Autism Strategies under development



Developments in Francophone Belgium

In April 2016, the Walloon Government, the Wallonia-Brussels Federation and the Brussels government have coordinated their actions with all sectors related to autism in order to develop a common, proactive policy to improve the care and living conditions of all individuals concerned (children, adults, families etc.)¹

The main objective is to enable individualised and life-long support and ensure inclusion in society through four common lines of action:

- 1. A precise inventory of the lack of solutions for people with autism or dependency needs
- 2. Screening/diagnosis and the announcement of disability
- 3. Information and awareness
- 4. Training of professionals
- 5. Better and more tailor-made support
- 6. Monitoring for cross-cutting impact
- 7. Participation in social life
- 8. Transportation to schools

Avis de la société civile :

Voici, dans les grandes lignes, les principales lacunes et imprécisions que le Gamp et la Plateforme AutiSolidarité ont relevées à propos du Plan Autisme Transversal:

1/ Manque de choix dans les approches thérapeutiques de l'autisme (accent mis sur l'approche analytique et non sur les approches comportementales et éducatives donnant des résultats concrets et efficaces).

2/ Absence de références aux recommandations des Bonnes Pratiques (EBM) nationales (KCE, CSS) et internationales (OMS, Union Européenne,) : ABA, TEACCH, PECS, etc....

3/ Manque de planification, d'une programmation des mesures et moyens, d'un échéancier précis et de critères d'évaluation.

¹More information: http://prevot.wallonie.be/plan-transversal-autisme-une-politique-commune-forte-entre-la-wallonie-bruxelles (accessed 29/08/2016)

- 4/ Absence de budgétisation pour de très nombreux postes et d'un budget global.
- 5/ Absence de références à la prise en charge intensive dès le diagnostic.
- 6/ Absence d'une formation obligatoire à l'autisme pour tous les intervenants de la petite enfance (médecins, enseignants, éducateurs, personnel paramédical).
- 7/ Absence d'une transversalité élargie à toutes les compétences de l'Etat (soins de santé, transport, formation des écoles supérieures et universités ...).
- 8/ Manque de références à davantage d'inclusion dans l'enseignement ordinaire.

En outre, malgré la progression alarmante de l'autisme dans le monde, ces dernières années, la Belgique francophone accuse encore un retard important, par rapport à d'autres pays, en matière de recherche scientifique, sur cette question. D'après les informations figurant dans Scopus - la plus importante base de données de publications scientifiques de niveau international -, 199 travaux ont été publiés sur la problématique de l'autisme, entre 2010 et 2016, par des chercheurs attachés à diverses universités belges. Sur ces publications scientifiques belges, seulement 15 (soit moins d'1%) proviennent des Universités de la Fédération Wallonie-Bruxelles.

The "M-Decree" in Flanders²

In March 2014, the Flemish Parliament passed the Decree concerning measure for pupils with specific educational needs, known as the "M-decree", aimed at ensuring greater access to mainstream education for children with disabilities. The Decree introduces a new Type 9 for 'children with autism without intellectual disabilities' within the system of disability typologies under which it is assessed if a student has special needs. The decree entered into force in September 2015.

Providing the right for reasonable accommodation, the M-decree establishes that students can be referred to special education only if schools can prove that they have tried all "reasonable adjustments". In particular, it states that every child with a disability has the right to be enrolled in regular school if it is possible to follow the regular curriculum with reasonable adaptations, such as extra-time to make tests.

However, the M-decree has raised several criticisms from DPOs. As underlined in the complaint submitted by the MDAC to the European Committee of Social Rights in 2014, the Decree appears to be discriminatory since it does not apply to children who cannot follow the regular curriculum, thereby excluding children with more significant intellectual or learning disabilities. Furthermore, no new funding mechanisms have been introduced in order to increase the number or range of support mechanisms that schools or local authorities can provide to students who require accommodations³

² Cera. R, (2015). National Legislations on Inclusive Education and Special Educational Needs of People with Autism in the Perspective of Article 24 of the CRPD

³ European Committee of Social Rights Mental Disability Advocacy Center (MDAC) v. Belgium, Complaint No. 109/2014. https://www.coe.int/t/dghl/monitoring/socialcharter/Complaints/CC109CaseDoc1_en.pdf. Accessed 17 Sep 2014.

General Disability Policies Relevant to Autism



Healthcare

Accessible communication for patients with disabilities

- The Law of on Patients' Rights requires that medical staff use clear language when communicating with the patient (Art. 7 para. 2 of the Law on Patients' Rights). This means that the language used by medical staff shall be 'adjusted to the patient, with due consideration for the patient's age, education and ability to understand' (Federal Public Service Health, op. cit., p. 5).
- Art 7 para. 2 of the Law on Patients' Rights also stipulates that 'the patient has the right to have a confidant assist him/her or has the right to the information (...) exercised through such person. The Law on Patients' Rights does not define the term 'confidant' but the Federal Public Service Health, Food Chain Safety and Environment indicates that the confidant can be 'a family member, friend, other patient or any other person designated by the patient to assist him/her in obtaining information on his/her state of health, accessing to his/her health record or obtaining a copy of his/her health record, and in lodging a complaint'.⁴
- Deaf persons are often left to take the initiative of providing a sign-language interpreter. This is particularly problematic given that due to the limited number of interpretation hours to which they are entitled, they have to pay the travel costs and are dependent on the availability of interpreters and the opening hours of the office, with the result that deaf persons cannot receive services on an equal footing with other citizens.⁵

Examples of good practice

• A project called 'cultural mediation' has been running in Belgium since 1999. According to the document *Les personnes sourdes face aux inégalités d'accès aux soins de santé de qualité,* sign language interpretation by video conference is planned to be set up from 2013 in two hospitals, namely in UZ Gent and CHU Charleroi.⁶

Developments in Healthcare

According to press releases, the Belgian Health Minister, Laurette Onkelinx, said that
'Telemedicine is a promising development for the future, in particular for chronic patients.
The Belgian government supports the development of six pilot projects in the country with a
view to draw a general framework for telemedicine in Belgium and consider with
stakeholders how to create a new nomenclature that would allow the reimbursement of
telemedicine services'

⁴ Federal Public Service Health, *op. cit.*, p. 6.

⁵ Position of the associations and advisory structures representing persons with disabilities, Shadow report coordinated by the Belgian Disability Forum, 20 February 2014, paras 93-94; Available at:

http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/BEL/INT_CRPD_NGO_BEL_16564_E.pdf (accessed 03/02/2016)

⁶ Association Socialiste de la Personne Handicapée: *Les personnes sourdes face aux inégalités d'accès aux soins de santé de qualité*, 2013, p. 7, Available at : http://www.asph.be/Documents/analyse-etudes-2013/Etude-ASPH-2013-personnes-sourdes-inegalites-acces-soins-sante-qualite.pdf (accessed 03/02/2016)

Education

- In the 2014 CRPD's final observations on Belgium's implementation of the Convention for the Rights of Persons with Disabilities, it was noted with concern that Belgium is among the European states with the lowest percentage of children with disabilities in mainstream educational settings⁷.
- The number of students with disabilities in tertiary education is very low. High schools and universities are not accessible and their environment is very competitive. It is also impossible to obtain a degree, if one cannot meet the educational objectives. Recent budget cuts for higher education do not help to improve the situation. In Flanders, however, universities are currently trying to improve their policies towards students with disabilities and have reactivated the Support Centre for Inclusive Higher Education (SIHO).
- In Belgium, specialised education remains the rule. Education in Flanders, for example, appears to increase segregation instead of being inclusive. Comparative data on education of children with disabilities in Europe show that the percentage of pupils in segregated special education in the Flemish community is the highest in Europe⁸, something that was noted with concern by the CRPD⁹. One of the reasons is the lack of funding for the support of students in regular schools.
- In Flanders, progress has been made over the past ten years, but they have come about without and real regulatory framework. In parallel, in many school establishments, the problem of physical accessibility remains considerable. The application of principles of reasonable adjustments is necessary at this level.

Employment

- The unemployment level of disabled persons is very high in comparison with other EU countries, despite the fact that Belgium has emerged quite well from the financial crisis.
- Problems at the recruitment stage include remaining stereotypes, making it particularly hard for disabled people to find jobs.
- The so-called "benefit trap" (the relatively small difference between the integration allowance and "normal" income, as well as the fact that if disabled people lose their jobs subsequently they no longer receive a replacement income) is also seen to be a reason for high unemployment among persons with disabilities.
- An insufficient number of persons with a disability are active in regular employment. The government appears to be failing to achieve its own targets related to the employment of persons with a disability in its departments. The new 'maatwerk'-decree is still missing individual support measures¹⁰.
- For employment in the private sector, there is no quota, but rather a system of incentives (premiums or reductions of expenses).

⁷ United Nations Committee on the Rights of Persons with Disabilities (2014) *Observations finales concernant le rapport initial de la Belgique*. Available at :

http://tbinternet.ohchr.org/Treaties/CRPD/SitePages/Home.aspx?RootFolder=%2FTreaties%2FCRPD%2FShared%20Documents%2FBEL&FolderCTID=0x0120000321B1401B4FC0429F97111EBEDA8A2B&View={AE0F57C6-95B1-4D13-B7AF-94B9CAF64D63} (accessed 10/11/2015)

⁸ Precise figures not stated: Source De Beco, G., (2014). *ANED 2014 Task 5 – European semester country fiche on disability.* Belgium: Academic Network of European Disability Experts.

Available at: http://www.disability-europe.net/countries/belgium (accessed 10/11/2015)

⁹ United Nations Committee on the Rights of Persons with Disabilities (2014) *Observations finales concernant le rapport initial de la Belgique*. Available at :

http://tbinternet.ohchr.org/Treaties/CRPD/SitePages/Home.aspx?RootFolder=%2FTreaties%2FCRPD%2FShared%20Documents%2FBEL&FolderCTID=0x0120000321B1401B4FC0429F97111EBEDA8A2B&View={AE0F57C6-95B1-4D13-B7AF-94B9CAF64D63} (accessed 10/11/2015)

^{10 12&}lt;sup>th</sup> session of the Committee on the Rights of Persons with Disabilities - Dialogue with Belgium 18 – 19 September 2014



¹¹ Liste de points concernant le rapport initial de la Belgique – Note du BDF à l'intention du Comité des droits des personnes handicapées