

## DIABETES

# Diabetes in children and youth in less-resourced countries

## Diabetes en niños y jóvenes en países con menos recursos

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### Abstract

Type 1 diabetes (T1D) in children and adolescents is a complex disorder. Management requires access to insulin, blood glucose monitoring, diabetes education, and health professionals skilled in T1D. Some or all of these components of care are unavailable in many lower-income countries. Many young people die at from diabetic ketoacidosis soon after symptoms first develop, and are generally misdiagnosed with another condition. Others receive inadequate blood glucose controls and have poor quality of life, and subsequently die early from diabetes complications.

Over the last 30 years, various transnational efforts have been undertaken to help address this need. One of these is Diabetes Australia's Life for a Child (LFAC) program, which by providing supplies and other support, assists with the care of over 50,000 young people with diabetes in 48 countries. LFAC has developed a concept of "Intermediate Care" – a cost-effective approach in between the earlier approach of "Minimal Care" (associated with poor outcomes), and the Comprehensive, Guidelines-based care in high-income countries.

Aside from providing insulin, blood glucose monitoring, and other supplies, LFAC undertakes extensive activities in educating health professionals, developing diabetes education materials, advocacy, and in partnership with recipient centres, research activities on access to care, epidemiology, new components of care, and other areas.

With such initiatives, outcomes are improving in many countries. It is estimated that around one quarter of those in need of such support are receiving it. This

is substantial progress, but much more needs to be done. Advances in technology, in particular continuous glucose monitoring, have widened the gap between high- and low-income settings, and therefore novel approaches to using these technologies in resource-limited settings also need to be developed.

### Background

Most diabetes in children is type 1 diabetes (T1D), although type 2 diabetes (T2D), monogenic diabetes, and secondary diabetes also occur. The management of T1D in children and adolescents is complex and challenging, even in highly-resourced settings. Effective control of blood glucose levels is imperative in order to prevent both dangerous acute complications and serious long-term complications. Attention needs to be paid to the varying psychological and social impacts and contexts for the child and their family. Self-management skills are critical, and when combined with recent technological advances such as continuous glucose monitoring (CGM), excellent results can be achieved, with the young person leading a full life and having an almost normal life expectancy.

In less-resourced countries, young people with diabetes have often died very quickly due to a lack of governmental provision of insulin and blood glucose monitoring, and a lack of healthcare professionals skilled in T1D management and diabetes education<sup>(1-4)</sup>. A further problem demonstrated by some studies of sub-Saharan Africa<sup>(2,3,5,6)</sup>, and synthesis of these and other epidemiological data by the T1D Index project<sup>(7)</sup> is that the commonest cause of death for children with T1D globally is death from ketoacidosis at clinical onset. This is because the T1D is not diagnosed – the sick child is instead misdiagnosed with one of

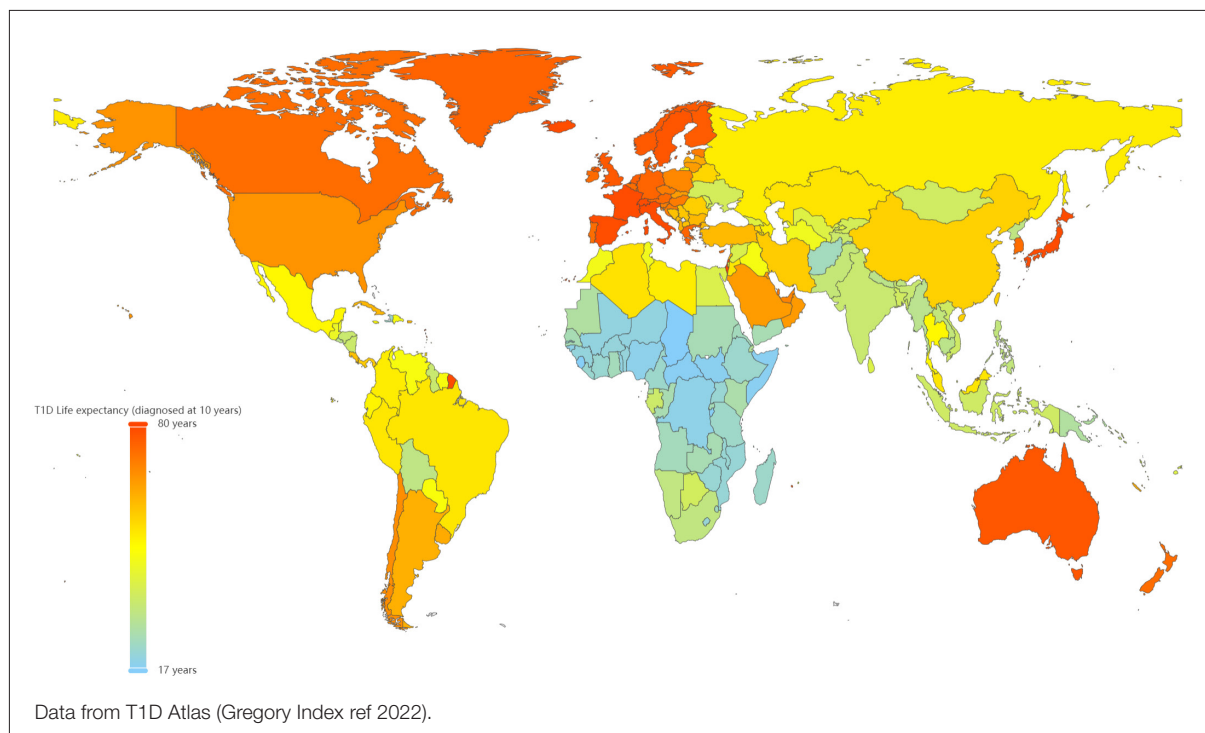


Figure 1. Estimated life expectancy of a 10-year old diagnosed with type 1 diabetes in 2021, by country.

a wide range of other diseases, including infections such as gastroenteritis, pneumonia or malaria, acute abdomen, or other medical conditions.

Figure 1 shows data from the T1D Index<sup>(7,8)</sup>, displaying how the estimated remaining life expectancy of a 10-year old newly diagnosed with T1D in 2021 varied from seven to 70 years across the world. Panel A in Figure 2 shows this wide gap in care between high- and low-resourced settings.

### Efforts to improve care in less-resourced countries

Various efforts within specific countries and also transnationally have been launched to address this need over the last 30 years. The transnational efforts include the International Diabetes Federation Insulin Task Force, the Life for a Child Program<sup>(9)</sup>, Changing Diabetes in Children<sup>(10)</sup>, Action4Diabetes<sup>(11)</sup>, Insulin for Life<sup>(12)</sup>, the ACCISS project<sup>(13)</sup>, Diabetes Empowerment International<sup>(14)</sup> and others.

### The Life for a Child Program

Life for a Child (LFAC)<sup>(9)</sup> was established in 2000 with the vision that “No child should die of diabetes”. It is a program run by Diabetes Australia in Sydney. The program supports diabetes centres in less-resourced countries, aiming to provide the best possible care, given local circumstances, to children and youth with diabetes. In most countries assisted, LFAC support can be provided up to 25 years of age, with this being extended to 30 years of age in low-income

countries (as defined by the World Bank). LFAC is now supporting the care of over 50,000 young people in 48 countries, and aims to extend this to 150,000 young people in 65 countries by 2030.

The cornerstone of LFAC support is the provision of insulin, insulin delivery devices, blood glucose meters and strips, and HbA1c testing. The main sources of funding are The Leona M and Harry B Helmsley Charitable Trust, JDRF, and unrestricted funding from Eli Lilly. Key partners include Direct Relief, International Society for Pediatric and Adolescent Diabetes (ISPAD), JDRF, Foundation for Innovative New Diagnostics (FIND), and others, together with various leading academic institutions and other non-governmental organisations. Pharma provides support through donations from Eli Lilly, Lifescan and embecta, and reduced cost supplies from Trividia, Roche, Siemens Healthineers and Abbott. The use of products is decided upon solely by LFAC in all cases.

Improvements in outcomes and rapid increases in prevalence have been documented from various countries. In addition to supplies, LFAC also provides support for diabetes education, logistics, transport and communications in many of the countries that are supported, as well as supporting education and training, research, and advocacy.

In the field of education, LFAC has developed an online library of existing and new resources in 24 languages<sup>(15)</sup> including novel carb-counting resources, management guidelines for less-resourced settings,

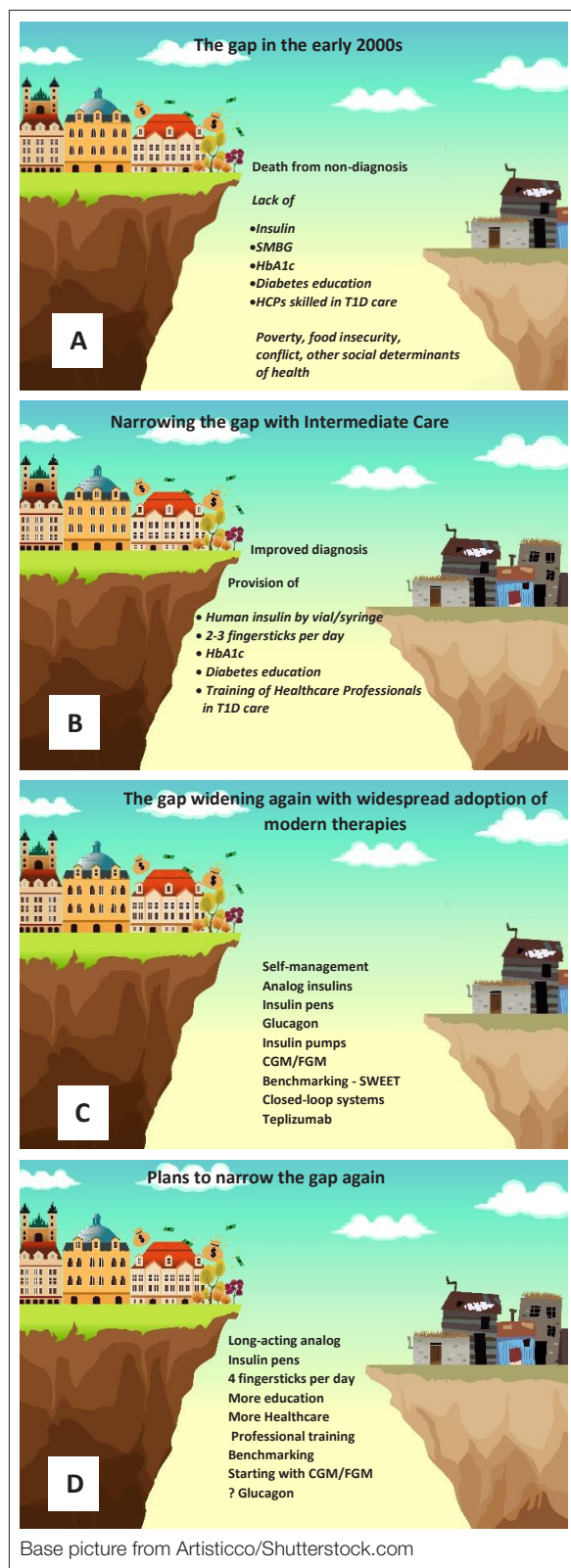


Figure 2. Efforts to close the gap between type 1 diabetes care in high- and low-resourced settings.

and others. Health professional training has been provided through LFAC-ISPAD workshops in various countries, and support for various medical and

nursing courses on paediatric diabetes, especially in sub-Saharan Africa.

In terms of research, LFAC has published over 70 papers on access to care, epidemiology, clinical characteristics, outcomes, psychosocial aspects, thermostability, cost effectiveness, and other topics in collaboration with partner centres in 22 countries.

Finally, LFAC supports advocacy efforts at country, regional, and international levels, aiming to increase national and international support and promote sustainability within countries. These efforts include work highlighting diabetes care as a human right, such as the paper by Brennan et al.<sup>(16)</sup> and a toolkit<sup>(17)</sup>, representations to the World Health Organization, and the “Changemaker” Program which supports young advocates<sup>(18)</sup>.

### Levels of care, and “Closing the Gap”

A paradigm of levels of care was developed by LFAC<sup>(1,19)</sup>, as it became apparent that there was a very large gap between the “Guidelines-based Comprehensive Care” available in high-income countries and the “Minimal Care” provided in many lower-income countries, with the associated very poor outcomes. The outcomes of Minimal Care are shown in Panel A of Figure 2. As Guidelines-based Comprehensive Care was too expensive to provide in low-resourced settings, the concept of “Intermediate Care” was developed, involving adequate insulin (generally human insulin but analog if possible) preferably in a basal-bolus regimen, 2-4 blood glucose tests per day, HbA1c testing, diabetes education and simple screening for complications.

Intermediate Care has been shown to substantially improve outcomes. For instance, the number of young people with diabetes in Mali has increased from 14 in 2007 to over 1,000 today<sup>(2)</sup>. This level of care has also been shown to be cost-effective from a health economics perspective<sup>(20)</sup>.

Through LFAC and the other groups mentioned above, along with multiple local initiatives, LFAC estimates that around one quarter of the young people who need this support globally are now receiving this level of care, with the percentage growing each year. Figure 2 Panel B illustrates the “Closing of the gap” that resulted from the widespread introduction of Intermediate Care.

The greatest challenges in rolling out this level of care include reaching regional and especially rural areas in large countries, providing care in the seemingly increasing number of areas where there is conflict or political chaos, and where there are no “local champions” with an interest in T1D and the capacity to develop and manage a program.

However, this gap has again grown wider in recent years (Panel C of Figure 2) due to the universal availability in high-income settings of analog insulins, pens, and pumps, and especially CGM, and now Automated Insulin Delivery / Closed Loop Systems. Furthermore, new drugs such as teplizumab<sup>(21)</sup> and baricitinib<sup>(22)</sup>, along with stem cell treatments offer hope for a future prevention and/or cure of T1D, but this will probably be at a high financial cost.

LFAC is therefore now endeavouring to close the gap again (Panel D in Figure 2) with the introduction of long-acting analog insulin, insulin pens, and CGM in particular. Analog insulin and the provision of insulin in cartridge rather than vial form has substantially higher costs than human insulin in vial preparations, which opens up sustainability issues. As a result, LFAC and its partners have undertaken various studies to determine its possible benefits in less-resourced settings.

CGM is unarguably beneficial. For the first time, children and young people with diabetes, their parents, and their healthcare professionals are able to understand the full scope and patterns of blood glucose excursions, and therefore able to optimally respond and improve blood glucose control. It is eye-opening and transformative, but it is very expensive, and also requires expert diabetes education and ongoing support. Work has started on understanding the challenges and benefits of introduction of CGM in less-resourced settings, and LFAC and various other groups have studies underway to assess the acceptability and impact of this technology, and the possible use of intermittent CGM.

In conclusion, whilst there are still many unmet needs in the care of young people with diabetes in less-resourced settings, a great deal has been achieved through the combined efforts of LFAC and many other groups. Simply put, the international diabetes community is helping its own, with increasing success. We believe that if this momentum can be sustained it will transform the lives of hundreds of thousands of young people with diabetes, who would otherwise have succumbed or remained chronically unwell.

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