



Declassified¹
AS/Soc (2020) PV 01add2
19 May 2020
Asocpv01add2_2020

Committee on Social Affairs, Health and Sustainable Development Minutes

Public hearing on “Supporting people with autism and their families”, held in Strasbourg, on Thursday, 30 January 2020

In the framework of the report currently in preparation on “Supporting people with autism and their families” with Ms Sevinj Fataliyeva (Azerbaijan, EC/DA) as rapporteur, the Committee held a public hearing with the participation of:

- ✓ Mr Daniel Morgan Jones, “The Aspie World”, UK
- ✓ Ms Olivia Cattan, President of “SOS Autisme France”

Mr Leite Ramos, the Chairperson, briefly introduced the guest speakers who would participate via a video link and gave the floor to the rapporteur.

Ms Fataliyeva presented the preliminary draft report, highlighting the main points for discussion. She notably stressed the fact that some 75 million persons worldwide concerned by the autism spectrum disorder faced stigma and inequalities on a daily basis with regards to accessing basic rights and services (education, employment, health care, the justice system, social services, etc.). In this respect a survey of national legislation and practice had been carried out via the European Centre for Parliamentary Research and Documentation, and constructive contributions had been received from the parliaments of 33 countries. Despite growing public awareness of autism, diagnosis and support for people with autism continued to be a hurdle in many countries. The United Kingdom (UK) was a positive example of dealing with autistic persons, therefore a fact-finding visit was planned to London through the invaluable support of Lord Touhig. To that end and in order to complete the report, it was necessary to request a prolongation of the reference.

Mr Jones then took the floor to explain his work for “The Aspie World” in the UK: creating video content addressed to parents of and children with autism, giving ‘tips and tricks’ on better living with autism and thus helping everyone better understand what the disorder entails. Some of those videos were used by professionals for training purposes. Autism usually involved a sensory processing disorder whereby some ordinary sounds and smells overwhelmed the persons concerned. Crowds led to a sense of oppression, which made it difficult for some autistic persons to travel, to shop, or impaired their ability to work or access public services. Many places were adapted to serving persons with physical disabilities but hardly anything was foreseen for those with enhanced mental needs, such as in the case of autism. Despite multiple such complications, Mr Jones had finished his university degree in chemistry. Autism-centred training was especially needed in the public sector and notably in health care. In the UK, a street-project of a “sunflower lanyard” had been put in place to foster public awareness and assistance to autistic persons.

Ms Cattan described her experience as a mother of an autistic child as well as president of a specialised NGO that supported awareness-raising efforts on autism. Parents of autistic children in France were often obliged to privately hire helping personnel, given that public assistance (in the form of an AVS – *auxiliaire de vie scolaire*) was difficult to obtain. Links with several enterprises and sports clubs were being developed aiming to boost access of autistic persons to employment and sport activities. In France, the situation could be seen as catastrophic and some 40-years’ delay could be seen in many crucial areas, for example diagnosis. In Paris, there were only three good specialists on autism, and more than a year of waiting for scheduling an appointment was the norm; the situation in other regions in France varied significantly.

¹The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 19 May 2020, held by videoconference.

Most support for autistic persons was only partially covered, only speech therapy was fully covered by the public system, and much of the necessary support was not covered at all. Some families with autistic children had out-of-pocket expenditure for specialised services totalling over €3000 per month. Another example was that of dental care services adapted to autistic persons which were also very difficult to get. In schools, some improvement could be seen for early-age classes, but difficulties persisted at high-school level. Regarding employment, only about 1% of autistic persons in France were employed. Some sectarian approaches had been recently identified in France in extreme cases and some autistic persons were subjected to hazardous unauthorised treatments that could endanger their health and even their life. Society should be better informed about the various forms of autism spectrum disorders. France had been condemned by the European Court of Human Rights and by United Nations bodies for its lack of support towards autistic persons and their families; incremental progress in some areas had been achieved thanks to parents' involvement, as highlighted in Ms Cattan's book, which would soon be published.

Ms Fataliyeva asked the guest speakers how national parliaments could help autistic persons and if programmes for disabled persons would be an appropriate means.

Baroness Massey wondered what kind of support could significantly improve the situation of autistic persons.

In reply, **Mr Jones** gave his personal example. He had been able to advance in life thanks to the help of a personal assistant: he had thus managed to overcome accessibility issues, to set up a daily routine and to learn to communicate better. However, that person had lost his job after the government had withdrawn financing for this type of positions. Adequate training for "helpers" was also crucial.

Ms Wonner thanked Ms Cattan for doing precious work on animating an NGO and offered her comments on the situation in France. Although the latest minister of health was steadily pushing for improvements, there was a time lag before the effects could become visible in real life across the country. The specialist training for paediatric psychiatrists also was taking time. However, several important projects were accelerating, and the Secretary of State for Solidarity and Health was committed to taking further steps towards helping families with autistic children.

Ms Cattan regretted that tangible improvements were "too little and too late" from the parents' position. Autistic persons and their families were struggling daily and occasionally were confronted with outright discrimination or ill-treatment. Families could not substitute themselves for what needed to be done at state level.

Lord Touhig, speaking as the Vice-President of the National Autism Association in the UK, stressed the time lag – often several years – to correctly diagnose autistic spectrum disorder and the difficulties such children encountered in the educational system without being properly accompanied. Moreover, on the tenth anniversary of the National Autism Act, there were still some 85% of autism-affected persons who could never get a job. An all-party group in the British Parliament was looking for ways to close this gap by involving employers more actively.

Mr Jones confirmed that getting a full-time job was a tremendous challenge for an autistic person. Some would pass interviews successfully and face refusals once on the job. To fill the gap between working and not working, both autistic persons and potential employers needed specialised training. Another possibility would be to encourage the certification of virtuous employers.

Ms Estrela asked if there was any statistical evidence of the prevalence of autism among boys compared to girls. If this were the case, would this mean that girls were discriminated at a diagnosis stage?

Ms Cattan said that she had written a book on autistic women. She had described there the medical wandering of many French women who would receive a very different medical diagnosis depending on the specialist they visited. However, she had found no cases of gender-based discrimination. Actually, autistic women seemed to integrate into society better than autistic men.

Ms Catovic underscored the need for more social support for autistic persons in addition to more appropriate medical support and treatment. Inclusion of autistic persons into society passed largely through their families.

Ms McCarthy referred to cases of medical misdiagnosing whereby autistic persons would end up being treated in mental care units. For adolescent girls, it was particularly important to have adequate medical counselling which was different for anxiety problems or issues arising from autistic spectrum disorders. This was necessary in order to better handle schooling failures and dropouts. The currently used patterns of medical counselling did not fit the needs of autistic children.

Ms Cattán thanked the parliamentarians for sharing their concerns and possible solutions which could lead to improvements in the quality of life for autistic persons. Different countries chose to follow different approaches and could learn from each other's experience. Neurodiversity should not be seen as a burden but rather as a source of enrichment.

Mr Jones agreed that gender issues could arise when a diagnosis was given, since most autism specialists were men who might lack sensitivity when evaluating female patients. Medical screening should be improved at primary school-level for pupils, to this end, personnel should be properly trained and funded.

Ms Fataliyeva thanked the experts for sharing their views which would serve as a basis for her future work on the report.

The Chairperson warmly thanked the experts for their contributions and closed the hearing.

Committee on Social Affairs, Health and Sustainable Development
Commission des questions sociales, de la santé et du développement durable

List of members (84 seats) / *Liste des membres (84 sièges)*

Chairperson / *Présidente* :

M. Luís LEITE RAMOS		Portugal
---------------------	--	----------

Vice-Chairpersons / *Vice-Présidents* :

Mr John HOWELL		United Kingdom / <i>Royaume-Uni</i>
Mme Edite ESTRELA		Portugal
Ms Nina KASIMATI		Greece / <i>Grèce</i>

ZZ...	Albania / <i>Albanie</i>	ZZ...
M. Pere LÓPEZ	Andorra / <i>Andorre</i>	Mme Mònica BONELL
M. Mikayel MELKUMYAN	Armenia / <i>Arménie</i>	Mr Ruben RUBINYAN
Mr Franz Leonhard ESSL	Austria / <i>Autriche</i>	Mr Michel REIMON
Mr Stefan SCHENNACH	Austria / <i>Autriche</i>	Ms Doris BURES
Ms Sevinj FATALIYEVA	Azerbaijan / <i>Azerbaïdjan</i>	Mr Nagif HAMZAYEV
Ms Ganira PASHAYEVA	Azerbaijan / <i>Azerbaïdjan</i>	Ms Ulviyye AGHAYEVA
Mr Bob DE BRABANDERE	Belgium / <i>Belgique</i>	Ms Els VAN HOOFF
M. Simon MOUTQUIN	Belgium / <i>Belgique</i>	Mme Latifa GAHOUCI
Ms Snježana NOVAKOVIĆ BURSAC	Bosnia and Herzegovina / <i>Bosnie-Herzégovine</i>	Mr Amir FAZLIĆ
Mr Nikolay ALEKSANDROV	Bulgaria / <i>Bulgarie</i>	Mr Krasimir BOGDANOV
Mr Georgi YORDANOV	Bulgaria / <i>Bulgarie</i>	Ms Ivelina VASSILEVA
Ms Marijana BALIĆ	Croatia / <i>Croatie</i>	Mr Mihael ZMAJLOVIĆ
Ms Christiana EROTKRITOU	Cyprus / <i>Chypre</i>	Mr Constantinos EFSTATHIOU
Ms Zdeňka HAMOUSOVÁ	Czech Republic / <i>République tchèque</i>	Ms Alena GAJDŮŠKOVÁ
Mr Jaroslav KYTÝR	Czech Republic / <i>République tchèque</i>	ZZ...
Ms Tanja LARSSON	Denmark / <i>Danemark</i>	Mr Jan E. JØRGENSEN
Mr Urmas REITELMANN	Estonia / <i>Estonie</i>	Ms Vilja TOOMAST
Ms Minna REIJONEN	Finland / <i>Finlande</i>	Ms Tarja FILATOV
M. Bernard CAZEAU	France / <i>France</i>	M. François GROSDIDIER
Mme Jennifer DE TEMMERMAN	France / <i>France</i>	Mme Nicole TRISSE

Mme Martine LEGUILLE BALLOY	France / France	Mme Martine WONNER
Mme Laurence TRASTOUR-ISNART	France / France	Mme Sophie AUCONIE
Ms Nino TSILOSANI	Georgia / Géorgie	Mr David SONGULASHVILI
Ms Sybille BENNING	Germany / Allemagne	Mr Josef RIEF
Mr Andrej HUNKO	Germany / Allemagne	Ms Cornelia MÖHRING
Mr Matern von MARSCHALL	Germany / Allemagne	Ms Doris BARNETT
Mr Ulrich OEHME	Germany / Allemagne	Mr Christoph HOFFMANN
Mr Sokratis FAMELLOS	Greece / Grèce	Mr Kyriakos VELOPOULOS
Ms Nina KASIMATI	Greece / Grèce	Ms Foteini PIPILI
Mr Tibor BANA	Hungary / Hongrie	Mme Zita GURMAI
Ms Mónika BARTOS	Hungary / Hongrie	Mr Jenő MANNINGER
Mr Bergþór ÓLASON	Iceland / Islande	Mr Birgir THÓRARINSSON
Mr Joseph O'REILLY	Ireland / Irlande	Mr Thomas PRINGLE
Mr Fabio DI MICCO	Italy / Italie	Mr Gianluca PERILLI
Mr Emilio FLORIS	Italy / Italie	Ms Maria RIZZOTTI
Mr Gaspare Antonio MARINELLO	Italy / Italie	Ms Barbara GUIDOLIN
Mr Gianfranco RUFA	Italy / Italie	Mr Manuel VESCOVI
Ms Linda OZOLA	Latvia / Lettonie	Ms Dana REIZNIECE-OZOLA
Ms Susanne EBERLE-STRUB	Liechtenstein / Liechtenstein	ZZ...
Mr Virgilijus PODERYS	Lithuania / Lituanie	Mr Kęstutis MASIULIS
Mme Françoise HETTO-GAASCH	Luxembourg / Luxembourg	M. Marc SPAUTZ
Mr Etienne GRECH	Malta / Malte	Ms Rosianne CUTAJAR
Ms Inga GRIGORIU	Republic of Moldova / République de Moldova	Mr Liviu VOVC
M. José BADIA	Monaco / Monaco	Mme Béatrice FRESKO-ROLFO
Ms Marija Maja ČATOVIĆ	Montenegro / Monténégro	Mr Predrag SEKULIĆ
Ms Reina de BRUIJN-WEZEMAN	Netherlands / Pays-Bas	ZZ...
Ms Ria OOMEN-RUIJTEN	Netherlands / Pays-Bas	ZZ...
Mr Nikola POPOSKI	North Macedonia / Macédoine du Nord	Mr Antonijo MILOSHOSKI
Ms Silje HJEMDAL	Norway / Norvège	Ms Emilie Enger MEHL
Ms Danuta JAZŁOWIECKA	Poland / Pologne	Mr Tomasz LATOS
Mr Bolesław PIECHA	Poland / Pologne	Mr Zbigniew GIRZYŃSKI
Mr Andrzej SZEJNA	Poland / Pologne	Mr Krzysztof TRUSKOLASKI
Mme Edite ESTRELA	Portugal / Portugal	M. Pedro CEGONHO
M. Luís LEITE RAMOS	Portugal / Portugal	ZZ...
M. Cezar Florin PREDA	Romania / Roumanie	M. Viorel Riceard BADEA
Mr Ionuț-Marian STROE	Romania / Roumanie	Ms Cristina-Mădălina PRUNĂ
Ms Adriana Diana TUȘA	Romania / Roumanie	Mr Valeriu Andrei STERIU
Mr Igor KAGRAMANYAN	Russian Federation / Fédération de Russie	Mr Sergey LISOVSKIY
Mr Sergey KALASHNIKOV	Russian Federation / Fédération de Russie	Mr Iaroslav NILOV
Ms Alfiia KOGOGINA	Russian Federation / Fédération de Russie	Ms Oksana PUSHKINA

Mr Sergei PAKHOMOV	Russian Federation / Fédération de Russie	Mr Alexandr PROKOPIEV
M. Giuseppe Maria MORGANTI	San Marino / Saint-Marin	Mr Marco NICOLINI
Ms Elvira KOVÁCS	Serbia / Serbie	Ms Dubravka FILIPOVSKI
Mr Aleksandar ŠEŠELJ	Serbia / Serbie	Mr Miljan DAMJANOVIĆ
Mr Ján MAROSZ	Slovak Republic / République slovaque	Ms Renáta KAŠČÁKOVÁ
Ms Andreja ZABRET	Slovenia / Slovénie	Mr Andrej ŠIRCELJ
Mr Antón GÓMEZ-REINO	Spain / Espagne	ZZ...
Mr César SÁNCHEZ	Spain / Espagne	Ms Carmen LEYTE
Ms Susana SUMELZO	Spain / Espagne	Mr José CEPEDA
Mr Alexander CHRISTIANSSON	Sweden / Suède	Mr Ola MÖLLER
Ms Carina OHLSSON	Sweden / Suède	Ms Annicka ENGBLOM
Ms Sibel ARSLAN	Switzerland / Suisse	M. Christian LEVRAT
M. Jean-Pierre GRIN	Switzerland / Suisse	M. Olivier FRANÇAIS
Ms Emine Nur GÜNAY	Turkey / Turquie	Mr Mehmet Mehdi EKER
Mr Hişyar ÖZSOY	Turkey / Turquie	Ms Feleknaş UCA
Mr Ali ŞAHİN	Turkey / Turquie	Ms Sena Nur ÇELİK
Ms Selin SAYEK BÖKE	Turkey / Turquie	M. Haluk KOÇ
Ms Olena KHOMENKO	Ukraine / Ukraine	Ms Larysa BILOZIR
Ms Yuliia OVCHYNNYKOVA	Ukraine / Ukraine	Mr Andrii LOPUSHANSKYI
Mr Oleksandr SKICHKO	Ukraine / Ukraine	Ms Lesia ZABURANNA
Mr John HOWELL	United Kingdom / Royaume-Uni	ZZ...
Baroness Doreen E. MASSEY	United Kingdom / Royaume-Uni	Mr Conor McGINN
Ms Kerry McCARTHY	United Kingdom / Royaume-Uni	Mr Steve DOUBLE
Mr John PRESCOTT	United Kingdom / Royaume-Uni	Lord Don TOUHIG

OTHER PARLIAMENTARIANS / AUTRES PARLEMENTAIRES

Representatives of the Turkish Cypriot Community / Représentants de la communauté chypriote turque (*)

Mr / M. Hamza Ersan SANER

*In accordance with Resolution 1376 (2004) / Conformément à la Résolution 1376 (2004)

OBSERVERS/ OBSERVATEURS

PARTNERS FOR DEMOCRACY / PARTENAIRES POUR LA DEMOCRATIE

Mr / M. Allal Amraoui.....Morocco / Maroc

EMBASSIES / PERMANENT REPRESENTATIONS AND DELEGATIONS **AMBASSADES / REPRESENTATIONS ET DELEGATIONS PERMANENTES**

Ms / Mme Ramona Maria CIUCĂ, Deputy to the Permanent Representative, Permanent Representation of Romania to the Council of Europe/ Adjointe du Représentant Permanent, Représentation permanente de Roumanie auprès du Conseil de l'Europe ;

SECRETARIAT OF DELEGATION OR OF POLITICAL GROUP /
SECRETARIAT DE DELEGATION OU DE GROUPE POLITIQUE

Mr / M. Hakan MURAT, Delegation Secretary, Turkish delegation to PACE / Secrétaire de délégation, délégation de la Turquie à l'APCE

Mr / M. Nick WRIGHT, Delegation Secretary, British delegation to PACE / Secrétaire de délégation, délégation du Royaume-Uni à l'APCE

ALSO PRESENT / EGALEMENT PRESENTS

Ms / Mme Bénédicte COLIN, collaborator, Federation of Catholic Family Associations in Europe / *collaboratrice, Fédération des Associations Familiales Catholiques (FAFCE)*

COUNCIL OF EUROPE STAFF / SECRETARIAT DU CONSEIL DE L'EUROPE

SECRETARIAT OF THE PARLIAMENTARY ASSEMBLY /
SECRETARIAT DE L'ASSEMBLÉE PARLEMENTAIRE

Ms / Mme Tanja KLEINSORGE Head of the Secretariat / *Cheffe du Secrétariat*
Ms / Mme Aiste RAMANAUSKAITE Secretary to the Committee / *Secrétaire de la commission*
Ms / Mme Yulia PERERVA Secretary to the Committee / *Secrétaire de la commission*
Mr / M. Guillaume PARENT Co-Secretary/ *Co-Secrétaire*
Ms / Mme Bogdana BUZARNESCU Principal Assistant / *Assistante Principale*
Ms / Mme Melissa CHARBONNEL Assistant / *Assistante*
Ms/ Mme Françoise SCHIR Assistant / *Assistante*