

**GOLD IN  
HAND** PLUS



# DID Care

**Quality criteria from a client perspective**

**C.J.C. Kalsbeek & V.J.D. Platteel**



**CALEIDOSCOOP**

landelijke vereniging  
voor mensen met een dissociatieve stoornis

# DID Care

## Quality criteria from a client perspective

In the context of the project 'Gold in Hand Plus: making effective use of experiential knowledge and self-management' (*Goud in Handen Plus: ervaringskennis en zelfmanagement effectief inzetten*)

Amersfoort, third edition, June 2015

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## Colophon

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# Contents

07	<b>Foreword</b>
08	<b>Route to quality criteria</b>
10	<b>Background information</b>
14	<b>Summary of the criteria from a client perspective</b>
17	<b>The quality criteria in descriptive form</b> <ul style="list-style-type: none"><li>1 Treatment conditions for DID</li><li>2 Feelings of insecurity are made manageable</li><li>3 The client and therapist together prepare a stabilisation plan</li><li>4 There is suitable support for clients with DID in crisis</li><li>5 In the treatment for clients with DID, there is attention for others directly involved</li><li>6 Attention to animals in treatment of clients with DID</li></ul>
42	<b>Recommendations</b>
45	<b>Afterword</b>
	<b>Appendix A: Research methods</b>
	<b>Appendix B: Participant list</b>

# Foreword

The book you have in your hands is the gold that was mined from the project Gold in Hand Plus. The gold consists of the knowledge of clients with a severe dissociative disorder (DID or DDNOS). They indicated what for them is the optimal reception, diagnosis and treatment. This knowledge is an indispensable addition to the knowledge that is available from evidence-based practice. Care providers and organisations that come into contact with clients with severe dissociative disorders can use this knowledge to improve their approach.

The complexity of the treatment of severe dissociative disorders and the intensity and duration of the treatment make it extra clear how important it is to coordinate these treatments with the wishes and needs of this client group. Persevering with long-term and intensive treatment is only possible after all if the client feels themselves understood and supported by his care providers. Only then can the client summon the hope, courage and motivation to bring the treatment process to a satisfactory conclusion.

With the criteria and recommendations in this book, care providers and teams gain an extra aid to contributing to an optimal treatment process. The book is also a call to health insurers and other stakeholders to employ the information recorded. In this way, they can still better fill their role with regard to clients with severe dissociative disorders.

In the same way that the treatment of dissociative disorders is a slow and sometimes difficult process, mining for gold is a process that has to be conducted with care and precision. For this reason, special thanks are due to Cecilia and Vanesse who succeeded in collecting the gold from the clients and in converting it into specific criteria and recommendations. Thanks also to the expert clients and care providers from the sounding board groups for their comments and suggestions, from which the gold gained an extra lustre. However, those who deserve the greatest tribute are the clients who participated in the various focus groups. They volunteered to speak openly about their experiences with their condition and with the care provision. Our thanks to them for being willing to share their sometimes very personal experiences. In doing this, they made their gold available for this book, so that new generations of clients can profit from it.

Tom Horemans, psychiatrist

*Project advisor*

# Route to quality criteria

Caleidoscoop, the national association for people with a dissociative disorder, was started up in 2012 with the collaborative project 'Gold in Hand Plus'. In this project, quality criteria from a client perspective were developed for dissociative disorders: dissociative identity disorder (DID) and dissociative disorder not otherwise specified (DDNOS). For better readability, in the rest of this book, we will refer to (people with) DID, by which we also mean DDNOS. The quality criteria from a client perspective illustrate in a specific and useful way what the care consumers have stated they find important in the treatment of their dissociative disorder.

Five steps have been taken to arrive at these quality criteria from a client perspective. These steps are briefly explained below:

## 1. Qualitative research

Within the project 'Gold in Hand Plus: making effective use of experiential knowledge', four focus groups were organised in which 22 people (all women) with a dissociative disorder shared their experiences, from which emerged what is important for them when considering good care for the treatment and the consequences of it. Using the coding method, the results from these focus groups were collected and bundled into the research report 'Discussing DID' (*Praat mee over DIS*). Amersfoort: October 2013.

As far as the researchers, advisor, sounding board group and expert group are aware, no qualitative research has previously been done with clients with DID or DDNOS, and there is not yet a Dutch treatment guideline. Exactly when evidence-based guidelines are missing, it is important to ask people themselves about their experiences and needs in care.

See Appendix A for more information about the research methods used.

## 2. Sounding board group

The information that was contributed by the respondents was presented for assessment and reflection to a panel of care professionals: the *sounding board group*. This group had a multidisciplinary setup. One of its duties was to ensure the usability of the results from the focus groups. The sounding board group had an advisory role. Chair of the sounding board group and also external advisor for the whole project was Dr Tom Horemans, linked as psychiatrist and programme manager to the Specialist Trauma Centre (TRTC), the MHC Eindhoven psychotrauma centre.

## 3. Expert group

The *expert group* comprised people who are experiential experts, who could share their expertise and also that of others, for example volunteers from Caleidoscoop. Because the quality criteria were to be developed from a client perspective, the expert group had a decisive voice in this project.

## 4. Draft quality criteria

After the sounding board group and the expert group had reacted to the research report and in discussion had indicated priorities about it, the researchers went to work with this feedback to arrive at *draft quality criteria from a patient perspective* via the modified AIRE instrument<sup>1</sup>. These draft criteria were discussed at the second meeting of the sounding board group and the expert group.

## 5. Read-through

With the feedback from this second round, the researchers started to focus the draft criteria more closely. The second version of the draft criteria was presented to the sounding board group and expert group for reflection via an e-mail questionnaire. This was the *read-through*. All answer forms were summarised together, supplemented with a reaction in the form of a report on what had been done with the recommendation, and sent to the reading group together with the last (final) version of the quality criteria.

<sup>1</sup> 'Appraisal of Indicators through Research and Evaluation': this guideline for the development of quality criteria was developed with the AMC in 2006, commissioned by the Dutch Order of Medical Specialists.

# Background information

Two dissociative disorders are central to this project: dissociative identity disorder (DID) and dissociative disorder not otherwise specified (DDNOS). These disorders are described briefly below. This chapter serves only to assist readability and is in no sense exhaustive. The contents of this chapter are largely based on information from Caleidoscoop<sup>2</sup> unless another source is cited.

## DID

Dissociative identity disorder (DID; formerly multiple personality disorder or MPD) is the most widely known and most severe dissociative disorder. This disorder is characterised by a lack of integration among different aspects of the identity, the memory and the consciousness. Each personality state (identity or alter) may be experienced as if it has an independent personal history, its own self-image and its own identity, including its own name. This might also mean its own age, sex and sexual inclination, religious conviction, and even its own physiological characteristics such as visual acuity and reaction to medication. The different identities often also each have their own memory contents, which cover a limited part of the individual's history; they are not always aware of each other's existence. In many cases, what is called a primary identity does exist, bearing the name of the individual and sometimes forming a connection between the identities (although not necessarily between all the identities).

## How DID arises

Having DID proves almost always to be associated with a history of serious and persistent traumatisation in early childhood, during which the identity of the person is still being formed (in general before the eighth year of life). This may take the form of emotional neglect, mental, physical or sexual violence (including incest) or combinations of these. The traumatisation could have happened in the family of origin, in the wider living environment of the child, or in both domains. In its first years of life, the child tries to associate (integrate) impressions and experiences, and this plays a part in forming the basis for its future personality and consciousness: the ego. When this process is disrupted too seriously and persistently, this can have permanent consequences for the child's mental development. One such consequence is the permanent inability to bring certain aspects into relationship with each other (dissociation versus association/integration).

Scientific research into the biological consequences of Post-Traumatic Stress Disorder (PTSD) has demonstrated that temporary or permanent changes in the neurobiological area can arise, particularly in the area of the hippocampus, that are accompanied by dissociative symptoms. In combination with the personality formation at a very early age, this can lead to the child developing a dissociative disorder.

## Characteristics of DID

The characteristics of DID according to the DSM-IV classification system are as follows:

- There are two or more identities or personality states that can be sharply distinguished from each other (each with its own relatively long-term pattern of perception of, dealing with and thinking about the environment and itself);
- At least two of these identities or personality states regularly determine the behaviour of the individual;
- The inability to remember important personal information is too great to be explained by simple forgetfulness;
- The disorder is not the result of the direct physical effects of a substance (for example blackouts or chaotic behaviour during alcohol intoxication) or a physiological condition.

Frequently associated characteristics are: depressive symptoms, disruption of personal or professional relationships, sexual dysfunction, anxiety, shame, feelings of guilt and sometimes also farther-reaching characteristics, such as self-harm, suicidal ideation and suicide attempts.

## DDNOS

Dissociative disorder not otherwise specified (DDNOS) is the residual category that DSM-IV defines for all disorders. This means that this diagnosis is made when there is indeed a dissociative disorder, but not all the conditions that are necessary to assign someone into one of the four standard categories are fulfilled. It also happens that, during diagnosis, insufficient clarity can be achieved about some aspects; in such a case, someone could temporarily be given the diagnosis of DDNOS, this usually being changed later to for example the diagnosis of DID.

DSM-IV defines this category as follows: the primary characteristic is a dissociative symptom (in other words: a disruption of the usually integrated functions of consciousness, memory, identity and perception of the environment) that does not comply with the criteria of a specific dissociative disorder.

The examples include:

- Pictures that resemble the dissociative identity disorder but do not meet all the criteria for this disorder (for example, the absence of two or more sharply mutually distinguishable identities or personality states; no amnesia for important personal information).
- Derealisation that is not accompanied by depersonalisation in adults.
- Dissociative conditions that arise in people who had been subject long-term and intensively to intense influence (for example brainwashing, re-education or indoctrination as a captive).

## Diagnosis and treatment<sup>3</sup>

Diagnosis generally happens via structured interview techniques. One of the most-used techniques here is the SCID-D test.

A DID treatment is generally of long duration (many years) and intensive (one to two sessions per week). Periods of intermediate relapse are not unusual. The treatment is an outpatient one; admission sometimes happens for short periods, for example in connection with intense reliving experiences or because the client's living environment is too great a hindrance for effective therapy. The treatment of DDNOS generally features many similarities with that of DID although individual differences do arise, given that the characteristics may differ somewhat.

Effective treatment of dissociative disorders may consist of a combination of different methods, but always includes psychotherapy preferably by an expert in the field of psychotrauma and dissociative disorders. The aim of the psychotherapy is to promote the integration of feelings, thoughts, perceptions and memories. It concerns the expression of thoughts and feelings and where necessary the integration of different concepts. The aim is to create more unity of the personality, to strengthen the internal order and to combat disruption at work, in the social life and at home. Sometimes also, a choice is made of a treatment of individual psychotherapy in combination with a structured part-day treatment.

In the treatment of trauma-related symptoms, the principle in most cases is an approach set up in three phases. This proceeds as follows:

- Phase 1 concerns symptom reduction and stabilisation, so that the patient becomes stronger and is better able to tackle the tasks of daily life.
- Phase 2 is about treating the traumatic memories, if this is possible. This treatment is always interleaved with the symptom reduction and stabilisation of phase 1.
- In phase 3, the treatment is targeted at having the patient develop a new lifestyle, a style that is appropriate to an integrated personality. This phase also alternates with the treatment of phase 2 and the symptom reduction and stabilisation of phase 1.

In far from all cases is it possible or desirable to go through all three phases. Stabilisation is usually the primary objective. Many patients with DID or DDNOS find it most desirable to involve the different personality states in the stabilisation phase of the therapy. A treatment that is only targeted at combating symptoms is perceived by many of them as a prohibition on speaking or not being allowed to express things. Sometimes a choice is made of a treatment of individual psychotherapy in combination with a physically-oriented or creative therapy.

To date, there has been little controlled and long-term effects research focused on the treatment of DID. The treatment of DID until now has therefore mainly been based on clinical experience. In general, short-term psychotherapy for patients with a complex dissociative disorder has proven to do more harm than good.

## Psychotherapists, psychiatrists and other therapists

Clients with DID may be in treatment with a (self-employed) psychotherapist or psychiatrist, or at a smaller or larger MHC (mental healthcare) institution. Within these institutions, the trauma treatment is usually set up to be multidisciplinary and non-verbal and part-day treatment is often added to the individual psychotherapeutic treatment.

## Specialist Trauma Centre (TRTC)

A Specialist Trauma Centre (TRTC) is an outpatient specialist centre focusing specifically on the complex consequences of chronic traumatisation in early childhood. The diagnosis and treatment of complex trauma-related problems is work for specialists who often require to operate as a team. In the Netherlands, there were not yet many of these specialists and teams. For this reason, from 2007, specialised centres for complex trauma-related problems were set up in the Netherlands, known as Specialist Trauma Centres (TRTCs).

<sup>3</sup> This paragraph is based on:  
[www.moeilijkemensen.nl/index.php?option=com\\_content&task=view&id=113&Itemid=116](http://www.moeilijkemensen.nl/index.php?option=com_content&task=view&id=113&Itemid=116)

## Summary of quality criteria

### 1. Treatment conditions for DID

**In the treatment of clients with DID, it is necessary that:**

- the practitioner recognises the diagnosis of DID;
- the practitioner is (or becomes) and remains a DID expert;
- attachment can occur within the treatment relationship.

### 2. Feelings of insecurity are made manageable

**The making manageable of feelings of insecurity is essential for entering into a treatment relationship. Important in this is that:**

- the feeling of insecurity is jointly operationalised and made concrete in the treatment room and in the treatment;
- therapists deal with this proactively, while control remains with the patient;
- there is clarity during every consultation, for example about the duration;
- the choice and form of (additional) treatment are coordinated with the wishes and needs of the individual client.

### 3. The client and therapist together prepare a stabilisation plan

**In the stabilisation plan is described how a crisis can be avoided and how the client, the practitioner and the crisis response team should behave if a crisis occurs.**

In the stabilisation plan, the following points may be included, among others:

- The practitioner's role.
- The role of family and friends.
- Telephone by prescription (*TOR*).
- The involvement of Psychiatric Intensive Home Care (*PIT*).
- Acute admission possibilities including Bed By Prescription (*BOR*).

14

### 4. There is suitable support for clients with DID in crisis

**The crisis support for clients with DID is suitable. Important in this is that:**

- the crisis support is accessible without requiring GP referral or the barrier of an obligation to be in treatment at the MHC institution providing the crisis support;
- the location of the support is geographically accessible within the region where the client lives;
- the location of the support is set up so that account can be taken of the feelings of insecurity;
- the care providers at the crisis support know how to deal competently with people with DID;
- the stabilisation plan is respected and followed.

### 5. In the treatment for clients with DID, there is attention for others directly involved

**In the treatment for clients with DID, there is explicit attention for others directly involved, such as children, partners and friends of the client. Important in this is that:**

- family and friends are included in the stabilisation plan;
- family and friends are helped to deal with the client when other identities are in the foreground;
- the practitioner is alert to possible secondary traumatisation in family and friends;
- the practitioner pays attention to possible care needs of these others and refers them on if necessary.

### 6. Attention to animals in treatment of clients with DID

**Animals may have added value for the quality of life of clients with DID. In the treatment it is considered individually whether animals would be helpful or not.**

15





# CRITERIA

The quality criteria  
in descriptive form

*“What I really want to emphasise is that the therapist-client relationship is extremely important. That they get enough time to grow and obtain the safety and time. Safety and trust, if you can’t build this up with your therapist, no trauma processing can take place. At the moment, much emphasis is being placed on cost consciousness. I have come a long way on my journey. I am nearly at the end. My identities had never been able to have their say, had never been able to tell what happened. My story would never have come out as it has come out, if I had not got the time to make a bond with and to gain trust in my therapist. And this is impossible in a two-year process, in a three-year process, in now-and-again in between modules of twelve sessions. I am convinced of it, I believe it solemnly.”*

# CRITERION 01

## Treatment conditions for DID

In the treatment of clients with DID, it is necessary that:

- the practitioner recognises the diagnosis of DID;
- the practitioner is (or becomes) and remains a DID expert;
- attachment can occur within the treatment relationship.

*“At the TRTC there was a hold on referrals or too long a journey time or something. So then I went looking for a self-employed therapist. And I found one. I did ask if she knew about dissociation, or could handle it. And I was really so fortunate with her. She does not have a lot of experience with it, but is prepared to read, to be trained. My therapist did say: ‘I’m only going to continue with you if I can get supervision from the TRTC.’”*

# Explanation

In the Netherlands and Belgium, for the diagnosis of a dissociative disorder, use is almost always made of the criteria in the DSM (Diagnostic and Statistical Manual of Mental Disorders).

In May 2013, the fifth (English) version of the DSM was introduced. The previous version (DSM-IV TR) is however still the most used. This version describes the various dissociative symptoms, based on which five dissociative disorders are formulated. Within these come DID and DDNOS<sup>4</sup>. From the research and the meetings of the sounding board group and expert group it emerged that not every psychologist or psychiatrist recognises the diagnosis. This could have disastrous consequence if a client with DID got a practitioner who does not recognise DID.

In the courses for MHC psychologist and psychiatrist, there is insufficient attention to DID, trauma and bonding. In practice, therapists gain little experience with this. For this reason, there are few practitioners who have the DID expertise to treat people with DID adequately. It emerges from the research that clients are in treatment with a (self-employed) therapist who does not have DID expertise, but has contact with a TRTC for advice. As long as there is a shortage of therapists specialised in DID, it is advisable that motivated practitioners can approach a regional TRTC for advice and guidance.

The degree of presence and attention from the practitioner play a major role in the feeling of security of the client with DID.

The therapist is seen unconsciously by the client as a role model. The expert group indicated that the therapist is not infrequently the first healthy role model for people with DID. The therapist must be aware of this.

The treatment duration for dissociative disorders is much longer on average than that for other disorders. As well as expertise about the condition, it is crucial for treatment that a bond can develop between the client and practitioner. It emerges from the research that making real contact (clicking) with the practitioner is essential for a treatment to proceed. The creation of a treatment relationship is step 1 in initiating treatment. It must be possible to structurally discuss and evaluate the treatment relationship. If the client indicates a desire to go into therapy with a fellow practitioner due to clicking, this must be open to discussion. If a practitioner does not have DID expertise and cannot or will not treat under TRTC supervision, he or she has the duty (of care) to ensure that the client does receive the right care.

*“So I miss this clarity very often in my treatment and that makes it extremely difficult. Before you can actually get to a bit of processing, you actually have to be able to explain everything. How your thinking works. Yes, that’s just very hard. If it doesn’t click then you can’t make a whole lot of things clear.”*

*“I had a therapist who hadn’t learnt much about DID, and although he was open to it, he was really wide of the mark. If I was suffering a lot from the angry identities, he would say: You’ve just got to say: ‘I’m not listening to you. You don’t exist, you need to be sent away.’ And things like that. So that went badly.”*

*“For me, it’s always been that if I had the feeling that a therapist didn’t understand where I was coming from and did not want to start a long-term relationship with me... then I don’t do it. Because that is essential to be able to treat DID. I want to do without it as far as possible, but then I need a certain attachment and a certain dependence and if I can’t get it, well you could just carry coals to Newcastle so to speak.”*



22

# CRITERION 02

## Feelings of insecurity are made manageable

The making manageable of feelings of insecurity is essential for entering into a treatment relationship. Important in this is that:

- the feeling of insecurity is jointly operationalised and made concrete in the treatment room and in the treatment;
- therapists deal with this proactively, while control remains with the patient;
- there is clarity during every consultation, for example about the duration;
- the choice and form of (additional) treatment are coordinated with the wishes and needs of the individual client.

23

"As the second girl I've never had long hair. This charcoal drawing serves as a symbol for the innocent angel that had to grow up under such a serious threat. Only much later did I learn that it had also shaped me as a person."

# Explanation

In essence, DID concerns insecurity in a bonding relationship. Helping to create a feeling of security in these clients is of essential importance, otherwise no treatment is possible. It is therefore crucial that therapists take whatever the client perceives as unsafe seriously and makes it manageable. Insecurity may exist in the building where the treatment is taking place for example.

It emerges from the research that security is present in things that seem minor, such as covering a mirror or painting in the treatment room. It is important that therapists help in thinking up a solution, and yet control remains with the client. Safety is coordination. Clients have indicated that therapists can help proactively in this. Because it is sometimes difficult for clients to express this themselves. Therapists could for example ask clients: 'What do you need to feel safe in this treatment room?' And: 'Where would you like to sit?'

Clarity in the treatment and in the different treatment components is essential. The duration of a consultation or treatment is a much-discussed aspect in the research. Clients indicate that time delineation is important, that predictability is safety, but this can also backfire if it causes the client to feel under pressure to speak.

This also depends on what phase the treatment is in. In phase 2 (trauma processing), more time will possibly need to be taken for each consultation than in phase 3. It is desirable that there is a possibility for consultations to run on. It can moreover increase the clients' self-determination to give them the job of preparing the consultation.

Some clients indicate that therapy in a group context is experienced as inherently threatening, even if it involves a homogeneous DID group. Elements that can play a role in this are the context, the structure and the supervision of the group. A group with few or unclear rules that is thus less predictable is perceived as the most threatening. A group may be perceived as less threatening if the setting is clear, such as a (skill) training course with an expert supervisor.

There is little evidence-based research into the effectiveness of treatments for DID. It emerges from the research that occupational therapies provide a valued alternative to, or are considered as an addition to, talking therapy. It is important that the choice and form of additional occupational therapies are coordinated with the wishes and needs of the individual client. Through this coordination, feelings of insecurity are made manageable.

*"There is sometimes safety in very minor things. But these are sometimes things I didn't think of asking for before, while I do need them. So it is great if that person knows it too, or knows they have to ask it, or that it will come up. So ask specifically: 'What do you need to feel safe?' And then answers come that I could not have made up myself. But it's great, that you can still find that solution."*

*"It starts with something simple such as a building, I believe. That little room where I was sitting with the DID therapist, it was a very narrow, long room and the therapist was sitting between me and the door. Yes, that makes me panicky. The room where we're sitting now, it is more spacious and we've set it up so that he sits in a place where there is enough distance and where I have the feeling I can get out. Yes, just that he thinks: 'So what makes it safer for you so that you can get up to telling things,' or something. And that's, yes, I think it's very important."*

# CRITERION 03

## The client and therapist together prepare a stabilisation plan

In the stabilisation plan is described how a crisis can be avoided and how the client, the practitioner and the crisis response team should behave if a crisis occurs.

In the stabilisation plan, the following points may be included, among others:

- The practitioner's role.
- The role of family and friends.
- Telephone by prescription (*TOR*).
- The involvement of Psychiatric Intensive Home Care (*PIT*).
- Acute admission possibilities including Bed By Prescription (*BOR*).



26

27

This artwork is called 'Having fun'. Just having fun with paint and a comb. Recommended for everybody. I notice that, in contrast to 'ordinary' people, I seem to have remained more childlike. If people react positively to my 'just doing daft things', I respond that I have a playful heart; in contrast to many who have a thickened heart."

# Explanation

The therapist and client together prepare a stabilisation plan (also known by other names, such as a crisis prevention plan). This plan gives the client and other people involved a grip on what to do if a crisis threatens. It is regularly considered whether the stabilisation plan is still adequate for the phase the client is in at that time. The role of the practitioner is also included in the stabilisation plan.

The role of family and friends is described in the plan too. Through their presence, family and friends can provide diversion and thus stabilisation for the client. It could for example be agreed to undertake something together regularly, to go for a meal at someone's home once a week, or to go and stay over with an acquaintance once a month.

Clients have indicated that a phone appointment (TOR arrangement) could prevent a crisis admission. Some clients have had valuable experiences with PIT care (psychiatric intensive home care) in the prevention of a crisis. PIT care can also help in the client's home situation, such as support for the partner and children and other people involved.

If a crisis cannot be averted, an acute admission may be necessary. It is important that the care providers who are involved in this are made aware of the client's stabilisation plan. In the case of a crisis admission, the practitioner informs the care providers dealing with the admission about the client's arrival and he ensures that the individual stabilisation plan is available for them to refer to at the admission location.

*"I have a stabilisation plan. I prepared it together with my therapist at the clinic. It's a great plan. So now I can function too. I know by heart how it works. But in the clinic, the crisis team, they have to follow it too, because in fact the communications rules are in it, how you keep it right for me. But it's always missing. They say: 'We've got it.' If you ask, they haven't got it, it's lost or somebody had sent it and they don't know if it's arrived. They also don't know who's done it wrong and who hasn't."*

*"In difficult periods I regularly make use of PIT care [intensive home care]. This is supervision in the home situation also meant to avoid admissions. And in combination with therapy to try to keep things stable at home as long as possible. Sometimes it works and sometimes not. And sometimes that's none for six months and sometimes three times six appointments in four months. It all depends on how it's going. Luckily there's always a fixed person so in the course of time you do built up a bond with them."*



## CRITERION 04

There is suitable support for clients with DID in crisis

The crisis support for clients with DID is suitable.  
Important in this is that:

- the crisis support is accessible without requiring GP referral or the barrier of an obligation to be in treatment at the MHC institution providing the crisis support;
- the location of the support is geographically accessible within the region where the client lives;
- the location of the support is set up so that account can be taken of the feelings of insecurity;
- the care providers at the crisis support know how to deal competently with clients with DID;
- the stabilisation plan is respected and followed.



# Explanation

It emerges from the research that it is not always straightforward for people with DID to make use of a bed on prescription (BOR) arrangement. Sometimes for example, the doctor's surgery is not aware of the stabilisation plan, which holds back the admission. Or the treatment takes place in a different region from where the client lives, so it is not possible to get a bed-on-prescription in the home region. The DID-specific crisis response within an MHC institution must also be available to clients who are in treatment elsewhere.

Some clients can literally not get to a crisis refuge due to geographical distance. Clients indicate that when in crisis they cannot drive and are not able to just step into an (unknown) taxi due to the feeling of insecurity. Reaching the crisis refuge independently however is often a

condition of being allowed to come. A possible way out is a car-on-prescription arrangement with permanent drivers, linked to the refuge or the municipality.

It emerges from research that crisis response and BOR arrangement do not always link up with the needs of clients with DID. Some clients in the research emerge worse than when they went in; sometimes there is extra trauma. Others no longer dare to go to the crisis refuge at all. This may for example be due to the unsafe location where triggers are lurking or due to the lack of DID-experienced care providers at the crisis refuge. A crisis refuge where clients have to share a room with the homeless is not suitable for people with DID. Alcohol fumes and noise are two of the triggers these clients might thus be exposed to (see also the research

*"I wanted a bed-on-prescription arrangement in my town but I was with a TRTC in another town. So it wasn't on. I've been at it for three years and in all these three years it's not worked. So now I don't have a therapist at the TRTC anymore. But I haven't been able to set up that bed-on-prescription arrangement in all these three years, because it's such an involved thing. I could have got the bed-on-prescription arrangement but at that TRTC in that place there so to speak. So I'm worn out and tired and finished and I still have to travel for an hour and a half, it's just not on."*

report). For some clients with DID, it is not (always) possible to see that they are in the middle of a crisis. This detail should then be included in these clients' individual stabilisation plans. Care providers at the crisis refuge should respect and comply with the client's individual stabilisation plan.

It is clear from the process that clients with DID need two different kinds of refuge. One type provides a safe environment. In the other, what is needed is a peaceful environment.

Sometimes people with DID mainly need peace, a brief respite from their own environment, to prevent a crisis. When there is no danger or risk of suicide, a crisis refuge is not the most suitable place for people with DID to achieve peace. The expert group has made it clear that a refuge (bed) in a peaceful and as far as possible trigger-free environment with a hostess is exactly what is needed. This refuge does not have to be organised within psychiatry (see also recommendation 3 for alternative ideas for places of rest and refuge).

*"I also have a bed-on-prescription and I do make use of it. It changed location a year ago. But it's not a suitable location for me. You have a great many rooms with people addicted to alcohol or with drug problems or who are homeless. And that gives you the stumbling blocks and triggers you don't need. It's very hard to find a way for myself in all this."*

*"I once had a crisis admission. And there was a very clear description. The psychiatrist at the time had clearly described what they had to do and what they shouldn't do. And that was actually extremely good. An open institution. With all the agreements you have, and that they mustn't make any diagnoses themselves, mustn't try anything themselves. That was just very good. That really helped me a lot. But then it was already known at the crisis department: 'If so-and-so comes in, then you have to deal with them like this.'"*



# CRITERION 05

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In the treatment for clients with DID, there is attention for others directly involved

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In the treatment for clients with DID, there is explicit attention for others directly involved, such as children, partners and friends of the client. Important in this is that:

- family and friends are included in the stabilisation plan;
- family and friends are helped to deal with the client when other identities are in the foreground;
- the practitioner is alert to possible secondary traumatisation in family and friends;
- the practitioner pays attention to possible care needs of these others and refers them on if necessary.

# Explanation

It is known that optimal involvement of those most closely involved contributes to the client's recovery. These involved people may be the child, partner or friends of the client. Some people who participated in the focus groups in the study have no partner or family. For those who do have them, it is important that care providers pay attention to these family and friends. These people for example need to learn how to deal with the client's different personalities.

This criterion also concerns the wider social network. For this network could provide much relief. The network may be important in the stabilisation and can provide diversion. If there is a wider field to fall back on and the system can form a safety net, there is less pressure on the therapy.

Good support of those most closely involved is the other side of the coin. By this means it can be prevented that they in turn have to call upon care provision. If a friend, partner or family member has psychiatric problems, this also has an impact on the lives of family members, other relatives and friends. They are confronted with drastic situations and can thus feel anxious and uncertain<sup>5</sup>. What should they do in crisis situations? Can they contribute constructively to stabilisation or recovery? But how? For the friends and family (just as for the therapists) there is also a risk of secondary traumatising.

Some TRTCs offer partner groups for kin of clients with DID. It emerges from the evaluation of these groups that there is a great need for a follow-up process from these partner groups. It merits recommendation to make groups for partners, children and kin suitable for clients with DID.

*"After my divorce, my daughter still lived with me, she was 12 at the time. Then at a given time I went to the RIAGG (regional mental health care outpatients), they had these leader groups. These are groups for children of parents with psychiatric problems, so they can discuss things they come up against, look for solutions. Then I just said: 'Can't she go there because I live alone with her, we are so close together, she's got no diversion. To create a bit of space for herself.' Because then I lived with her in a tiny flat. Just us two, so I thought that was much too close together. When I was still married she had enough diversion and space in the rest of the family. But not at that time. And then I got sort of yes, she does need something so I registered her for it."*

*"Last year I had four months of PIT care. And a whole while when I started in 1995. Then my youngest child was 5 and the oldest 7 and then I also had intensive home care. At that time the PIT care was organised differently. I had intensive home care then to help me and the children because I was so dissociative then. There was supervision for me then and for the children too. So yes, I've got lots of experience with it. And the person from then still comes twice a year or thereabouts to see us all. To see how it's going for us. They came right from when the children were small. And they say: 'That was such an experience.' Then they were able to still come for a while. Several times a week. Then it was not so strictly bound to the rules. My children are now 22 and 24. The boys are doing well. The boys are happy."*



38

# CRITERION 06

## Attention to animals in treatment of clients with DID

Animals may have added value for the quality of life of clients with DID. In the treatment it is considered individually whether animals would be helpful or not.

*"I've got a cat. It always comes to bed with me. And if I don't go to bed on time or if I'm putting it off, she really starts to stare at me like: 'Hey, it's bedtime.' So she is actually saying: 'I want to go to bed now.' So at a certain point I just give in. She always sleeps next to my pillow. I can always feel her. Her soft coat and the warmth and when she starts to purr. And if I wake up in the night having had a nightmare or if I'm lost or something, if I succeed and touch her and she starts to purr, that helps me to feel safe, if you like. And she's just sweet. Not especially that she helps me or anything, just by being sweet. And indeed that feeling of being loved unconditionally, I can't really get that from people, but I can from animals."*

39

# Explanation

It emerges from the research that animals can be extremely important to clients with DID. What often fails with people frequently succeeds with animals: a healthy bond can be formed. For people with DID, their relationship with an animal is often their first healthy bonding relationship. Caring for the animals moreover provides structure. Physical contact with animals can work therapeutically. Animals can feel when things are going well or not and whether/when dissociation is happening. Animals can bring people back to the here and now.

Animals and particularly (assistance) dogs can literally enlarge clients' experiential worlds. Some clients in the research have their own official trained assistance dog, such as a PTSD assistance dog. This dog was also employed as part of the treatment.

The PTSD assistance dog is a dog especially trained to watch and help people with Post-Traumatic Stress Disorder (PTSD)<sup>6</sup>. A PTSD assistance dog helps its master to deal with stress caused by traumatic experiences. The PTSD assistance dog is in the first place a 'buddy': one who is always there, gives attention and feels trusted. But a PTSD dog provides more than only that. It can spot the first signs of a nightmare and has learned to react to this. The dog also learns to recognise accumulating stress. If his master has a panic attack, the dog leads

him away out of the stressful situation. And in any event, he also forms a buffer between his master and other people. Clients learn to participate again in social intercourse, together with their dog, dare to go outside again, and can go shopping just like anyone else. In this way, a PTSD assistance dog ensures an improved quality of life.

The positive experiences with animals reported in the research were with different animals. Dogs, cats and horses, and also rabbits and birds. The expert group argues in favour of employing animals more widely in the treatment of DID. However, it will certainly not be an option for everyone. Some people are afraid of animals. Caring for animals might act to reflect the past and must therefore be discussed in the treatment.

The care of the animals must be organised and guaranteed. Possibly at the start or during a crisis, the client's system might play a role, for example as backup for the care of the animals. It must be decided after due consideration whether and when animals could be a help for the individual client and his treatment.

*"The reason I have a horse is because it gives me such a great feeling of responsibility and so much emotional connection. I get the feeling that it connects me better to the earth, gives me a greater feeling of responsibility to stay on the earth than people could ever give me. That it reduces the suicidal notions. Because I have an animal I am responsible for and I often don't have that feeling with people."*

*"A few years ago, I made the decision to get an assistance dog. First as a puppy. What I do notice is that I feel safer in the house with her there. That if I drifted away, she would attract attention. Bark if I had a nightmare. I also had to go outside, walk on the street, so at one point I did go outside, even though I found it quite a strain... She really is specifically for people with psychiatric problems and actually trained for PTSD – DID if you like, these are obviously closely related... When she was a year old I did the intake in consultation with my therapist. So the assistance dog is an integral part of the treatment. This means she also comes along to the talking therapy sessions and if I drift away she draws the therapist's attention so that they can calm me down again. She calls him in if you like. This is really very important... And what I really like about her in such a therapy process is that she closely reflects how things are going for me. If I am feeling unsettled or dissociating badly, she becomes very disobedient and doesn't listen. So that constantly reflects my own process. I live alone. I now have much less home supervision, almost none now, because I have her. I can now shop independently. I can study again. I now have occupations, even though as a volunteer. And it has a great integrating effect, because you have to. And she is trained for more of my aspects. So she can deal with these. But it does always bring you back to the here and now. It works to integrate and gives self-sufficiency. You are already so dependent on all these people around you and now you have a bit where that is not the case. My social world has really got bigger."*

## Recommendations

Four recommendations arose from the research among clients and the process that followed this in order to arrive at the quality criteria. These recommendations extend further than the individual treatment relationship. They concern the professional group of therapists, the patient organisation and the encouragement of research. The recommendations have where possible been further expanded in the implementation phase of the project Gold In Hand Plus. We present these recommendations below:

### 01 Attention to DID in education and refresher courses

It scarcely needs to be argued that there need to be more therapists with knowledge about early childhood chronic traumatising, such as DID. Once there is (more) knowledge about this at the MHC, not only can the correct diagnosis be made more quickly, but the correct treatment can be started earlier. In psychology and psychiatry courses, depending on the institution, superficial or no attention is paid to DID. It merits recommendation for a (refresher course) module about DID and other forms of early childhood chronic traumatising to be developed, for example by therapists (at TRTCs and elsewhere), clients (via Caleidoscoop) and educational centres together.

### 02 Further research into the effectiveness of therapy and new treatments

No realistic or valid figures are known about the incidence or prevalence<sup>7</sup> of DID. Further research into this merits recommendation.

To date, there has been little controlled and long-term effects research focused on the treatment of DID. The treatment of DID until now has mainly been based on clinical experience. More research into the effectiveness of treatment for early childhood chronic traumatising in general and into DID and DDNOS in particular is desperately needed.

<sup>7</sup> Incidence is defined as the number of new cases of an illness in a time period, per number of population. Usually incidence is indicated per thousand people per year, and sometimes per hundred thousand per year. Incidence should not be confused with prevalence, which indicates how many people in a given number at a given time are suffering from an illness.

The positive effect that animals and pets can have on the lives of clients with DID is clear from the research. For some people, the official assistance animal is even part of their treatment. It would be sensible to investigate the use of animals in therapy in a validated study.

### 03 Ideas for crisis support

It emerges from the research that the present crisis support is not particularly suitable for clients with DID. The location of the refuge must be set up so that account is taken of the feelings of insecurity. This is not the case in practice. Clients should certainly not emerge from the refuge in a worse state than they were on arrival. Possibly suitable locations for crisis support for these clients are locations near a care farm or an anthroposophic clinic. It could also be a social safety net of experiential experts – an experiential knowledge centre.

These ideas will be further investigated in the implementation phase of the project. In this, distinction will be made between the type of crisis that mainly demands a safe environment and the type that needs peace. This peace is intended to prevent an actual crisis (such as the first-mentioned that demands safety).

### 04 DID awareness campaign

If this project has made one thing clear, it is that there is still a huge amount that needs to be changed in the fundamentals if we are to achieve proper accessible care for people with DID. There is very little knowledge about DID in healthcare, in politics, or in society. The distressing tales about how difficult the treatment course of clients with DID have been deserve to be heard. Creation of awareness has been nominated as an objective as part of the implementation phase. By drafting a DID book based on the research report, supplemented with interviews with therapists, and to distribute it via an action committee or make it available somewhere. This plan will be elaborated into a DID awareness campaign in the implementation phase.

# Afterword

Besides contact with partners in adversity and information provision, Caleidoscoop has also set itself the objective of representing the interests of clients with DID and DDNOS. In order to achieve this objective, it is important to gain a view of how the clients perceive their treatment. No qualitative research involving clients with DID and DDNOS has previously been conducted anywhere in the world as far as is known. We are also proud that, in this research, we asked the people themselves about their experiences and needs as regards the treatment of their problems.

The Support Bureau (*HOB*) took the initiative for the project Gold in Hand Plus, in which we, together with three other patient associations, accepted the challenge of initiating this research. It concerned a project in which the experiential expertise of clients is collected by means of scientific research and translated into quality criteria from the client's perspective. With this research, we hope to be able to contribute to a better quality of life for clients with DID and DDNOS.

The quality criteria and recommendations originating from this research could in the near future contribute to more effective treatment. During the implementation period, the recommendations will gain concrete form.

We are very thankful to all clients in the focus groups, the expert group, the artists and the professionals in the sounding board group. We place great value on their active and motivated contribution. Without them, this research would never have come into being. We also wish to express our thanks to the chair of the sounding board group, Tom Horemans. On behalf of Caleidoscoop, we thank project leader Cecilia Kalsbeek and researcher Vanesse Platteel for their efforts.

On behalf of Caleidoscoop clients' association

**Wilma Ruis**

*President of Caleidoscoop*

**Peter Verharen**

*Caleidoscoop delegate*

# Appendix A: Research methods

In the study 'Discussing DID' (*Praat mee over DIS*), use was made of qualitative research methods. The method used is explained below. At the same time, the manner in which patient-friendly, scientific research was conducted and how the privacy of the respondents is guaranteed will be covered.

## Qualitative research

Qualitative research is focused on obtaining information about what is happening with a certain target group and why. This form of research reveals in-depth information by investigating the target group's underlying motivations, opinions, wishes and needs. It considers the why of dominant opinions and particular behaviours. In this, conscious motivations of the target group are discussed, while unconscious motivations may also be revealed. In this study, use was made of focus groups.

## Recruitment and response

All 150 members and donors of Caleidoscoop were contacted via a personal letter. Also, recruitment forms were distributed via various TRTCs (Specialist Trauma Centres). In total, 41 people applied to participate in the focus groups. These included one man. In the application form, respondents answered questions about matters including the diagnosis (the type and time of diagnosis), the first contact with the therapist (psychologist, psychiatrist and/or MHC), the current treatment,

the treatment in the past, the years of treatment targeted at DID/DDNOS and the phase of treatment. In order to allow the focus group meetings to proceed as safely as possible, there were conditions on participation. Participants had to have experience with group therapy or contact with fellow sufferers, to be good at remaining in the here-and-now and able to travel independently.

## Focus groups

A focus group is a structured discussion with a small group of people (on average seven), supervised by an experienced discussion leader, who is supported by an assistant. The discussion leader allows the group to contribute subjects spontaneously and pays particular attention to keeping the focus on the research question. Where necessary, the discussion leader asks further questions and possibly introduces subjects from a previously-prepared topic list. This only happens if these subjects have not yet come up spontaneously.

The method is applied to obtain information about the preferences and values of (diverse) people with respect to a certain subject.

Another purpose is to be able to explain why they have these opinions. During a focus group, a structured discussion is conducted for about two and a half hours with an interactive group in a tolerant, reassuring environment. No attempt is made to reach consensus.

A focus group may be seen as a combination of a targeted interview and a discussion group. The method is flexible; participants get the chance to question each other and to consider the answers deeply. Focus groups, in contrast to individual interviews, allow the participants to develop and present their views in a rather natural social context, which probably links up more closely with the way in which people form their opinions in everyday circumstances. Moreover, the discussion can clearly expose the underlying reasoning and thoughts on which people base the opinions they have stated out loud.

Based on the collection of experiences from people with a dissociative disorder, both good and bad experiences, it becomes clear what they expect from the care, what they need and what helps them. For this, their experience of their condition and the adaptations they must make in their daily life are also of importance. In the discussion with other clients their own experience becomes clearer. "I don't have that, what I have is..." The method is relatively simple for the participants, so that they rapidly understand what the process comes down to and what is expected of them.

## Scientifically responsible

Although it is anecdotes that are collected, scientific research needs to surpass the anecdotal level. When is qualitative research valid in the social sciences? When the research meets the following requirements: it is (1) set up systematically, (2) transparent and (3) reproducible<sup>8</sup>. The study 'Discussing DID' (*Praat mee over DIS*), complies with all these requirements.

The research was set up in a systematic manner. The methods used and data are transparent. All focus groups were transcribed verbatim and are open – by appointment – for consultation. The research is reproducible. If it were conducted in a similar way with the same population, very probably comparable outcomes would be obtained. This happens primarily when there is information saturation.

## Information saturation

Information saturation is a major concept in qualitative research. It in fact means that the researchers have continued just long enough with the holding of meetings for focus groups that they obtained no more new information. This also means that if a meeting for a focus group with a comparable design were held again, the same answers would be obtained. This reproducibility and comparable outcomes make the research scientifically responsible.

A-1

A-2



## Ethical considerations

In the ethical considerations, the two basic concepts used were *informed consent* and *confidentiality*<sup>9</sup>.

*Informed consent* means that the respondents are told about all relevant aspects of the research. They are able to understand these aspects. Besides this, the respondents have to be able to make a rational decision about their cooperation in the research, and this cooperation must not arise from coercion or other 'improper' influences.

*Confidentiality* in this context relates to the protection of the identity of the respondents when the research is published. It was expressly the intention to comply with this, by reporting the quotes anonymously and keeping the description of the participant's profile concise.

Places, the names of doctors, therapists and specific institutions or centres were omitted and replaced by an X or Y. To be able to place the information, it is indicated in the quotes whether they concern an MHC institution, a self-employed therapist or a TRTC. The respondents gave permission to make sound recordings.

## Selection procedure for focus group participants

All applications were grouped by province. Then the people were approached with a specific proposal for participation in a focus group with fellow patients in the neighbourhood. If someone could not come at that time, someone else on the list was called.

## Participant profile of respondents

To protect the privacy of the respondents, the participant profile was consciously kept concise. In total, 22 women participated in the focus groups. Spread all over the Netherlands, four meetings of focus groups were held.

## Analysis and reporting

Sound recordings were made of the focus groups that were then transcribed verbatim. After completion of the data collection, all data were analysed with the help of coding. Coding is a method in which all information is read through several times. From the data, major themes in the topic list were nominated. Then connections were made between the different themes. For each theme, the information was grouped to serve as a foundation for the findings. For each theme, a selection was also made in the quotes; the choice fell on the one that best reflected what the theme concerned was about. The research report, including the results, was presented to the sounding board group and expert group for reflection.

## Draft quality criteria

After the sounding board group and the expert group had reacted to the research report and in discussion had indicated priorities about it, the researchers went to work with this feedback to arrive at *draft quality criteria* from the client's perspective via the modified AIRE instrument<sup>10</sup>. These draft criteria were discussed at the second meeting of the sounding board group and the expert group.

## Read-through

With the feedback from this second round, the researchers started to focus the draft criteria more closely. The second version of the draft criteria was presented to the sounding board group and expert group for reflection via an e-mail questionnaire.

This was the read-through. If necessary, discrepancies from the read-through were discussed with the advisor. All answer forms were summarised together, supplemented with a reaction in which it was stated what had been done with a recommendation. The whole was sent to the reading group together with the last (final) version of the quality criteria.

<sup>9</sup> Hardon, A. et al. (2001): *Applied Health Research. Anthropology of health and health care*. Amsterdam: Het Spinhuis.

<sup>10</sup> 'Appraisal of Indicators through Research and Evaluation': this guideline for the development of quality criteria was developed with the AMC in 2006, commissioned by the Dutch Order of Medical Specialists.

# Appendix B: Participant list

The following people collaborated in the realisation of the quality criteria for the care of dissociative disorders from the client's perspective:

## Focus groups

The 22 women who participated in the four focus groups, spread throughout the Netherlands.

## Expert group

The seven expert clients who are not mentioned by name for privacy reasons.

## Advisor

The Advisor and Chair of the sounding board group,

[Tom Horemans](#), psychiatrist

## Sounding board group

[Marieke Hoven](#), Psychomotoric Therapist

[Marjan de Jong](#), Verbal Therapist

[Marleen Muthert](#), Expressive Therapist

[Ingrid Nissen](#), Psychomotoric Therapist

[Tom Oortwijn](#), MHC Psychologist/Psychotherapist

[Desiree Tijdink](#), Psychiatrist

## Researchers

[Cecilia Kalsbeek](#), Project Leader and Discussion Assistant

[Vanesse Platteel](#), Project Worker, Discussion Leader and Chair of expert group

## Sponsor and delegate

The executive board of Caleidoscoop, national association for people with a dissociative disorder, Delegate [Peter Verharen](#)

## Illustrations

p. 20, charcoal drawing - [Janneke Klein Tijssink](#)

pp 24 and 36, paintings - [Erna Sievers](#)

p. 28, photo - [Lisa Beukers](#)

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# GOLD IN HAND PLUS

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The book you have in your hands describes the gold that was mined from the project 'Gold in Hand Plus'. This gold consists of the knowledge of clients with dissociative identity disorder (DID) and dissociative disorder not otherwise specified (DDNOS). In focus groups, they indicated what for them is the optimal reception, diagnosis and treatment. This information is an indispensable addition to the knowledge that is available from evidence-based practice. In this project, quality criteria from a client perspective were developed for people with DID. The criteria were formulated after unique qualitative research with clients and after discussions with healthcare professionals and experiential experts. These criteria can support care providers and clients to improve DID care.

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