

Lack of access to insulin: undermining the Rights of the Child

Authors: *Olivia Heller¹, Olivier Duperrex^{2,3}, Philip D. Jaffé^{3,5,6}, Jeffrey Goldhagen², Carola Abidha^{4,7}, Ann Skelton⁵, Yvon Heller⁶, Jean-Dominique Vassalli^{3,6}, David Beran^{1,3}*

Affiliations:

¹ *Division of Tropical and Humanitarian Medicine, Geneva University Hospitals*

² *International Society for Social Pediatrics and Child Health*

³ *University of Geneva*

⁴ *Heidelberg Institute of Global Health (HIGH), Faculty of Medicine and University Hospital, Heidelberg University, Heidelberg, Germany*

⁵ *UN Committee on the Rights of the Child*

⁶ *The Child rights Institute*

⁷ *Center for Development Research (ZEF), University of Bonn, Bonn, Germany*

2024 marks the centenary of the League of Nations' Declaration of the Rights of the Child. The Geneva Declaration highlighted the health needs of children and proclaimed the duty of governments to respond to these needs.¹ Its influence led to the adoption of the 1989 Convention on the Rights of the Child that imposes obligations on governments, with regard to the right to life (article 6) and the right to health (article 24), which must be granted to every child without discrimination (article 2).²

Insulin's first use in 1922 transformed type 1 diabetes from a fatal to a manageable chronic disease. Insulin has been considered as an essential medicine since WHO established the Essential Medicines List in 1977. In addition, the Committee on the Rights of the Child asserts that States have an obligation to make all essential medicines mentioned on this list available, accessible, and affordable.³ Regrettably, insulin remains inaccessible to many of the 9 million people worldwide living with type 1 diabetes.^{4, 5} Beyond the direct impact on morbidity and mortality, a lack of access to insulin undermines the rights to life, survival, and development (article 6) and right to health (article 24). Indirectly, lack of access to insulin and diabetes care infringes on the child's right to education opportunities (article 28) and even the right to leisure (article 31).

In addition to the obligations of States to their own populations, parties to the Convention should also contribute to global implementation of children's rights through international cooperation. This cooperation must prioritise the health of children in resource-limited settings and low-income and middle-income States.³ In addition to government responsibilities, General Comment 15 also highlights the role of non-governmental organisations, the international community, and the private sector.³ With respect to diabetes and access to insulin and care for type 1 diabetes, these roles have been framed by WHO through the Global Diabetes Compact and a resolution approved by Member States in May, 2021,⁶ with the target that "100% of people with type 1 diabetes have access to affordable insulin treatment and blood glucose self-monitoring" by 2030.⁷

These global declarations lay the foundation for action. The 100th anniversary of the Rights of the Child, 2 years after the centenary of insulin's first use, is an opportunity to highlight the issue of lack of access to insulin and diabetes care and catalyse a global rights-based response to help address it. To meet the global target of 100% access to affordable insulin and self-

monitoring tools, it is also critical to improve regional and national data collection on type 1 diabetes and access to insulin. These data must both document existing challenges and drive global responses and advocacy by mobilising a global response from the public, private, and business sectors—within and beyond the health sector. Finally, there is the need to ensure accountability at national, regional, and global level. (Box 1)

Box 1. Actions that can be taken to increase access to insulin and respect the child’s rights convention

Support improvement of global, regional and national data collection on type 1 diabetes and access to insulin

- Carry out studies on the barriers to access to insulin, self-monitoring equipment and care
- Highlight challenges beyond health system that children and youth face with regard to managing their diabetes, e.g. stigmatization, access to education, etc.
- Address access to insulin as a component on periodic submissions and reports to the Committee on the Rights of the Child

Advocate for improved access to insulin and self-monitoring equipment

- Actively involve and maximize participation of children, youth, and families of people with type 1 diabetes in any action taken
- Foster the creation of independent voices to advocate for the rights of children and youth on the issue of access to insulin and diabetes care
- Ensure that bi-lateral and multi-lateral donors and organizations address the issue of type 1 diabetes and provide necessary financial and technical support to assist low- and middle-income countries
- Engage with the private sector to reduce the cost of insulin and related diabetes supplies

Communicate to different audiences

- Establish platforms for exchange between advocates in the area of Children’s Rights and health to share experiences to nurture sharing of experience and collaboration
- Translate scientific and technical knowledge on access to insulin and diabetes care to effectively share results with different audiences
- Ensure that social aspects of diabetes care are included at different stages of medical, nursing, public health, and other health-related training

Ensure accountability at national, regional and global level

- Hold governments accountable for providing affordable healthcare to their populations
- Submit comments to the United Nations Committee on the Rights of the Child on this topic based on the information collected
- Ensure that mechanisms are established at all levels in diabetes management to guarantee appropriate access to insulin, self-monitoring equipment and diabetes care and support to ensure continuity of care across the life course (from diagnosis and care in childhood to transition in adult care)
- Monitor progress towards WHO’s target of: “100% of people with type 1 diabetes have access to affordable insulin treatment and blood glucose self-monitoring”

As stated by Kofi Annan, on the 10th Anniversary of the Convention on the Rights of the Child, “...children's rights can no longer be seen as optional. Respecting them is not an act of charity. It is a binding obligation. No one must be allowed to get away with violating or neglecting children's rights. Almost every area of government policy affects children in some way, directly or indirectly.” As concerned global citizens, it is incumbent upon us to ensure that access to insulin and comprehensive diabetes care, enabling children with type 1 diabetes to realise their fullest potential, becomes a shared responsibility for all, and satisfies the Convention on the Rights of the Child.

Suggested actions are listed in the appendix and require input from a diverse audience of experts and people with lived experience. Their aim is to initiate discussion and debate to find ways of addressing the issue of access to insulin and diabetes care with a focus on taking a rights-based approach and ensuring multi-stakeholder engagement.

DB is a Commissioner on the *Lancet Diabetes & Endocrinology* Commission on type 1 diabetes and is the main grant holder for a project supported by the Swiss Agency for Development and Cooperation which contributed to the costs of a workshop on this topic held in Geneva on Sept 17, 2022 (Children Rights And Health—The Case Of Access To Insulin). J-DV is a Member of the Board of the Fondation Brocher. All other authors declare no competing interests. We wish to thank the participants in the aforementioned workshop, which led to the development of the concepts in this Correspondence. The workshop was supported by the Swiss Agency for Development and Cooperation and the Fondation Brocher.

Acknowledgements

The authors wish to thank the participants in a workshop in Geneva in September 2021 which led to the development of the concepts in this Commentary. The workshop was supported by the Swiss Agency for Development and Cooperation and the Fondation Brocher.

Declarations of Interest

DB is a Commissioner on the The Lancet Diabetes & Endocrinology Commission on type 1 diabetes.

References

1. League of Nations. Geneva Declaration of the Rights of the Child. Geneva: League of Nations, 1924.
2. UN General Assembly. Convention on the Rights of the Child. New York, 1989. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>
3. Committee on the Rights of the Child. CRC/C/GC/15, General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health Geneva: Committee on the Rights of the Child, 2013. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/crccgc15-general-comment-no-15-right-child-highest>
4. Green A, Hede SM, Patterson CC, et al. Type 1 diabetes in 2017: global estimates of incident and prevalent cases in children and adults. *Diabetologia* 2021; **64**(12): 2741-50.
5. Beran D, Lazo-Porras M, Mba CM, Mbanya JC. A global perspective on the issue of access to insulin. *Diabetologia* 2021 ; 64: pp. 954-962.

6. World Health Organization. Reducing the burden of noncommunicable diseases through strengthening prevention and control of diabetes. Geneva: World Health Organization, 2021.

7. World Health Organization. First-ever global coverage targets for diabetes adopted at the 75th World Health Assembly. 2022. <https://www.who.int/news-room/feature-stories/detail/first-ever-global-coverage-targets-for-diabetes-adopted-at-the-75-th-world-health-assembly> (accessed 20 Jan 2024).