



Statement Delivered by Global ARCH

Venue: United Nations High-Level Meeting Preparatory Process

Date: May 2, 2025

Panel Discussion 1: Tackling the determinants of noncommunicable diseases and mental health and well-being through multisectoral and effective governance and collaborative action.

I am reading this statement on behalf of the following:

1. Global ARCH
2. Fundación Estrellita de Belen, Venezuela
3. Brave Little Hearts Zimbabwe
4. Fundación Corazones Luchadores, Chile
5. Rare Warriors of Bengal Association, India
6. Justice for Heart Warriors, India
7. Ayuda a Corazón de Niño, AC México
8. Kawasaki Disease Canada
9. HeartCharged, US
10. Somerville Heart Foundation, UK
11. CHD Malaysia
12. Conquering CHD, US
13. Fundación Maria, Honduras
14. Heart Heroes Fiji
15. Brave Little Hearts South Africa
16. Amigos de Corazón, Peru
17. European Congenital Heart Disease Organization
18. Finnish Association for Heart Children and Adults, Finland
19. Big Heart to a Small Heart, Croatia
20. Children's Heart Foundation, UK
21. Brave Little Hearts Namibia
22. Hole in the Heart, US
23. Connecting Hearts to End Heartbreaks (CHEER Hearts), Nepal
24. Tanzania Children Heart Support Group
25. Amigos do Coração Goiás, Brazil
26. CHD Connects Heart by PYO



27. Namibia Rheumatic and Congenital Hearts

28. Fundación Menudos Corazones, Spain

29. Panhellenic Heart Disease Association, Greece

Today, I represent these groups and Global ARCH, a global alliance of patient- and family-led organizations and partner groups working to improve lifelong outcomes for individuals living with childhood-onset heart conditions. Our work reflects a collaborative model that brings together diverse disciplines and lived experience to create solutions that go beyond traditional silos.

We greatly appreciate the work by Member States, WHO, UN, and all stakeholders to advance efforts to prevent and control NCDs and to promote mental health and well-being. Your leadership and commitment are critical to improving the lives of millions impacted by NCDs around the world.

Our community, living with the realities of NCDs and mental health challenges from birth or early life, is often overlooked in discussions and policy design.

Across our network, we witness how fragmented health systems, social inequities, and environmental factors combine to deepen disparities. Today, I focus not on data but on the people feeling these impacts.

In Mexico, a mother was told her baby, William Gabriel, would only live a few days. Ten months later, she learned the diagnosis was wrong and her child had a treatable heart defect. For nearly a year, she mourned instead of seeking surgery. When she found out there was still hope, she cried with relief. Surgery is now being planned.

This story shows how gaps in early diagnosis, referral systems, and communication between providers can lead to avoidable suffering. During that time, she mourned not only her baby, but the birthdays and futures she believed would never come. Addressing these failures requires collaboration across sectors to give families not just accurate information, but the hope and care they deserve. It is not just about health systems; it is also about education, outreach, and social support to ensure people receive the right care at the right time, from the right people.

Clark (age 9, USA) was born with a congenital heart defect that went undiagnosed until 24 hours after his birth. While late detection is not uncommon, there were indications during pregnancy that should have prompted additional testing, which may have identified the defect earlier. Following his diagnosis, accessing appropriate services has been an ongoing challenge. There is a significant shortage of providers who understand the neurodevelopmental delays Clark is experiencing, as well as a lack of therapists equipped to support very young children dealing with PTSD and other mental health services.

Clark's experience shows how even in high-resource settings, siloed systems leave families navigating complex challenges alone. Addressing these gaps requires coordination between



maternal and child health, early childhood education, mental health services, and social care systems to ensure children get the right support at every stage.

These stories are not unique. They show what happens when childhood-onset conditions are left out of health policies and investments and why structural change is urgently needed.

As we approach the 2025 High-Level Meeting, we urge Member States to:

- Expand global NCD targets to explicitly include childhood-onset and congenital conditions
- Integrate early screening, timely treatment, and lifelong care for childhood-onset NCDs, including congenital conditions, across all levels of the health system, in coordination with education, social services, and mental health systems.
- Include these conditions in universal health coverage to prevent catastrophic costs for families.
- Improve data collection by incorporating childhood-onset NCDs into national health information systems and linking data across sectors to inform equitable policies.
- Train and invest in a healthcare workforce equipped to meet the lifelong and cross-disciplinary needs of this population.
- Ensure meaningful inclusion of patients and families as partners in designing and evaluating policies and services across health, education, and social sectors. Those with lived experience must be recognized as essential partners, not just recipients of care.

Nothing about us, without us. Our patient- and family-led organizations are committed to continuing our work to support and advocate for our communities in the areas that matter most. However, we cannot do this alone. We need your leadership and collaboration across disciplines that includes lived experience as a core source of expertise. This is essential to ensure that individuals living with childhood-onset NCDs and mental health conditions are fully included in national strategies, financing, and services. Without deliberate inclusion, too many will continue to be left behind.

Together, we can make real change.

For more information, please contact:

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Panel Discussion 2: Reshaping and strengthening health systems and all forms of financing to meet the needs of people living with and at risk of noncommunicable diseases and mental health conditions.

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Today, I represent these groups and Global ARCH which is a global alliance of patient- and family-led organizations and partner groups working to improve lifelong outcomes for individuals living with childhood-onset heart conditions.

We greatly appreciate the work by Member States, WHO, UN, and all stakeholders to advance efforts to prevent and control NCDs and to promote mental health and well-being. Your leadership and commitment are critical to improving the lives of millions impacted by NCDs around the world.

Our community, living with the realities of NCDs and mental health challenges from birth or early life, is often overlooked in discussions and policy design.

Across our network, we see how weak primary care, lack of specialist services, and financial barriers lead to delayed or inadequate care. Today, I focus not on data but on the people feeling these impacts.

In Canada, one individual (now in her 60s) with congenital heart disease saw the wrong type of cardiologist from age 18 to 33. She lived just a few kilometers from a major adult CHD center, but no one ever referred her. It wasn't until she arrived in the emergency room with a life-threatening cardiac event that the oversight was discovered.

This story highlights the consequences of poor care coordination and a lack of awareness across providers and systems. A multisectoral approach, including education, referral networks, digital health tools, and primary care engagement, is essential to ensure no one falls through the cracks during critical life transitions.

In Tanzania, Ferdinand lived with an undiagnosed heart defect for 16 years. He was misdiagnosed with pneumonia as an infant, and due to lack of care, developed heart failure. Although it was too late to fully repair the damage, a new government-supported center is now



providing earlier diagnosis and treatment for others. Ferdinand is now studying medicine to help others like him.

His story highlights how delayed diagnosis and lack of access to specialized care can have lifelong consequences. Improving outcomes requires a multisectoral response, including stronger primary care systems, health worker training, government investment, education pathways, and inclusion of patient and family organizations can empower young people like Ferdinand to lead change.

This can happen anywhere. These stories show how even in high-income countries, fragile systems can fail children and families at every stage.

As we approach the 2025 High-Level Meeting, we urge Member States to:

- Ensure global NCD targets and national health strategies explicitly include childhood-onset NCDs and congenital conditions
- Integrate early screening, treatment (including surgery), and lifelong care across all levels of the health system
- Include these services in universal health coverage to protect families from financial hardship
- Strengthen data and financing systems by tracking childhood-onset NCDs and using that data to guide equitable resource allocation
- Invest in a specialized workforce trained to meet the long-term physical and mental health needs of this population
- Ensure sustained, meaningful inclusion of patients and families in designing and evaluating health systems and financing models. Those with lived experience must be recognized as essential partners, not just recipients of care

Nothing about us, without us. Our patient- and family-led organizations are committed to continuing our work to support and advocate for our communities in the areas that matter most. However, we cannot do this alone. We need your leadership to ensure that individuals living with childhood-onset NCDs and mental health conditions are fully included in national strategies, financing, and services. Without deliberate inclusion, too many will continue to be left behind.

Together, we can reshape health systems to serve everyone, everywhere.



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