

Summary of advisory report on the participation of young people with developmental or behavioural disorders

The SER has unanimously adopted an advisory report on the participation of young people with developmental or behavioural disorders. In the report entitled 'The benefits of a bespoke approach', the SER stresses that to be able to participate in society, these young people require help that is tailored to their needs. The entire body of rules and facilities for these young people is too complex, so what is needed is a single coordinating professional who can guide a young person on his or her 'trek through the institutions'. In the longer term, the Government must review ways of structurally improving the cohesion of the entire regime of rules and facilities.

Summary

In this advisory report, the Social and Economic Council of the Netherlands (SER) reviews the possibilities of making young people with developmental or behavioural disorders, or similar problems, better prepared to participate in society. On behalf of the Government, the Minister for Youth and Families requested the SER's advice on 22 December 2008. The Council has arrived at the following findings and conclusions.

Wide-ranging problems

This report is concerned with young people with a developmental disorder (autism, ADHD, slightly limited mental capacity) as well as young people with behavioural problems or multiple problems that are reflected in psychological, social, cognitive or behavioural problems and/or social problems (homelessness, drug abuse, debt). By multiple problems, the Council means young people who are faced with a combination of disorders, psychological and/or behavioural problems and/or social problems. This report covers young people up to the age of 27.

Focus on young people with multiple problems

The Council observes that – with the right support – young people with a single problem have relatively better prospects of entering the labour market than young people with multiple problems. The combination of very diverse psychological and behavioural problems and/or disorders means that young people with multiple problems require different types of highly differentiated support.

A real danger is that these young people will not make full use of the care and facilities that are available, leading to exacerbation of the problems. The problems can further escalate due to the absence of a safe home environment, the use of alcohol or drugs, the accumulation of debt and the lack of future prospects at school or work. Consequently, these young people are confronted with an often lengthy, difficult and complex 'trek through the institutions'. There is a considerable risk that they will drop out, because they repeatedly have to explain their situation and because their complex problems are not solved.

Growth in the use of facilities

The Council shares the Government's concern that a growing number of young people with developmental or behavioural disorders or multiple problems might find it difficult or impossible to enter the labour market. This creates a serious risk that they will remain dependent on public welfare facilities for their entire lives and that their talents will go to waste. The Council finds that the greater use of public welfare facilities is due only to a very limited extent to an increase in the occurrence of the various developmental or behavioural disorders or multiple problems. More significant causes are better identification of problems, the growing complexity of society, a

greater emphasis on labour productivity and performance and a certain 'push out' from regular facilities (to special-needs education, for example).

The Council stresses that it was unable to find any evidence to suggest wrongful use of facilities, referred to by the Government as 'unnecessary medicalisation'. However, there has been no research into whether or not improper use has been made of public facilities by these young people, or the extent to which it might occur, so the Council is unable to make any final judgment on that point. The Council also points out that with many disorders, patients will continue to need some support (to help them live independently) during certain periods throughout their lives. The Council does wish to draw attention to the aforementioned phenomenon of 'push-out': the growing tendency of regular facilities to refer clients to special facilities or arrangements. The Education Council will shortly produce an advisory report on this problem in the domain of education. The Council also observes that some aspects of the financial arrangements for care and support for young people with problems contain 'perverse' incentives that unintentionally promote ineffective care, which sometimes also lasts longer than is strictly necessary for the young person concerned.

Proposals for the short term and the longer term

The Council feels that the following improvements are needed in the short term in order to maximise the participation opportunities later in life for the young people who are the subject of this report:

- there should be more emphasis on prevention, early identification and early intervention;
- the system should be geared more to the individual needs of young people by making the support more demand-driven and introducing more customisation and cooperation;
- the position of professionals should be strengthened;
- and finally, greater attention should be devoted to young people's later participation and to preparing them for it during periods when they need care and/or are pursuing an education.

These proposals are explained in more detail below. With these proposals, the Council follows the line already taken by the Government with various policy proposals and formulates a number of conditions that it feels are essential for the success of the proposed policy as a whole. One of those conditions is the careful monitoring and measurement of the effects of the policy initiatives. It also feels that obligations should be attached to policy proposals by linking specific targets to them wherever possible.

The Council urgently calls on the Government to formulate a sound vision of how the cohesion between the many individual facilities and financial streams for young people with problems can be improved in the longer term. The building blocks for a more cohesive system are a better match between the care offered and the help needed, particularly for individuals with complex and multiple problems, a more demand-driven and customised approach, closer cooperation and more attention to preparing individuals for participation in society according to their ability. One subject that needs to be reviewed is the very complex and wide-ranging issue of the lack of cohesion in the institutional frameworks in first-line and second-line care, both within and between domains (care, education, justice, home, work and income). In that context, the Council calls for special attention to strengthening the cohesion within the four columns of youth care (youth mental health care, care for those with a slightly limited mental capacity, provincial youth care and the relationship with judicially-imposed care).

The separate institutional frameworks are a problem for both young people and professionals. This applies mainly to young people with multiple problems whose needs in terms of support are very diverse. The institutions are bound by heavily supply-driven statutory frameworks. Separate funding streams create a lot of bureaucracy and

the many subsidies for projects hamper the accumulation of knowledge and experience. It is difficult to manage costs and 'waterbed effects' (the shift of problems to another area) occur as a result of the various financial streams. There is also evidence of 'perverse incentives' that undermine the speed and effectiveness of care. In Section 4, the Council mentions a number of examples, such as supply and/or money-driven needs assessment, the provision of additional funds to eliminate waiting lists and financing based on staffing rather than on results.

The Council recommends, for example, that the Government should conduct a thorough analysis to assess how the match between the institutional frameworks and their separate financial streams can be improved with a view to shifting the focus far more to the young person and customising the support. The Council urges the Government to actively seek input from field workers in developing its vision for the longer term. Before then, the Council urges the Government to start implementing the four following suggestions for improvement as soon as possible.

More specific attention for prevention and early identification

Closer attention to prevention and early identification of problems and intervention is necessary, according to the Council, to significantly increase the prospects of social participation in the future for children with problems. It will reduce the risk of multiple problems and social exclusion and, hence, in time the use of public facilities such as more expensive care and/or income support. Early identification will lead to more referrals so the use of care will initially increase, but these additional investments in the early phase will yield savings in the longer term, as has been shown by various prevention programmes that are discussed in Section 4. It is impossible to say what the ultimate net balance of additional costs and savings will be.

The Council feels it is important to preserve the benefits of early identification and avoid the negative consequences of attaching a diagnostic label to young people. Besides the early identification of problems, it therefore calls for a campaign to change the image of young people with disorders. One way of preventing the labelling of these young people is through better public information about common disorders or behavioural problems (along the lines of the *Cultuuromslag Wajong* publicity campaign). The Council also recommends the use of other instruments, such as teaching programmes in schools and training courses for professionals.

As regards prevention, the Council expressly recommends investing more in strengthening the self-reliance and problem-solving capacity of families, particularly disadvantaged families. The Family Group Conferences (known in the Netherlands as *Eigen Kracht Conferenties*) are a good example of this. Studies that have been carried out into prevention programmes show that early interventions in high-risk families can be cost effective and, for example, reduce the number of early school leavers in these families. Programmes that have proved effective in helping parents to raise children, such as *Vroeg, Voortdurend en Integraal* or *Triple P*, should therefore be extensively followed up. The peer group approach, in which young people learn from and motivate each other, should also be used wherever possible.

The Council also supports the policy that has been introduced to promote cooperation in the chain of first-line care and help and more clearly define who should take control, and when. A clear answer is needed to the question of who is in charge and when. The Council therefore agrees that municipalities should have a coordinating role in prevention and in strengthening the cooperation between organisations engaged in the prevention of problems. It is also important for municipalities to coordinate effectively if cooperation on a larger regional scale is necessary. Special attention should also be given to the further implementation of the Centres for Youth and Families, particularly in terms of making access easier for those families that find it difficult to approach the institutions. In that context, greater use of an outreach approach would be appropriate. The Council also calls

for close monitoring of developments surrounding the Centres and accurate assessment of the effect they have, for example by introducing an evaluation of their results.

In the Council's opinion, positive steps are also being taken in regular education to improve the care in and around schools. Examples include the further strengthening and expansion of the Care Advice Teams, the 'plus facility' for young people who are unable to cope with the workload and social work in secondary vocational schools (MBO). Aspects that the Council feels demand attention are the further simplification of the transition between different types of school and between school and work and further implementation of policy to prepare young people for their later participation in the workforce. The SER's advisory report *Meedoen zonder beperkingen* contains numerous specific recommendations on these points that are also relevant for the young people who are the subject of this report (see +paragraph 4.3.3 for an overview of the recommendations).

Finally, the Council urges the Government to consider more stringent measures to prevent alcohol and drug abuse among young people and to discourage them from obtaining credit. Both excessive alcohol use and debts have the effect of reinforcing problems.

A better match with individual needs for support: customisation, demand-driven and cooperation

The Council stresses that in view of the diversity of the group of young people this report is concerned with, a one-size-fits-all approach to the provision of help and support for these young people is misplaced and ineffective. Any approach must start with the individual and his or her possibilities. The Health Council also stressed the importance of a tailored individual approach in its recent advisory report *Autismespectrumstoornissen* (2009).

The Council observes that because of the nature and complexity of their problems, young people with multiple problems might have dealings with a great many different agencies, such as referral agencies, needs-assessment institutions and implementing organisations, in various domains, including care, education, housing, justice, work and income. Inherent to this system is the risk of lengthy and repeated needs-assessment procedures and fragmented help that is not properly tailored to the young person's specific needs. Part of the reason for this lies in the separate institutional frameworks and financial arrangements.

As already mentioned, the Council advises the Government to thoroughly analyse how this system can be made more cohesive. In the short term, the Council recommends that procedures should be devised to make it easier for young people themselves to secure the required support that is tailored to their own specific demands or needs.

It recommends three improvements:

- *Better coordination of different needs assessments.* Better coordination between the agencies that assess a young person's needs is an important condition for determining the proper counselling and support for that person. The point of departure should therefore be the nature and extent of the support the young person needs. To achieve this, the Council recommends improving the match between the needs assessments for different facilities and making them easier and more accessible for the applicant, as well as accelerating the handling of the procedure.
- *A single coordinating professional.* Secondly, the Council recommends that there should be a single coordinating professional to assist, coach and counsel young people with multiple problems in organising the necessary tailored support. In principle, this role can be fulfilled by a professional in any domain, but he or she must be fully aware of the expertise and possibilities in other disciplines. Above all, it is important that the relationship between the young person in question and the professional is based on

trust. The young person concerned must therefore have a significant say in the choice of the professional or agency that performs the coordinating role. The coordinating professional must also have overriding authority, be available for a lengthy period and have sufficient resources and facilities (a smaller 'caseload', for example) to perform this labour-intensive task.

- *Better cooperation.* Major improvements could result from closer cooperation among professionals, not only in different domains but sometimes also within the same domain. Various ministries have already taken initiatives to improve cooperation. Examples of this are the establishment of Care Advice Teams to provide a more permanent structure for care in and around schools and the efforts to tackle the problem of early school leavers or to improve the transition from practical schools/special needs education to secondary vocational education. To underline the need for better cooperation and to make it more or less obligatory, the Council recommends investigating how cooperation can be enforced more effectively. One possibility is for the Government to make administrative arrangements at national level or conclude agreements with relevant organisations. A context should be created in which cooperation is rewarded. One suggestion from the field is the option of programme ownership. That would involve one of the relevant institutions assuming responsibility for a young person until he or she can function stably in society for an extended period of time (for example six months). Here too, it is very important that the agency that 'owns' the programme enjoys the trust of the young person.

Strengthening the position of professionals

It is essential to strengthen the position of professionals if the many policy proposals concerning this group of young people are to succeed. The Council feels that it is very important to increase the expertise in the timely identification of what is wrong with a young person. Professionals will have to look beyond the confines of their own discipline and communicate with colleagues in other disciplines. One aspect of this is to increase their knowledge of developmental disorders and multiple problems. Another issue to be addressed is how young people can be better prepared for their later participation in society. This can be achieved by providing additional training for professionals, but also by covering the subject in more depth in the basic training for care providers, teachers and other professionals.

Increasing the professionalism of professionals involved with the target group is another important point requiring attention. More needs to be done to retain them for the profession and to equip them properly for their demanding and varied jobs. There should be more possibilities for professional advancement in the discipline during the career, together with appropriate training possibilities, opportunities for further professional training, promotion and increased remuneration. There are signs that the labour market for professionals in youth care does not function particularly well, partly because of the high pressure of work, the lack of career prospects and the work climate. There is also a threat of labour shortages in education for similar reasons. Against this background, the Council recommends taking further steps to make working in this important social sector more attractive.

Professionals say that in providing integrated care for a young person they are confronted with rules that are too rigid and prevent them from going beyond their own areas of responsibility. Consequently, they are sometimes unable to offer young persons the help that they would like to provide and that young persons actually need. It is therefore important that the Government's plans to reduce the number of rules not only allow professionals to spend more time with the client but also give them greater scope to provide the specific help or support that the client needs. This aspect should also be considered during the recommended in-depth review of how the coherence of the institutional frameworks can be improved in the longer term. The professional must be able to practice his or her profession without restrictions.

Strengthening preparation for participation

On the basis of an analysis of a number of important policy developments in the various domains, the Council observes with approval that the Government's ambition is to promote and facilitate the participation of vulnerable groups. However, there are still many warnings from practitioners in the fields of education and care suggesting that these developments often still have to take effect. Particular attention is needed for improving the preparation for young people's participation, which involves developing their potential and talent with a view to their later participation.

Employers and employees have an important role to play in promoting the participation of young people with an impairment. The Council is pleased to observe that despite the economic crisis there are still employers who want to create jobs for young people with disabilities. Agreements have been concluded with groups of employers and the number of collective agreements containing arrangements relating to jobs for young people with disabilities is increasing. As far as the role of the social partners is concerned, the Council notes with approval that, in response to the SER advisory report *Meedoen zonder beperkingen* (August 2007), they published the *Recommendation of the Labour Foundation for the promotion of the participation of young persons with a handicap in Dutch industry* (April 2008). The accompanying explanatory memorandum contained, among other things, further guidelines to help employers and employees to implement the recommendation in practice at local level. The agreements can be implemented by providing regular jobs for these young people, but also by creating internships and temporary places so that the young people can gain work experience as a stepping stone towards regular work. The explanatory memorandum also contains a list of measures designed to make it as easy and as risk-free as possible for employers to hire these young people.

The Council feels that the social partners and the Government are on the right course with this approach, but is at this time unable to properly assess those aspects for which additional measures are needed to help achieve the targets for participation. The effects of the measures that have recently been taken or are going to be taken are cannot yet be measured in practice. The Council wishes to stress once again that also for young people who are the subject of this report, the focus in preparing them for participation should not be on their limitations but on their capacities and talents. Even young people with developmental disorders, mental handicaps or psychological, behavioural and multiple problems can participate in the labour market and/or in society. The SER advisory report *Meedoen zonder beperkingen* contains numerous specific suggestions and recommendations aimed at increasing participation that are also relevant for the young people who are the subject of this report (for a list of those suggestions and recommendations, see paragraph 4.6.2).

The jobs in which they will generally be able to perform best will sometimes have to be modified ('job carving') or created. This will repeatedly call for customisation, based on a careful evaluation of the individual's capabilities rather than his or her limitations. The placement of a young person from the target group will also call for specific tailored support for the individual on the work floor, often for an extended period or even permanently. This will place demands on the employer's social responsibility, a demand that many employers are in fact willing to meet. The Council stresses that it will also require effective support and facilitation by the employer and colleagues on the work floor. On this last point, it refers to a positive initiative of the Dutch Trade Union Federation (FNV), in which colleagues are trained as mentors to provide the necessary support on the work floor.

In the Council's view, many of the young people to whom this report relates are able and willing, with the right help and support, to function in the labour market or in another form of suitable work. What is also needed is good supervision, support on the work floor and a certain tolerance of their discordant behaviour. Although it often takes more time and/or effort to bring their talents to the fore, the Council feels that effort is very much worth

making: most of these young people are very keen to work and – with the right support and in the right job – are capable of growing into loyal and productive employees.

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