A national action plan to improve care of severe mental illness

Summary

Crossing the bridge

Kennis delen over herstel, behandeling en participatie bij ernstige psychische aandoeningen

Phrenos kenniscentrum

September 2014
Colophon

Project group
Philippe Delespaul, Mark van der Gaag, Irene van der Giessen, Ronald van Gool, Frank van Hoof, Tom van Mierlo, Jeanne Nitsche, René Keet, Ico Kloppenburg, Ralph Kupka, Rob Laane, Anouk Mateijsen, Louise Olij, Elsbeth de Ruijter, Floor Scheepers, Richard Starmans, Bert Stavenuiter, Martine Veneman, Jaap van Weeghel (chairman), Chrisje Couwenbergh (secretary)

Text
Chrisje Couwenbergh
Jaap van Weeghel
With grateful acknowledgement for the contribution of the project group members

Translation
Vu Vertaalcentrum
Utrecht: Kenniscentrum Phrenos, september 2014.

Cover design
Streeff.nl (Gerald Vruggink)

© Crossing the bridge, Kenniscentrum Phrenos, 2014. This action plan is written under the auspices of Kenniscentrum Phrenos.
www.kenniscentrumphrenos.nl 030-2931626
Crossing the bridge. A national action plan to improve care of severe mental illness

Summary

Transition to care in the community
For several decades a transition has been underway which places the care of psychiatric patients in the community rather than in institutions, and which spreads the responsibility for providing treatment, guidance and support for these patients across several sectors and organizations. So far, the Netherlands has not been a front-runner in this transition; now, however, things are being accelerated under the banner of ambulant care. The shift has been largely instigated by changes in policy objectives, regulations and funding, which are edging more and more towards primary care and participation. These are fundamental changes, not least for people with serious mental health issues, and they must not be combined with swingeing spending cuts on essential specialist treatment and care. On the other hand, they may offer opportunities for the various players involved to correct shortcomings in the current system.

Who are the patients with serious mental health issues?
People with serious mental health issues suffer from severe psychopathology and chronic limitations. They have multiple care needs and their treatment, guidance and support in the different domains of life requires careful coordination. Most of the people in this group suffer from psychotic disorders, but the category of serious mental health issues also covers anxiety, personality and mood disorders, and addiction. 1.3% of the total population (216,000) or 1.6% of the population between the age of 18 and 65 (160,000) has been diagnosed with serious mental health issues (including addiction and forensic mental care). Approximately 75% is cared for by the GGz (Dutch Association of Mental Health and Addiction Care) or other providers.

What do they need in terms of support?
The target group consists of people who, because they suffer from serious mental health issues, must be able to easily access good, low-threshold medico-psychiatric and psychological services.¹ Their needs, however, seldom slot in neatly with the remit of the GGz. Frequently they concern universal themes, such as personal acceptance, social relationships, and participation in society. They want the same things out of life as everyone else but are in a disadvantaged position and hence are less able to attain them. For instance, they have a lot of ground to make up in terms of physical health, treatment, security, income, work, and relationships. Half of the members of this group say that they would like more support to participate in society.

What constitutes good care for this group?
Good care should be geared to three dimensions of recovery: besides clinical recovery (which requires good medico-psychiatric and psychological services and learning self-management) it should address social recovery (which requires rehabilitation and prevention and combatting of stigmatization) and personal recovery (which comes primarily from the patient himself; self-help groups and patient-recovery groups are

¹ This includes psychiatric nursing.
crucially important, but supportive treatment and rehabilitation interventions can also make a difference. These three dimensions constantly influence one another in individual recovery processes.

Accordingly, the treatment, guidance and support programmes for people with serious mental health issues must be geared to individual needs and the realization of personal goals. The unfulfilled needs frequently lie in the sphere of physical and mental health, social relationships, participation (including work), and personal recovery. Good treatment, guidance and support will aid recovery, promote empowerment and participation, and combat stigmatization. Security is vitally important, but so is responsible risk-taking, which is achievable by investing in a trusted and motivating working relationship with the patient. Family members and close acquaintances should contribute as partners to the treatment, guidance and support; where necessary they too should be supported in their role. The treatment and guidance programme must meet the individual's needs, reflect the phases and dimensions of recovery, and consist as much as possible of evidence-based, effective interventions. It must be cohesive and based on continuity, promote physical health, and make good use of new technologies. In short, the treatment, guidance and support efforts must help people with serious mental health issues to optimize their potential for recovery and citizenship.

**Trends in visions of good care**

We have identified six long-term trends in visions of good care for people with serious mental health issues. Symptom stabilization is no longer the sole or primary aim: personal and social recovery are equally important. Second, professional input should be accompanied by activities that flow from the personal strength, commitment and energy of the individual concerned. Third, good treatment, guidance and support should target not only the patient but also his/her immediate circle. Fourth, inter-sectoral cooperation must be in place. Fifth, more and more interventions are combining treatment with rehabilitation. Finally, psychiatric and somatic care need to be better integrated to restore the physical health of these patients. These six trends have concrete implications in the search for the best way to organize treatment, guidance and support.

**Good care in a new landscape and another playing field**

The treatment, guidance and support for people with serious mental health issues in the new, emerging care landscape which is still being developed will transcend legal and budgetary structures. More ambulant care and the winding down of intramural capacity will increase the need for support in the community, closer to home. The key players will have to find new ways of interacting at district level. However, it would not be wise to decentralize the care for this group and place the responsibility for organizing it solely with the municipal authorities. Specialized medical diagnostics and treatment for psychiatric disorders in the narrower sense are indispensable and must be available across the entire spectrum of care.

**How can good care be organized?**

Care must be organized in a way that facilitates and promotes recovery and participation, the core concepts in treatment, guidance and support programmes for people with serious mental health issues. Accordingly, a broad, socially integrated infrastructure needs to be in place, comprising a network of people and services in which different sectors (GGz, municipal authority, patient and family organizations, insurers, welfare, etc.) work together. Members of the target group and their immediate circle will occupy an important position in this network, in the dual role of consumer and producer of care.
and support services. They will promote their interests and support personal recovery from regional ‘recovery colleges’ (still to be set up).

**Basic principles for the organization of recovery-oriented care**

- Treatment, guidance and support are offered as much as possible within the community.
- All treatment, guidance and support facilities can be easily reached (flexibly upscaled and downscaled) and accessed by clients (and their immediate circle), regardless of the costing regime.
- Close cooperation among network partners (including, and on an equal level with, people suffering from serious mental health issues and their immediate circle) is essential.
- In the support network people must work towards recovery and apply evidence-based techniques; any tensions between the two must be addressed in the working processes of the care providers.

**The ambition: fewer care needs, more recovery**

The ambition is to help people with serious mental health issues to catch up with the rest of society. To achieve this, we need a proactive agenda that will substantially increase recovery in the various domains of life and thus reduce the need for care to an equal measure. This ambition includes leading people with serious mental health issues who are not yet receiving care, or who have dropped out of care, towards the treatment, guidance and support that they need. The different strands of this ambition can be translated into clear, trans-sectoral outcome indicators and norms, first at national level, and then translated to regional level and individual clients. Using the recently developed vignette model (see page 55) the target group can be defined on the basis of the different types of treatment and guidance the members are receiving.

**Steering towards recovery**

Phase-oriented, individualized care can be encouraged by determining the care needs with the patient and his or her nearest and dearest. This is an arduous process at present, especially in F-ACT (Assertive Community Treatment) and other forms of ambulant care, because the treatment, guidance and support for each patient is often financed from different government budgets (under the Health Insurance Act, the Act on Exceptional Medical Expenses/Long-Term Care Act, the Social Support Act, and the Ministry of Justice (for patients with a forensic background)) and reintegration funds provided by the Employee Insurance Agency (UWV) and the municipal authorities. Each of these sources is run by a different body which sets its own registration and accounting requirements. These diverse sources of funding constitute a huge obstacle for the realization of comprehensive care geared to individual recovery processes.

The challenge is to remove this obstacle, but without jeopardizing the right to specialist treatment and access to the necessary funding. The solutions must also chime with what has already been developed or is considered desirable in terms of costing models in the broader healthcare sector, particularly in long-term and multidisciplinary care. It is perfectly within the realm of possibility that an efficient costing model for serious mental health issues will set an example for other branches of long-term, multidisciplinary healthcare.

There are various costing models available, which can be examined for suitability. Models for overall costing might be a step in the right direction; for example, a form of capitation, in which payment is based not so much on the ‘volume’ of care, but rather on
its value and results. In plain terms: moving from ‘input funding’ to ‘outcome funding’. This kind of funding should not, of course, be combined with cost savings, especially in medico-psychiatric and psychological services. Both these aspects of care will continue to be needed and must remain easily accessible, all the more so in view of the under-treatment that has been highlighted in this group.

That said, comprehensive funding for all concerned would be more interesting if a percentage of the shared savings were used to improve treatment, guidance and support, and to boost research and innovation. Technically it will not be easy to merge budgets and change to capitation funding, and existing interests may also get in the way. But it is a development perspective that can inspire and motivate the network players in a region to join forces and work for value creation.

**Regional networks**
Starting with a nationally set standard of good care, it would be best to organize the networks for the treatment, guidance and support of people with serious mental health issues at regional level. Obviously, this should fit in with the working agreements on the reforms in Long-Term Care (under the Long-Term Care Act), for which a consultation structure is being set up with the main providers, client organizations, and funding sources in each of the 43 designated regions in the Social Support Act.

**Administration**
Administrative cooperation and coordination in the network is vital in this scenario. At regional level the cooperation must be accompanied by a determination to realize the recovery ambitions, to create the right preconditions for recovery colleges, and to steer towards outcomes, which should also be monitored and rewarded. Internal competition is not conducive to the ambitions for recovery-oriented treatment, guidance and support, and must therefore be avoided.

**Implementation**
At implementation level, a blueprint for the future regional landscape for people with serious mental health issues is neither feasible nor desirable. The parties concerned will have to build on the existing situation. The Trimbos Institute is working on a regional framework for the transition to ambulatory care and de-institutionalization. This framework is designed to help regional players to reach agreement on the future effort and capacity that will be needed for the group with serious mental health issues.

**Fitting in with relevant policy agreements**
Trends in legislation and policy are inclining strongly towards treatment, guidance and support in the community. There are very few provisions to guarantee, stimulate or improve other approaches to recovery-oriented care. Given the complexity of recovery-oriented care, and as the investment costs and benefits are often trans-sectoral, it is unlikely that improvements will happen spontaneously. The players must formulate quality standards at national level and create the right preconditions for the cross-domain integrated approach envisaged in regional networks. This can be realized within the current framework; no system changes will be required, and it will be possible to build on the working agreements for the reforms in Long-Term Care. This should anchor the role of people with serious mental health issues and their immediate circle.

**Recommendations**
**For good care**

1. **Flesh out the definition of serious mental health issues on the basis of the dimensions of the recovery concept**
   A dimensional approach to the recovery concept will enable further subdivision of the phases in which people with serious mental health issues find themselves. After all, what sets this group apart is the existence of problems and perceived shortcomings in all three dimensions (clinical, social and personal recovery) and the close interaction between them. This will make it easier to map out the needs in the different phases. This approach must be worked out in more detail.

2. **Use the above subdivision as the starting point for determining treatment, guidance and support plans; involve the partners from different social sectors**
   Using a phase-based and dimensional approach to recovery, the task is then to create a treatment and support plan that is complete, client-focused, transparent and coherent. The needs vary so widely that they cannot be met by GGz alone, so input must be sought from other social partners.

3. **Formulate a shared vision of good care**
   The players involved should formulate a shared vision and a shared ambition for ‘good care for people with serious mental health issues’, based on the core message of this plan of action: good treatment, guidance and support is a collective effort that must help and encourage people with serious mental health issues to utilize or better utilize their potential for recovery and citizenship. The shared vision will give national and regional direction to the forthcoming changes in policy and organization, and the funding efforts for this group of patients.

4. **Set a national care standard for serious mental health issues**
   Policy at national level will continue to be necessary to guarantee good care for these clients. We therefore advise that the shared vision be translated into a national care standard (i.e., a standard for all forms of treatment, guidance, support and self-management needed by this group). The care standard should not only describe the way prevention and care is organized but also set quality indicators. It must be built on the specific guidelines for the different types of serious mental health issues and be compatible with the forthcoming disorder-specific care standards. Above all, the treatment, guidance and support must be geared to the needs of the individual. It must also take account of the different dimensions of recovery and the phase in which the individual finds him/herself at any given moment, and consist as much as possible of guideline-compliant interventions. If this national care standard is endorsed by all concerned (people with serious mental health issues, close friends and family, GGz, healthcare insurers, the government, municipal authorities), it will offer a shared, concrete framework for planning the professional functions and facilities in each region.

**For the new care landscape and playing field**

1. **Develop an integrated, district-based approach to serious mental health issues, with good coordination and cooperation between the client, family and friends,**
neighbourhoods, generalist district teams, GPs, specialized support and guidance, and specialist GGz treatment
In principle, the input from the above three sources (generalist district teams, specialist facilities, and specialist treatment, guidance and support from F-ACT teams) will be complementary. Complementarity is also crucial to the realization of the shared goal of promoting recovery and participation.

2. Ensure that state-of-the-art treatment, guidance and support for serious mental health issues can be accessed by all the people in the target group, regardless of their position in the care landscape
Access to state-of-the-art treatment should not depend on the place where an individual is first referred to or where he/she is staying at any moment in time. Treatment, guidance and support needs should be mapped out fully (all domains) and regularly (at least once a year). People should have access to good care on the basis of these needs regardless of their position. The professionals responsible must be up to speed with the available services and how to access to them.

For the organization of treatment, guidance and support

1. Help to set up recovery colleges for members of the target group and their family and friends, and give them a central role in the regional support network
The position of people with serious mental health issues and their family and friends can be strengthened in regional recovery colleges that focus on self-help services, the development of treatment innovations, support with participation, and the promotion of interests at government level. This recommendation can be further developed and implemented under the auspices of the GGz National Platform.

2. Set an ambition nationally and locally for ‘improving recovery by one third’
The ambition is to improve the recovery of identity, health and participation by one third and thus enable people with serious mental health issues to catch up with the rest of society.

3. Develop national outcome indicators and outcome instruments for recovery
If a one-third improvement is to be realized, then attainment of the desired outcomes must be rewarded. Measuring tools are needed in this respect. Further development of the desired outcomes on the basis of Anthony’s Service Outcome Schema (1993) would be a start. The available outcomes should also be included.

4. Define the current consumption of treatment and support by people with serious mental health issues with the vignette model
The vignette model (based on the entire population prevalence) offers all concerned (care providers, healthcare insurers, municipal authorities, and clients and families) a shared baseline, a ‘snapshot’ of the status quo, which can serve as a starting point for further partnership agreements and partial or full capitation, especially in view of the under-treatment highlighted for this group (Van Weeghel et al., 2011).

5. Reach agreement on the costing and shared savings of the collective efforts
Overall costing models such as capitation may be more appropriate than volume-based costing for attaining the desired outcomes, especially if a substantial part of the shared
savings can be used to improve treatment, guidance and support, and to encourage research and innovation. This should be done within the existing parameters and the current costing regimes; in other words, the medico-psychiatric and psychological services will remain within the Health Insurance Act. Experiments in alternative costing methods could be conducted for long-term disorders, both mental and physical. This goal cannot be realized at once, but it offers a perspective for development that can inspire and encourage the regional players to pursue value creation in collaboration.

6. Organize treatment, guidance and support in regional networks
It is best to organize networks for serious mental health issues regionally, but on the basis of a national care standard and quality framework, and in line with the infrastructure of the 43 designated regions in the Social Support Act.

7. Reach administrative agreements to facilitate collaboration
A shared, trans-domain vision of recovery, and an administrative framework agreed by the municipal authorities, care providers, healthcare insurers and patient organizations for the delivery of good treatment, guidance and support are crucial to the attainment of the shared ambition. Draw up a policy plan and a quality agenda in the regional network.

8. Use the regional framework for the transition to ambulatory care and de-institutionalization that is currently being developed by the Trimbos Institute to organize and map out the future regional landscape for the treatment, guidance and support programmes for people with serious mental health issues.
This framework provides the regional players with guidelines for reaching agreement on the future effort and capacity that will be needed for people with serious mental health issues.

Crossing the bridge: spearheads for a nationwide plan of action

1. Nationwide project for the development of regional recovery colleges
The position of people with serious mental health issues and their families and friends can be strengthened in regional recovery colleges that provide self-help services, work on care innovations, offer support with participation, and promote interests at government level. People with serious mental health issues play a central role in this project. This recommendation can be worked out in detail and implemented under the auspices of the GGz National Platform.

2. National working agreements
The legal frameworks and costing systems need to be further harmonized to establish the preconditions for realizing good treatment, guidance and support for the target group. One option is to enter into national working agreements with the different social partners and players in the field (municipal authorities, healthcare insurers, care providers, patient and family organizations), possibly by building on or joining working agreements recently made with players in the field for long-term intramural mental healthcare (see letter by State Secretary Van Rijn, 24 March 2014), which address, amongst others, a quality agenda, a cockpit function, monitoring, and the organization and facilitation of regional networks. The regional framework for the transition to ambulatory care and de-institutionalization that is being developed by the Trimbos Institute and the vignette model are also being used to facilitate the regional networks.
3. An innovation programme for serious mental health issues

A national innovation programme linked to the above working agreements can give a serious boost to the quality of the treatment, guidance and support. This innovation programme in the form of, for example, an academic workplace, would place the rehabilitation of people with serious mental health issues high on the national agenda and add momentum to the development, evaluation and implementation of innovative interventions and working methods for this group. Make optimal use of ICT with an eye to nationwide roll-out.

For information on national innovation in participation and labour, the reader is referred to the inter-sectoral and inter-departmental project on promoting participation among people with mental health issues (Bevordering participatie van mensen met psychische problemen) led by the Ministry of Social Affairs and Employment.

Recommendations for an innovation programme on serious mental health issues:

- Formulate a shared vision of good treatment, guidance and support for people with these disorders. The essence is that good treatment, guidance and support help people in this group to utilize – or better utilize – their potential for recovery and citizenship.
- Develop the definition of serious mental health issues further on the basis of the three dimensions of the recovery concept.
- Set a national care standard for serious mental health issues. Policy at national level will continue to be necessary to guarantee good care for this group. We therefore advise that the shared vision be translated into a national care standard (i.e., a standard for all forms of treatment, guidance, support, and self-management needed by this group). The care standard not only describes the way prevention and care are organized but also the quality indicators. It must be firmly based on the disorder-specific treatment guidelines and care standards for the various disorders within the group of serious mental health issues. Above all, the treatment, guidance and support must be geared to the person. It must take account of the different dimensions of recovery and the phase in which the client finds him/herself, and consist as much as possible of guideline-compliant interventions. If this national care standard is endorsed by all players (people with serious mental health issues, close friends and family, Ggz, municipal authorities, healthcare insurers, national government), it will offer a shared, concrete framework for planning the professional functions and facilities in each region.
- Develop national outcome indicators and outcome instruments for all dimensions of recovery.
- Develop a tool for testing the quality of the treatment and support services for people with serious mental health issues, which is similar to the KRAS system for testing the quality of regional services for schizophrenia sufferers.

The main challenge facing the national innovation programme is to help realize the ambition of a one-third improvement in recovery (of health, participation and personal identity) and to help people with serious mental health issues catch up with the rest of society. This ambition calls for a long-term, inter-sectoral plan that must derive shape and substance from the innovation programme and the existing monitors in this field. A baseline measurement of the three dimensions of recovery is needed soon.