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Developing an interactive website for adolescents with a mentally ill family member

**Louisa M. Drost,[1] Pim Cuijpers,[2] and
Gerard M. Schippers[3]**

Abstract

Adolescents with a mentally ill parent are at high risk for developing a disorder themselves. It is widely recommended that these adolescents be provided with preventive interventions designed especially for them, but their avoidance of professional help is a common problem. Because most teenagers in Western societies use the World Wide Web as a means of social interaction, use of the Internet for reaching these young people would appear to be a promising option. In this article, the authors describe the development of Survivalkid.nl, an interactive, Internet-delivered, preventive intervention for supporting adolescents with a mentally ill family member. Usage statistics with regard to frequency and duration of visits and amount of activity during visits suggest that: (a) the target group has been better served than before the site was launched; and (b) we have accomplished our goal of expanding the range of support.

From epidemiological studies, we know that children of parents with a mental illness (COPMI) are at high risk for developing a serious disorder themselves (Beardslee, Versage, & Gladstone, 1998; Bijl, Cuijpers, & Smit, 2002; Lieb, Isensee, Höfler, Pfister, & Wittchen, 2002; Ross & Compagnon, 2001). Other research suggests that these children's needs are often overlooked (Gray & Robinson, 2009; Mordoch & Hall, 2002)

During the past 15 years, prevention programmes have been developed in many Western countries (Beardslee, Gladstone, Wright, & Cooper, 2003; Beardslee et al., 2002; Goepfert, Webster, & Seeman, 2004; Hetherington & Baistow, 2001). These programmes aim to provide parenting skills for people with a mental illness and to promote resilience in their offspring. The desired outcomes for the children are healthy development (passing developmental milestones), adequate performance in school, and emotional and behavioural adjustment (Hinden, Biebel, Nicholson, Henry, &

[1] Indigo/GGZ Drenthe, Community Mental Health Centre; University of Groningen, the Netherlands
[2] Free University, Amsterdam, the Netherlands
[3] Academic Medical Centre, University of Amsterdam, the Netherlands

Corresponding author:
Louisa Drost, Indigo/GGZ Drenthe, PO Box 10029, NI 9400 CA Assen, the Netherlands.
Email: louisa.drost@ggzdrenthe.nl

Katz-Levy, 2006). Consistent with this approach, many community mental health centres in the Netherlands have adopted interventions for families in which the parents have various mental disorders. For adolescents, groups have been formed for discussing problems at home and learning how to cope with them. A major hindrance to these programmes, however, is that teenagers and young adults are difficult to contact. Despite intensive public relations efforts, very few of the targeted participants actually attend the sessions (van der Veen & Voordouw, 2008).

Overcoming the barriers to service delivery

The problem of not being able to reach teenagers has been described earlier (Rickwood, Deane, Wilson, & Ciarrochi, 2005; Zwaanswijk, Verhaak, Bensing, Ende, & Verhulst, 2003). Many of them feel ashamed of their situation or have low expectations that healthcare providers will respect their confidentiality (Jacobson, Richardson, Parry-Langdon, & Donovan, 2001). Shaw (2001) explained how developmental issues, such as the adolescent's increasing desire for autonomy, seem incompatible with receiving support from adult professionals. Teagle (2002), moreover, found that parents were reluctant to encourage their teenage offspring to seek help. This might be an even greater problem when parents themselves are under psychiatric care (Ramchandani & Stein, 2003). The dominance of adult needs, parental denial, feelings of shame, and anxiety about losing custody may all hinder recognition of the children's needs (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004). Moreover, concern about the stigma associated with psychiatric disorders can discourage adolescents from seeking help (Goepfert, Webster, & Seeman, 1996; Riebschleger, 2004). Studying the depiction of psychiatric patients on television, Diefenbach and West (2007), for instance, found that people who suffer from a mental illness were disproportionately portrayed as having a significant negative impact on society.

For young people, the Internet has become a commonly used medium for finding information, entertainment, and social contacts (Lenhart, Rainie, & Lewis, 2005). According to Sun et al. (2005), adolescents in high-risk populations are particularly likely to surf the web. Thus, through the Internet, professionals might be able to offer easy access to information and support and to create a way to exchange experiences anonymously (McGinty, Saeed, Simmons, & Yildirim, 2006). Developing an online community forum in consultation with young people, and assisted by them, Webb, Burns, and Collin (2008) demonstrated, for instance, the potential that the Internet has for social networking, which in turn might help prevent mental health difficulties, reduce stigma, and facilitate help-seeking. To remove hindrances for service delivery and utilization, it would seem advisable, therefore, to adapt interventions targeting young people for non-traditional delivery systems.

We agree with Linke, McCambridge, Khadjesari, Wallace, and Murray (2008) that detailed information about the theoretical underpinnings, content, and structure of an intervention makes it easier to interpret the results of an evaluation of it. Thus, in this paper, we describe the development of Survivalkid, an interactive Internet-delivered preventive intervention for supporting adolescents with parents who suffer from a mental health problem. We also present results from a preliminary study of adolescents' use of the intervention.

Choosing an intervention for Internet delivery

According to Ritterband et al. (2003), online help should be modelled on an effective face-to-face intervention. However, few prevention programmes designed specifically for adolescents whose parents are mentally ill have been thoroughly evaluated (Fraser, James, Anderson, Lloyd, & Judd, 2006; Saxena, Jané-Llopis, & Hosman, 2006). One reason for the paucity of studies is the lack of

participants. The results that have been reported suggest that prevention workers should aim at a better understanding of the parent's illness, feelings of family togetherness and a sound judgment of their circumstances for the children (Beardslee, Wright, Gladstone, & Forbes, 2007; Beardslee, Wright, Salt, & Drezner, 1997; Clarke et al., 2001; Hoefnagels, Meesters, & Simenon, 2007).

While developing a family-based intervention, Riley et al. (2008) reviewed the psychosocial mechanisms that explain how maternal depression negatively affects children's development. They identified five factors associated with poor child development: the family's inadequate understanding of the depression syndrome; lack of family interaction and communication; ineffective parenting practices; high levels of stress and family conflict; and little social support from outside the family. Linking intervention components to identified risk factors, the authors indicated that the most important components of the intervention were educating the parents about depression, teaching the children coping and communication skills, and helping them deal with feelings like anxiety and guilt.

Currently, little specific information is available on children's views about what helps them to cope successfully. A few qualitative studies have examined the experiences of the offspring of mentally ill parents and their needs in times of crisis (Garley, Gallop, Johnston, & Pipitone, 1997; Handley, Farrell, Josephs, Hanke, & Hazelton, 2001; Mordoch & Hall, 2002; Stallard et al., 2004). Themes emerging from these studies include trying to understand what is going on, being unable to cope in times of risk (e.g., withdrawing or assuming too many responsibilities), and having difficulty finding support because of the lack of social networks. While developing good-practice guidelines in Australia, Fudge and Mason (2004) consulted young people themselves. They found that supportive adults, siblings, and peers; participation in activities; having access to relevant information; being able to get away from difficult situations or people; and having someone to talk to were all factors that helped the children cope with their unwell parent.

In addition to such work in Australia (Australian Infant, Child, Adolescent and Family Mental Health Association, 2004), guidelines for professionals working with mentally ill parents and their children have been set up in the United States (American Academy of Child & Adolescent Psychiatry, 2000) and several European countries, including the United Kingdom (Falkov & Lindsey, 2002) and the Netherlands (Bool, Smit, Bohlmeijer, & Sambeek, 2001). Like other Dutch interventions, the curricula for group sessions with adolescents and with young adults are based on the national guidelines.

Because the manuals used for these "best-practice" interventions have strong structure and content, we chose them as the starting point for developing the content for our website. Some other features of these interventions also make them appropriate for online adaptation: first, the fact that the recommended as the easiest way to communicate provides an opportunity for online interaction and fun; and secondly, because the curriculum comprises various components, a site menu containing the different units could be developed, and site visitors could choose which units they wanted to use. We selected the following key components for the website: explanations about the parents' illness, instruction in coping skills, opportunities for mutual understanding, and the possibility to contact a staff member.

How can one build a useful website?

The development of the Survivalkid website involved an iterative process. The elements included: (a) a literature search for empirically-based suggestions from experts on how to build a useful website; (b) feedback from a focus group in which former members of face-to-face prevention groups participated; (c) the formation of a development team; and (d) advice from mental health professionals, researchers, and an expert on website design.

We aimed to create an online location where members of the target group would stay long enough to meaningfully process some of the content provided and where they would return if their current situation required them to seek additional information or emotional support. Although there is growing consensus that Internet interventions can be effective (Cuijpers, van Straten, & Andersson, 2008; Emmelkamp, 2005; Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004), we found relatively few results on how these interventions had achieved their effects.

In a Delphi study, Crutzen et al. (2008a) interviewed experts about how to achieve optimal exposure to Internet-delivered interventions for adolescents that encouraged them to follow a healthy lifestyle. The authors concluded that such an intervention should be immediately attractive and easy to use, and it should provide individualized feedback and relevant and reliable information. Because websites that are engaging and highly interactive appeared to enhance their attractiveness, Cunningham, Rapee, and Lyneham (2006) recommended using a multimedia approach, and Wright et al. (2002) reported that the use of surveys, quizzes, and games stimulated users' learning. Having found that the degree of emotional relief that users of an online support group experienced was significantly correlated with their degree of active involvement, Barak and Dolev-Cohen (2006) recommended inviting site visitors to contribute to the site by, for instance, posting on a bulletin board a personal story, a favorite poem, or simply a message.

Crutzen et al. (2008b) asked adolescents participating in a focus group to describe the factors that influenced their revisiting a website. The most important factors mentioned included the kind of experience they had had with the intervention during the previous visit, their own inclination to change the behaviour targeted by the intervention, whether new content had been provided, and whether they had been reminded to visit the site again.

Brouwer et al. (2008) interviewed experts about factors related to the use of Internet interventions aimed at adults. They advised that potential users might need to be motivated to visit an online intervention, the content provided should be personally relevant to the users, and it should be regularly updated. Wangberg, Bergmo, and Johnsen (2008) studied adherence of the adult users in three different Internet-based trials. Attrition was substantial, but the authors suggested that automated follow-up of users via email and individualization (e.g. providing personalized feedback) would likely increase adherence.

Not all adolescents are proficient Internet surfers. Several studies (Borzekowski & Rickert, 2001; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Hansen, Derry, Resnick, & Richardson, 2003) found that students often did not know where to find reliable information, how to formulate questions that they wanted answered, and sometimes could not spell search terms correctly. Although emotionally supportive, answers that young Internet users find through chat rooms or online bulletin boards are often inappropriate (Gould, Munfakh, Lubell, Kleinman, & Parker, 2002; Suzuki & Calzo, 2004) or even detrimental (Whitlock, Powers, & Eckenrode, 2006). Subrahmanyam, Greenfield, and Tynes (2004) found that when chat room contributors were anonymous, they were more likely to discuss sensitive topics and use explicit language. Anonymity might facilitate advice seeking, but it also might cause vulnerable young people to make friends with inappropriate people. Ybarra, Alexander, and Mitchell (2005) found that while online young people with major depressive symptomatology were more likely to interact with strangers. Their results are consistent with Wolak, Mitchell, and Finkelhor's (2003) conclusions that teenagers in need of support are trying to find it by using chat rooms. Not all of them, however, will receive encouragement. Ybarra and Mitchell (2004), in fact, reported that 15 percent of the young Internet users whom they interviewed said that while in a chat room during the previous year they had made nasty comments or tried to intimidate someone. Monitored chat rooms, however, where basic rules of etiquette are maintained, seem to attract less rude visitors (Subrahmanyam, Smahel, &

Greenfield, 2006), and having the possibility to contact a professional (Spek et al., 2006) seems to improve the effectiveness of online interventions. Consistent with these observations, Manhal-Baugus (2001) emphasized the importance of maintaining a protected environment in which users feel comfortable disclosing confidential information. Finally, Ritterband, Andersson, Christensen, Carlbring, and Cuijpers (2006) emphasized the importance of empirically evaluating all online interventions.

On the basis of our literature review, we concluded that an online intervention that is attractive, easy to read, interactive, individualized, secure and monitored, and well promoted would be a valuable source of support for our target group. The teenagers in the focus group agreed with this conclusion, but they also stressed the importance of being able simply to make contact with peers and have fun.

Developmental work

Designing an online intervention requires an interdisciplinary approach (Ritterband et al., 2003). Accordingly, we organized a team that included two clinicians, one of whom is a COPMI prevention specialist, and a representative from a company specializing in new media design that we contracted to develop the project. The company employs professionals such as programmers, graphic artists, and database developers. We could consult several different mental health professionals and researchers, a linguist, and the mental health centre's webmaster as the need arose.

Privacy.   Our goal was to expand the reach of the available preventive support in order to serve as many people as possible. To reduce barriers to use, we created a home page that offers potential COPMI users, their parents, and other interested people explanations and a demonstration of how the site works. To be able to access the private sections of the site, adolescents in the target group are invited to register. For purposes of evaluation and to individualize the information provided, registered users are requested to give their age and level of education (for matching readability) and gender (for matching the pictures). They are also asked to choose a username, password, and an email address that does not reveal their identity. In turn, the newly registered user can confirm his or her membership. Due to the confidential nature of information provided by users, several layers of protection are employed. The foremost is that all traffic takes place over a secure http connection, a protocol that is commonly used for confidential online transactions. A second layer is the login procedure that requires users to authenticate against a username/password combination. The third layer is applied by encrypting all privacy related data that is stored on the web server. Finally there are several privacy rules established on the website (e.g., not to reveal one's identity or that of someone else). Rule breakers can be banned from the secure website. The website management team, for its part, must confirm that it will use any data collected only for evaluation purposes.

Attractiveness, readability, interactivity, individualization.   We paid a great deal of attention to the appearance of the website. The choice between drawings (which might be fun to see, but might quickly become boring or be too childish for the older visitors) and photographs (there was an issue of who would want to pose) was difficult. Eventually, the graphic artists suggested using silhouette images based on photographs (see Figure 1). In them, the models are not recognizable; moreover, through the use of a variety of textures, the pictures can be changed for each person's subsequent visits.

The online intervention was modelled on manuals that had been used for face-to-face group sessions; however, the content had to be adapted for online delivery. Information about various

Figure 1. Silhouette images based on photographs.

kinds of mental disorders was changed into a series of short blocks of text, each with a distinctive header (e.g., "What does it mean?"; "How will it be cured?"), and real-life stories related to each block were adapted to the reading level of two different age groups (12-16 year olds and 16-24 year olds). A weekly survey was added that included such statements as, "If my mother feels depressed, I will not go out with my friends". Visitors are encouraged to respond to the survey and to make comments in a forum about this and other features of the site. They may also start a new discussion or tell their own story.

The psycho-educational exercises in the manuals were developed into interactive games. "Finding your friends", a task for examining and enhancing one's network of friends, for instance, was designed as a sociogram that uses animated expanding circles (representing home, school, leisure activities, etc.) in which possible friends appear. A visitor can download an empty sociogram and fill it in. (Figure. 2).

Two questionnaires were modified for Internet delivery. One was designed for early detection of psychosocial problems in secondary school students (Reijneveld et al., 2003); the other one is used for participants to evaluate the group sessions (Huinen & Valkenberg, 2005). Upon completion of a questionnaire, the person is given immediate feedback, for example, "Your answers suggest that you are not very happy"; "Why don't you visit the next chat room session and talk with your peers?".

Opportunities for guided and monitored contact with peers.   Both the forum (i.e., a message board) and the chat room sessions are monitored. The chat room is accessible only at specified times, and the sessions are announced on the user's private home page. Users may sign up at their
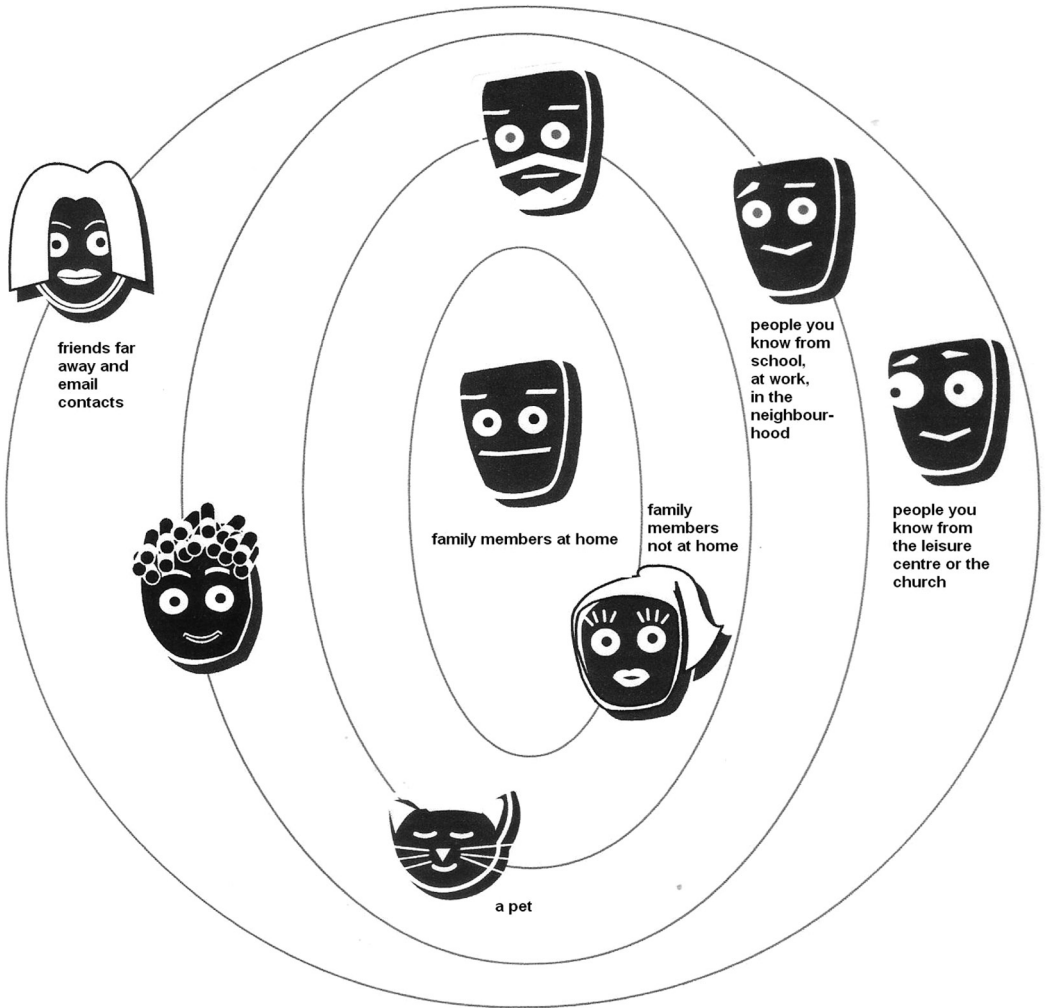
Figure 2. An empty sociogram to find one's own friends

own home page to be reminded of a chat session via an email or text message; there they can also subscribe to the newsletter. During chat sessions, a group facilitator is present who leads the discussion when necessary. If a user wants it, the facilitator can immediately offer him or her a private chat session with a colleague. Other ways in which site users make contact with a professional prevention worker are to make an appointment for private chat, or exchange messages with the professional via a secure email service. Referral to regular treatment is another option offered. A chat room can also function as a "classroom"; in fact, specialized courses have been developed for particular target groups, such as victims of domestic violence.

Implementation. An instructional manual was compiled detailing staff responsibilities and how the content management system operates. The COPMI specialist was appointed as Survivalkid webmaster and overall coordinator. Eight group facilitators from the community mental health

Table 1. Demographic characteristics of visitors (*N* = 397) logging in from June 2006 to June 2008

	Sex		Age (in years)		Educational level		
	Female	Male	< 17	≥ 17	Lower	Higher	No answer
Number	326	71	234	163	177	159	61
Percentage	82.1	17.9	58.9	41.1	44.6	40.0	15.4

centre (three psychologists and five nurse practitioners) were trained as online counsellors. They communicate their experiences by means of a logbook in which they tell their colleagues the visitors who participated in chat conversations, how things went, and to whom private chats were offered. They receive supervision from the COPMI specialist.

Evaluation.   For purposes of evaluation, participants are asked to indicate their age, gender, and level of education. The system keeps a record of the number of visits that each person has made, the number of pages viewed, the length of the visits, and test results if they are available. Email correspondence and chat-room conversations are kept in the secure database.

Public relations and publicity

Fellow clinicians were asked to draw their patients' attention to the additional support for their teenage children that the website offered. Posters, leaflets, and flyers were displayed in waiting rooms. They were also distributed to professionals (in schools, medical centres, etc.) who might apprise adolescents of the website. Additionally, relevant organizations (e.g., welfare work and youth-care agencies) were asked to provide a link to our website from their website. Finally, the launch of Survivalkid in June 2006 was reported in the local newspaper, and one of the focus group participants was interviewed on a radio programme.

Usage

From June 2006 through to June 2008, the website statistics showed that the home page had 10,000 hits and an average of 600 different visitors each month. During this period, 397 young people logged into the site; their demographic characteristics are shown in Table 1. Of them, 313 (78.8 %) came from the local region.

The average age of the 397 visitors was 16.4 years. Our efforts to tailor web content seem to be successful, seeing that older as well as younger adolescents participated and 44.6 percent of the site users had received lower education. The majority of the visitors were female: 82.1 percent. This is in line with earlier results (Fukkink & Hermanns, 2009; Gerrits, Zanden, Visscher, & Conijn, 2007). Girls especially are (health) information seekers and communicators (Lenhart, Rainie, & Lewis, 2005). Alongside that, girls have been found to need more support for living with a mentally ill family member than boys do (Landman-Peeters, 2007). Two hundred and thirty-seven participants (60%) visited the site several times; 51 people (12.5 %) made more than 15 visits.

Through an online questionnaire, 26 regular visitors expressed their appreciation for the opportunity to find information and to receive mutual and professional support anonymously. Visitors judged the most helpful features of the website to be, in order, the common chat room, the private chat sessions, and the experiences that the peers reported. Asked for their family

Table 2. Diagnoses of family members as given by questionnaire respondents (*N* = 26)

Diagnosis*	
Depression	14
Anxiety Disorders	2
Schizophrenia, Borderline Personality Disorder, Autism	6
Eating Disorder, Substance Use Disorder	6
Attention Deficit Hyperactivity Disorder (ADHD)	5
Anti-social Personality Disorder	2
Do not know	6
Something else	6

* more than 1 answer possible.

member's diagnosis they answered as shown in Table 2 (Drost, Sytema, Windmeijer, Witteman, & Schippers, 2009).

Conclusions

The increasing penetration into the home of the personal computer and the Internet provides an opportunity for developing non-traditional approaches to service delivery. Accessible at all times of the day, the Internet allows a visitor the opportunity to find support or to communicate with others any time he or she feels the need.

Well designed, supportive websites might be a welcome supplement to care as usual. For adolescents to be able to know that they can receive a quick response when they have a concern can be reassuring. Members of an online community don't have to wait for the next group session or the next appointment with a professional to discuss their experiences openly. Visitors can also have the comfort of knowing that they can return to the site whenever they are experiencing a difficulty. In this way, young people can be empowered, rather than having to rely on support from outside agents (Maybery, Ling, Szakacs, & Reupert, 2005)

The success of the service can be derived from the number of visitors from the region logging in: nearly nine times as many in the first two years after launching than the number of children participating in face-to-face groups organized by the local Mental Health Centre in the five years previously (*N* = 36). Of all the visitors, 60 percent returned to the site one or more times. We appear, therefore, to have accomplished our goal of expanding the range of support.

In future, we will undertake additional analyses of the data that have been collected. We will also analyse the contents of the email and chat messages, aiming to determine how online communication between young people and healthcare professionals can influence consultation processes and alter healthcare outcomes (Harvey et al., 2008). Additionally, cost-effectiveness issues (Ritterband et al., 2006) will need to be considered.

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Author biographies

Louisa M. Drost has studied developmental and clinical psychology and psychotherapy. She worked for years as a clinical psychologist at several institutes for (mental) health care. Currently, she coordinates the development and evaluation of projects in the domain of mental health care improvement, especially e-health projects.

Pim Cuijpers, PhD is Professor and Head of the Department of Clinical Psychology, at the Free University, Amsterdam. He has published about 300 professional publications. He has specialized in research on the prevention and psychological treatments of mental disorders, especially depression. Pim Cuijpers worked for 15 years as a psychologist and prevention specialist and was head of the Prevention Department at the Trimbos Institute.

Gerard M. Schippers, PhD is a psychologist and psychotherapist, and Professor at the Amsterdam Institute for Addiction Research (AIAR), Academic Medical Centre Amsterdam. His main interests are in evidence-based substance abuse treatment, cognitive behavioural therapy and brief interventions. He has published a number of books and (co)authored over 100 articles in peer reviewed journals. He is chief editor of the Dutch Journal *Verslaving* [Addiction].