

RETURN-TO-WORK COACHING SERVICES FOR PEOPLE WITH A CHRONIC DISEASE BY CERTIFIED ‘EXPERTS BY EXPERIENCE’: THE NETHERLANDS

1. Organisations involved

- Centre Chronic Illness and Work (CCZW)

Patient organisations

- National Association for Fibromyalgia Patients (FES)
- Repetitive Strain Injury Association (RSI vereniging)
- Poly-Osteoarthritis Peer Support Association (Pal)
- Multiple Sclerosis Association of the Netherlands
- National Association Sjögren Patients
- Rheumatism Foundation
- Turner Syndrome the Netherlands

External partners

- HAN University of Applied Sciences
- Top Kairos, a national training academy, accredited by Hobéon
- Ministry of Health, Welfare and Sports
- Netherlands Organisation for Applied Scientific Research (TNO)

2. Description of the case

2.1. Introduction

2.1.1. Reintegration agencies

In the Netherlands, reintegration agencies exist to support people to return to work and find a job that is suited to their altered situation and abilities. Counselling coaches offer guidance, (re)training courses or training in interview effectiveness. There are currently over 2,000 reintegration agencies in the Netherlands. The 175 largest reintegration companies in the country work together with approximately 40,000 counselling coaches.

An individual may be referred to a reintegration agency in a number of ways:

- (1) *By the employer:* According to the Gatekeeper Improvement Act (*Wet Verbetering Poortwachter*)¹, where a worker is still employed but on sick leave for more than 1 year, and it is unclear if he/she can return to his/her former position, an employer may contact a reintegration agency for help. Alternatively, where an employer wishes to invest in the prevention of, for example, chronic diseases, he/she may also contact a reintegration agency for support. In these cases the costs of the services offered are paid for by the employer.
- (2) *By the Employee Insurance Agency (UWV – obligatory for all employees):* People who are unemployed and/or at home because of an illness or occupational accident, and are receiving an allowance (disability benefit), qualify to receive support and guidance from reintegration agencies to find suitable work. In this case, it is the Employee Insurance Agency that makes the decision to involve the reintegration agency and covers the costs of the services offered.

¹ Information about the Gatekeeper Improvement Act retrieved 04/11/2015 from: <http://www.arboportaal.nl/onderwerpen/wet-verbetering-poortwachter>

- (3) *By the municipality:* According to the Participation Act (*Participatiewet*)², the Dutch municipalities offer social assistance and social security benefits to people in need, and support them in finding suitable work. Reintegration agencies can be called upon to support such processes. The municipality, in this case, covers the costs of the guidance and counselling offered. However, because of recent budget cuts, this seldom happens in practice.
- (4) *By individuals themselves:* People may can contact a reintegration agency on their own initiative, paying the cost themselves.

2.1.2. Centre Chronic Illness and Work

The Centre Chronic Illness and Work (CCZW) is a knowledge centre that focuses on living and working with a chronic disease or disorder. Until recently it worked closely with reintegration agencies to support those with a chronic disease to return to work. Budget cuts and a downsizing of the market mean that the centre stopped working with the reintegration agencies a few years ago. The centre now focuses solely on medical, professional and coping aspects of each individual. The reintegration agencies tended to limit their focus to work and professional aspects of reintegration.

The CCZW was founded by, and is entirely run by, people suffering from a chronic illness. It provides advice and expertise, organises workshops and seminars, and carries out various projects to ensure that those with a chronic illness are able to participate in society and in the job market. The CCZW has existed for about 10 years and became an independent organisation in 2012.

At the moment, the main activity of the centre is the project 'Certification of Experts by Experience: Work and Participation' (*Certificering ervaringsdeskundigen Werk en Participatie*), whereby individuals with particular illnesses are trained to coach others with chronic conditions. For this project, the centre partners with seven national patient organisations, whose aims are to raise awareness, finance scientific research, provide information, organise activities and advocate for better living and working conditions of the patients they represent. These seven organisations focus on the following chronic diseases and conditions: fibromyalgia, repetitive strain injury (RSI), poly-osteoarthritis, multiple sclerosis, Sjögren syndrome, rheumatism and Turner syndrome. Using 3-year grant funding received by these patient organisations from the Dutch Ministry of Health, Welfare and Sports, the CCZW trains and delivers two experts by experience per year per patient organisation, leading to 42 trained coaches by the end of 2015.

2.2. Aims

The project aims to provide targeted and personalised reintegration and return-to-work services for people with a chronic disease. Professional and certified coaches – who are experts by experience in the sense that they are suffering from a chronic disease themselves – are trained to support patients to find the best ways to cope with their illness and symptoms and to enhance their participation in society and in the job market.

2.3. What was done, and how?

2.3.1. Who are experts by experience?

'Certification of Experts by Experience: Work and Participation' is a certification programme built around the philosophy that certain coaching and training skills are generated not only by knowledge but also by personal experiences. People with a chronic illness are therefore trained to make use of their own personal experiences with disease in order to help others who are going through similar processes. The coaching is not illness-specific; the processes and difficulties that people experience are similar among different chronic diseases, and coaches can provide useful support to a broader array of patients.

² Information about the Participation Act retrieved 04/11/2015 from: <https://www.rijksoverheid.nl/onderwerpen/participatiewet>

It is not possible for everybody to become an expert by experience. The centre works solely with professionals who already have a degree in patient counselling or in coaching. This, combined with the fact that these people are suffering from a chronic disease themselves, allows the centre to offer high-quality and personalised return-to-work and reintegration coaching services. Moreover, all coaches receive a certificate at the end of their training, which is accredited by Top Kairos, a Dutch training institute. This safeguards the professional quality of the services offered.

2.3.2. The content of the training programme

To become an expert by experience, qualified applicants must complete a professional training programme within 6–9 months. In addition to an introductory day at the centre and an assessment of the programme at the end of the training period, each participant must complete different modules and tasks at his/her own convenience. A mentor is available to provide support whenever necessary. Topics addressed in the programme include self-reflection, self-management, empathy, cooperation and empirical knowledge. The programme takes approximately 60–80 hours to complete, and is offered free of charge, with participants incurring only travel costs to attend the introductory day and take the end assessment. At the end of the training programme, the coaches receive a certificate, which allows them to have their 'soft skills' recognised professionally.

Starting last year, the centre has also collaborated with the Hogeschool van Arnhem en Nijmegen (HAN) University of Applied Sciences, which offers independent scientific and expert advice. This university has developed a self-management module for chronically ill people, which has now been integrated into the training programme. This partnership allows trainee coaches to provide feedback and comments on their experience of the training.

2.3.3. Implementation of the 'experts by experience' project

Since its start in 2013, 10 experts by experience have so far successfully completed the professional training programme, with an additional 14 people starting the training in 2014. People who are interested in becoming an expert by experience can register online, after which a strict selection procedure commences. Candidates should have a background or degree in coaching and patient counselling, have a chronic disease themselves, and be open to applying and making use of their own personal experiences related to their disease to further improve their coaching skills and helping others who also suffer from a chronic disease.

Throughout the project the seven patient organisations have the opportunity to become involved. Depending on their time and availability, they can, for example, take part in the selection interviews or sit in during the assessment at the end of the training programme. Additionally, the centre is in continuous contact with the individual patient organisations throughout the duration of the project. Meetings are organised between the centre and the patient organisations, including joint meetings with all seven organisations to discuss their experiences and how they believe the programme should be further developed.

2.3.4. How the services of the experts by experience are being used

Following completion of their training, the CCZW and the patient organisations promote the services of the experts by experience. The work schedule of any expert by experience depends on personal situations, circumstances and the overall demand for coaching services, and no guarantee is given of a full-time job as a coach. Most of the demands for their services come from employers or individuals with a chronic disease who believe that they would benefit from, for example, interview training. The coaches are not employed by the centre but will receive reimbursement from the employer, the UWV, a municipality or an individual (depending on the body or person submitting the request). However, in all cases, the centre stays in close contact with coaches who have successfully completed the training programme.

The professional background and degree of the coach (for example psychology or physiotherapy) are considered when he/she is matched to a patient, to ensure that the coach is able to offer the right kind of support and expertise that the patient requires. For example, if a patient is suffering from a physical problem, a coach with a background in physiotherapy would be favoured. The content of the

counselling also depends very much on the personal situation of the patient, as well as the initial motivation to start the process. For example, if the request came from an employer, the objective of the counselling services is often to find the patient a new or adapted job, whereas, if the request came from a patient him/herself, the requirement may be more strongly related to dealing with the symptoms and consequences of the disease.

2.4. What was achieved?

Ten people have thus far successfully completed the 'experts by experience' training, with an additional 14 currently participating in the programme. As the coaches are themselves suffering from a chronic disease, they are not always capable of completing the programme. It is considered to be quite intensive, and the health condition of the people signing up may not always allow them to complete all the modules and tasks within the allotted time. In the light of this, an evaluation of the current 'experts by experience' project is planned.

Before this project, the centre had worked closely with reintegration agencies to offer coaching services. Through this former initiative (structured similarly to the 'experts by experience' project), 14 coaches were trained.

In 2011, TNO evaluated the collaboration between the centre and the reintegration services. This evaluation assessed whether or not the services offered by the coaches had been effective. In total, 190 people received coaching and counselling support, of whom 132 finished the full trajectory. Of these 132 people, 28 % (37 people) found a job or became self-employed and 10 % (13 people) found voluntary work or started a traineeship to develop new skills. Unfortunately, 25 % (33 people) were unable to negotiate a reintegration contract with an employer; these most likely overlapped with the 35 people (27 %) whose health condition deteriorated.

In 2013, the centre received the 'Model of Good Practice' certificate from the European Network for Workplace Health Promotion (ENWHP) for promoting healthy work for people with a chronic illness. This certificate was awarded to the centre for its innovative and unique approach to supporting chronic patients by offering them coaching services by people who themselves have a chronic disease.

Experiences of coaches (PGOsupport, 2014)

'After a career of 25 years I was no longer able to carry out my job because of my chronic illness, rheumatism. My former employer proposed that I become a coach to support others suffering from a chronic illness. My experiences with the illness and the constraints it was posing on my daily life allowed me to really add something useful to the rehabilitation process of others.'

'In order to become a coach you have to follow an intense, 7-month long training programme, during which you have to prove that you are able to support others in similar situations and to encourage them to participate in society again. Additionally, you learn how to further increase your own strength and capabilities and how to use these for others.'

Experience of beneficiary (PGOsupport, 2014)

A woman with Bechterew's disease (ankylosing spondylitis), which is a chronic inflammatory disease of the axial skeleton, had been unemployed since 1982. However, thanks to the coaching programme, she found herself a job in 2006 and is now working as a saleswoman in a shoe shop. 'Thanks to the support and guidance I received through the programme, I found the courage and power again to take on a paid job. My self-confidence is back and the programme was able to get me out of my vicious circle.'

2.5. Success factors and challenges

The following success factors were identified:

- *Support from people with similar experiences:* The concept of providing support to people with a chronic illness by people who themselves are suffering from a chronic condition has been received very positively. The coaches are able to empathise and provide personal, targeted advice and support.
- *Accreditation:* The fact that the training programme is accredited by an official institute offers the coaches professional recognition and provides added value to the programme's professionalism.
- *Cooperation with the university:* The scientific input and independent advice from HAN University has further added to the training programme's professionalism and high quality.
- *Cooperation with the patient organisations:* Close cooperation and active involvement of the patient organisations often result in a widespread promotion of the services offered by the coaches, as these organisations fully understand and recognise the importance of the role that these experts by experience play for chronic patients.

The following challenges were identified:

- *Funding:* Because it is financially dependent on the 3-year grant from the Ministry of Health, Welfare and Sports, the continuity of the training programme is not guaranteed.
- *Opportunities to provide coaching services:* The number and frequency of the opportunities for coaches to provide counselling services and support to chronic patients depend almost entirely on the number of requests received.

2.6. Transferability

The approach described here is transferable to support services in other areas or related to different diseases. The concept of working with and training people who are experiencing, or have experienced, the same issues has universal appeal.

Transfer of this approach to other Member States is also possible, particularly where similar reintegration agencies or support services already exist as a platform for the programme.

2.7. Further information

Centre Chronic Illness and Work (*Centrum Chronisch Ziek en Werk*, CCZW)
Postbus 711
5600 AS Eindhoven
The Netherlands

Contact person: Robbert Janssen, Director CCZW

3. References and resources

- Website of the Centre Chronic Illness and Work (CCZW), soon also available in English: <http://www.centrumchronischziekenwerk.nl/>
- European Network for Workplace Health Promotion (ENWHP) (n.d.), *Good practice the Netherlands – Qualified patient-coaches to coach patients in return-to-work*. Retrieved 04/11/2015, from: http://www.enwhp.org/fileadmin/user_upload/pdf/PH_Work_CZ_W_Netherlands.pdf
- PGOsupport (2014), 'Ervaringsdeskundige coaches werken', 14 May. Retrieved 04/11/2015, from: <http://www.pgosupport.nl/page/Nieuws/Ervaringsdeskundige-coaches-werken?mod%255B198%255D%255Bn%255D=670&mod%5B198%5D%5Bpage%5D=1&mod%5B198%5D%5Bn%5D=670>
- Interviews with Robbert Janssen, Director CCZW, on 23 September 2014 and 8 October 2014.