Child and adolescent psychiatry in Iceland

Report from a brief study tour

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Summary

Aim of the study

In Iceland the prescription and consumption of methyl phenidate for the diagnosis Attention Deficiency Hyperactive Disorder (ADHD) is high, seen from an international perspective. The aim of the study is to try to evaluate how well the system in Iceland gives support, care, and treatment to children with psychiatric problems and which improvements that can be made. The report focuses on ADHD, but the proposed changes will most likely also benefit children suffering from other psychiatric disorders.

Findings

- The system seems to be working quite well when it comes to finding and also giving care and treatment to children and adolescents with psychiatric problems, including ADHD.
- The different professions working with child and adolescent psychiatric problems that we met were hardworking and committed to doing the best for their patients/clients.
- The prevalence of ADHD in Iceland is consistent with internationally obtained data.
- It is not from this study possible to state that the pharmacological treatment of ADHD in Iceland is too high or too frequent.
- Waiting lists are too long.
- Children with psychiatric disorders are given reasonably good medical care, but not enough psychosocial and cognitive-behavioural support.
- There are not a sufficient number of adequately trained professionals within the municipalities and the health care system to give the families the support that they need to be able to better cope with the situation at hand.
- Schools throughout the country employ needed extra staff when a child is diagnosed, thus allowing children, except the most severe cases, to attend the local schools.
- There is a lack of local centres that can serve as the primary level in diagnosing, care, support and treatment and there is an apparent need for better communication between the health care system and the municipalities as well as with and within the school system.
- The nominal head of BUGL does not have the means to run the centre as one coordinated unit, since there is a large number of sometimes competing command structures.
- The recruitment of new specialists is a great problem.

- In many parts of the country there are no structures locally that can build on the improvements that the patients have achieved at the national centres.

Proposals

- To cover the basic needs in the country another seven or eight local centres are needed. The centres should be modulated on the centres in Keflavik and Grafarvogur.
- The local centres should work towards strengthening cooperation and communication between all parties involved in the care and treatment of the children. They should also, in collaboration with BUGL, serve as centres for continuous professional development of all personnel involved. Furthermore, they should also, as they do in the Keflavik area, try to reach all parents with information and training.
- The build-up of the local capacity should concur with BUGL having the role as the national referral centre.
- BUGL should also function as a national resource centre, a centre for research and implementation of new methods.
- The head at BUGL must have the necessary organizational authority for BUGL to be able to run as one consistent unit.
- Teachers and all other personnel working with children should be given access to continuous professional development giving them the skills needed to be able to tend to the needs these children have.
- The psychologists in the school system should not be prohibited to give therapy, on the contrary, it should be one of their responsibilities.
- The need to recertify a diagnosis in order for the local school to get extra resources should be delegated to the local centres.
- The practice today, where junior doctors do their on-call duty at the clinic of general psychiatry ending up with less than the ordinary forty-hour week through compensation for work done on-call, should end.
- A chair in child and adolescent psychiatry at the Reykjavik University should be considered in order to develop scientific research and to strengthen the appeal and the knowledge base of the speciality.
- Clinical guidelines should be developed to ensure a high and uniform national standard in diagnosing, care and treatment of neuropsychiatric disorders, as well as other disorders. As we understood it, clinical guidelines are forthcoming regarding neuropsychiatric disorders. The importance of successful implementation cannot be overstated.
- More local homes for care and treatment and special schools with focus upon social support might also be needed. For children with very severe problems, a reconsideration of the national policy that all children should attend local schools might be necessary, allowing the local school time to employ and train sufficient staff.

- Specially trained teachers, ordinary teachers, school nurses, psychologists and other personnel working in the school system need to be given better knowledge of the nature, symptoms, progression, treatment and care of ADHD and other neuropsychiatric disorders.
- The professionals within the educational system should shoulder the responsibility of looking after children up to the age of nine between 14.00 and 17.00 during school days.

Child and adolescent psychiatry in Iceland

The starting-point for our study is the fact that in Iceland the prescription and consumption of methyl phenidate for the diagnosis Attention Deficiency Hyperactive Disorder (ADHD) is high, seen from an international perspective. In our study we have tried to evaluate how well the child and adolescent psychiatry functions in Iceland and, if possible, what could be done to make the situation better for children with neuropsychiatric and other disorders, and their families.

We have not arrived at a standpoint as to whether the prescription of methyl phenidate really is too high. We have, however, studied the system as it is today and we are from our observations proposing changes that we believe will lead to improvements with only a reasonable addition of resources. During our visit to Iceland we met all child and adolescent psychiatrists in the country, many psychologists and nurses working within the field of child and adolescent psychiatry, representatives from the ministries of health, social welfare and education. We also interviewed experts from the field of pharmacology and pharmacovigilance, general practitioners (GP), school nurses, school psychologists, social workers and representatives of the consumer organizations.

We visited BUGL, Studlar and Greiningar and were informed about their different areas of work, their successes as well as the problems they are facing. We further visited centres in the Keflavik area and in Grafarvogur. Centres, attached to the local health centre, with special resources and knowledge of psychiatric problems faced by children and adolescents. We also met with the head of the Centre for Child Health Services (MHB), a unit in the process of starting with a remit of being a secondary level institution for children with psychiatric problems.

In our discussions we came to the conclusion that the room for improvement that exists in the care and treatment of children with ADHD might be the same, or similar, to possible improvements in the care and treatment of other psychiatric disorders in children and adolescents. Our report, thus, deals with how well the system in Iceland gives support, care, and treatment to children with psychiatric problems and which improvements that can be made. The report focuses on ADHD, but the proposed changes will most likely also benefit children suffering from other psychiatric disorders.

In contrast to the criticism sometimes voiced regarding the child and adolescent psychiatric care and treatment in Iceland, we first want to say that the system actually seems to be working quite well when it comes to finding and giving care and treatment to children and adolescents with psychiatric problems, including ADHD. Furthermore all the different professions working with child and adolescent psychiatric problems that we met were hardworking and committed to doing the best for their patients/clients.

The prevalence regarding ADHD in Iceland seems to be between four and up to above five per cent of the child and adolescent population, which is consistent with internationally obtained data. This indicates that the system for detection and diagnosing

finds most of the individuals suffering from ADHD. We have not been studying the prevalence of other child and adolescent psychiatric diagnosis in Iceland.

There can be many reasons for the difference in pharmacological treatment between Iceland and other western European countries; higher and more adequate detection rate, different therapeutic traditions including higher dosages, more patients above twenty on medication and/or a relative lack of social and therapeutic community based support for the patients and their families. It is worth noting that, according to oral information, twenty per cent of the DDDs (Defined Daily Doses) for males and forty per cent of the DDDs for females are consumed by patients older than twenty years old.

Furthermore, in the other Nordic countries there has been a heated, and sometimes inflamed, debate as to whether or not neuropsychiatric disorders really merit a diagnosis. Are these problems just a reflection of a child unfriendly society with a medical profession too close to the pharmaceutical industry and too eager to medicate an unusual normality? Seemingly in Iceland, you have been spared the most extreme positions in this debate and thus can look upon these disorders with a more detached view, arriving at models of care and treatment less based on ideology and more on existing scientific evidence.

Thus, it is not possible to categorically state that the pharmacological treatment of ADHD in Iceland is too high or too frequent, it might be so that that the pharmacological treatment in other countries is too low or too infrequent.

As we have understood it, when a child has a psychiatric problem, the parents or the preschool/school psychologists/nurses will contact a GP or a paediatrician for an evaluation and possible referral to a specialist. In many cases, however, the diagnosis ADHD will be set by a psychologist working for the municipality (often employed in the school system). However, the patient will normally be started on medication only after having seen a child and adolescent psychiatrist in private practice, at BUGL, or after having seen a specialized paediatrician. GPs would normally not initiate medication with methyl phenidate but may very well continue to medicate when the diagnosis is set. The prevalence figures of ADHD in Iceland indicate that these children are detected.

For children with psychiatric disorders attending the compulsory school system, starting at the age of six, schools will be given extra resources, although only after having the child diagnosed at BUGL or a couple of other institutions, thus creating queues at these few centres. The local centres (see below) that we propose should have the capacity and be given the right to diagnose, thus eliminating the queues and allowing more time for care and treatment. Seemingly, the system gives children with psychiatric disorders reasonably good medical care, although waiting lists are a problem, but not enough psychosocial and cognitive-behavioural support to the children and their families. In the Reykjavik area and in Akureyri access to psychosocial and cognitive-behavioural support seems to be greater. However, according to representatives of the consumers, the situation is different in the smaller communities in the countryside.

Seemingly, the municipalities and the health care system do not seem to have a sufficient number of adequately trained professionals to give the families the support that they would need to be able to better cope with the situation at hand. Schools throughout the country seem, however, to employ needed extra staff when a child is diagnosed, thus allowing children, except the most severe cases, to attend the local schools.

One of the shortcomings that we have observed is the lack of local centres that can serve as the primary level in diagnosing, care, support and treatment. Furthermore there is an apparent need for better communication between the health care system and the municipalities as well as with and within the school system. The compulsory school should not, as sometimes is the case, be uninformed of children with severe psychiatric problems starting first grade, especially when a diagnosis already has been set at the pre-school level. The local centres should strengthen cooperation and communication between all parties involved in the care and treatment of these children. They should also, in collaboration with BUGL, serve as centres for continuous professional development of all personnel involved.

The positive experiences seen in the Keflavik area with an integrated and comprehensive approach and the likewise positive, but limited, experience from Grafarvogur, as well as the well functioning centre in Akureyri, support the idea that a limited number of local centres, attached to and integrated with the primary health care centres, can strengthen local capabilities to the extent that primary support, care and treatment can be handled locally.

Akureyri is a well functioning centre with a resident child and adolescent psychiatrist. However, due to the lack of specialists in child and adolescent psychiatry in Iceland, several centres of that kind would be difficult to create. Therefore the centres we propose should rather be modelled on the centres in Keflavik and Grafarvogur.

Thus we believe that an addition of one psychologist, one social worker and one part-time occupational therapist, to the existing health care centre and the existing staff attached to the school system and/or the social welfare system of the municipalities, will give sufficient manpower to handle all not too severe cases of ADHD, and other psychiatric conditions, locally.

These centres should also, as they do in the Keflavik area, try to reach all parents with information and training. Parents with children that have special needs, e.g. ADHD, should be given special attention to help them address the needs of their child/children.

Teachers and all other personnel working with children should be given access to professional development giving them the skills required to be able to tend to the needs these children have. Psychological support and therapy should be given by trained professionals at the centre and by the psychologists and social workers attached to the schools.

The psychologists in the school system should not be prohibited to give therapy, which,

as we understood it, is the case today. On the contrary, it should be one of their responsibilities. Today their work is too focused on diagnosing even in cases where a diagnosis has already been reached through previous testing. This unnecessary work impinges negatively on the possibilities of giving the children and their families needed psychosocial support. The school psychologists should be able to use the knowledge they have of these children and their families to strengthen the local therapeutic efforts and the support that the families and their child/children require.

To cover the basic needs in the country we believe that, in addition to the existing centres, another seven or eight centres would be sufficient.

In order to have a uniform standard and approach throughout the country we believe that BUGL should be the national resource centre. Thus BUGL must, on a regular basis, send consultant child and adolescent psychiatrists to the local centres to review their work, to give expert advice and to help with continuous professional development. BUGL should also serve as a national referral centre for the most severe cases. The need to recertify a diagnosis in order for the local school to get extra resources should be delegated to the local centres. The personnel at BUGL will then have time to focus on being a specialist referral centre rather than rediagnosing patients who should be cared for locally.

BUGL has a problem with the constant over-demand of bed capacity. On an average they use 130 per cent of their capacity. They also have problems with long waiting periods, especially for referrals without a stated urgency, where at the moment a year can pass before the patient is seen.

Last year, 2005, BUGL received approximately 450 referrals. We do not know how many professionals were involved in these cases, but with seven to eight specialists in child and adolescent psychiatry, it means roughly 60 new referrals per psychiatrist per year. Even accounting for the fact that not all new cases are attended to by a psychiatrist, the number of referrals is quite high.

By creating centres that will handle all non-severe cases locally, the number of referrals to BUGL will drop. We also believe that the demand for beds will drop since inpatient investigations can be prioritized to a greater extent than today and thus be handled without delays due to staff attending to outpatients.

Some of the specialists in child and adolescent psychiatry have private policlinics in addition to their employment in the public sector. As far as we have been able to see, this does not interfere negatively with the care and treatment of the patients. Rather, more working hours seem to have been added to serve the needs of children and adolescents with psychiatric problems.

If, however, the authorities would like to influence the patient mix and the methods used in the private practices, it is most likely best done through the reimbursement system, i.e. with economic incentives.

Another very important factor for how BUGL will function is the command structure within the organization, i.e. what kind of leadership role that the head of BUGL can and should have. Today BUGL is part of the clinic of general psychiatry at the National Hospital. The doctors have the head of BUGL as their chief, who, in his turn, reports to the head of general psychiatry. The head at BUGL is, if we have understood things correctly, responsible for setting priorities, deciding which methods should be used, who should see the patients, etc. He is also at least partly responsible for keeping the budget. The psychologists, on the other hand, have another head in charge, as do the social workers and the occupational therapists.

Furthermore, in the health care system in general in Iceland, there are always two heads at the clinics; one physician and one nurse, the latter being head of all the nursing care staff. At BUGL, this means that the nurses and the nurses' helpers have their own head, who, in her turn, reports to the nursing head at the clinic of general psychiatry. The two heads at BUGL are at the same administrative level and neither of them is responsible for the paramedical staff, who have yet another head.

For all practical purposes this means that a rather large number of command structures potentially compete for influence. Since the chain of command is profession based, there also seems to be a potential for prioritizing the interests of ones own profession, thus sub-optimizing the workings of the institution. The nominal head of BUGL really does not have the means to run the centre as one coordinated unit. The different professions practically speaking have veto power over suggestions for change in methods, routines, or recruitments. To make BUGL run as one consistent unit, we strongly believe that the head must have the necessary organizational authority.

For BUGL to serve as a revised national centre requires BUGL to be run as one integrated entity with the head being responsible for all hiring and firing of co-workers. She or he should also be allowed to decide, after consultation, upon methods, routines, etc., i.e. to ensure that the service to the local centres and ultimately to the patients is evidence-based, efficient and cost-effective.

The sole head then would have the possibility to develop the work of the unit. That also means that she/he can, and should, be held accountable if the unit does not live up to the responsibilities given. In the present situation, it is very difficult to hold the head responsible for possible shortcomings since it is not in his power to enforce necessary changes.

The way referrals are handled at BUGL has received criticism from several of the local representatives that we met. The some times year long waiting times were criticized, but also the fact that in some cases patients have been met by co-workers at BUGL with a weak professional background, or personnel with a too low level of formal qualifications. Furthermore, when the work at BUGL is done, patients are not seldom sent home without the local actors being given information in time to plan local support and care. We have been told of examples where the local actors get a days notice to attend the necessary briefing meeting at BUGL before taking full responsibility locally for the patient.

To come to terms with the problems related to the different affiliations of the referring institutions a copy of the referral should always be sent to the local health care centre. The centre will get a response to the referral without causing any problems regarding patient confidentiality since the local centre and BUGL both belong to the health care sector. The health care centre, furthermore, then must communicate the findings with the other local actors and participate in the support, care and treatment that the patient needs.

BUGL must be able to handle the administrative contacts with other units in a professional manner. One of the many responsibilities of the head of BUGL will be to professionalize the interface between BUGL and the local, referring and caring actors.

Should BUGL be an independent unit? The idea has been put forward as well as the suggestion that BUGL should belong to the clinic of paediatrics. We do not believe that a change of mother clinic or for that matter full independence really is a crucial issue. The speciality of child and adolescent psychiatry is very small and vulnerable in Iceland. To be able to attract new doctors in training to become specialists, the unit must be able to structure the work to be done, have full responsibility over what methods to use, whom to hire etc. If these things can be accomplished, we believe that the possible affiliation to another clinic to be of secondary importance. Likewise we do not see the physical location of BUGL outside of the hospital area as a great problem.

However, the recruitment of new specialists is a great problem. The practice today, where junior doctors do their on-call duty at the clinic of general psychiatry ending up with less than the ordinary forty-hour week, through their compensation for work done on-call, should end. The present system does not give the junior doctors a real chance to meet the speciality of child and adolescent psychiatry. The importance of this problem for the possibility of recruiting new doctors should not be underestimated. If the clinic of child and adolescent psychiatry should continue to be part of the clinic of general psychiatry, then this problem has to be solved.

In order to strengthen the status of the speciality and increase the evidence-based approach within the speciality, we believe that several actions need to be taken. One being that BUGL should be a national centre for research and implementation of new methods. We have understood that the pros and cons of establishing a chair in the speciality has been discussed but that no consensus has been reached.

We believe that it might also be useful to consider creating a chair in child and adolescent psychiatry at the Reykjavik University in order to develop scientific research and to strengthen the appeal and the knowledge base of the speciality.

To ensure a high and uniform national standard in diagnosing, care and treatment of neuropsychiatric disorders, as well as other disorders, it is of great importance that clinical guidelines are developed. As we understood it, clinical guidelines are forthcoming regarding neuropsychiatric disorders. These will evidently be comprehensive and cover criteria for diagnosing, social support, care and treatment.

Comprehensive guidelines will be an important tool in shaping attitudes towards and actions for patients with neuropsychiatric problems. It should, in our opinion, also be stated in the guidelines when to refer to a specialist.

In order for the guidelines to be properly implemented and used to shape local and national routines, great care should be given to disseminating and discussing the background, content and recommendations set forth in the guidelines.

The members of the group bringing forth the guidelines should, together with staff from BUGL, arrange regional conferences to ensure that all relevant staff in schools, including pre-schools, municipal welfare services, and health care system, understand, accept and agree on the criteria, working methods, routines and cooperation set out in the guidelines.

The result of the implementation process will to a great extent decide how well children throughout the country will be cared for in the coming years. Thus, the importance of successful implementation cannot be overstated.

The two other main institutions working with children with neuropsychiatric disabilities/disorders, Studlar and Greiningar, are referral centres with a partly different focus. They cooperate with BUGL regarding these patients and we have no reason to question the way they are working. MHB is a third institution that serves as a secondary level institution for children with various kinds of problems. These institutions are important parts of the health care system and should be an integrated part of the support and care offered to children with severe disorders and their families. For patients with ADHD and other psychiatric conditions not classified as mental disabilities, BUGL should continue as the national referral centre.

We were informed during our visit at Studlar that in not so few cases, even though the children improve during their therapy at Studlar, there is no structure locally that can build on what has been achieved. The children return to the exact same social situation as they were before they came to the centre. Local centres of the kind we have proposed will help remedy this situation.

Today there are seven homes for care and treatment of children severely affected by neuropsychiatric disabilities. Although national policy states that all children should attend local schools, there might be room for a reconsideration of that policy for children with very severe problems, allowing the local school time to employ and train sufficient staff. Maybe an expansion of local homes for care and treatment and special schools with focus upon social support is also needed.

This said, we do not have any specific suggestions as to whether there is a need for more places at the seven special homes for care and treatment of the most severe cases. The number of homes for care and treatment should reflect the needs so that students with severe difficulties receive the special education that they need without other students suffering. In most cases this will be possible to arrange through the local school system, but it is important that needs should decide access to national support rather than a strict

application of the ambitious goal that all children should attend the local schools.

Teacher training should encompass knowledge and skills related to teaching children with neuropsychiatric disabilities. Since the prevalence for ADHD is around four to six per cent of the child population all teachers will be exposed to children with these, and related, problems. Pre-school teachers as well as teachers in the compulsory school system need to be given sufficient understanding of the nature of ADHD and other neuropsychiatric problems. They should understand the need for stability and support, the effects of care and treatment, including side effects of pharmaceutical therapy, possibilities for change of severity and symptoms over the years, and the necessity of asking for further help when the problems are too difficult to tackle in the local school.

The need for continuous professional development in this field, as in other fields, should not be underestimated. The evidence-based methods that are used today are based on science and experience only a few decades old. We will surely witness further development of scientific knowledge in this field in the years to come. Thus, all professionals that are involved in the upbringing and care of children need to have knowledge and experience, through being trained, in how to manage neuropsychiatric, and other, disorders.

Specially trained teachers, ordinary teachers, school nurses, psychologists and other personnel working in the school system need to be given better knowledge of the nature, symptoms, progression, treatment and care of ADHD and other neuropsychiatric disorders. Preferably the implementation process of the new clinical guidelines should be used to further and deepen the personal and institutional knowledge of these disorders within the school system.

Today the responsibility for looking after children up to the age of nine between 14.00 and 17.00 during school days does not rest upon the schools but with another part of the municipal welfare services. That should, in our opinion, be changed. The professionals in the educational system should also shoulder this responsibility. They have, and certainly will have, a greater experience and knowledge of ADHD and other neuropsychiatric problems, than the staff employed by the municipality in general. Furthermore, it is most likely beneficial for the affected children to have continuity in personnel as well as in methods and approaches.

As a consequence of this responsibility, children should also, after the ordinary school hours but still within the school, be cared for by teachers or other professionals with specific knowledge of and training in caring for children with psychiatric problems.

We have not in our work taken a position on the line of demarcation between responsibilities between the municipalities and the state regarding the social services. The reason for this is that we, at present, do not have enough knowledge of the legal and financial responsibilities of today. This situation may need further study and definition.