

Young people's needs and priorities for improved support and education: a call for action

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Most young people's lives are hectic. They all involve a degree of chaos, and the usual trials and tribulations of friendships, romance, college, and so on. Add the diabetes into the mix, with its unique challenges, and the situation can feel overwhelming. The authors of this report, young people who have been living with diabetes for some years, have all met several diabetes healthcare providers. Unfortunately, although many adults involved in diabetes care are keen to help young people to make the most of their life, this does not always appear to be the case. Since the majority of healthcare providers do not have diabetes themselves, they do not understand the real challenges and issues, and how these impede the persistent attempts of young people to achieve good blood glucose control.

At the International Diabetes Federation (IDF) Congress in Cape Town 2006, the IDF Youth Ambassadors found that despite the diversity of our geographical locations and cultures, many of us had experienced similar issues relating to diabetes. Diabetes can feel like a complex puzzle with many parts that have to fit together for us to be able to live life to its fullest. To get an overview, we decided it would be useful to compile the many thoughts and issues that were prioritized by an international group of young people.

The youth leadership workshop, prior to the IDF Congress, included training in applying business leadership frameworks for our volunteer work in

Figure 1: Prioritized attitudes, wishes and needs

		IMPACT		
		Low	Sign	Major
URGENCY	Low		5	7
	Sign		8	1, 9
	Pressing		2	3, 4, 6

1. Lack of focus on siblings
2. Lack of connections to other children with diabetes
3. Needs for support for parents (networks, education, money, time to let go)
4. Deficit of communication within the family (family code-of-conduct/agreement)
5. Stigma of living with diabetes
6. Apathy/burn-out from living with diabetes
7. Lack of support to make smart/healthy choices
8. Distrust of own and other's capabilities of dealing with the child with diabetes
9. Lack of comprehension of how the emotions are connected to diabetes

diabetes advocacy. We learned how to determine key priorities in order to allocate resources effectively and maximizing positive results. Once the issues have been clearly defined, a strategy and plan of action can be devised to tackle each one appropriately.

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This analysis was applied to the DAWN (Diabetes Attitudes, Wishes and Needs) youth initiative, a global Novo Nordisk A/S initiative in partnership with IDF and the International Society for Pediatric and Adolescent Diabetes to improve psychosocial support for children with diabetes and their families. Having recently spent several days sharing stories about living with diabetes in various different countries, we were invited by the DAWN youth committee to list and prioritize the issues that in our opin-

ion were key to improving the life of young people with diabetes, particularly with regard to psychosocial issues (Figure 1).

A strong emphasis was placed on the need for improved support and education to be provided in a number of ways. Diabetes advocates and health-care providers need to target young people, their parents, and siblings with education and support. Indeed, society as a whole needs an increased understanding of diabetes in order to be able to provide effective support for those of us with diabetes.

We placed a strong emphasis on the need for improved support and education.

Some of our issues were related to day-to-day living within the family; others aimed to challenge fundamental problems in society. Other issues are directly related to individuals living with diabetes.

We would very much like to encourage all people who are involved in diabetes care to look closely at the way we have prioritized our wishes and needs. In this way, we can unite as a team in our treatment, rather than parents dealing with rebellious teenagers they struggle to understand.

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