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# Using a life course health development framework to combat stigma-related health disparities for individuals with intellectual and/or developmental disability (I/DD)

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ABSTRACT

In the U.S., 1 in 6 children has an intellectual and/or developmental disability (I/DD). This population experiences a multitude of negative health outcomes across the life course, relative to the general population. Stigma—the social devaluation of individuals with certain characteristics, identities, or statuses within interpersonal, educational, healthcare, and policy contexts—is a potentially preventable contributor to health disparities. To date, existing approaches for addressing and preventing stigma are limited to discrete and siloed interventions that often fail to address the lifelong, cumulative impacts of the specific types of stigma experienced by the I/DD population. In the current paper, we describe three elements of Life Course Health Development (LCHD)—a novel translational framework that draws on evidence from biology, sociology, epidemiology, and psychology—that healthcare providers can use to prevent stigma-related health disparities and improve outcomes for individuals with I//DDs. We discuss the utility of targeting prevention to sensitive periods; prioritizing interventions for the most damaging types of stigmas; and leveraging supports from multiple service systems and sectors. By incorporating evidence from life course science into efforts to address stigma-related health disparities, providers can more effectively and strategically prevent and combat stigma-related health disparities for the I/DD population in childhood and across the life course.

## Overview

In the U.S., 1 in 6 children has an intellectual and/or developmental disability (I/DD), including ADHD, autism, cerebral palsy, learning disabilities, seizures, and developmental delays, with or without intellectual impairment.[1] Children with I/DD often experience disproportionate negative physical and mental health outcomes—often unrelated to their I/DD—across the life course.[1] Autistic individuals, for example, experience almost three times the mortality rate—and a 16-year lower life expectancy—relative to non-autistic populations.[2,3] They experience disproportionate rates of immune, metabolic, cardiovascular, and neurological disorders, as well as anxiety, depression, functional somatic symptoms, and other co-occurring physical and mental health conditions.[2,3] In the current paper, we describe the role of individual- and structural-level experiences of *stigma* in contributing to the health of the I/DD population. Broadly, we conceptualize stigma as the convergence of four processes: 1) distinguishing and labeling human differences; 2) linking labeled persons to undesirable characteristics (i.e., stereotypes); and 3) placing labeled persons in distinct categories to separate them from the majority, which leads to 4) the labeled persons experiencing status loss, discrimination, and unequal outcomes.[4]

The current paper discusses how the Life Course Health Development

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(LCHD) approach—defined in detail in the literature[5–8]—can be applied to understand and more effectively address stigma towards individuals with I/DD (Fig. 1). The LCHD approach draws from research from several fields—including biology, sociology, epidemiology, and psychology—to explain how individual- and population-level health trajectories are determined by interactions between biological and environmental factors across the life course.[9] In alignment with developmental science,[10] the LCHD framework regards individuals themselves as active agents interacting within their developmental ecosystems, which include their families, neighborhoods, and communities.[5–8] The LCHD framework has high utility for conceptualizing the pervasiveness of stigma within developmental ecosystems—in childhood and across the life course—and illuminating opportunities for interventions to address the most potent types of stigma at key developmental transitions across the lifespan.[5–8] This approach can spur efforts to develop and test interventions to address stigma and create scalable and sustainable solutions.[5–8]

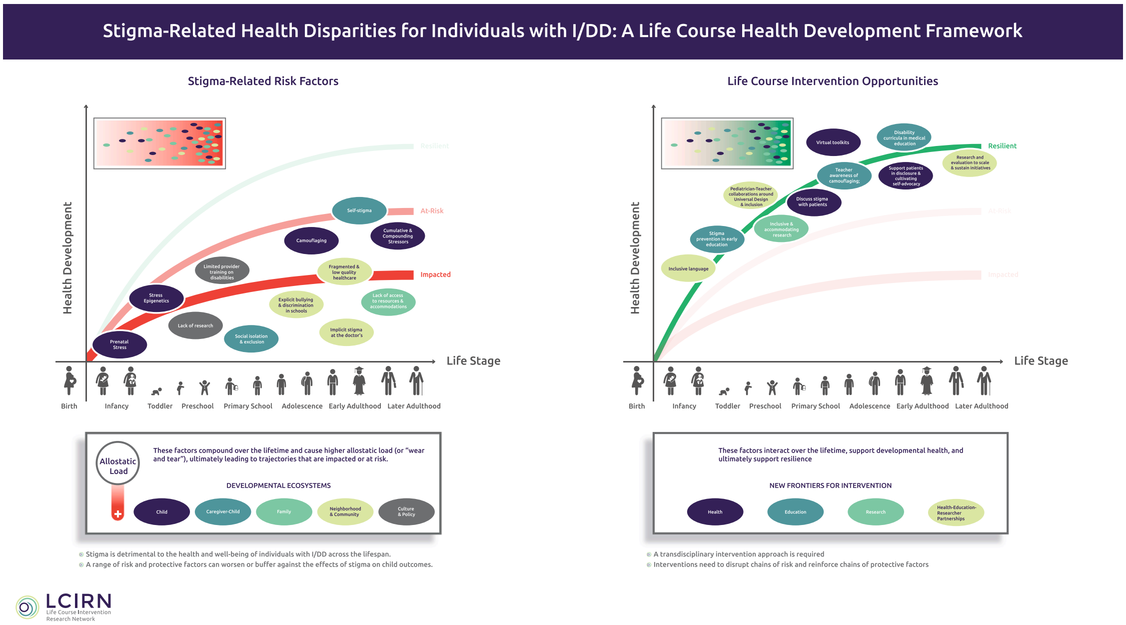
## Background

Individuals with I/DD experience stigma beginning in childhood, initially in the form of *implicit stigma*: insidious—rather than direct or overt—negative labeling that can result in strained or uncomfortable social interactions, lower quality of life and self-esteem, and other consequences.[4,11–13] Elementary school children, for example, exhibit preferences for their peers without I/DD and distance themselves from their peers with I/DD.[14] In adolescence, stigma towards children with I/DD manifests more explicitly and results in *stigma-based bullying*—defined as bullying motivated by stigma—with children with I/DD significantly more likely to report experiencing bullying than their peers without I/DD.[15,16] In adulthood, stigma often manifests as differential treatment, exclusion, and encounters of barriers to success in post-secondary education and employment, as well as within communities more generally.[17] Across the life course, persistent and cumulative experiences of stigma create *internalized or self-stigma*—the process of cognitively or emotionally absorbing experienced stigma.[17] Indeed, individuals with I/DD are well-aware of instances of rejection, exclusion, and discrimination[18] occurring in interpersonal, education, research, practice, and policy settings.[19,20] Over time, individuals with I/DD come to anticipate being stigmatized, which can lead to reliance on behavioral and cognitive strategies that, in turn, worsen the effects of stigma. *Camouflaging,* for example, is defined as deploying specific behavioral and cognitive strategies to mask traits associated with a particular disability or condition to appear more “typical.”[21]

Stigma results in negative health outcomes via multiple pathways.[19,20] In the general population, stigma is both directly and indirectly damaging to mental and physical health. Perceived or experienced discrimination produces heightened physiological stress responses,[22] accumulates over time, and creates “wear and tear” or allostatic load.[23] For the I/DD population, stigma has been found to elicit maladaptive coping behaviors, including substance use and disordered eating[24]; increases in vulnerability to emotional and interpersonal challenges; and reduction in overall psychological well-being.[25] Experiences of stigma may also prevent people with I/DD from accessing necessary health-promoting and preventive services.[25] Further, internalized stigma is linked with poor mental health and depression[18] and camouflaging leads to continuous distress; low well-being and self-esteem; poor quality of life; exacerbated anxiety, depression, and suicidality; delayed diagnosis; and compromised health care in autistic individuals.[26–29]

There are significant limitations in existing approaches for preventing and addressing stigma towards the I/DD community. Most existing interventions, for example, target explicit and conscious attitudes and behaviors.[12] While explicit stigmatizing attitudes and behaviors dissipate with age and can be targeted via short-term educational programming or interventions, implicit stigma remains consistently negative over time and is typically unchanged from intervention.[12] This is particularly relevant when considering stigma prevention in healthcare settings, as providers, in many cases, are not cognizant of their own biases related to disabilities.[30] As an example, research using data from over 25,000 healthcare providers suggests that most providers demonstrate low explicit but high implicit prejudice, which results in them viewing individuals with I/DD as less capable and having a tendency to fail to provide accommodations to their patients with I/DD.[30]

In addition, existing approaches often take the form of individual-level interventions seeking to change downstream attitudes and beliefs.[31] This approach has limited utility for effecting change in the upstream systemic factors that perpetuate stigma.[4,11,32,33] As an example, stigma in healthcare settings partially originates from a lack of a focus on the I/DD population in medical education and training.[34] The



These factors compound over the lifetime and cause higher allostatic load (or “wear and tear”), ultimately leading to trajectories that are impacted or at risk.

- Stigma is detrimental to the health and well-being of individuals with I/DD across the lifespan.
- A range of risk and protective factors can worsen or buffer against the effects of stigma on child outcomes.

These factors interact over the lifetime, support developmental health, and ultimately support resilience

- A transdisciplinary intervention approach is required
- Interventions need to disrupt chains of risk and reinforce chains of protective factors

**Fig. 1.** Stigma-related health disparities for individuals with I/DD: a life course health development framework.

majority of medical schools lack a disability-focused curriculum component[35] and only half of U.S. medical school deans report that their schools offer curricula about biopsychosocial aspects of caring for patients with I/DDs.[36] Without addressing the persistent and cumulative nature of stigma across the life course—and its lack of adequate attention in medical school—interventions are likely to have limited utility. Finally, most existing interventions often lack a robust research component; in the event that they do include research, they typically involve small samples and findings are not generalizable or scalable.[31]

### *LCHD-Based recommendations*

In the following section, we present recommendations for healthcare providers, including pediatricians, primary care providers, family medicine physicians, nurse practitioners, and others—utilizing a LCHD approach—for combating and preventing stigma-related health disparities in the I/DD population.

### *Recommendation: align stigma interventions with developmental science*

Timing changes how a particular risk or protective factor affects health.[9] Focusing on sensitive periods—when an individual is particularly susceptible to these factors—can ensure efforts concentrate on periods in the life course when interventions can be most impactful.[37] Sensitive developmental periods have traditionally been conceptualized as occurring in early childhood,[38] yet contemporary developmental science suggests that periods of transitions and instability are pivotal opportunities for intervention.[37,39] Table 1 outlines individual, interpersonal, and systemic interventions to prevent and address stigma towards the I/DD population and provides resources for healthcare providers to support their efforts in these areas.

*Early Elementary School.* There is scant research on I/DD-specific stigma prevention efforts for children, although approaches to address mental health-related stigma are emerging.[40] The majority of mental health stigma interventions, however, are geared towards high school students.[9] In conceptualizing stigma prevention efforts for the I/DD population, it is critical to develop approaches that can be implemented before stigmatizing attitudes develop: ideally during the transition to elementary school.[31,41,42]

The American Academy of Pediatrics (AAP) supports pediatricians' active role in the development and implementation of families' Individualized Education Plans (IEPs).[43] Pediatricians can ensure IEP goals focus on promoting children's social inclusion and connectedness with peers.[44] These efforts align with recent calls for more neurodiversity-affirming interventions that "reframe the goals of interventions to focus on supporting the strengths" of individuals with I/DD and "creating environments that foster them."[45]

Beyond this role, pediatricians can advance early stigma prevention efforts by leading by example. In particular, providers can utilize *inclusive language* in patient interaction and office materials.[46] Dwyer et al. (2022), for example, offers an inclusive language guide by outlining terminology that autistic self-advocates find to be stigmatizing in healthcare settings and providing suggestions for alternatives. As an example, providers can use language such as "signs" or "indicators" rather than "red flags" when describing conditions. They may also rely on language such as "area of challenge" or "difficulty" rather than "deficit;" "co-occurring" rather than "co-morbid;" and/or "focused or intense interests" rather than "restrictive interests."[46] Rather than referring "problem behaviors," providers can utilize more specific descriptions of the behaviors.[46]

There is also potential for pediatricians to support schools in stigma prevention efforts. Pilot projects suggest that both teachers and parents support such efforts for elementary school students.[47] Multiple models for collaborative healthcare-school partnerships are currently being evaluated in the literature.[48,49] As an example, research supports the feasibility and acceptability of having medical students, during their pediatric clerkship, observe school classrooms that include young children with disabilities.[50] Additionally, school-hospital partnerships have paved the way for the implementation and evaluation of Multitiered Systems of Support (MTSS) that embed prevention and health-promotion programs at the school and classroom-level. There remains, however, a principal need to more intentionally align national, state, and local infrastructures to facilitate such models and collaborations.[51]

*Transition to Adolescence.* During the transition from childhood to adolescence, stigma often manifests as more overt, which can take the form of bullying.[15] The majority of anti-bullying interventions, however, are single session, focused on short-term outcomes,[16] and target individual-level behavior or cognitive change, rather than on structural policies and practices that facilitate bullying.[16] Healthcare providers can serve an important role in stigma-based bullying prevention efforts.[52] As an example, pediatricians can draw from recommendations for supporting other marginalized populations who experience bullying and empower caregivers to identify and respond to potential indicators of bullying.[53] They can also draw from recommendations to pediatricians to prevent and address cyber-bullying.[54] Given providers' overall lack of confidence in supporting patients with I/DD identified in the research,[55] additional training and education regarding supporting adolescent patients at-risk for bullying—particularly those multiple marginalized intersectional identities (e.g., autistic LGBTQ+ youth)—is warranted.[56]

*Emerging Adulthood.* Pediatricians can also mitigate stigma in the transition to adulthood. Research supports the importance of self-advocacy for emerging adults with I/DD.[57] Pediatricians can support their patients in cultivating self-advocacy skills in healthcare,

**Table 1**
Aligning stigma interventions with developmental science.

| Key developmental transitions | Goals | Example interventions | | Example resources for healthcare providers |
|---|---|---|---|---|
| | | Individual / interpersonal | System-level | |
| Elementary school | Prevent and / or proactively address I/DD-related stigma | Utilize inclusive language in patient interactions and office materials | Collaborate with educators to:<br>-Develop IEPs focused on social inclusion and connectedness<br>-Cultivate collaborative healthcare-school partnerships | Dwyer et al. (2022) Inclusive Language Guide[46]<br>School-Clinic Education and Training Partnerships[50]<br>Multitiered Systems of Support (MTSS) for School-Based Prevention[79] |
| Adolescence | Address stigma-related bullying and / or overt discrimination / rejection | Empower caregivers to identify and respond to bullying | Develop and disseminate training and education to providers and educators to respond to bullying | Expert-Generated Anti-Bullying Recommendations[80]<br>AAP Recommendations for Cyber-Bullying[54] |
| Emerging adulthood | Empower the I/DD community with self-advocacy | Cultivate self-advocacy skills and knowledge in healthcare | Collaborate with their patients to foster self-advocacy skills in employment, education, and other settings | AASPIRE Toolkit[58]<br>Toolkit for Primary Care Providers: Health Care for Adults with Intellectual and Developmental Disabilities from the Vanderbilt Kennedy Center[59] |

educational, and vocational contexts by applying the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit in their practices.[58] This toolkit affords access to the Autism Healthcare Accommodations Tool (AHAT), which creates a customized accommodations report for patients to give to their healthcare providers.[58] There are a range of additional relevant toolkits geared towards healthcare providers.[59]

These clinical, patient-level efforts can be more effective if met with systems-level reforms. The AASPIRE toolkit provides guidelines for communicating with patients using multiple modalities (e.g., written, verbal, etc.) within clinics, as well as suggestions for ensuring inclusive and accessible healthcare.[58] More broadly, clinics can engage in quality improvement efforts to identify and test strategies that can effectively promote the health of their patients with I/DD. As an example, federally funded Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs across the U.S. aim to provide comprehensive, interdisciplinary training related to supporting patients with I/DD. Preliminary findings from the LEND Program Quality Improvement (LPQI) Network demonstrate initial feasibility of this model.[60] Given that emerging adulthood is characterized by increases in developmental capacities related to autonomy, providers can consult the AASPIRE guidelines for strategies to partner with youth with I/DD in these quality improvement efforts.[61]

### *Recommendation: prioritize interventions that address chains of risk*

Chains of risk are patterns of risk clustering where exposure to a particular type or quality of adversity leads to exposure to another. This patterning results in a chain, or an accumulation of, risk factors.[9] Elucidating chains of risk can inform the strategic identification of effective intervention targets.[9] Below, we focus on two critical chains of risk for the I/DD population.

*Chain of Risk: Camouflaging.* Anticipated or experienced stigma can lead individuals with I/DD to engage in camouflaging: deploying specific behavioral and cognitive strategies to appear more “typical.”[21] Interventions that promote disability disclosure have been suggested to reduce feelings of isolation and alienation, and in turn, may prevent or mitigate internalized stigma and camouflaging.[62] Providers can ask their patients with I/DD about factors that might facilitate comfortable disclosure and help them identify opportunities to leverage those factors.[62] These conversations should align with principles of *cultural humility* by recognizing that their own worldview as providers likely differs from that of their patients, and disclosure should be approached with this perspective in mind.[63] To this end, providers can refer to—as well as direct patients to—self-advocacy organizations that can support them in cultivating the confidence and skills that can facilitate disclosure, including the Autistic Self-Advocacy Network (ASAN).[58,64] Particular attention should be paid to those with multiple marginalized intersectional identities who may experience multiple forms of stigma.[65]

In alignment with the priority in LCHD to develop sustainable and scalable approaches, these approaches can be combined with system-level interventions—such as those in schools, healthcare settings, and other contexts—that mitigate the need for individuals with I/DD to rely on camouflaging. Although there is sparse evidence on such interventions, research has begun to document camouflaging as a barrier to children’s learning and social interactions in mainstream classrooms, finding that camouflaging leaves autistic girls—who also potentially experience stigma due to intersectional marginalized identities[65]—-feeling exhausted and anxious in class and teachers are often unaware of their struggles.[66] These findings further underscore the importance of healthcare-education partnerships.[48,49]

*Chain of Risk: Chronic Stress.* Providers may have the opportunity to forefront system-level interventions that target allostatic load among individuals with I/DD through uptake of systematic screening and referral for Adverse Childhood Experiences (ACEs) and other Social Determinants of Health (SDOH).[67] At the practice level, universal SDOH collection and reporting, partially through Z codes available through the International Classification of Diseases, 10th Revision (ICD-10), can proactively identify patients who can benefit from social supports and services.[68] Beyond SDOH screening, providers may consider implementing quality improvement projects that assess the utility of utilizing specialized measures validated for the I/DD population, including those assessing chronic stressors (e.g., the Juvenile Victimization Questionnaire) and coping mechanisms (e.g., the Camouflaging Autistic Traits Questionnaire).[56,69,70] On a patient level, this would add additional insight into potential mechanisms contributing to problematic laboratory biomarkers (e.g., heightened cortisol)[71,72] and guide assessment and intervention. Systematic screening would ideally result in referrals to services and supports that can address chronic stressors, including experiences of stigma. On a population level, universal screening will provide data that can support the implementation or expansion of population-level public health initiatives targeting stigma.

### *Recommendation: engage in transdisciplinary collaborations*

An LCHD perspective emphasizes that scalable and sustainable approaches cannot exclusively occur at the individual level. Rather, interventions are maximally beneficial if they span individual, interpersonal, and systemic levels.[5,6,9] This often requires *transdisciplinary approaches* that blend and leverage the collective expertise of health, education, and policy stakeholders in an integrated manner, rather than rely on each entity to offer discrete and siloed support.[9]

There are multiple avenues for transdisciplinary collaborations, including among researchers, practitioners, policymakers, and educators. With respect to addressing I/DD stigma and related health inequities, researcher-practitioner partnerships are particularly critical. In practice, this might entail providers facilitating efforts to make research more inclusive for individuals with I/DD, such as those they see in their practices. Together, researchers and practitioners can advocate for removing arbitrary exclusion criteria that may prevent individuals with I/DD from participating as research participants or collaborators.[73] As an example, providers working in academic medical schools can advance efforts towards accessible and inclusive research design,[74] which includes ensuring research outcomes are meaningful for individuals with I/DD.[75] Given that initial interventions targeting stigma-related health disparities will be largely untested upon initial implementation, it will be crucial to ensure that research and evaluation are integrated throughout all phases. Outcome measures would ideally be person-centered and tailored based on patients’ capacities and utilize varied approaches (e.g., surveys, interviews, focus groups, etc.).[76]

Providers can also serve as a bridge between researchers and policymakers to ensure research translates into policies that can support the I/DD population. Given that many providers are often situated in the nexus of research and policy—by serving in academic institutions, engaging with national and local chapters of professional organizations, and communicating with policymakers[77,78]—they may be well-positioned to serve in this capacity.

## Conclusions

Stigma is detrimental to the health and well-being of individuals with I/DD across the lifespan. Healthcare providers can potentially use the LCHD framework to better serve this growing segment of the population. In the current paper, we offer LCHD-based recommendations to help healthcare providers translate LCHD evidence into efforts that can promote optimal health for this population. Advancing these approaches will require wider recognition of stigma as an ongoing contributor to health inequities for this population. LCHD can facilitate efforts to transform multi-level systems to optimize health outcomes for individuals with I/DD.

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