Country Report – Belarus

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Following the IDF Europe Board's decision regarding the country reports for some of our member associations, I travelled to Belarus in September 2009 in order to perform the interviews necessary for the present country report. The report notes the status of the services offered for the **people with diabetes (PWD)** in Belarus, the status, and achievements of the **Belarusian Humanitarian Non-Governmental Organization "Children's Diabetes" (ByCD),** as well as the more general relationship between the four major stakeholders in the area of diabetes: the persons with diabetes (PWD), the medical professionals, the public health institutions and the private medical services and pharmaceutical providers.

Belarus has a population of about 9.6 million and the official data state that the prevalence of diabetes in Belarus is 1.9 % (about 186,226 people with diagnosed diabetes). The Diabetes Atlas (2009) indicates for Belarus an estimated prevalence of 9.2% which is in great discrepancy with the figures registered by the health system (1.9%).

The country statistics reported by WHO do not include diabetes as a major risk factor the public health. No statistical data or research results are registered by WHO.

Belarus has a national health system where the Ministry of Health has overall responsibility, although the funding of primary and secondary care is devolved to the regional level. Tertiary services (highly specialized hospitals) are funded directly from the Ministry of Health budget. The relationship between different layers within the system is hierarchical and most policy decisions are made centrally. There are few private service providers in the system, and, with the notable exception of some nongovernmental organizations (NGOs), most organizations are state bodies. The organization and financing of primary and secondary care services happens at the local level (both regional and district level), with minimum standards set centrally by the Government in accordance with current priorities of the country. The minimal standards are determined on the basis of the available capacity of the Government and the Ministry of Health within a certain time frame and can be refined if necessary. Day-to-day management and financing of the system therefore happens at the local level and the key actors are regional and district governments and Regional Health Care Departments; however, the hierarchical administrative arrangements and regulatory framework mean that ultimate management power lies with central Government, namely the Ministry of Health, the Parliament and the President.

The health system provides the core medical services and medication for all the citizens affected diabetes. While certain medical facilities may compete with any EU health unit in terms of assigned teams, specialists or laboratory equipment, there are certain draw backs it terms of consistency of medication, access to medication, effective and coordinated education. The system tends to rather treat and support drastic complications then to address prevention or quality long term treatment. Like in most of the CIS countries, registering as an invalid provides the person with additional financial resources which are (in certain cases) essential for better managing the condition.

There is one diabetes organization registered with IDF: the Belarusian Humanitarian Non-Governmental Organization "Children's Diabetes" (ByCD).

The ByCD was established in 1992. It is a mixed organization bringing together health professionals and lay persons. The organization has a federative structure and its members are local organizations from Minsk and other 27 cities. Out of its 28 members, 22 are legally registered as local chapters of ByCD. These members are independent legal entities with bylaws similar to the republican organization (ByCD). The other local organizations are "self supported" groups without legal status. According to the Belarusian law ByCD is a "republican" organization. It has an advisory and coordinator role for its members and it represents the interests of the members and the general population affected by diabetes (not necessary members of the association) at republican level. All its activities are performed with the support of volunteers. It does not have a regular publication or a web site. The association represents about 2800 active registered members from across the country.

The four stakeholders

During all the interviews, the relationships between all the stakeholders were highlighted.

There are several PWD associations registered in Belarus. In most cases the local organizations are independently registered and they are affiliated with the republican organization. Some of the local organizations are not officially registered as they qualify as "self supported" groups. The involvement and participation of the youth in the associative life is considered to be problematic as the interest of the young adults with diabetes is to secure the start of a professional career or for establishing a new family. Still, in all the organizations met there were young adults performing executive functions within the organizations on a regular basis.

Some of the organizations were started due to the problems with insulin (some 15 years ago) when the quality was improper (animal insulin) and the distribution was irregular. Besides lobby, present services include peer support offered by the volunteers. As with the management of the associations, people do not know/feel that the services offered might have a higher impact if the involved volunteers attend specialized training.

In one local organization there are 32 active members but they chose to speak up and act for some 600 PWD in their region.

Organizations contribute and receive a quarterly journal edited and printed by Novo Nordisk. The journal is considered to be a very important added value for all the organizations and their members.

Organizations may have only mail addresses but no official office, as they would be obligated to rent an office, and they do not have the money to do that. The officials do not help here (the city hall or the medical units). Each organization has a bank account, but most of the costs are dealt with direct support from the different contributors (space, transportation, meals, or needed materials).

Local organizations have an organizational structure similar to the ByCD: are coordinated by a volunteer group of people who is elected every five years; individuals are elected to perform audit or monitoring of financial activities; there are no limits in the number of terms to be accomplished by any person. Strategic decisions and executive responsibilities are staying with the same people (the board of management). Local organizations have a yearly plan adjusted every month according to the needs; the yearly plan is done by the organization's board and also follow the plan of the national organizations; activities are not followed by budgets in the yearly activity plan; activities are budgeted on a case by case basis. Organizations may receive support from both pharmaceutical and non-pharmaceutical companies as well as charities; if listed as a charity organization one may receive 1% of a commercial company profit – but the list is developed by the office of the president.

One of the problems raised by local organizations is the fact that more generic products tend to penetrate and be accepted on the market.

All the organizations are well connected with the local health specialists. In one region the PWD organization is asked to offer peer support each time a new case of diabetes is registered.

The problems revealed by the PWD associations are related to their limited access to funds and resources, the fact that diabetes is not accepted on the priority list of the health officials, the fact that education of the PWD is not yet considered as an essential element in addressing diabetes, and prevention is not yet seriously taken by the health officials and professionals. According to the NGO Sustainability Index the associative life is greatly limited and controlled by the Government.

Besides the PWD associations there is also a professional association of the endocrinologists which is not affiliated with IDF, but almost all the endocrinologists from the Belarusian Association of Endocrinologists are active members of ByCD.

PWD reported that the medical act does not represent a problem, as all the medical services, core medication, and some self monitoring materials are covered by the state (see also "Access to medication" above).

Life with diabetes is difficult but people feel that they should be optimistic. One of the first problems after learning about their condition was depression (stress). Doctors might present diabetes (type 2) as a mild condition, and PWD may also consider it as such. Awareness or late complications are the elements which can convince certain PWD that the condition is serious and that they should become responsible for the daily treatment. People feel that the general view that "diabetes is just another way of living" is not proper: diabetes is an enemy that has to be defeated. If not taken care of, diabetes may kill you. They feel that the image conveyed by the officials is diminishing the importance of the condition and also it encourages people not to manage it carefully. Correctly addressing the body weight problems of the type 2 PWD, is not on the list of regular treatment. Even if advised to loose some weight, there is little support to really get the body mass decreased. The psychological support offered in adult hospital is not proper and it does not achieve its mission. The diabetes diagnosis impacts young adults (with type 1) so strongly that even talking about how they were discovered or about their daily life will bring tears in their eyes.

Children attend the courses in the regular schools while they can also continue their education if they have to stay in a hospital. Colleagues and friends are aware of the condition and also they are told how to react in case of a hypoglycaemia episode. Children are taught how to adjust their insulin dosages to fit their condition. It is reported that certain sport teachers are reluctant to accept children with diabetes in the regular classes. For the other teachers, they are informed on a need to know basis. Children carry with them their insulin, testing materials and also sweets. They are aware of November 14. All children receive food in school but there is no special diet for different conditions. Every school has a medical cabinet and a medical nurse attending it, so children can use it for testing or injecting insulin.

Most of the children with diabetes are registered as "invalids" to receive some social financial support from the government. Parents say that the title is not important for the children, but the amount of support may contribute to insuring a better management of diabetes (for example for buying extra test strips, as the government offers only one strip a day for free). After the age of 18, the invalidity is granted only if there are recorded real disabilities due to late complications or other causes. In addition, if a family has a child with diabetes the mother is allowed to retire (and receive a pension) at the age of 50. For the persons who have to retire before time the pension received is about 100 EUR. In families where the child develops diabetes there is a higher rate of abandonment by the fathers. Thus, the family is almost obliged to apply for invalidity in order to cope with the financial burden of the condition. In the same time, families with children with diabetes are more frequently accepting to foster other children with diabetes or are materially or financially supporting children and youngsters with diabetes.

Active persons might choose to hide the fact they have diabetes as they might loose their job or they might be limited in exercising their profession (like not being allowed to travel abroad or to receive a driving license). In some cases diabetes prevents people to start a family due to the perception of diabetes. In order to receive a driving licence one has to go once a year to the assessment commission. The managing doctor is the one to recommend a PWD to receive a driving license. The approval of the driving licence is done by the assessment commission which includes medical experts and representatives of the traffic inspection.

Persons with type 2 are complaining about their access to medication (not always in the pharmacies) and the fact that they have to pay for the glucometer (~22-45 EUR) and the test strips (~25EUR/100 st.) if they choose to manage their diabetes. For the insulin dependent persons the prescription is not for what brand or type of insulin they need but what insulin is available in the pharmacy. Some PWD found that they can better manage their diabetes if they use analogue insulin but, as these are not compensated by the health system, it is a very high price they need to pay (while receiving a pension of about 100 EUR they need to pay for a box of five 3ml pen fills 65 EUR). Analogue insulin is compensated by health system in some cases (local budgets), when PWD have prescription for analogue insulin according to regional regulations.

People are looking for a treatment milder than injections, with less aggressiveness (like a shot a day) or painless glucose testing. The information presented at the TV stations, like the insulin patches or a cure for diabetes via xeno-transplantation are setting false

hopes into families. Several families mentioned the need for a delivery system able to inject half units.

In some regions education programmes started only 15 years ago.

People would like to have access to more test strips as they are appreciating the impact of the self monitoring. Certain regions are offering support for students and pregnant women to access test strips and better control their condition. Adult PWD may receive 1 test strip per day free of charge if they are registered as invalids (group 1 or 2).

Insulin dependent PWD would like to be able to receive their medical prescriptions once every three months not every month. PWD on oral medication receive prescription once every three months. Visiting the doctor may take as much as three hours (also depending on the distance to the outpatient clinic), and in most of the times it interferes with the work or school.

People complained that the places in the rehabilitation units are sometimes sold for Russia or Ukraine and not offered for free for their use. PWD can buy vouchers for the rehabilitation units. Outpatient rehabilitation is offered for free to PWD.

In Belarus the PWD are managed by several medical professionals: general practitioners, therapists, paediatricians, and endocrinologists most of them from public institutions.

In one of the republican hospitals out of the 60 beds of the endocrinology department some 80% were occupied by persons with diabetes from Minsk and from other regions. The work carried out by these professionals is impressive, though most of is due to the system. The Republican Endocrinology Centre is visited by 250 patients a day. Most of these persons are affected by diabetes. In a republican outpatient unit two ophthalmologists reported performing more than 10 laser operations per day.

The interest for specializing in certain areas of diabetes (like podiatry, neuropathy, patient education or diabetes economics) is in most cases triggered by the personal interest to achieve an academic degree. Such personal interests are supported by the colleagues and accepted by the administration of the health units.

Most of the specialists met, are attending international diabetes meetings (EASD, ISPAD, ADA, IDF). Young specialists have limited access to travel grants outside the republic.

Doctors feel that there is still a lot to be done in the area of patient and general practitioners education as well as motivating the patients to comply with the recommended line of treatment. Authorities do not have diabetes on their priority list and certain needs (like a constant supply of one medication for each patient, or proper devices for insulin delivery for infants) are regarded as unreasonable or excessive requests.

Compliance with the recommended treatment is one of the problems in managing diabetes both in young and old persons. In some cases only a severe complication

(foot problems, renal problems) may bring more attention on how diabetes is managed on a daily basis.

Medical professionals recognize that in the last years the age of onset of diabetes in children is lower and lower (3 to 6 years of age compared with 14-15 years some ten years ago). Paediatricians reported that the children treated with analogue insulin (younger children) have better results than the other ones (average HbA1c of about 7.4% vs. 8%) but they are afraid to decrease this level as they feel that hypoglycaemia might become a problem for the families.

The salary for an endocrinologist is lower than for a general practitioner and due to this, an increasing number of specialists are choosing to go into general practice.

There are discontinuities in the supply of lab consumables and medication and such temporary situations might trigger crisis which affect both the medical professionals (as they need to find solutions for such situations) as well as the persons with diabetes. The rigidity of the distribution system puts additional stress on the health professionals as the subsidised medication has to be strictly consumed to comply with financial and pharmaceutical requests – and not necessarily addressing the real needs of the PWD.

Nurses have limited responsibilities in the medical act. They perform mostly the bureaucratic activities as well as certain medical procedures. In certain locations nurses are requested to deliver the education sessions without any clinical responsibilities. Dieticians and educators are not recognized as professions.

There is an Association of Endocrinologists which brings together the specialists from the main education and research health units in Belarus. The group in Minsk is having monthly meetings were professional issues are discussed. Even if these events are between peers, the tendency is to use lectures rather than discussions. Some leading professionals in the Association of Endocrinologists are also members of the board of the ByCD.

Public health authorities

Policy making is a closed business in Belarus. Drafts are not publicly discussed. A lot of regulating documents are directly issued by the office of the President of the country.

The health committee of the National Assembly is aware of the issues related to diabetes and its complications. The condition is not on the top list of the National Assembly or of the Ministry of Health (considering the low prevalence) but, as the President recently signed the Inter-parliamentary "Agreement on Diabetes", certain activities might focus on this condition. Even if not directly, the quality of life of children and youth is of great importance for the politicians, and one of the recent pieces of legislation, addressing the protection of children, has a focus on diabetes as well. The health commission also showed openness to work with the civil society and encouraged the ByCD to actively contribute to work of the health commission.

The Ministry of Health is considering the active diagnosis of chronic diseases as well as the best treatment especially for children and youngsters. It is directly interested in developing a pro-active young generation. While there is interest to cooperate with the health professionals in any legal document to address prevention or screening for

diabetes, the Ministry is also more open to international cooperation. The Ministry will consider for the future (also following the Inter Parliamentary Agreement on Diabetes) a national strategy to address diabetes.

The local pharmaceutical producer for diabetes medication, Belmedpreparaty, is a state owned company. After its agreement with Novo Nordisk, the company managed to improve its production line and quality management system so that it received the certificate to put on the market two types of human insulin in vials. The present market share is about 70% and the intention of the management is to increase its production capacity to 100% and over. The first batches of human insulin were issued in 2006. The company is also interested in getting into agreements with other pharmaceutical companies. In 2010 they will start to work for the production line of pen fills (also with raw material and technology from Novo Nordisk). All their diabetes related products undergo frequent laboratory tests in the factory and in the National Agency for Drugs (every batch of insulin is tested). If the company managed to incorporate the new technologies, it still missed a corporate culture: their approach to diabetes is strictly "selling drugs" and nothing else. We discussed with both the foreign partners and the local leadership the need to go beyond this old attitude if the company wants to become the leader on the local market – technical assistance as well as constant contact with and support of the PWD and health specialists is needed in order to be sure that the products are correctly used and that the development of the new products follows the needs of the market. This needs to start with a shift in the attitude of the staff and the leadership.

The private companies offer limited health services and most of the pharmaceutical products for the public health system and for the general population. The medical services for diabetes are limited to some outpatient cabinets. The local pharmaceutical producer, Belmedpreparaty, produces insulin (animal and human) and two oral glucose lowering products from imported raw materials (Chinese).

The import taxes are limited to 5%. There are certain ceilings for the overheads the commercial dealers may charge for bringing (about 5% for the glucose meters and strips) or distributing diabetes related drugs and equipment. Pharmacies may also add up to 23% overhead to the products they sell. Tax exemption is admitted only for the products approved via a decree of the President or included in the special exemption lists. Humanitarian help is tax exempted.

Licensing a new product may take anywhere between 4 months and one year and may involve clinical trials in locations chosen by the authorities. Once the clinical trials are successfully passed, the license is offered for up to 5 years. After this period there is need for re-licensing the product. Bureaucracy may be avoided by strictly following the law and closely coordinating with the authorities.

The large glucose meters companies have higher prices and too high for the local market. There are several generic products being present on the market and accepted due to their lower prices. Donations of meters are rather often but they cannot cover the whole country and for longer periods. "Lifescan" meters are offered for 50 USD (38.5 EUR), less than in other countries in the region. Test strips are for about 30 USD (23 EUR) for 50 test strips. A newly established Swiss company offers meters for 25-35 USD (19.2-27 EUR) and test strips for 15-20 USD/50 st. (11.5-15.4 EUR). Going out of the capital city the wealth is decreasing progressively and the capacity of the people to

buy their own testing materials is also decreasing. The distribution is organized in specialized pharma-technical network of shops. People with higher education are looking for the brands. The uneducated or poorer persons are going for the lower price. Certain companies offer free meters on a regular basis. Donations are managed via a governmental warehouse and the donors have to pay for the storage (which sometimes blocks donations as hospital or end users cannot pay for the dues). One of the problems highlighted by the commercial pharmaceutical companies is regarding the tenders organized by the Ministry of Health: even if the Ministry of Health specialists look at the technical details of the products, clinical results, reliability, one of the main parameters for choosing a winner of a tender is the lower price. Local tenders are offered by the local clinics and the procedures are more convenient (less bureaucracy)

Novo Nordisk has a good partnership with the local producer Belmedpreparaty for packaging human insulin. At the time of the visit the insulin is brought from Denmark and packed in vials (Actrapid and Protophan). The local company was the first in Belarus to receive a ISO 9000 certification and, since 1999 they are offering vial insulin for the insulin dependent adults. The local production of human insulin triggered a higher switch from other products to human insulin. In the same time doctors needed updated information about the use and management of the treatment with human insulin, and this was done with the support of the Novo Nordisk company and specialists from Minsk. There still might be problems with the storage and transportation of the final products. For 2010 it is scheduled to upgrade the local production for pen-fills.

One of the insulin companies' concern is the low level of insulinization (number of insulin units per day per person, and the percentage of the type 2 PWD treated with insulins) compared with other countries in Europe.

It seems that only two of the pharmaceutical companies are interested in supporting the education programmes for PWD, most investing the education of the medical professionals. Unfortunately their investments lack consistency and duration. In most of the cases they use existing expertise in the capital city rather than bringing new education products or technologies. As there is little coordination between companies, there might be similar programmes going on and targeting different outcomes

Most of the companies offering oral medication are targeting endocrinologists as well as therapists and cardiologists. Companies cannot directly market their products with the end users.

Even if the foreign companies inherited from their main company a certain social responsibility package, there is no formal assessment of the effectiveness of the investment, and such practices cannot be successfully transmitted to other organizations.

Generic products are not heavy presence on the Belarusian market, but there is a growing temptation to allow such products on the market. The government has an agency for the control of the medical products and it claims to have very up to date equipment and procedures.

Foreign companies have technical support representatives and all the commercial operations (import, taxes, distribution, participation to tenders, etc.) are taken care of

by locally registered commercial companies. The national tenders are made for the centrally financed medication, but none of the representative could tell if the tender is made for certain varieties of medication, for quantities or for ceiling prices. All hope that the national registry will bring some light and reliability in assessing the needs and in planning. All the procedures for the national tenders are heavily regulated. There are also tenders initiated by local hospitals or local administrations. Such tenders are more relaxed in terms of paperwork.

Pharmaceutical companies offer funding for NGO activities. As they cooperate with all the lay and professional organizations on the market these companies also have a good knowledge of the activities and impact of the NGOs. They are the primary financial supporters for the participation of Belarusian specialists to local and international congresses and meetings.

Private companies feel that there is still a lot to do to change the attitude of the doctors working with chronic diseases (improve communication skills) along with professional skills needed for a correct treatment of the condition, patient education is also seen as a key element to addressing diabetes.

The health services provided to the PWD

Country statistics

Belarus registered in 2008 186,226 persons with diabetes (1.9%), out of which 13333 have type 1, 172306 have type 2, and 587 have other types of diabetes. Children with diabetes (<18 years) represent 1410 cases with 31 having type 2. The incidence of diabetes is in increase from about 80 per 100,000 in 1995 to 267 per 100,000 in 2008 (3.3 times in only 13 years). In 2008 the highest incidence was registered in the *oblast* (region) of Vitebsk (323) while the lowest in the *oblast* of Minsk (232).

In terms of late complications, the country registers a decrease of chronic kidney failure and blindness while the amputation rate is slightly increased (between 2007 and 2008). The total number of new cases of people affected by severe late complications of diabetes in 2008 is 580, out of which 278 had amputations, 255 registered chronic kidney failure and 47 blindness.

The level of diabetes management (compensation) of the persons with diabetes was also registered in 2008 for a limited group of 3400 persons: 35% of the adults had a level of HbA1c lower than 7.5% (22% in the case of children), some 17.5% had a level between 7.5 and 8.5% (19.2% of the children) and 47.5% of the adults and 58% of the tested children had the level higher than 8.5%. The proportion between adults and children was not similar to the general population structure.

Mostly because of social reasons, some 1276 children (out of 1410) were registered last year with a degree of handicap (for children the handicap does not need to be physically present – this is a way to compensate certain costs and allows the parents to access a larger list of medication and services). For the adults the handicap is assessed according the medical records and last year there were registered about 17,750 persons with handicap.

The causes of death directly attributed to diabetes represented 189 cases in 2008. The largest number is because of kidney failure (136), then gangrene (46) and coma (7).

Some 31,800 persons receive treatment with insulin (100% of type 1 and 9.7% of type 2). Almost 11% (3500) use the pen for the delivery of the insulin. In 2008 34.3% received animal insulin. The officials declared that treatment with animal insulin will be stopped in 2010.

A local study performed in 2007 revealed that about 60% of the children included in the study had the HbA1c higher than 9%, and about 30% between 7 and 9%. The study also revealed the real life impact of the diabetes education, looking for compliance, self management, correct use of the medication, patterns of reaction and incidence of hypoglycaemia incidents. In a local outpatient clinic for children the average level of HbA1c was reported at about 8%.

The Diabetes Atlas (2009) indicates for Belarus an estimated prevalence of 9.2% which is in great discrepancy with the figures registered by the health system (1.9%).

In 2002 WHO listed diabetes as the tenth disability group for females, with a share of 2.3% of DALYs.

Health system data

The legal environment in Belarus addresses several aspects of diabetes services and medication in both general and specific pieces of legislation. The latest regulation adopted is the ratification of the CIS agreement in the area of fighting diabetes (signed by the CIS representatives in November 2008 in Kishinev) "The medical-social protection of the citizens suffering from diabetes mellitus".

The country does not have a national programme to address diabetes.

The government uses the council of the Republic's Chief Endocrinologist when matters regarding diabetes are to be considered in any legal document. The legal system does not perform consultations with interested parties before any piece of legislation is promoted for adoption. Patient groups are not official partners of the Ministry of Health, and professional groups are consulted only occasionally.

The legal system insures that the access to health services and core medication for diabetes is free of charge for all the citizens of the country. Chronic late complications are also covered (even if for some cases registration of a degree of disability is needed to secure the proper access to medication) and medical services and core medication are offered for free.

In Belarus diabetology is not a separate speciality. Diabetology is included under endocrinology or endocrine-paediatrics. Children (up to 17 years old) are diagnosed and managed by paediatricians with a specialization in endocrinology. Adults may be diagnosed and managed by general practitioners (less frequent), therapists, or endocrinologists.

As with the general medical units, the country is geographically covered by a structured, hierarchical system of outpatient and inpatient endocrine units. Districts may have city polyclinics or central district hospitals with endocrinology departments for out patients. The regions (*oblasts*) have the regional endocrinology dispensaries, city endocrinology dispensaries or the outpatient units of the endocrinology sections of

the regional hospitals. At republican level there is the reference centre in Minsk, hosted by the Republican Centre for Rehabilitation. There are four inpatient units with endocrinology departments that accept patients from the whole republic. 2 have official republican status (the Pediatric Clinic No2 in Minsk and the Republican Centre of Radiation Medicine and Human Ecology in Gomel) and two (Minsk City Hospitals No 1, No 10) even if allocated only for the population of Minsk, offer services for any citizen of the country.

At district level the inpatient units for endocrinology are in the endocrinology or therapy departments of the city or district hospitals. The endocrinology departments of the regional hospital offer inpatient treatment at regional level, while at republican level there are four hospitals (as described above).

In 2008 there were recorded 503 endocrinologists, working full (442) or part time for endocrine cases. Most of the specialists working in the area of endocrinology are female due to the low level of salary for this speciality. The therapists and general practitioners are mostly in the rural areas and at district level. Their main task is to manage the PWD with oral therapy or diet. All the insulin treated PWD are managed by endocrinologists.

The Association of Endocrinologists, as well as the other professional bodies develop and issue medical protocols for the correct diagnosis and management of diabetes. These guide lines are developed either for the specialists or for the general practitioners. There are also information and training materials developed for the use of the PWD. On special occasions (like for the celebration of November 14) specialists from higher levels are travelling to the regions and districts and offer training and information sessions for medical professionals or for PWD. Commercial pharmaceutical companies (non local) are also using the expertise of the higher level specialists to promote proper management of diabetes as part of their corporate social responsibility or marketing activities.

Access to health services

Access to treatment for people with diabetes is free of charge. The geographic coverage of the country is also good. The facilities visited (covering republican, regional, district and city levels) have the main instruments to assess the condition of the PWD (professional glucometers, machines for HbA1c determination, ophthalmology cabinets, diabetic foot cabinets, microalbuminurea testing, C peptide, etc.). Usually, the more complex cases are referred to the higher levels (regional or republican) where both the laboratory facilities and the health professionals can correctly assess the cases and offer the proper solutions. In Minsk there are three centres for ophthalmology (one with republican status) where eye examination is offered. In Minsk laser treatment may be performed in two clinics.

The distribution of the endocrinology specialists is according to the population allocated to the facility (e.g. in Minsk lives about 20% of the country's population and there are registered 20% of the endocrinologists). Not all the positions are filled with specialists (endocrinologists), so in certain locations professional advice may be offered only in the regional centres.

Considering the registered figures, there is one endocrinologist for every 370 PWD.

Information to patients is provided by the ByCD, as well as specialised hospitals and clinics, local associations and different private initiatives, e.g. pharmaceutical companies. Some of the information materials are seen as biased, as information is restricted by the main sponsor of the publication.

Public screening activities are performed either within certain research programmes (PhD and other academic positions are still targeted by a large number of medical professionals) or during awareness campaigns supported by the industry and PWD associations. Considering the involved costs, such campaigns are not frequent. Epidemiological studies are also rather few and in most cases are addressing limited populations. A number of public health activities are run by the Ministry of Health including public campaigns on nutrition and diabetes. The PWD associations are organizing with the support of commercial companies awareness campaigns mainly close to either local events or to the World Diabetes Day. It was indicated the intention to promote a project similar to the Novo Nordisk caravan used in Russia, with a mobile diabetes cabinet for actively screening population in the country for early detection of IGT, diabetes and diabetes related complications. At the time of the visit the endocrinology dispensary of the city of Minsk was planning a mass screening process starting with a risk assessment form and followed by blood glucose determination for the persons at risk in 40 mobile stations.

The onset of diabetes may be recognized by the paediatricians, family doctors /general practitioners or by in-patient doctors.

Children (under 18) are referred to the republican level hospital in Minsk (Paediatric hospital no. 2). The hospital has 40 beds for children with endocrinology conditions. Here the child is tested, trained (along with a family representative) and offered a scheme of treatment. The family may contact the specialist in the following period in order to fine tune the treatment and to deal with special situations. The child will be expected in the outpatient clinic (at the district or regional level) within one month for assessment and readjustment of the treatment. If the parameters are stable, the regular checkups and monitoring may be done by the local paediatrician-endocrinologist. The republican hospital offers dietary and medical education for the children and families. For smaller children (usually under 5) one parent or care taker may be allowed to stay in the hospital. For older children, parents are asked to attend daily training sessions but they need to find their own lodging outside the clinic. Children receive individualized meals. Dietary formulae are provided for different ages and conditions. Children may continue their school education while in hospital with the support of a hospital employed educator. The in-patient stage for a child is on a regular basis of about 14 days. Once a youngster turns 18, it cannot use any of the paediatric services and has to attend only adult health service. It also looses its access to cartridge insulin (starting next year children will be offered cartridge insulin after their 18th anniversary) and the disability status is assessed on the basis of the medical chart.

The adults might be referred to an endocrinologist by general practitioners or therapists or following the results of lab tests usually done for other conditions. The diagnostic is established by an endocrinologist who also prescribes the treatment. In most of the cases, the treatment adjustment is done in the outpatient units. If insulin therapy is needed, the person will spend up to two weeks in an endocrinology ward of a district, regional or republican hospital. Some of the wards also include education

sessions and psychological support. In certain locations any new case is announced to the local peer support group. City endocrinology dispensaries offer services mainly for the insulin dependent (type 1 and 2) and the more complicated cases with type 2 on oral medication.

Private medical practices are limited in Belarus and most of them focus on out patient diagnosis and management. There is at least one private medical service for diabetes. Private laboratories for diabetes are not so popular as the service and capacity of the public ones should fully cover the needs and their services are offered for free. The only draw back is when the budgetary restrictions delay or make impossible certain lab tests (if the funds for consumables or maintenance are not enough), and PWD need to turn to the private facilities.

PWD with secondary complications are referred to the respective specialists. In most cases specialist cabinets are also located in the endocrinology dispensaries or polyclinics. Even at district or city level eye fundus screening or foot examination can be performed in specialized cabinets. The republican facilities have the possibility of computer aided eye screening. Laser treatment is currently offered in several locations. One republican health unit reported performing some 2000 treatments for diabetes retinopathy in one year. At present the laser equipment in the republican ophthalmology unit has technical problems and cannot be used. Podiatry is not recognized as a separate speciality and it does not have a recognized track for education. The job may be performed by either a trained endocrinologist or a knowledgeable surgeon. It is recognized that after the employment of a foot specialist the number of amputations decreased and at present most of the amputations are finger amputations. One podiatrist may see 12-25 PWD a day for regular check-up and small surgery/treatment. Most of the regional and republican out patient units have full teams of specialists addressing endocrinology conditions (including CVD, ophthalmology, foot or neuropathy, and nephrology).

Diabetes nurses are not recognized a special group of medical professionals. In most cases they have limited responsibilities, mostly bureaucratic. There is no special training for the diabetes nurses. Sometimes they are involved in the education process. Nutritionists or dieticians are rarely employed and if they are, they are shared with many other conditions. The functions of educators, nutritionists and dieticians are assumed in most cases by the endocrinologists. Psychologists are employed by the republican level clinics. Still, their approach is far from proper for the needed professional and emotional support.

None of the hospitals has a fixed number of beds for diabetes. If needed the patients with diabetes are accepted in the therapy or endocrinology departments. Children are always referred to the paediatric endocrinology wards.

In the outpatient units a specialist might see as much as 25 – 30 patients a day. In paediatric wards the proportion is about 50%, and in the adults wards the proportion of diabetes is up to 75-80% of the visiting patients.

According to the protocols, once a year each PWD should be checked for any late complications (nephrology, neuropathy, cardiovascular condition). If needed the specialists may recommend more frequent check-ups.

There are no geographic obstacles in accessing the specialized clinics. The country is almost flat, it is provided with good highways and a decent network of roads and railways. The regional facilities are less than 250km (in five out of the six regions less than 120km) from any point in their allocated territory. If needed helicopter emergency service may be provided.

Blood glucose level as well as HbA1c may be tested in most of the district facilities and their cost is covered by the system. Children are expected to test their HbA1c level every three months. For the adults the tests are less often. All the tests related to diabetes and its secondary complications are covered by the health system. In the polyclinics or in the general hospitals cooperation between specialities is a regular thing. As a general rule, diabetes health professionals' participation in other medical procedures on one of their own patients is accepted. HbA1c test might be 16800 BY rubble (3.7EUR) if not referred by a medical doctor.

Both the health officials and the practicing specialists address well the core treatment of diabetes but still lack sensitivity and understanding of the importance of the "smaller" things (consistency in medication, following if the proper skills are learned and enacted, listening to their patients, empathy, etc.).

Access to the republican centre services and facilities is for free if referred by a specialist, regardless where the person is coming from.

The regional and national centres also may offer rehabilitation services for all the persons with endocrinology problems. Rehabilitation is an important part of the treatment schemes, even if the specific targets of the "rehabilitation" treatment are not in all cases very clear.

In the country there are about 26 dialysis centres out of which four are in Minsk (one paediatric, one military and two for adults). The services are free for the persons needing dialysis and include (whenever possible) the transportation to and from the hospital (dialysis centre).

Access to medication

In Belarus it is offered a large range of medicines for diabetes but only a limited range is supported by the health system. The country has its own pharmaceutical producer of glucose lowering products (insulin and two types of tablets). Several foreign companies are present and distribute diabetes products on the Belarusian market: Novo Nordisk, Eli Lilly, Sanofi Aventis, Bioton, Servier, Hoechst, Berlin Chemie, Roche, Lifescan (J&J), Bionime, Syntrade and Abbott.

At the time of the visit all the children were offered treatment with foreign human insulin and pens. The other insulin dependent persons are using syringes and a variety of local and foreign insulin. Insulin pumps are rarely used in Belarus as they are too costly and the system does not cover the pumps or the consumables. For the time of pregnancy, women with diabetes might be offered insulin pumps and the necessary training (in the Institute for Mother and Child or in the regional endocrinology centres). According to a newly approved law, from 2010 all persons who developed diabetes before 18, will continue to receive cartridges (and imported human insulin) after their 18th anniversary. Pens and foreign insulin are also offered to pregnant women with

diabetes. Animal insulin is used only for compensating type 2 diabetes. Officially the production of animal insulin stopped in 2009 even if current statistics still account for a considerable number of users. Analogue insulins are used for children under a strict control and only in certain circumstances and for some adults when the treatment is prescribed by the specialist, according to local regulations. The number of children using analogue insulin is considered to be very little (about 11% with a higher concentration in Minsk – 30%). Short acting analogues are accepted in smaller children; the use of long acting analogues is accepted when there is an improper glycaemic balance or frequent episodes of hypoglycaemia. Analogues are only prescribed if there is good motivation for self monitoring (3 or 4 times a day) and good demonstration of skills.

Insulin (with the exception of the analogues) is procured via national tenders and it is offered free of charge. The medical standards of treatment do not have any indication regarding the type of insulin, and this allows health units and pharmacies to deliver any type of available insulin to the PWD. Some local governments supplement the local health budgets so that to insure the purchase of analogues – or individuals may decide to buy analogue insulin at the recommendation of the specialist. In order to insure the state control over the procurement and use of the free insulin they are only distributed by certain state owned pharmacies. Animal insulin was produced from several sources (Ukraine, Czech Republic, local – all times under the same brand) and it might not insure a constant quality of the product.

Availability of oral medication is dependent in most of the cases by the amount of the local administration contribution to the health budgets. If the contribution is more generous, more expensive or modern medicine may be available for the PWD. The regular oral medication includes Diabeton (Gliclazide), Siofor (Metformin) and Glibenclamide. Less frequently it is used Glimepiride or Glicvidone.

The medication for diabetes management (above mentioned insulin and oral medication) is fully compensated by the health system, along with the necessary dispensing devices (with the above mentioned limitations).

Blood glucose testing materials (at the level of one strip per day) are offered with 100% compensation for adults with a registered degree of invalidity and for all children. Locally produced meters can be acquired on a cost share basis: 90% for children and 50% for adults with a registered invalidity degree. Any person can buy blood glucose meters and strips but the cost is considered to be too high for a regular citizen. Companies may offer free upgrades of the meters, and in some situations they also offer free test strips via the patient associations or hospitals. CGMS is used only in special cases and in republican facilities as the costs of the consumables are high for the budget of the hospitals. In the Minsk city dispensary for endocrinology there is one CGMS that may be lent for three days to persons with diabetes. The costs of the consumables are supported by the dispensary budget.

Glucagon kits are registered and included on the compensation list. Since late 2009, the kits are offered only for inpatient care.

Some PWD with cardio vascular condition may receive statins (considered still an expensive procedure).

Access to training

Diabetes education is offered in most cases in the specialized ward of endocrinology of the dispensaries and hospitals. Training in hospitals is offered mostly for type 1 PWD and in the training the outpatient units is mostly for type 2 PWD. Training is done based on generally accepted curriculum, developed by leading Belarusian endocrinologists. In some places there were signs that the Berger materials are used. Different facilities invested more or less for delivering appropriate training. Some of the health units are financially compensating the persons delivering the education sessions but the level of compensation is very low. In some of the units delivering training nurses are the ones directly involved, atop of their regular duties. In the paediatric hospitals medical doctors are taking the lead with help from the certain nurses. The injecting techniques or the glucose testing might be taught with the help of the nurses. Diet is part of the curriculum. Follow up education sessions may be offered in the regional or district facilities (some of which even have designated persons to provide only training sessions). A consistent training programme might extend for five days with two classes per day.

The first school for children with diabetes was started in 1992.

PWD associations do not have the facilities or the credentials to offer diabetes training. Commercial companies supplement some of the professional and PWD training but only with limited interventions (limited both in topic coverage and geographically). For delivery they use the services of recognized endocrinologists.

Education for medical professionals and patients is regulated by law.

Health units have sometimes specially designated spaces for patient education. The process is usually a small group one. The learning process is academic (only from the doctor to the patient) and does not employ special techniques which may be required by the age or structure of the students' groups. Even if the training sessions do not specifically assess the changes in the skills of the students, the medical professionals are looking for the improvements in the overall parameters (like HbA1c levels) of the students. In certain locations (smaller communities) the education process is better structured (up to five hours of education and practice), following a specific curriculum, number of training sessions and being tailored for children, parents or adults.

There are several education materials developed by the medical professionals and printed within clinical programmes or by associations. A unified curriculum and methodology of delivering diabetes education modules to the PWD and their families was developed and approved by the Ministry of Health in 1994, but at the time of the visit it was not used in all the locations of delivery. Educators are not recognized as a profession and the nutritionists (dieticians) are not employed by hospitals. Non medical topics are not addressed during the education sessions offered within the health units. Collateral topics (family or social life, school, work, legal advise, marriage, etc.) may be addressed during the discussion sessions offered by the PWD associations (and there with more peer support rather than professional expertise).

There is no unified track record of a PWD, regarding the sessions attended and the health results (impact of the training sessions).

The pharmaceutical companies deliver education modules mostly for the medical professionals. The education sessions offered by the pharmaceutical companies are hosted outside the health units.

In a limited study performed two years ago it was assessed the skill level of type 1 children. The study revealed that about 28% of the children did not receive any training besides regarding the injection or testing techniques. About 49% do not follow any diet or nutritional algorithm for treating their condition. 37% do not respect the correct timing for insulin administration, 85% use only the dosages prescribed by the doctors (no adjusting according to the condition), 66% do not have the right skills for reacting to hypoglycaemia situations and 50% of the children experience hypoglycaemia once a week.

The National Registry for Diabetes

The Belarus Ministry of Health financed the development and implementation of a national registry for diabetes. The Registry is operational since 2008. At the time of the visit almost all the type 1 PWD were registered in the database, along with about 60% of the type 2 PWD. All local health units mentioned their reporting and contribution to the registry (monthly reports aggregated at regional level and uploaded in the national database in Minsk). At the level of each region the health professionals have access to the results of these reports and they also may perform their own enquiries if they are interested. It is expected that the planning for the medication needs of the PWD will be better monitored and planed for using the national registry. The system is hosted by the republican reference centre. No additional money is paid for the maintenance of the database. The system registers the status of the PWD, prescribed medication, as well as of its late or collateral complications or conditions. Confidentiality is not a concern for the managers of the database.

Outcomes

During the visit there were a number o cases when practical solutions emerged in the discussions adding an extra value to the visit:

One of the persons from the association board had a problem in getting the Austrian visa for participating in the EASD conference and during the visit we talked with the J&J representative who helped with the invitation letter for the person.

The endocrinologist interested in diabetes economics was put in contact with dr. Katia Skarbek a health economist working for the IDF task force on diabetes Health Economics and the newly appointed IDF health economist.

USAID agreed to include in the training sessions for the GPs (focused on TB and AIDS) sessions or information materials about diabetes in cooperation with the BelMAPO. They also agreed to assess the ByCD association and if possible to include it in their civil society programme of training.

Medical doctors involved in research activities agreed to include at the end of their scientific papers practical recommendations to be used by their colleagues in the daily proceedings.

The Deputy Chief of the Health Commission in the National Assembly promised to be actively involved in the public activities which will be prepared for the WDD in her constituency. She also said that she will promote the messages of the WDD with her colleagues in the National Assembly.

The representatives of Sanofi Aventis accepted to work with the ByCD a professional exchange system in order to improve the management capabilities of the association and to enhance the connection between the commercial company and the patient organization (either by a shadowing system or by having a visiting manager volunteering for certain activities in the association).

The Syntrade company is interested in more actively supporting the PWD education and suggested that if text for the education programme is approved and provided, the company may support the printing of the manuals and posters needed for a consistent education programme.

Both the medical professionals and the association representatives suggested that it would be a good idea if prior to the WDD IDF sends out a message to all the Ministries of Health asking them to support the efforts of their organizations in celebrating WDD.

Conclusions

Belarus has managed to maintain a health care delivery system that provides a comprehensive package of care to the entire population, which is generally free at the point of delivery. The stability in service provision was achieved by introducing incremental reforms to the inherited Soviet system. Continuing to promote hospital care and the extensive use of health specialists has had a very limited impact on population health.

The population is dissatisfied with the overcrowded and impersonal primary care services and with the busy and burnt-out primary health care doctors. While the core medication and services are offered for free to all the needing citizens, there is a limitation in the options offered to the PWD. Excess governmental control and the lack of shared responsibility of the health professionals is translated in rigid medical protocols, waste of the time of the PWD, overcrowding the cabinets of the specialists with bureaucratic jobs and finally a lack of attention to what matters for the people with a chronic condition. The system is focusing on treating rather than preventing (see the limited interest in the correct treatment of adult PWD, while the more costly treatments for the late complications are fully supported by the system) – prevention is still addressed by tertiary specialists and not by the primary care doctors. Health professionals are not satisfied with the level of salary and this is reflected in the composition of the endocrinology teams and the tendency to migrate to other, better paid specialties.

The adopted way of incremental approaches to the health system reform, also makes possible for policy-makers to build consensus to ensure that once reforms are passed into law, so that they can be implemented more swiftly. This might be a real opportunity for the involvement of stakeholders at all levels of care to become involved in the development of future reform programmes. Unfortunately, the main stakeholder and contributor, the patient, is not included in any of these policy making processes. The country officials recently ratified the agreement of the Inter-parliamentary

Assembly on fighting diabetes – both the professionals and the PWD are looking to see more decisions and activities in implementing this agreement.

However, regardless the way the health system is designed, dramatic improvements cannot be achieved without other developments in society.

The ByCD is assuming the responsibility to advocate for the interests of the PWD in Belarus as well as to offer its members some of the services which cannot fit into the public package: peer support, social events and additional professional advice. By complying with the legal environment the area of activity of the association is seriously limited. Still, the organization managed to deploy an extensive range of resources in arranging the country visit. The mix of professionals and lay persons in the management of the organization provides the best use of the available human capacity. The leadership of the organization is deeply motivated to pursue in achieving the organization's goal to further the life of the people living with diabetes is Belarus.

In supporting the work of the PWD organization IDF is expected to: continue and extend the communication with the member organizations, share the IDF E activities, positions and documents more frequently and in an active way, help the member organizations in developing projects and finding the proper funding resources, backup certain activities of the organization which address officials (via support letters or with presence to these events), and help the local professionals in developing effective education programmes for general practitioners and persons affected by diabetes.

List of annexes

Annex 1 – List of sources and references
Annex 2 – Schedule of the visits
Annex 3 – Pictures and maps