

# Persons Who Acquire HIV at Birth Need Better Support

People who acquire HIV from their birthing parent during pregnancy, childbirth, or during breast or chest feeding, as well as those who acquire the virus via blood transfusion before 5 years of age, are considered to be cases of perinatally-acquired HIV. Affected individuals themselves, however, are organizing under preferred terms of “Dandelions” or “Lifetime Survivors” which are the names of two networks they are forming to provide mutual support and advocacy. For brevity, throughout this brief, we will refer to Lifetime Survivors and Dandelions interchangeably for this whole group of people and we are not specifically referring to members of either the Dandelions Movement or the Lifetime Survivors Network. It is estimated that in 2019, there were 12,355 Lifetime Survivors out of roughly 1.2 million people with HIV in the U.S.<sup>1</sup>

Research, including the landmark AIDS Clinical Trial Group (ACTG) 076 study published in 1994, has shown that screening for HIV during pregnancy, and once diagnosed providing antiretroviral therapy, can effectively prevent HIV transmission during childbirth. Preventing perinatal acquisition of HIV, sometimes called mother-to-child transmission or vertical transmission, remains a major concern globally. The United States, however, has essentially achieved what is considered virtual elimination. This represents a major policy success. According to the Centers for Disease Control and Prevention (CDC), in 2022, only 42 babies were born with HIV<sup>2</sup> out of 3.7 million live births.<sup>3</sup> Elimination of perinatal HIV is tied to the dual goals of an incidence of less than one case per 100,000 live births and a perinatal transmission rate of less than one percent. The dual elimination goals were first achieved in the U.S. in 2019,<sup>4</sup> but ongoing transmission has meant that they have fluctuated near these dual goals from year-to-year. Globally, according to UNAIDS, around 120,000 children aged 0-14 acquired HIV in 2023, the vast majority of which are attributed to perinatal transmission.<sup>5</sup> These accounted for 9% of all transmissions in that year, a decline of 38% since 2015 accompanied by a 43% decline in AIDS-related deaths.<sup>6,7</sup> Nonetheless, recent progress at lowering this rate has stalled. In the U.S., the focus on prevention, however, has not been met with a corollary commitment to supporting and addressing the unique needs of persons that acquired HIV perinatally. Dandelions have been asserting themselves to establish their unique place in the HIV movement and to demand policy responses to address their unique challenges:

## 1. RECOGNIZING PERSONS BORN WITH HIV AS A VALID AND DISTINCT PART OF THE HIV COMMUNITY

A central challenge for Lifetime Survivors is simply to be seen. Because they comprise only about 0.1% of people with HIV they are often only recognized by their other identities, whether this is on the basis of their race, sexual orientation, or gender identity. This obscures an understanding of unique challenges, health concerns, or perspectives of this important segment of the HIV community. For these individuals, significant

## A SMALL PART OF THE HIV COMMUNITY WITH UNIQUE NEEDS AND PERSPECTIVES

Policy action is needed to:

### RECOGNIZE PERSONS BORN WITH HIV AS A VALID AND DISTINCT PART OF THE HIV COMMUNITY

Federal agencies should collect and disseminate longitudinal data on clinical and social outcomes for Dandelions

CDC should publish a data snapshot of key demographic data about this population

All HIV stakeholders should ensure that Lifetime Survivors are included in various forms of HIV stakeholder engagement

### ADDRESS UNIQUE HEALTH CARE NEEDS ACROSS THE LIFESPAN

The Ryan White HIV/AIDS Program (RWHAP) Part D and the AIDS Education and Training Centers (AETC) Programs should increase their capacity to support these individuals from childhood throughout the lifespan

Aging advocacy organizations should collaborate with Lifetime Survivors to provide mutual support for improving HIV services across the lifespan

### SUPPORT THE DEVELOPMENT OF PEER-LED ADVOCACY AND EDUCATION ORGANIZATIONS

HIV coalitions and HIV services organizations should support the Lifetime Survivors Network and Dandelions, Inc. as vibrant and sustainable organizations

psychosocial challenges manifest in growing up with pressures to keep their status hidden or risk social friction surrounding where and to whom they disclose their status. Acceptance from friends and peers in these formative years was never guaranteed. In adulthood, aging may accelerate as hepatic, cardiac, renal, and neurological comorbidities become more likely, bringing with them emotional and financial distress.<sup>8</sup> Policy guidance is needed to cultivate robust support for the specific mental and physical health needs that come with being HIV-positive for all, or nearly all, of one's life.

**POLICY ACTION**

**Federal agencies should collect and disseminate longitudinal data on clinical and social outcomes for Dandelions.**

It is easy to understand that Lifetime Survivors face unique clinical and social challenges, but these specific challenges are not well understood. There are gaps in our knowledge of the clinical manifestations and experiences of children with HIV; there is even less comprehension of clinical challenges in adulthood arising from or exacerbated by having lived with HIV since birth or early childhood. Similarly, the social obstacles facing these individuals are complex and often poorly addressed. Whether it is the National Institute of Allergy and Infectious Diseases (NIAIDS), the Centers for Disease Control and Prevention (CDC) Medical Monitoring Project (MMP) or some other federal program, there is a need for a longitudinal study of the clinical and social needs of this population to understand their health and social outcomes over time and across the lifespan.

**POLICY ACTION**

**CDC should publish a data snapshot of key demographic data about this population.**

While it is well known, for example, that HIV disproportionately impacts Black Americans, this

disparity is much higher for Dandelions. Reporting on perinatal transmission in 2022 showed that two-thirds of these diagnoses were in Black people.<sup>9</sup> Other basic facts about this unique population are not commonly known, hindering the development of effective advocacy and policy responses. For other populations, CDC has developed simple, accessible fact sheets to help policy makers and the broader population understand key features and policy needs of a group. CDC should develop something similar for Lifetime Survivors that gives information about the gender and age breakdown of this group, highlights key prevention and health care successes and challenges, and defines key social determinants of a good, high-quality life for these individuals.

**POLICY ACTION**

**All HIV stakeholders should ensure that Lifetime Survivors are included in various forms of HIV stakeholder engagement.**

The HIV community consists of many diverse and overlapping constituencies. Throughout its history, different groups have stepped forward to demand greater attention and prioritization of their unique needs. Recently, women, for example, have spoken up about being overshadowed by the much larger number of men with HIV, advocating for greater action and resources to address HIV among women. Our collective community is made healthier and stronger by both recognizing unique needs and experiences and respecting the right of specific groups to advocate for themselves, while also striving for cohesiveness across the broader community of people living with and affected by HIV. Now is a moment where Lifetime Survivors are calling for a greater acknowledgment of their needs. Whether it is federal, state and local program officials or policy makers, providers, researchers, or advocates, all of these groups need to recognize the appeals for attention and support and consciously work to better integrate Dandelions into broader HIV programs and policy.

## WHAT MAKES A LIFETIME SURVIVOR?

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Lifetime Survivors navigate many complex issues within their families, socially, and economically.

- Approximately two-thirds of Lifetime Survivors are Black and face institutional racism in addition to the challenges that often come with being HIV-positive.
- Many have parents with substance use disorders which has created added challenges during childhood, and many have lost parents, often at a young age.

Rather than being driven by loss and sorrow, however, the guiding force of a Lifetime Survivor is resilience. They are adept community-builders who cultivate a sense of family with one another as they pursue safety and wider recognition. Their deep-seated dignity drives the demand for more financially supported and well-informed care.

**They combat stigma through creating visibility for themselves, bringing a chair to the table when a seat is not offered.** Their ability to use their personal experiences and knowledge to drive impactful solutions makes them an integral part of both the community of people living with HIV and also the HIV response.

## 2. ADDRESSING UNIQUE HEALTH CARE NEEDS ACROSS THE LIFESPAN

While a high quality of life is about more than health and health care, these are undeniably foundational to achieving it. Lifetime Survivors have noted shortcomings in care models in both the pediatric and adult primary care spaces. Subjects such as sexual health, status disclosure, access to comorbidity screenings, and the cultivation of trauma-informed healthcare support must be incorporated into policy to make care more effective across healthcare environments. Whereas many practitioners with Lifetime Survivors as patients frame care as a means of delaying mortality, the focus must shift to building stronger and healthier minds and bodies to create the best quality of life. To maximize the economic accessibility of high-quality care, support must be more available to Lifetime Survivors seeking outpatient care from specialty medical centers under Part D of HRSA's Ryan White HIV/AIDS Program (RWHAP). At present, a significant policy challenge is that Lifetime Survivors age out of Part D services and are shifted to receiving services exclusively from other parts of the RWHAP which do not have the same level of specific expertise for this population.

### POLICY ACTION

**The Ryan White HIV/AIDS Program (RWHAP) Part D and the AIDS Education and Training Centers (AETC) Programs should increase their capacity to support these individuals from childhood throughout the lifespan.**

People who have been living with HIV since infancy report that the transition from childhood and pediatric care to receiving adult services has been particularly fraught. This simultaneously reflects the cold reality that many adult providers are unfamiliar with the developmental needs of adolescents and young adults, while also reflecting the caring and supporting environment in which many Lifetime Survivors have received HIV and other health care from clinics and programs supported by the RWHAP Part D Program. With so few Lifetime Survivors spread across the country, it is impractical to build and support a separate care program for them across the lifespan. At the same time, the Part D program, whose purpose is to meet the unique needs of women, infants, children, and youth, could be re-conceptualized to permit individuals to continue to receive services through the program into adulthood. While this may require a legislative change, the Secretary of Health and Human Services (HHS) should assess whether they have the authority to deem persons that acquired HIV perinatally as youth at any age for purposes of eligibility for Part D services. Such a change is necessary due to the need for accessible comprehensive care beginning in the earliest stages of life, paired with the risk of care being fractured and unsustainable by aging out of Part D into other programs. Further, the Part D Program or the AETC Program could develop provider training resources to better support the needs of Dandelions across the lifespan, especially at key transition points from adolescence to adulthood and from working age into retirement.

### POLICY ACTION

**Aging advocacy organizations should collaborate with Lifetime Survivors to provide mutual support for improving HIV services across the lifespan.**

Advocates for people 50 and over who are aging with HIV, including many long-term survivors, have recognized that Lifetime Survivors are part of

## DANDELIONS OFTEN HAVE DISTINCT CLINICAL AND SOCIAL NEEDS

### CLINICAL

In the pediatric care space, ART must be introduced as early as possible to protect against neurological issues such as memory loss and executive dysfunction.<sup>1</sup> This phase of care must also utilize screenings for endocrine, cardiovascular, and immunological complications that may occur later in life. In adolescence, practitioners must emphasize safe sexual practices in balance with acknowledging the value of pleasure so that adolescent Dandelions may have fulfilling sexual lives without worrying about compromising their partners' health.<sup>2</sup> As teenage Dandelions become adults, a transitional pathway must be forged in collaboration with adult primary care practitioners so that care is not interrupted.<sup>3</sup>

### SOCIAL

Creating greater visibility for Lifetime Survivors can make an enormous difference for those who have not disclosed their status or found community among those who share it in cohorts such as the Lifetime Survivors Network. Empowering people to join and grow the community in these spaces has strong potential to combat internalized stigma surrounding perinatal HIV, creating a greater sense of hope and resilience, and in turn increasing the likelihood of ART adherence and positive health outcomes associated therein.<sup>3</sup>

### Sources:

1. Bergam S et al., *The long-term health outcomes of people living with perinatal human immunodeficiency virus*, *Clinics in Perinatology*, 2024 September 20;1(4):849-64.
2. Tassiopoulos K et al., *Sexual risk behavior among youth with perinatal HIV infection in the United States: Predictors and implications for intervention development*, *Clinical Infectious Diseases*, 2013 January 15;56(2):283-90.
3. Kang E et al., *Navigating stigma trajectory and mental health among young adults living with perinatal HIV in New York City*, *AIDS and Behavior*, 2021 February 1;25(11):3712-20

the aging community. At the same time, their needs are often fundamentally different. Building on the expressed desire to be inclusive of Dandelions, aging advocates should seek opportunities to partner with Lifetime Survivors in a way that articulates a shared purpose, but also acknowledges distinctive needs and perspectives of these different groups.

### 3. SUPPORTING THE DEVELOPMENT OF PEER-LED ADVOCACY AND EDUCATION ORGANIZATIONS

Progress in HIV-related policy and care is often the result of effective community mobilization. Today, this type of mobilization is needed on behalf of Dandelions. Because there is such a small cohort of people, it is incumbent on other parts of the HIV community to be good allies and partners to support their education and advocacy efforts.

Many Lifetime Survivors consider themselves to be subject-matter experts, having been given a thorough understanding of their nuanced medical needs through years of highly involved care. Intentional funding is needed to advance the service-oriented groups that are spearheaded by members of this population so that their recommendations on how to close gaps in their care are meaningfully heard and brought to fruition. In the medical office, policy must ensure that practitioners are educated to meet Lifetime Survivors' level of expertise, removing the responsibility of patients to educate practitioners on the details of perinatal HIV.

#### POLICY ACTION

**HIV coalitions and HIV services organizations should support the Lifetime Survivors Network and the Dandelions Movement as vibrant and sustainable organizations.**

Many new and smaller organizations struggle to achieve long-term sustainability. HIV organizations, coalitions, and individuals have experience that can enable these groups to that ensure their survival and helps to focus them on the unique contributions they can make to HIV policy and advocacy. Core capacities of other individuals and organizations that can be

helpful include organizational development and capacity building, leadership development, and the assistance that external partners can offer in helping to refine and bolster policy priorities of these groups.

### THE TIME IS NOW

Many people think of dandelions as weeds, but in many cultures around the world, they are a symbol of hope, healing and resilience. For the HIV community, they are beautiful flowers that brighten our diverse garden. As we continue to work to ensure that babies are not born with HIV, we need to redouble our efforts to lift up, listen to, and engage with Lifetime Survivors to ensure that they thrive across the lifespan.

### ENDNOTES

1. Centers for Disease Control and Prevention, *HIV Surveillance Report, 2019*, <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html> (last visited January 13, 2025).
2. Centers for Disease Control and Prevention, *Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 territories and freely associated states, 2022*, HIV Surveillance Supplemental Report 2024, 2024 May 1;29(2):38.
3. CDC National Center for Health Statistics, *Birth Data*, <https://www.cdc.gov/nchs/nvss/births.htm> (last visited October 19, 2024).
4. Lampe M et al., *Achieving elimination of perinatal HIV in the United States*, *Pediatrics*, 2023 May 1;151(5).
5. UNICEF, *Elimination of Mother-to-Child Transmission*, <https://data.unicef.org/topic/hivaids/emtct/> (last visited January 10, 2025).
6. UNAIDS, *Global HIV & AIDS Statistics- Fact Sheet*, <https://www.unaids.org/en/resources/fact-sheet#:~:text=Global%20HIV%20statistics,infected%20with%20HIV%20in%202023> (last visited January 10, 2025).
7. UNAIDS, *Unfinished Business: Only the Urgent and Accelerated Delivery of HIV Services Will Keep the Promise of Ending AIDS in Children by 2030*, [https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2024/july/20240722\\_transforming-vision-into-reality](https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2024/july/20240722_transforming-vision-into-reality) (last visited January 10, 2025).
8. Yusuf H et al., *Preventing and diagnosing HIV-related comorbidities in adolescents*, *Topics in Antiviral Medicine*, 2022 June 1;30(3):537-44.
9. Centers for Disease Control and Prevention, *Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 territories and freely associated states, 2022*, HIV Surveillance Supplemental Report 2024, 2024 May 1;29(2):38.