medication regimens for interactions or cumulative burden, a gap that becomes increasingly consequential as he ages.

Devon’s baseline functioning included employment on a full-time basis and active civic engagement. Recently, he noticed increased recovery time and reduced stamina, though his autonomy and participation remain central to his identity. Devon has also noted that aging with a physical disability intersects with questions of intimacy and sexuality that his medical team has never addressed. Changes in pain, fatigue, and bladder function have affected his intimate life, yet these impacts remain outside the scope of his specialist appointments and absent from his care record. Devon demonstrates strong psychological assets: he describes his work as meaningful, maintains active civic engagement despite increasing physical demands, and orients toward problem-solving rather than limitation. These characteristics, purpose, optimism, and a growth-oriented approach to disability, are clinically relevant but absent from most participation-focused outcome frameworks.

For Devon, good health means continued independence, meaningful work, and the ability to communicate and participate on his own terms.

Research Challenge: Conventional functional measures such as grip strength or basic activities of daily living underestimate Devon’s autonomy and fail to capture reductions in participation related to fatigue, pain, or lack of communication access. Conventional measures also fail to capture psychological strengths such as purpose, optimism, and growth mindset that may buffer against age-related decline in participation. Nor do they address sexuality and intimate functioning, which are affected by pain, fatigue, and bladder dysfunction but treated as outside the scope of participation research.

Adapted Measures

- Individualized participation and goal attainment measures, including person-centered outcome measures such as those developed through the ***NCQA Person-Centered Outcome (PCO) Measures initiative*** (National Committee for Quality Assurance, n.d.) and Goal Attainment Scaling (GAS), which evaluates progress toward individually defined goals (Kiresuk & Sherman, 1968).
- Assessments of autonomy when appropriately supported by technology
- Modified measures of activities of daily living that account for assistive technology, such as the ***Waisman Activities of Daily Living Scale (W-ADL)***, a validated 17-item informant-rated measure developed specifically for adolescents and adults with developmental disabilities that scores task completion "with help", including the use of assistive devices, as a meaningful form of performance rather than as a deficit (Maenner et al., 2013).
- Adapted measures of psychological strengths relevant to participation, such as purpose-in-life and dispositional optimism scales modified for adults with physical disabilities, to document assets that standard participation frameworks overlook.
- Sexuality and intimate functioning assessments appropriate for adults with physical disabilities, including measures of how pain, fatigue, and bladder dysfunction affect intimate life, and whether support systems address this domain at all.

Why It Matters: These measures center healthy aging on creativity, independence, and purpose rather than physical capability alone. Psychological characteristics including purpose and growth mindset, which are central to how Devon defines his own health, are measurable assets that geroscience frameworks should capture alongside functional decline. Sexuality and intimate wellbeing also belong within participation-domain outcomes: for Devon, as for other aging adults with childhood-onset disabilities, these are dimensions of autonomous life that have clinical relevance and deserve research attention.

Sarah (50, Autism and IDD): Caregiver Aging and Support Transitions

Figure 4: Stock photo of an older woman.

Background

Sarah is a 50-year-old autistic woman with no intellectual disability, who lives with her mother, who has been her primary caregiver since childhood. Sarah was diagnosed early and has spent most of her life in inclusive educational and community settings. She communicates verbally, works part time at a library, and relies heavily on her mother for transportation, health care navigation, and daily planning.

Sarah's medical history includes anxiety, gastrointestinal issues, and use over a long period of selective serotonin reuptake inhibitors. Her baseline functioning has been stable for many years, with consistent employment and routines. Recently, her mother's declining health has introduced uncertainty and stress, resulting in increased anxiety, sleep disruption, and reduced community participation for Sarah.

Sarah also describes herself as someone who "figures things out," and her years of navigating complex systems with limited support suggest meaningful reserves of resilience, self-efficacy, and purpose, psychological assets relevant to how she may adapt to impending support transitions but not currently assessed or documented. Sarah has also expressed that she would like to have a romantic relationship but has not had access to support or education in this area. For autistic adults without intellectual disability, sexuality is often framed as a personal matter outside the clinical encounter, yet research documents high rates of unmet intimacy needs and lack of relationship support in this population, with direct implications for emotional health and aging (Pecora et al., 2020).

Sarah’s circle of support beyond her mother is limited, and no formal transition plan is in place. Her symptoms fluctuate in response to caregiving stress and changes in routine.

For Sarah, good health means stability, continued employment, emotional security, and confidence that her support needs will be met.

Research Challenge: Traditional geroscience outcomes rarely account for aging of caregivers or the destabilizing effects of changes in the support circle for people with IDD. Traditional outcomes also fail to capture psychological strengths that may predict resilience during transitions, or sexuality and relationship needs as legitimate health domains.

Adapted Measures

- Assessments of caregiver support and readiness for transitions including measures of the physical and psychological capacity of caregivers to continue providing support over time, not only whether a caregiver is currently able to meet existing needs, but whether they have the capacity to keep pace with the changing and potentially increasing support needs of the adult with IDD as both the individual and caregiver age simultaneously (Heller & Caldwell, 2006; Egan et al., 2022).
- Measures of emotional wellbeing linked to stability of support including the ***WHO Quality of Life – BREF (WHOQOL-BREF) Environmental Domain***, which captures quality of life dimensions directly relevant to the stability and adequacy of one's living environment, access to services, financial resources, and transport. All of which are destabilized when a primary caregiver's capacity declines (WHOQOL Group, 1998; Skevington et al., 2004). It is important to note that the WHOQOL-BREF was not developed or validated specifically for people with IDD; however, for verbally communicative adults like Sarah, its environmental domain items may be readily accessible, and it represents a promising candidate for adaptation and validation in this population.
- Measures of psychological strengths including self-efficacy, resilience, and purpose, using validated tools accessible to verbally communicative autistic adults such as the ***General Self-Efficacy Scale*** (Schwarzer & Jerusalem, 1995), to document assets that may buffer the impact of caregiver transition.

- Sexuality and relationship support needs assessment using structured tools appropriate for autistic adults, to identify gaps in education, support access, and safety, and to establish these as baseline health domains monitored during periods of transition and instability.

Why It Matters: Capturing aging of caregivers and support transitions is essential to understanding healthy aging trajectories for people with IDD. Unlike neurotypical elderly patients, whose caregivers are often their adult children, many aging people with IDD have relied on a parent as their primary caregiver for most of their lives. Thus, transitioning to a new caregiver can involve tremendous grief and stress. Psychological strengths such as self-efficacy and purpose are likely protective during caregiver transitions and should be measured, not assumed. Sexuality is also a health domain with direct relevance to emotional wellbeing and aging, one that becomes especially vulnerable when stable support structures are disrupted.

VI. Critical Considerations for Researchers

These considerations are foundational and cut across all subsequent principles and outcome measures. They describe the population context in which geroscience research involving people with IDD must be designed and interpreted.

- **Diversity within IDD:** Move beyond approaches based only on an IDD diagnosis and use case profiles that reflect an individual's lived experience and unique circumstances. For example, some people have multiple IDD conditions, and each IDD condition can result in a wide range of functional abilities and challenges.
- **Support Systems:** Recognize circles of support and aging caregivers as modifiers of outcomes.
- **Autonomy and Decision Making:** Treat self-determination and dignity as outcomes, not merely as means to other health endpoints. This requires measuring whether people with IDD are supported to make meaningful choices about their own care, daily lives, and futures, (through supported decision-making frameworks) rather than evaluating autonomy solely through proxies such as independent.
- **Contextual Factors:** Account for cohort effects, geography, policy environments, and economic vulnerability.
- **Clinical Considerations Specific to IDD:** Address co-occurring conditions, polypharmacy, and aging patterns specific to a condition.

VII. How Geroscience Researchers Should Use These Principles

- **Application to Study Design**
    - Include people with IDD as partners in research design, not only as participants.
    - Incorporate context, support systems, and environments into analytic models.
    - Design studies to detect meaningful change within individuals over time, not only cross-sectional group-level differences.
- **Application to Measurement**
    - When appropriate, standard geroscience measures should be integrated throughout the entire research process, from study conceptualization and design through dissemination of results and incorporation into public policy, used in combination with adapted approaches that account for baseline differences, communication needs, and assistive supports.
    - Select measures that are feasible and interpretable for people with IDD across settings.
    - Include indicators that capture strengths, stability, and resilience, rather than focusing only on decline. Research in IDD has historically been organized around deficits, impairment, and the prevention of negative outcomes, an orientation that risks obscuring the capacities, adaptive strategies, and personal resources that people with IDD develop across their lives. A growing body of work argues for a strengths-based approach that assesses and builds upon positive attributes such as character strengths, self-determination, and resilience as meaningful outcomes, rather than treating them solely as buffers against risk (Niemiec et al., 2017; Albaum et al., 2021). In the context of aging research, this means designing studies and selecting measures that can detect what is being maintained and what is flourishing, not only what is being lost.
- **Application to Outcome Reporting**
    - Disaggregate research findings by relevant individual characteristics beyond diagnosis alone.
    - Report outcomes in ways that align with IIDDEAL priority domains.
    - Include perspectives of research participants and caregivers to contextualize quantitative findings.

The sections that follow distinguish between guiding principles and outcome measures, which serve related but distinct roles in geroscience research involving people with IDD.

Guiding principles establish how geroscience research should be designed, interpreted, and adapted to reflect lived experience, baseline differences, and equity considerations. Outcome measures, by contrast, define what is measured to assess aging, healthspan, and intervention effects. Maintaining this distinction ensures that adaptations for people with IDD preserve core geroscience constructs while improving relevance, validity, and interpretability.

VIII. Geroscience Guiding Principles for Adapting Geroscience Research for People with IDD

These guiding principles reflect consensus across working group discussions and are intended to shape how geroscience research is designed and interpreted when people with IDD are included. They do not prescribe specific outcome measures; rather, they establish guidelines for adapting and contextualizing geroscience research approaches. These principles align with emerging calls in the broader geroscience field for frameworks that prioritize equity, access, and the integration of social determinants of health alongside biological research (Whitman & Tan, 2025).

Principle 1: Preserve Core Geroscience Constructs While Adapting Methods

- Geroscience research involving people with IDD should retain core constructs, including biological aging, function, disease burden, and survival. Adaptation should focus on measurement approaches and interpretation, not exclusion of domains.

Principle 2: Evaluate Aging Relative to Individual Baseline, Not Population-Based Norms

- Aging trajectories for people with IDD must be assessed relative to each person's baseline functioning. Lifelong disability should not be misinterpreted as age-related decline, and meaningful change should be defined within individuals over time.

Principle 3: Treat Supports, Accommodations, and Environment as Part of How a Person Functions

- Assistive technology, caregiver support, and environmental accommodations enable intrinsic capacity. The availability or lack of access to supports should be documented and incorporated into analyses rather than treated as confounders or exclusions.

Principle 4: Interpret Biological Change in Relation to Lived Experience

- Biological and clinical changes should be interpreted alongside comfort, participation, emotional wellbeing, and daily functioning. No single biological indicator should be assumed to represent healthy or unhealthy aging in isolation.

Principle 5: Center Social and Community Participation, Stability, and Resilience as Indicators of Healthy Aging

- For people with IDD, healthy aging often involves maintaining routines, roles, and relationships, and recovering from illness or disruption. Stability and resilience are meaningful outcomes and should be treated as core aging indicators.

Principle 6: Account for Contextual and System-Level Influences on Aging

- Aging trajectories are shaped by caregiver aging, service systems, access to and availability of care, changes in policy and programs, and social determinants. Geroscience research must explicitly consider these contextual factors when interpreting outcomes.

IX. Adapting Core Geroscience Outcome Measure Categories for IDD Populations

1. Biomarkers and Biological Measures of Aging

What participants emphasized: Biological measures are valuable and important for geroscience research, but they should not be treated as stand-alone indicators of healthy aging for people with IDD.

Key recommendations for adaptations:

- Biomarkers such as inflammatory markers, metabolic indicators, and emerging biological age measures (for example, DNA methylation clocks) should be interpreted alongside functional capacity, social participation, and daily life outcomes. Geroscience researchers have noted that biomarkers and biological age measures in clinical trials require careful interpretation and should be evaluated in relation to health outcomes rather than used as endpoints in isolation (Bauer & Newman, 2022; Beard, 2025; Cummings & Kritchevsky, 2022).
- For some conditions, such as Down syndrome, biomarkers related to Alzheimer's disease may become relevant earlier in adulthood and require age-appropriate interpretation (Zhou et al., 2025; Russell et al., 2026).
- Biological findings should be contextualized within the person's goals, supports, and lived experience.
- Participants should be cautioned against using biomarkers as proxies for independence, quality of life, or wellbeing without accompanying functional and experiential measures (Bauer & Newman, 2022).

Implication for research: Biological age measures and biomarkers should be paired with intrinsic capacity and social and community participation outcomes to avoid overemphasizing molecular change at the expense of meaningful function (Cummings & Kritchevsky, 2022).

2. Functional Assessments and Intrinsic Capacity Measures

What participants emphasized: Functional assessments are central to geroscience and intrinsic capacity frameworks, but standard thresholds often fail to reflect meaningful change for people with IDD.

Key adaptations discussed:

- Functional measures such as walking speed, Timed Up-and-Go, grip strength, or balance should be adapted to account for baseline ability and communication differences.
- Assessments should prioritize change over time within the same individual rather than comparison to norms.
- Measures should be conducted in familiar or community settings, when possible, as performance on functional assessments can be significantly affected by environmental context, anxiety, and unfamiliarity with the testing situation, factors that are particularly pronounced for people with IDD. Participating in standardized assessments can be a taxing experience for individuals with IDD, in part due to preferences for familiar and predictable routines and people, executive function challenges, and communication differences, all of which can suppress performance in unfamiliar clinical or laboratory environments (Silverman et al., 2021). Assessment in the home or community environment where the individual regularly operates is more likely to reflect their actual functional capacity, consistent with the principle of ecological validity in assessment, which holds that the predictive relationship between test performance and real-world functioning is strongest when assessment conditions approximate the environments in which individuals actually live and work (Chaytor & Schmitter-Edgecombe, 2003).
- Use of assistive technology and environmental supports should be documented and treated as enabling function rather than masking impairment.

Implication for research: Functional outcomes should capture whether a person can continue doing what matters to them, not whether they meet standardized benchmarks.

3. Disease, Multimorbidity, and Mortality Outcomes

What participants emphasized: Disease incidence and mortality remain important outcomes for people with IDD, but they do not adequately describe healthy aging on their own.

Key adaptations discussed:

- Disease outcomes should be interpreted alongside symptom burden, recovery, and impact on daily functioning.
- Multimorbidity should be assessed in the context of polypharmacy and interactions between conditions.

- Mortality outcomes should be complemented by measures of healthspan, such as years lived with maintained participation or reduced pain.
- Diagnostic overshadowing, the tendency of clinicians to attribute new or worsening symptoms to an existing IDD diagnosis rather than investigating them as potentially distinct medical or psychiatric conditions, and delayed diagnosis were identified as factors that may distort disease and mortality data in IDD populations (Shefer et al., 2024; Landes et al., 2021). When symptoms are repeatedly misattributed to baseline disability rather than recognized as signs of new illness, conditions go undiagnosed or are diagnosed at later and more severe stages, meaning that prevalence data for many conditions are likely underestimates in this population. This misattribution extends beyond clinical encounters into death certification, where IDD has been documented as inaccurately reported as the underlying cause of death on a substantial proportion of death certificates, a practice termed postmortem diagnostic overshadowing, obscuring actual causes of death and undermining public health surveillance of preventable mortality in this group (Landes et al., 2021; Landes et al., 2020). Improving the accuracy of cause-of-death reporting for people with IDD would likely reveal higher rates of deaths from acute respiratory disease, preventable aspiration events, and other conditions amenable to intervention (Landes et al., 2020). This systematic misattribution not only harms individual patients but introduces structural bias into population-level health data, making it difficult to accurately characterize health trajectories or design appropriately targeted interventions (ASPE/HHS, n.d.; Shefer et al., 2024).

Implication for research: Disease and mortality outcomes should be embedded within broader data on aging trajectories that include function, comfort, and participation.

4. Frailty, Deficit Accumulation, and Resilience

What participants emphasized: Frailty concepts are useful but must be adapted carefully to avoid labeling lifelong disability as age-related decline.

Key adaptations discussed:

- Deficit accumulation indices should distinguish lifelong impairments from new or worsening conditions.
- Frailty measures should focus on vulnerability to stressors and change-over-time rather than static impairment. In geroscience, frailty is increasingly conceptualized not as the sum of an individual's diseases and deficits, but as a state of depleted physiological reserves, or homeostenosis, the age-related narrowing of

homeostatic capacity recognized in clinical geriatric medicine (Taffet, 2003), in which the body's capacity to maintain homeostasis, the dynamic balance across interconnected biological systems, is critically compromised, resulting in heightened vulnerability to adverse outcomes following even minor stressors (Fried et al., 2021). For people with IDD, where lifelong differences in physiology, motor function, and adaptive behavior create atypical baselines, this homeostatic framework is especially relevant: frailty assessment should detect when the capacity to recover from stressors is declining, rather than simply measuring static impairment against general population norms.

- Measures of recovery, adaptation, and resilience following illness or disruption were viewed as especially relevant.
- Emerging intrinsic capacity domains such as resilience and biological intrinsic capacity were supported when interpreted longitudinally.

Implication for research: Frailty and deficit measures should focus on change, vulnerability, and recovery rather than baseline disability.

5. Social, Behavioral, and Participation Outcomes

What participants emphasized: Social and community participation and the ability to do meaningful activities were repeatedly identified as core indicators of healthy aging.

Key adaptations discussed:

- Measures should capture participation in work, relationships, routines, and community life, including religious and spiritual participation, which represents a meaningful and often overlooked dimension of community engagement for many people with IDD. Data from a national sample of 12,706 adults with IDD residing in 24 states found that nearly half (48.3%) had attended a religious service in the past month, and more than one third (34.6%) attended three or more times, suggesting that congregational participation is a significant and measurable form of community life for this population (Carter et al., 2015). Spirituality and religious participation are also well-established correlates of overall health and quality of life in geriatric populations and are routinely included in clinical geriatric assessment, yet they remain largely absent from IDD-specific aging research.
- Behavioral changes should be interpreted as possible signals of pain, distress, or unmet needs rather than as outcomes in isolation.
- Stability of routines, environments, and supports are central to wellbeing for many people with IDD, and this need should be recognized and honored in how healthy

aging is defined and measured. At the same time, research on healthy aging more broadly has identified growth mindset, the belief in one's capacity to learn, adapt, and develop, as a meaningful contributor to cognitive vitality and wellbeing in older adults (Sheffler et al., 2023). Importantly, this orientation toward growth is not absent in people with IDD: a scoping review of healthy aging perspectives in this population found that older adults with IDD expressed genuine interest in gaining wisdom, developing new skills, and participating in community activities as positive dimensions of aging (El Mrayyan et al., 2025). This suggests that healthy aging frameworks for people with IDD should hold both needs in view, the value of predictable, stable environments alongside the equally legitimate aspiration for new experiences, continued learning, and personal development, rather than assuming that stability is the only relevant goal.

- Emotional regulation and mental health are integral to aging trajectories.

Implication for research: Social and behavioral outcomes are not secondary measures; they are core geroscience outcomes for people with IDD. Spirituality and religious participation should be included as measurable domains within social and community participation frameworks, given their prevalence in this population and their established relationships with health and quality of life.

6. Resource Utilization and Care Transitions

What participants emphasized: Health care utilization reflects both health needs and system performance.

Key adaptations discussed:

- Emergency department visits, hospitalizations, and long-term care placement should be interpreted in the context of access barriers and quality of preventive, maintenance, and supportive care.
- Reduced utilization may reflect improved health or unmet needs, depending on context.
- Care coordination and shared decision-making are meaningful outcomes in their own right.
- Aging caregivers and support disruptions may be key drivers of increased utilization.

Implication for research: Resource utilization outcomes should be paired with measures of access, coordination, and support stability.

7. Patient-Reported and Proxy-Supported Quality of Life Measures

What participants emphasized: Quality of life is essential for interpreting whether biological or functional changes are meaningful.

Key adaptations discussed:

- Self-report should be used whenever possible, facilitated by use of plain language materials, and/or non-written formats.
- Proxy report should supplement, not replace, the person's own perspective.
- Measures should assess comfort, autonomy, emotional wellbeing, and satisfaction with daily life.
- Quality of life should be measured over time to capture stability or change.

Implication for research: Quality of life measures serve as the interpretive anchor for all other geroscience outcomes.

Figure 1.

Geroscience Outcome Category	Typical Geroscience Focus	Key Adaptations for People with IDD
Biomarkers & Biological Age	Inflammation, metabolic markers, DNA methylation	Interpret alongside function and participation; consider earlier relevance for some conditions (Bauer & Newman, 2022; Cummings & Kritchevsky, 2022; Zhou et al., 2025)
Functional Assessments / IC — Mobility & Physical Performance	Walking speed, grip strength, Timed Up-and-Go	Measure change relative to individual baseline; use familiar settings; include assistive supports as enabling rather than confounding (Chaytor & Schmitter-Edgecombe, 2003; Silverman et al., 2021)
Functional Assessments / IC — Daily Living & Independence	ADLs and IADLs: self-care, domestic tasks, communication, community participation	Use IDD-adapted measures; distinguish lifelong support needs from new functional decline (Maenner et al., 2013; Sullivan et al., 2011)

Disease & Mortality	Incidence, survival	Pair with symptom burden, recovery, and healthspan indicators; account for diagnostic overshadowing and death certificate inaccuracies (Landes et al., 2021; Landes et al., 2020; Shefer et al., 2024)
Frailty / Deficit Accumulation	Composite risk indices	Distinguish lifelong impairment from new decline; include resilience and homeostatic capacity (Fried et al., 2021)
Social & Behavioral Outcomes	Often secondary	Treat participation, stability, and emotional regulation as core outcomes (Mihaila et al., 2024; McCausland et al., 2023; Pham et al., 2024)
Resource Utilization	ED visits, hospitalizations	Interpret in context of access, caregiver aging, and system failures (Sullivan et al., 2011; Kramer et al., 2023)
Quality of Life	Self-report scales	Use supported self-report; supplement with proxy input (Cummins & Lau, 2005; McGillivray et al., 2009; Schalock et al., 2008)

X. Conclusion

People with IDD have long been excluded from the research that shapes how aging is understood, measured, and supported. Geroscience has an opportunity, and an obligation, to correct this, not only to avoid harmful misinterpretations of functional data and misapplication of health interventions, but because inclusive research produces better science. By aligning measurement priorities with those defined by the IDD community itself, and by anchoring those priorities within the intrinsic capacity framework, researchers can generate knowledge that advances both scientific understanding and real health outcomes for a population that has been systematically underserved. Future work should focus on piloting adapted measures, developing IDD-specific reference data, investing in the infrastructure for longitudinal inclusive research, and ensuring that the voices of people with IDD remain central, not incidental, to the research process. Advancing meaningful geroscience can provide vital and timely evidence to inform policy and program change. The vision is a geroscience field that measures what matters, serves every community, and supports healthy aging for all.

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