



**'Bridging the Gap: Optimising transition from child to adult mental healthcare'  
Meeting organised by GAMIAN-Europe and the European Brain Council**

**Hosted by Tomas Zdechovsky MEP  
European Parliament, 21 November 2017**

**Meeting report**

**Frédéric Destrébecq** thanked **Tomas Zdechovsky MEP** for hosting the meeting and provided some background information to the event, stating that transition of care from child/adolescent to adult mental health services is vitally important in determining patient outcomes. This is a priority topic for EBC as well as GAMIAN-Europe and fortunately, it is slowly gaining traction. However, the need remains to ensure that patients who are about to enter the transition phase are adequately supported now.

This is why earlier this year, EBC and GAMIAN-Europe hosted an expert meeting to explore the reasons why transition of care is currently suboptimal and to identify ways to remove barriers to continuity of care. This meeting has led to the development of a comprehensive Expert Policy paper, formally launched in today's meeting.

Speaking on behalf of EBC, Frédéric stressed that the document serves as a good policy tool to clearly identify existing gaps. It provides a number of specific policy recommendations, which relevant stakeholders can take note of and make use of to support their advocacy efforts in order to improve the situation for patients on the ground. He then thanked the experts for their invaluable input as well as Shire for supporting the development of this document.

Key note speeches

**Frédéric Destrébecq** then gave the floor to **Professor Swaran Singh (University of Warwick)** who first provided the definition of transition of care as 'the process of planning, preparing and moving a patient with a mental health condition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS)'.

As said before, this topic has gained recognition over the last 20 years, not least because of compelling statistics: research has clearly shown that the vast majority of all mental health disorders have their onset at a young age; 75 % starts before the age of 25 and of that, 50 % sets off before the age of 16. These are convincing numbers which clearly indicate the need for early intervention: the earlier the intervention, the more difference can be made. There has also been long standing concern about the problems of care at the interface between child and adult services, although this has not been well studied. The divide between child and adult psychiatrists is ideological, conceptual, clinical, and therapeutic. Clinicians differ on all elements of the patient journey, e.g. assessment, diagnoses, (type of) treatment and duration of treatment. Because of this divide, it was so far unclear what happens to young people who come to the end of their childhood care and have a need for adult care, in other words, those that move from CAMHS to AMHS.

Professor Singh conducted a large study (TRACK) which tried to identify the nature and magnitude of this divide having followed the care journey of young people and involving clinicians, care managers and their families. When discussing transition, account needs to be taken of three different kinds of transitions that adolescents experience: developmental transition (physiological processes), situational transition (leaving home, finding a job, going to college) and healthcare transition (moving from childhood healthcare to adult healthcare systems). The focus of Professor Singh's study was on healthcare transition, but future research should take all three aspects into account. From the results it became clear that one third of young people never makes it across the transition boundary; they were either not referred or did not want to be referred, wary as they were with the services. However, many of these young people that do not make it across the boundary have continuous clinical needs. In addition, a quarter of those that did make it across the boundary were not followed up. This means that half of those that reach the transition boundary fall

through the care gap. The study also found that those affected by ADHD and neurodevelopmental disorders faced the most difficulties. The study concluded that transition from CAMHS to adult care was “poorly planned, poorly executed and poorly experienced”.

Young people who fall through the care gap often have chronic disabling conditions, hence more attention needs to be paid at policy level. In the UK, this need was recognised and NICE has developed guidelines with respect to transition of care. Professor Singh chaired the NICE committee on transition; this found that transition is a problem across all medical specialties. However, the situation is worst in mental health. While initiatives to improve transition have been developed taken at the individual level, there is no universal model to effectively address these issues. Individual projects bringing together both services exist but in order to really make a difference, services might to be redesigned. And this will not be easy as people do not like to have their empires challenged and changed.

Professor Singh briefly referred to the EU-funded MILESTONE project, which is investigating the state of play regarding transition of care in 8 countries. The project is still ongoing; however, it is already clear that there are huge differences between the design of health care services across these countries. The study is following the care pathway of some 1000+ youngsters arriving at the transition boundary, with a focus on both who do and do not make it across. Within the study is a randomised trial of a model of managed transition, comparing it to treatment as usual. The MILESTONE project will come to end in January 2019, and the finding will be presented at a large event in April 2019.

In conclusion, Professor stated that that barriers to a smooth transition of care should be solved by clinicians working together. Clear criteria will need to be agreed on when a person needs to be transferred and what type services this person needs.

The second speaker, **Prof Geert Dom (University of Antwerp, Board member European Psychiatric Association)** introduced the Expert Policy Paper, which had already been referred to by Frédéric Destrébecq.

This Paper was developed with the input of some 20 expert clinicians, patient representatives, academics and mental health advocacy groups and recognises that many young people do not transition smoothly to AMHS, due in part to a lack of flexibility in age of transition and the availability of adult services. The Expert Policy Paper therefore aimed to inform EU and national-level stakeholders and policy makers of the importance and need for successful transition from child to adult mental healthcare services, to identify factors confounding this process and to make recommendations for improvement.

While the problems associated with transition from child to adult services apply to all mental health disorders, the Expert Working Meeting focused on ADHD as a case study; this condition provides a useful example in which to frame transition to adult services across the mental health sector as it is relatively common and often persists into adulthood. Access to adult ADHD services and support is generally poor.

What makes a transition successful? The ‘Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services’ (TRACK) study aimed to identify factors that facilitate successful transition. TRACK came forward with a number of recommendations, such as ensuring that the needs of the patient should be central to protocol and service development, collaboration between agencies, involvement of patients and carers the transition protocol, flexibility in age range for transition to accommodate differing needs and developmental stages of patients and collaboration between CAMHS and AMHS. Other studies have also highlighted the ‘transition gap’ between child and adult mental health services such as a UK National Health Service workshop and the Transition to Adult Mental Health Services (TRAMS) project.

With regards to ADHD, the Expert Policy paper identifies a number of barriers to successful transition relating to the timing of the transition from CAMHS, availability of care, differences in practices and culture between CAMHS and AMHS, poor adherence to treatment and medication, lack of ownership and accountability of care in the transition process. Overall, the social stigma attached to mental health is an overarching barrier.

Recommendations to remedy the situation relate to improving ADHD education of healthcare professionals, increasing the general public’s awareness of ADHD, improving management and planning of the transition process for patients with ADHD and promoting long-term continuity of care after transition to AMHS.

Professor Dom ended his presentation by outlining the elements of a best-practice transition pathway, which needs to identify problems and provide solutions for the diagnosis and awareness of the condition,

ensure ownership and accountability for patients, provide accessible mental health services and properly manage these services.

He concluded that the Expert Policy Paper can be considered as a framework for action to improve transition of care in mental health, not only in the area of ADHD. It is now up to stakeholders to use this document to advocate for the concrete implementation of this framework.

### Panel discussion

The first panellist, **Dolores Gauci (Board member, GAMIAN-Europe)** underlined the good cooperation with EBC in hosting the July meeting, which formed the basis of the Expert Policy Paper.

Transition of care from child to adult services is a priority issue for GAMIAN-Europe, as it is about ensuring the best possible care for anybody that is in need of care, irrespective of age or condition. Not having a smooth transition into adult services leads to a real risk - a risk of being stuck without being able to make progress at the very least.

The need for smooth transition is taken for granted in this area: nobody would argue about the relevance of continuity of care and a smooth care transition for, say, cancer or diabetes. Advocating that mental health should be addressed in the same way as physical health, that it should be on the same level as physical health is part of GE's core objective. Once this starts to be the general attitude towards mental health - of policy makers, health professionals and all those involved - many current issues faced by those affected by mental health problems will fall into place.

While all barriers to smooth transition as identified in the Paper are highly relevant, to GAMIAN-Europe Dolores Gauci highlighted those that are of special importance. One of these is the stigma attached to mental health and those that are affected by mental health problems. Patients and their families encounter examples of this pervasive stigma every day. Better information and education are required if we want to raise awareness and change attitudes. Cooperation across the board and a more integrated approach towards mental health between the various medical professionals and services involved would also help. Another important barrier is the current trend towards providing care in the community. While this trend can be viewed positively, there is an increased risk to continuity of care, due to the larger number of players involved and issues related to proper monitoring and follow up. These are risks that should be taken into account when care services are being put in place.

In relation to the proposed solutions, Dolores Gauci welcomed the Paper's strong references to the need to engage with patients and to put patients at the centre of their care and treatment process. This is the only way to ensure not only the relevance of the services to the patients but also increases the likelihood of compliance and uptake of services. Actively involving patients (and where necessary) their carers will decrease the risk of them dropping out of the care system.

**Andrea Bilbow (President, ADHD-Europe)** also warmly welcomed the Expert Policy paper, stating that it will be well received across Europe. It is comprehensive and seems to cover many if not all of the issues at stake. ADHD-Europe recognises the problem, and Andrea underlined that those living in the UK are lucky as services do exist there. These should exist for everybody across the EU. However, this is currently not the case; there are huge inequalities. In some countries, there are no services at all, let alone transition services. Member States are responsible for their health care services but in many cases this responsibility is not being taken very seriously.

Cost of treatment seems to be one of the major barriers. Referring to her personal situation, Andrea Bilbow underlined the importance of families to children. Even when they have become adults, they need their families for support and therefore, families need to be included in care services.

She also referred to the stigma that can be attached when children move from paediatric services into mental health services - all of a sudden, a person is labelled as having a mental health problem. This can cause them to drop off the edge and stop treatment - with all the negative consequences that that entails. The cost of nontreatment should be taken into account, such as people dropping out of employment.

Last year, ADHD-Europe developed a Declaration on transition of care; this clearly states what is required to improve the situation, in order to educate budget holders and politicians and to convince them to take action. Good transition of care is required if people affected by mental health problems are to find their way in life, employment and relationships.

**Terje Peetso (Head of Policy Section, Unit e-Health and Ageing Policy)** explained the work of the Commission in the field of ICT's, underlining that DG CONNECT has a unit which specifically addressed digital health. The aim is to contribute to the digitisation of health care and to make progress in research as well as deployment in this area. However, good progress can only be made if the end user is engaged in the development of the end product and when their interest and concerns are taken into account from the start. This holds true for the products as well as for the actual policy development which is related to digitisation. Terje Peetso's unit can also provide input in other digital policy developments from the health perspective.

In terms of transition of care, she underlined that digitisation and eHealth have a role to play, for instance in relation to facilitating the sharing of and access to health records. Of course, while sharing health records can be helpful, data security aspects and privacy of patients also need to be taken into account.

Terje Peetso also stated that the Commission funds research and innovation and that there are several initiatives that have a mental health focus, such as the MasterMind project; this focuses on depression and online cognitive behavioural therapy. There are many other examples of apps that have been developed to monitor various conditions, which support patients having access to care outside office hours and stimulate self-care and empowerment –for mental health conditions as well as physical disorders.

Other examples of EU-level activity were mentioned, such as the fundamental science being gained from the European Brain Project, which could lead to identifying better way of making use of artificial intelligence for better and faster diagnose and assessment purposes.

In any case, the feedback of patients and how they can provide this when products and services are being developed should not be forgotten as they are the real experts with respect to their needs and requirements.

**Professor David Nutt (President, European Brain Council)** stated that he was speaking from two perspectives:

Firstly, as a psychiatrist, having set up the second ADHD clinic in the UK and having seen many people fall through the care cracks, he underlined the value of this Expert Policy Paper. Transition of care from child/adolescent to adult services is highly relevant and action needs to be taken to address this.

Secondly, as President of the EBC, he stated that this project spans a span a lot of the priority areas of the EBC. Transition of care poses complex challenges, and it was very useful to engage a range of experts from different backgrounds in the development of the Expert Policy Paper, throwing lights on all those elements. This topic could also be taken further as part of another EBC activity, i.e. the Value of Treatment project.

Earlier EBC research revealed that the cost of brain disorders amounts to some € 800 billion per year. The Value of Treatment project has worked on the other side of that question; it is not looking at the cost of dealing with a disorder but rather at the costs related to not treating the disorder. Until now, 9 brain disorders have been analysed in this way but more remains to be done; ADHD could be an important area to address as well.

Clearly, investing in early treatment is the most useful way to make a difference, to patients as well as in terms of cost-effectiveness; the evidence is there. And evidence, as generated by project like the Value of Treatment, is what is required to convince policymakers.

Professor Nutt also stressed that, not having services in place (and therefore, no direct costs) does not mean that there are no costs involved. The costs related to lost opportunities (i.e. people not being able to work) should also be taken into account. Another (costly) risk relates to young people not having access to the care seeking their own treatment, turning to illegal drugs. And this is an outcome that nobody desires.

## Discussion

The following issues were raised:

- While the importance of smooth transition of care is increasingly recognised, the main challenge relates to the identifying and developing the required competences and putting in these services in place. The human factor needs to be taken into account as in many cases, health professionals do not like changes to their empires.
- One of the main barriers to change is the 'silo-ed' impact of cost. The cost of services may be occurring in one sector but the consequences (cost savings) are being felt in another. Issues relating to accountability and responsibility are key.

- The report was welcomed by many of the participants; some underlined the importance of the focus on ADHD as this seems to be a 'foundational condition' for other mental health problems.
- The issues related to transition are complex and there are no simple solutions. A policy statement has just been published by Professor Singh and colleagues in relation to the need to share training and resources and break through the transition divide;
- There seem to be resources which are not spent appropriately – in other words, better use needs to be made of existing resources.
- As regards transition of care there seems to be a need for human as well as for financial incentives, focusing on how to optimise care in care networks. Currently there are efforts to formalise informal care networks; this trend should be monitored and lessons should be learnt from good practice examples.
- The concept of the 'maisons d' adolescents' (France example) seems to be useful as these lower the barrier for young patients to seek help.
- Teresa May's government has announced more resources to be allocated to mental health; while positive, it will remain to be seen if this promise will actually materialise.
- Huge inequalities exist across the EU in terms of mental health services and access to these services. There should be more investment in mental health across the board.
- There may be too many services networks and in the end, they do not connect anymore. And when they do connect there can be conflicts. How to deal with new authority and move to shared decisions making? A useful first step might be to facilitate the exchange between all players involved, to raise awareness of each other's activities and views and prepare the ground for more profound change at a later stage. Conflicts about resources and where budget can be spent should be avoided.
- For some participants, stigma is the key barrier to any change for the positive in mental health. If policy makers were more aware at a personal and individual level and realise the impact of mental health, more resources would be put towards mental health. Stigma needs to be addressed at all levels and for all types of mental health issues.
- Health is competence of the EU Member States; the EU's role is to share and promote good practice wherever possible. The EU level also funds research and innovation related to keeping people in their own environment. There should be better use of resources rather than putting in more money, as there is a lot of waste within the health care systems. Analysis of patient pathways would be useful in order to see where resources should be used most effectively.
- It was underlined that more focus should be on the patients as they are not sufficiently involved in service development. Some of the resources could go to voluntary organisations as they can provide services where the more established services fail; they know what best to provide and they are in direct contact with patients. Working in collaboration with NGOs will help the established service providers the better address the problems. Services should be accessible and inclusive.

### Closing remarks

**Tomas Zdechovsky MEP** stated that he agreed to host the meeting as mental health features is one of his priority policy interests, also from a personal point of view. Last year, he launched a Written Declaration on mental health in migrants in the European Parliament. While this unfortunately did not get the number of signatures required, it did help to raise awareness of this topic in the Parliament and beyond. In doing this work, it became clear that mental health does not get the attention it requires. According to Tomas Zdechovsky, one of the reasons for this lack of attention to mental health issues is the stigma attached to mental health problems. If this stigma could be addressed effectively and lessened, mental health would get the attention it deserves. Unfortunately, this situation is still a long way off as even at EU level the interest in mental health issues is decreasing. This will lead to a decrease in the visibility of mental health and the need to address it where the opposite is needed; the EU level should take more action, rather than less. In relation to transition of care, Tomas Zdechovsky underlined its relevance as it is about access to mental healthcare and services, it is about continuity of care and it is about avoiding that young people fall by the wayside and get left behind. It is about equal opportunities and about ensuring

that young people with mental health issues have the best opportunities to fulfil their capacities and lead the lives they want to live. IN conclusion, Tomas Zdechovsky congratulated EBC and GAMIAN-Europe with the Expert Policy Paper and their further efforts to improve the lives of patients and underlined his willingness to continue to advocate the need to address mental health issues in the European Parliament.

Christine Marking, 23 November 2017