



The  
University  
Of  
Sheffield.

# **Improving care and treatment for adults with a visual impairment and serious mental illness**

## **From tacit knowledge to a logic model of current practice**

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## ABSTRACT

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### Introduction

Adults with a visual impairment (VI) and serious mental illness (SMI) have diverse and complex needs, making the provision of care and treatment challenging. Within the Robert Coppes Foundation, a specialist care provision organisation in The Netherlands, knowledge about the care and treatment for these adults exists but only in tacit form, making it difficult to describe and communicate the key elements of its approach. This study aimed to identify the tacit knowledge of professionals regarding the care and treatment of this population and transform this knowledge into a logic model.

### Method

A participatory action research approach was used to integrate clinical expertise, service users values and best research evidence. By revealing the tacit knowledge of professionals, eliciting the experiences and expectations of service users and searching for available evidence relevant to care and treatment, a logic model was constructed. This model was then validated by presenting this model to a larger group of professionals and service users.

### Results

Adults with VI and SMI were described as being vulnerable and with complex needs, having fragile trust, lacking feelings of basic safety and problems in attachment. Three different phases in care and treatment were identified: build-up, stability and intervention. The importance of a specialised setting was revealed, with an emphasis on the relationship between the professional and service user and the way care is facilitated by the organisation. Professionals expressed a need for working towards more specific outcomes and developing a uniform approach within the phases.

### Discussion

A clear logic model of current practice could be established, revealing the key elements in the care and treatment for adults with VI and SMI and aspects that are still unclear or need further clarification. These form the basis for future research leading to improvements of the care and treatment for these adults.

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## PREFACE

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After finishing my research master in behavioural sciences at the Radboud University in Nijmegen, The Netherlands, I started working at the Robert Coppes Foundation. I immediately felt connected and at home in this small and self-willed organisation and lost my heart to its service users, who struggled with complex needs due to their VI in combination with a SMI.

During the years, I worked as a care worker and behavioural scientist in this organisation. Due to the specific target group, its professionals (including myself) developed specific knowledge about how to best provide care and treatment to adults with VI and SMI. However, it was difficult to retrieve this knowledge, or name the specialist activities of this organisation. This became known as the 'Coppes-way', however no specific answer was available on what aspects could be identified as this 'Coppes-way'.

Furthermore, I struggled with the possibility to provide evidence-based practice, as different evidence-based protocols or working methods could not be one-to-one applied to our service users, due to their complex needs (as a consequence of their VI, SMI or other possible comorbidities and the combination of these). For each service user, a new or different path should be constructed.

When our CEO shared her ideas to transform our organisation to a centre of expertise, by making the tacit knowledge about the care and treatment for adults with VI and SMI explicit and build a knowledge base, I felt that this was an important step for improving the care and treatment to our service users. This formed the beginning of this research project, in which I was given the opportunity to gain answers on the struggles I experienced in current practice. Therefore, I am proud to present this PhD-project, in which a research was conducted from within the organisation and with a sector-wide perspective. The results of this research will provide the different professionals with the theoretical assumptions behind their working methods and offer a framework on which they can substantiate their decisions in practice and improvements can be made.

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## DECLARATION

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*I, the author, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means ([www.sheffield.ac.uk/ssid/unfair-means](http://www.sheffield.ac.uk/ssid/unfair-means)). This work has not been previously been presented for an award at this, or any other, university.*

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## CHAPTER 1: GENERAL INTRODUCTION

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In this dissertation the care and treatment for adults who have a visual impairment (VI) and serious mental illness (SMI) as provided by the Robert Coppes Foundation (RCF) is studied. The RCF is a specialised care organisation, providing outreach care, residential care and day-time activities for adults with VI who experience complex needs due to multiple morbidities. A substantial proportion of its service users experience a combination of VI and SMI. These adults have complex and diverse needs (Boessen et al., 2016). Each person experiences a unique combination of problems and needs, with a cumulative impact on their daily functioning. Their VI can trigger the problems related to their SMI and vice versa. Furthermore, their ability to compensate for their VI and/or SMI is low. For example, a person with VI and psychosis does not have the ability to do a visual reality check on their delusional thoughts.

Due to these challenges, these adults need a specific approach that cannot be provided by the general care providers for people with VI or mental health problems. Over the years, the RCF has gradually specialised in providing care and treatment for this target group and their approach seems to fit the needs of their service users (RCF, 2015). However, the organisation cannot provide a description of what the key elements of their approach are nor what the effects of their care and treatment are. As a result, they are not sufficiently able to demonstrate the importance of a specialised organisation for their specific service users. Professionals in the organisation see this as a gap and want to develop a more explicit and more clearly structured care and treatment approach, based on which their practice can be further professionalised and training and knowledge exchange can be provided. This is also important from an external accountability perspective: funders will want to know what value they get for their money. Finally, it is important for service users to have more insight into the programme they 'undergo'.

The aim of this research project was to work with professionals and service users of the RCF on the development of an agreed logic model of the care and treatment for adults with VI and SMI. This logic model should describe the key elements of the approach, its general aims, and the requirements that need to be met to optimally support the service users. To achieve this a participatory action research (PAR) approach was followed, in combination with literature reviews. Together with professionals the key elements of current practice and the reasoning behind them were made explicit. In the literature, a search for research evidence relevant to care and treatment of this target group was conducted, and with service users their experiences and expectations were

## CHAPTER 1

uncovered. The results from all these three sources (professionals, research evidence and service users) were combined into a logic model. This model was validated with a larger group of professionals and service users. The result is much more clarity about the specific approach of the RCF. This is an important step forward in the ambition to develop a more explicit care and treatment approach. Based on this logic model individual care plans can become more focused and targeted, and specific interventions can be more clearly evaluated for their effectiveness.

In this first chapter, the subject of the study is further introduced, by discussing the contextual background (section 1.1), the rationale for the study (section 1.2), and the aim and research questions formulated for the research project (section 1.3). The chapter ends with an overview of the structure of the dissertation (section 1.4).

### 1.1 Contextual background

In this section, the contextual background of the study is provided by defining VI and SMI, describing the prevalence of adults with VI and SMI, and describing the provision of VI-care and the way health care provision is structured in the Netherlands.

#### 1.1.1 Description and definition of visual impairment (VI) and serious mental illness (SMI)

##### VI

Visual acuity is measured with the Snellen chart, in which letters should be read in different lines with different sizes at 6 metres (20 feet) distance. An indication of the visual acuity can be given by describing the difference between the distance needed to read a line of the Snellen chart between a person with a normal acuity and that of a person with a visual impairment. For example, 6/12 indicates that a person with a visual impairment can read the line in the Snellen chart at 6 metres, that can be read at 12 metres by a person with normal acuity (Colenbrander, 2001). In the most recent version of the International Classification of Diseases (ICD-11, WHO 2019) the World Health Organisation (WHO) classifies a VI in six different categories, based on the visual acuity in the best eye of a person with the use of corrective aids. Also, the visual field of a person is taken into account. In table 1.1 (p. 20), these different categories are presented, representing the different notations of visual acuity as used in US (20/20 feet), Great Britain (6/6 metres) and Europe (decimal notation) (Colenbrander, 2001). Furthermore, a visual field of the better eye no greater than 10 degrees in radius around central fixation should be placed under category 3.

**Table 1.1**

*Categories of VI as defined by the WHO in the ICD-11 (WHO, 2019).*

<b>Category</b>	<b>Worse than</b>	<b>Equal to or better than:</b>
0. No VI		6/12 5/10 (0.5) 20/40
1. Mild VI	6/12 5/10 (0.5) 20/40	6/18 3/10 (0.3) 20/70
2. Moderate VI	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
3. Severe VI	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/400
4. Blindness	3/60 1/20 (0.05) 20/400	1/60 1/50 (0.02) 5/300 (20/1200) or count finger (CF) at metre
5. Blindness	1/60 1/50 (0.02) 5/300 (20/1200)	Light perception
6. Blindness	No light perception	

In the Netherlands, the guideline for vision disorders, rehabilitation and referral (Van Rens et al., 2011) defines low vision in a person as a visual acuity between 0.3 and 0.05 or a visual field between 30 and 10 degrees (categories 2 and 3 of the ICD-11) and blindness as a visual acuity below 0.05 or a visual field below 10 degrees (categories 4, 5, and 6 of the ICD-11). Van Rens et al. (2011) also emphasize taking into account other factors that could influence the visual function of a person, such as contrast, visual acuity in darkness and how a person can function with their VI on a physical, individual and social level, as is described in the International Classification of Functioning, Disability and Health (ICF) of the WHO.

### SMI

A mental illness affects a person's thinking, feeling or mood, leading to problems in daily functioning or in the ability to relate to others (American Psychiatric Association, 2013). A mental illness is present when the problems experienced by a person can be classified in one of the disorders described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). These disorders include mood and anxiety disorders, traumatic or stress-related disorders, psychotic disorders, addictive disorders and personality disorders (American Psychiatric Association, 2013). In the USA,

the National Institute of Mental Health (NIMH) divides mental illness into two categories: *any mental illness* and its more severe subset *serious mental illness* (SMI). The following definition of SMI was established in the act to inscribe the Substance Abuse and Mental Health Services Administration (SAMHSA) in the Federal Register of the USA (SAMHSA, 1993):

*'Adults with a serious mental illness are persons: (1) age 18 and over, (2) who currently or at any time during the past year, (3) have a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the DSM-III-R, (4) that has resulted in functional impairment which substantially interferes with or limits one or more major life activities...All of these disorders have episodic, recurrent, or persistent features; however, they vary in terms of severity and disabling effects.'* (p. 29425).

This definition is operationalised by Ruggeri et al. (2000) by describing two criteria: *'1. any mental disorder with a Global Assessment of Functioning (GAF) score  $\leq$  50 and 2. duration of service contact (care and/or treatment needed in any form)  $\geq$  2 years'*. (p. 149). GAF is used in the DSM-5 to indicate levels of functioning with scores ranging from 100 (excellent) to 1 (permanent danger to self or society) (American Psychiatric Association, 2013).

For this study, the Dutch version of the definition for SMI will be used (in the Netherlands the abbreviation EPA is used for SMI), which is formulated in Dutch by Delespaul and Consensusgroep EPA (2013) with the use of the following criteria:

*'... a person has a mental disorder in need of care or treatment; involving serious impairments in social and/or societal functioning; this is structural and over a longer period of time. The impairment is caused by and a consequence of the mental disorder and coordinated care from professionals in care networks is needed to realise a treatment plan.'* (p. 429-430, translation by the author).

Disorders that frequently lead to SMI in the Netherlands include non-affective psychoses (schizophrenia), problematic drug use, personality disorders and autism.

### 1.1.2 Prevalence of adults with VI and SMI in the Netherlands

In this section, the prevalence of persons with VI or SMI is first described separately. Based on these estimations, more information is given on the estimated number of persons with VI and SMI.

#### Prevalence of VI

In the Netherlands, the prevalence of people with VI was investigated by Limburg and Keunen (2009). They estimated that in 2008 a total of 310,900 people in the Netherlands either were blind (76,700 persons with a visual acuity of 0.02 or lower) or had low vision (234,200 persons with a visual acuity

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between 0.3 and 0.02). Based on these numbers, a projection was made for 2020, at which time they expected that 367,100 people would either be blind (85,300) or have low vision (281,800). This is around 2% of the total Dutch population. The main cause of blindness in the Netherlands is macular degeneration, but other highly prevalent causes are cataracts, refractive errors, glaucoma and diabetic retinopathy. Low vision is mainly caused by cataracts, but also by refractive errors, macular degeneration and diabetic retinopathy (Limburg & Keunen, 2009).

Bourne et al. (2018) have estimated the prevalence of VI in the world and for different regions. They estimated prevalence in 2015 as being 32.02 million blind people and 216.60 million people with low vision worldwide (around 3.5% of the total population worldwide); for Western Europe the prevalence is estimated to be 1.16 million blind people and 9.61 million people with low vision (around 5% of the total population in Western Europe).

### Prevalence of SMI

According to the WHO (2001b), a total of 450 million people worldwide were estimated to suffer from a neuropsychiatric condition in 2001. Prevalence rates for an SMI specifically were not given. Based on the World Mental Health Surveys of the WHO (Demyttenaere et al., 2004), around 2.3 % of the Dutch population was estimated being faced with SMI (approximately 375,000 persons). In 2011, the prevalence of people with SMI in the Netherlands was estimated at 281,000, showing that this number seems to be decreasing. Of this number a total of 160,000 persons are aged between 18 and 65 years and were expected to receive mental health, addiction or forensic care in 2012 (Delespaul & Consensusgroep EPA, 2013).

### Prevalence of adults with VI and SMI

A search for aggregated data about the prevalence of adults with VI and SMI was conducted by Van Buijsen et al. (2017). Different centres of expertise, public authorities and related organisations were contacted to obtain more information about prevalence rates. None of these organisations could provide aggregated data. An additional online survey sent to 621 care organisations that are members of the Dutch Association for Disability Care (VGN, according to its initials in Dutch), Dutch Association of Mental Health and Addiction Care (GGZ NL, according to its initials in Dutch) or Dutch Association of Nursing Homes (Actiz in Dutch), revealed that adults with VI and mental illness receive care and treatment in different organisations for disability care, mental health care or nursing homes. Among the 75 organisations that responded, a total of 34 different organisations reported that among their service users one or more adults had a combination of VI and mental disorder. Of these organisations, 15 organisations reported providing disability care, 3 reported providing mental health care, 10 reported being a nursing home and 6 reported providing care in another sector.

Based on the results of this survey, no exact data about the prevalence of adults with VI and SMI can be given. However, a rough estimation of the prevalence can be calculated based on the prevalence numbers calculated for a VI and SMI in the Netherlands. Demyttenaere et al. (2004) assessed that around 2.3% of the Dutch population is faced with SMI. If this percentage is recalculated for the projected number of 367,100 people having a VI in the Netherlands in 2020 (Limburg & Keunen, 2009), an expected 8,000 to 9,000 persons are faced with a combination of a VI and SMI, assuming for these purposes that VI and SMI are effectively independent health conditions and that the number of people with SMI and VI have remained stable since 2004 and 2009. Based on the results of the survey, it is expected that the group of persons with VI and SMI who receive care and treatment in the Netherlands are fragmented over different health care sectors. And therefore, it is difficult to quantify and understand the needs of these adults.

### 1.1.3 Provision of VI care in the Netherlands

In the Netherlands, three organisations specialise in providing care to persons with VI: Royal Dutch Visio (approximately 18,000 service users), Bartiméus (approximately 9000 service users) and RCF (approximately 250 service users). The first two focus on providing rehabilitative care to adults with acquired or deteriorated VI, residential care to children and adults with a combination of VI and severe intellectual disability, and specialised education for children with VI and comorbid problems. The RCF has a more limited focus, as described earlier in the introduction. Its main focus lies on providing residential care (internal or outreach) to adults with VI and multiple morbidities, including mental, mild intellectual, somatic, cognitive and/or social problems.

Together, these three organisations form the so-called 'visual sector'. In the past few years, the Dutch government has asked the organisations to cooperate in their activities in order to maintain their specific expertise. They receive specific funding for this. Together with two other associations for persons with a specific VI (the Eye Association and the Macula Association), the organisations have established the consortium 'Visual'. This consortium aims to improve the societal participation of persons with VI, strives for an inclusive society and stimulates a broad awareness of these subjects. In doing so, the consortium is committed to achieving the objectives for persons with VI as stated in the United Nations Convention for the rights of persons with disabilities (CRPD). The consortium has established a work plan for 2020-2022 (Consortium Visual, 2019). One of the aims in this plan is that the knowledge developed by the consortium is easily accessible for persons with VI and their personal and professional networks, in which persons with a VI are involved in all activities of the consortium. The knowledge activities are structured in five programme lines, such as 'I feel



good about myself' and 'I receive the best professional care' (see appendix 1 for a detailed description of all the programme lines). One of the projects coordinated by this consortium is Dare2Share (VIVIS, 2020), in which the application of a methodical and evidence-based working method by professionals is stimulated and facilitated. This is done by exchanging knowledge between the different organisations, describing working methods and evaluating their effectiveness.

### Care provided by the RCF

In 1984 the RCF started as a care organisation with a focus on young adults with VI, helping them to make the transition from living at home with their parents to living an independent life. However, after several years it was acknowledged that many service users did not reach this level of independence due to comorbid mental and/or other disorders, and so the focus of the care and treatment was shifted to providing long-term care. This was considered to better address the needs of these persons and their approach was different from that of the other care providers in the sector, who cater for those with less or other complex problems (such as persons with VI and a severe intellectual disability). Therefore, the RCF has profiled itself as an organisation with a specific population. This resulted in an increase of service users with more and more complex problems, including those with comorbid SMIs.

The RCF has reiterated the importance of continuing to be an advocate for adults with VI and multiple morbidities, including SMI. It has formulated a responsibility to provide these adults and their personal and professional networks with the latest expertise relevant for their care and treatment. It aims to create an environment in which innovation and creating, sharing and applying knowledge about this target group is facilitated by describing their care and treatment, by anchoring expertise as a standard working method within the organisation and by being acknowledged as the national centre of expertise for adults with VI and multiple morbidities in the Netherlands (RCF, 2015). The research presented in this thesis is intended to support the organisation in realising this ambition.

#### 1.1.4 Health care provision in the Netherlands

Currently, specific expertise regarding the care needs of adults with VI or SMI is scattered over different care sectors (namely, the mental health sector and visual sector). To explain why this is the case, first an overview is given of how health care is generally organised in the Netherlands, followed by an outline of the experienced difficulties in the care and treatment of adults with VI and SMI.

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Boot (2018) describes that the provision of health care in the Netherlands is separated into four main sectors:

- the *cure* sector, focused on treatment and cure of acute or chronic physical diseases or disorders, provided through hospitals and rehabilitation centres in a clinical or outpatient setting.
- The *care* sector, mainly comprising nursing homes or disability care services, which provide long-term care in such a way that elderly persons or persons with a disability can live as independently as possible.
- The *mental health care* sector, which provides cure and care to persons with mental health problems.
- The *social shelter* sector, providing care for homeless people, offering them the opportunity to be members of society.

Within each sector, in the first instance care or treatment is provided by a generalist (primary care). People with more complex problems are referred to a specialist (secondary or tertiary care).

### Care sector

Care and treatment for persons with a disability is primarily provided in the care sector. The VGN is the overarching organisation for disability care services, services that can be subdivided into organisations for people with an intellectual disability, physical disability, or sensory disability (auditory or visual). Additionally, the VGN acknowledges three specific groups: persons with severe multiple disabilities who show a combination of (severe) intellectual, sensory and physical impairments; persons with an acquired brain injury (within the group of persons with a physical impairment); and persons with a mild intellectual disability who receive forensic care. Health care services provided by these organisations is financed by the Long-Term Care Act (Rijksoverheid, 2014), and the eligibility for care and treatment of a person with a disability is assessed by the Care Assessment Centre (CIZ in Dutch). The CIZ indicates a corresponding care profile (specified for different disabilities, such as a mental health problem, intellectual disability, physical disability or sensory disability), based on which a decision is made concerning the type of organisation through which a person can best receive care and treatment. When a person has comorbid disorders, the CIZ will indicate the primary disorder, that is, the disorder that affects the person's life the most (CIZ, 2011). However, this does not always sufficiently reflect the complexity of a person's problems (VGN, 2019a), a fact that can result in them not receiving the most appropriate care and treatment.

### Mental health care

In the sector for mental health care, guidelines have been implemented to assure evidence-based practice and to maintain and improve the quality of care. A national steering board for

multidisciplinary guideline development in the mental health care sector, coordinated by the Trimbos Institute (n.d.), has developed different multidisciplinary evidence-based guidelines for the indication and treatment of mental disorders. Guidelines have been developed for anxiety disorders, bipolar disorders, depression, double diagnosis, personality disorders and psychotic disorders (see appendix 2 for a complete overview). Organisations in the mental health care sector follow these guidelines in their practice.

### Care for adults with VI and SMI

The disorder-based manner in which Dutch health care is structured makes it difficult to offer individualised care and treatment for adults with VI and SMI. Their needs fall between two sectors: care and mental health care. Neither the care nor mental health care sector is fully equipped to fulfil the complex care needs of adults with VI and SMI. The VI of these persons imposes difficulties on the use of standardised guidelines from mental health care and the evidence-based treatments and approaches indicated in these guidelines. For example, diagnostic tests that use visual assessment cannot be used for persons with VI, making it difficult to assess if a certain treatment is suitable for a person. Also, standard materials used in different treatments are usually printed and/or asks persons to write down their experiences in tables and should be adapted for persons with VI. Although adaptations can be made for persons with VI, this asks creativity of the professional and could influence the effectiveness of the treatment. On the other hand, in the sector for persons with VI, rehabilitation is mainly based on the needs resulting from the VI, and does not take the SMI into account, making it difficult for adults with VI and SMI to obtain suitable care and treatment. As a result, they can have their applications for care and treatment refused, often leading to experiences of failure and eventually resulting in persons who avoid recourse to health care services.

#### 1.2 Rationale for clarifying the specific approach of the RCF

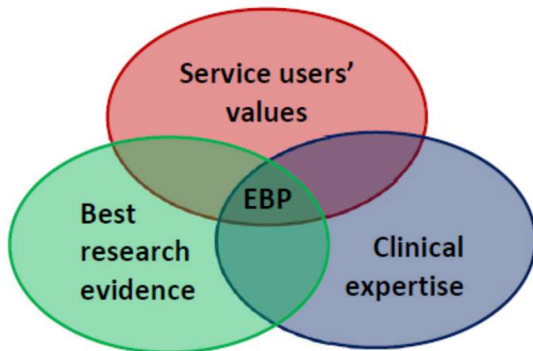
As stated above, the combination of VI and SMI in adults can result in complex and diverse needs. Despite sharing this specific combination of problems, this is still a diverse group. From one person to another a variety of different causes and diagnoses can be observed for the VI and the mental disorder, often combined with other comorbid impairments such as somatic, cognitive or physical impairments. Experiences of professionals in visual rehabilitation care indicate that the combination of the problems of their service users is more complex than the sum of its parts, as an increase of impairments leads to a decrease of possibilities to compensate (RCF, 2015).

Professionals aim to provide evidence-based practice, which is defined by Sackett and colleagues as the integration of *'individual clinical expertise with the best available external evidence from*

*systematic research'* (Sackett et al., 1996). According to Sackett et al. (1996), this clinical expertise is reflected in being able to make more effective and efficient diagnoses and being able to take the situation and preferences of each service user into account (figure 1.1)

**Figure 1.1**

*Overview of the three important sources that should be integrated to provide evidence-based practice (EBP).*



*Note.* Reproduced, in adapted form by the author, from: Transferring evidence from research into practice: 1. The role of clinical care research evidence in clinical decisions, Haynes et al., 1, p. 169, 1996, with permission from BMJ Publishing Group Ltd.

Providing evidence-based practice is considered a challenge by professionals who provide care and treatment for adults with VI and SMI (Boessen et al., 2016). Professionals express that suitable diagnostic methods and interventions are lacking, because mental health problems can have a different effect on persons with VI, making general interventions used in mental health care inapplicable (ZonMw, 2017). Furthermore, the effectiveness of such general interventions is mostly proven in studies that exclude persons with multiple morbidities. Due to the multimorbid problems and heterogeneity of this group, an absence of external evidence to support care planning is felt by professionals (Boessen et al., 2016).

As described in section 1.1.3, through the years the focus of the RCF has changed from being a training house for young adults with VI to providing long-term care and treatment for adults with complex needs, including service users with VI and SMI. These adults form a high percentage of its population of service users compared to those of the other organisations for VI in the Netherlands, namely Royal Dutch Visio and Bartiméus. Although the RCF chose to admit these service users, in the beginning its professionals did not have knowledge of or experience in providing care and treatment to these adults. Over the years, through their personal experiences the individual professionals have gained a rich knowledge base on how to best provide care and treatment to these persons. In a

preliminary study that aimed to explore the problems and needs of this group of service users (Boessen et al., 2016) professionals highlighted several specific components that were thought to be crucial to the delivery of effective care, such as building trust, and the adjustment of evidence-based interventions and approaches. However, this knowledge resides in the individual professionals as tacit knowledge and a uniform and systematic approach across and beyond the RCF is lacking.

### 1.3 Aim and research questions

The aim of this study was to establish an explicit description of current care and treatment of adults with VI and SMI in the form of a logic model, showing not only current care and treatment and its outcomes, but also the assumptions of professionals (underlying theories) and the elements in the context that influence the outcomes. To create this logic model, a participatory action research (PAR) approach with qualitative research methods was to be used to integrate the three important sources that lead to evidence-based practice as indicated by Sackett et al. (1996):

- Transfer the tacit knowledge of professionals regarding their care and treatment (clinical expertise) to explicit knowledge.
- Elicit the experiences and expectations of the service users of the RCF (service users' values).
- Search for the available evidence relevant to care and treatment of this target group (best research evidence).

The resulting logic model was to be validated by presenting this model to a larger group of professionals and service users.

The following research questions were formulated:

1. What are the problems and needs that characterise adults with VI and SMI and shape their care and treatment?
  - a. Which problems and needs and general characteristics do professionals identify in adults with VI and SMI?
  - b. Which comorbid problems and needs are reported in service users' records in the residential care facilities of the RCF?
  
2. What is the state of the art regarding the research evidence for adults with VI and SMI?
  - a. How is SMI as a comorbid problem in adults with VI represented in the literature when compared to the study of other comorbid problems in persons with VI?
  - b. Which published evidence is available relevant to the care and treatment for adults with VI and SMI?

3. What is the tacit knowledge of professionals regarding care and treatment for adults with VI and SMI?
  - a. What can be identified as the tacit knowledge of professionals and how do they describe the current care and treatment they provide?
  - b. Which assumptions do professionals make regarding the care and treatment for adults with VI and SMI?
  - c. Which important contextual elements do professionals consider to influence the care and treatment and its outcomes?
  - d. How can these insights be translated into a logic model?
  - e. In how far do the key elements, aims and requirements described in the logic model correspond to the important elements described in the literature?
  
4. What are the experiences and expectations of service users regarding their care and treatment?
  - a. What do service users identify as their problems and needs?
  - b. How do service users experience their care and treatment and what do they identify as important?
  - c. Which adjustments should be made to the logic model based on the experiences and expectations of service users?
  
5. In how far can the description and logic model of current care and treatment be validated as an accurate representation of current practice?
  - a. In how far do professionals acknowledge this description and the logic model?
  - b. In how far do service users acknowledge this description?

#### 1.4 Structure of the thesis

In this final section of the introduction a short outline for each chapter is given, providing an overview of how the thesis is structured corresponding to the above research questions.

In chapter 2, the theoretical framework is presented by describing the literature available on the transfer of tacit knowledge to explicit knowledge and on the transformation of this to an explicit description of current care and treatment.

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In chapter 3, the theoretical framework is translated into the research design and general procedure, providing an overview of the approach taken in the research project overall and in the different phases of the study.

In chapters 4 and 5, an explicit description of the problems and needs that characterise adults with VI and SMI is provided. These chapters are intended to create a clear picture about the persons that form the subject of study in the remainder of the thesis. In chapter 4, the problems and needs that characterise adults with VI and SMI are explored. Insights into these problems and needs are derived by conducting an iterative process of enquiry in which professionals were asked to share their knowledge on the general characteristics that can be identified in adults with VI and SMI. In chapter 5 this is supplemented with an overview of the specific comorbid problems and needs reported in the service users' records at the residential care facilities of the RCF.

In chapters 6 and 7, the available scientific research regarding adults with VI and SMI is presented. Chapter 6 describes the process and results of a mapping review of the research within the field of adults with VI and SMI and how this group is represented in the literature compared to the study of other comorbid problems in VI. In chapter 7, a scoping review is described that was conducted to gain insights into the research evidence available that is relevant to the care and treatment of adults with VI and SMI, including highlighting gaps in the evidence.

In chapter 8, the tacit knowledge of professionals regarding the care and treatment of adults with VI and SMI is made explicit. By means of a PAR approach professionals are facilitated to become aware of their tacit knowledge and to share this with the researcher and fellow professionals in individual interviews and group meetings. Based on their stories, an agreed logic model of the care and treatment for adults with VI and SMI was established, describing the key elements of the approach, its general aims, and the requirements that need to be met to optimally support the service users. This is then compared to the outcomes of the available research evidence.

In chapter 9, the experiences and expectations of the service users regarding their care and treatment is explored, by asking them to share their experiences of care and treatment, and to identify what they consider important in this care and treatment. Based on these outcomes the logic model as established by the knowledge of the professionals is further refined.

Chapter 10 describes how the explicit description of current care and treatment in the form of the logic model was validated, by a process of presenting the logic model to a larger group of

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professionals and service users and asking them if they acknowledge this description as an accurate representation of current practice.

In chapter 11, the main findings, theoretical and methodological considerations, main conclusion and implications for practice of the overall research project are discussed.



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## CHAPTER 2: THEORETICAL FRAMEWORK

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In this chapter, a theoretical framework is presented based on the literature available about how tacit knowledge can be translated into explicit knowledge (section 2.1) and on the literature regarding different methods and frameworks that provide insights into the important aspects for the description of an intervention (section 2.2). Furthermore, suitable research approaches and designs for this study will be described (section 2.3). At the end of this chapter, the implications of the theoretical framework for the research approach will be discussed.

### 2.1 From tacit knowledge to an explicit description of current practice

In this first section, the literature regarding the translation of tacit to explicit knowledge is described, by providing information about these concepts (section 2.1.1), how a transfer from tacit to explicit knowledge can be made (section 2.1.2) and how this can lead to different levels of knowledge (section 2.1.3).

#### 2.1.1 The concepts of tacit and explicit knowledge

Polanyi introduced the concept of *tacit knowing* in the 1960s (Fischer & Mandell, 2009; Morgan, 2008). Polanyi (1966) stated that '*We can know more than we can tell*' (p. 11) and therefore he claims that there are two dimensions in knowledge: *the tacit dimension* and *the explicit dimension*. Knowledge in the tacit dimension (also referred to as *tacit knowledge*) is '*highly personal and hard to formalize, making it difficult to communicate or share with others*' (Morgan, 2008, p. 5). Knowledge in the explicit dimension (also referred to as *explicit knowledge*) is also personal, but this can be '*codified or structured in a formal and systematic way, and expressed in written words, pictures and/or numbers and can be readily shared*' (Morgan, 2008, p. 5). Tacit knowledge is mainly acquired by informal learning through individual processes, such as direct experience, reflection and internalisation (Hoe, 2006). According to Nonaka (1994), tacit knowledge is '*deeply rooted in action, commitment and involvement in a specific context*' (p. 16).

#### 2.1.2 Facilitating the transfer from tacit to explicit knowledge

The transfer from tacit to explicit knowledge can be facilitated and is an important subject of research within organisational knowledge management. This is another research area than the topic of this thesis, however this research can offer important focus points for facilitating the transfer from tacit to explicit knowledge. Within organisational knowledge management, different authors state that it is through dialogue and sharing of experiences, that mutual trust can be enabled and a mutual language can be built. Together these factors help persons to become aware of their own tacit

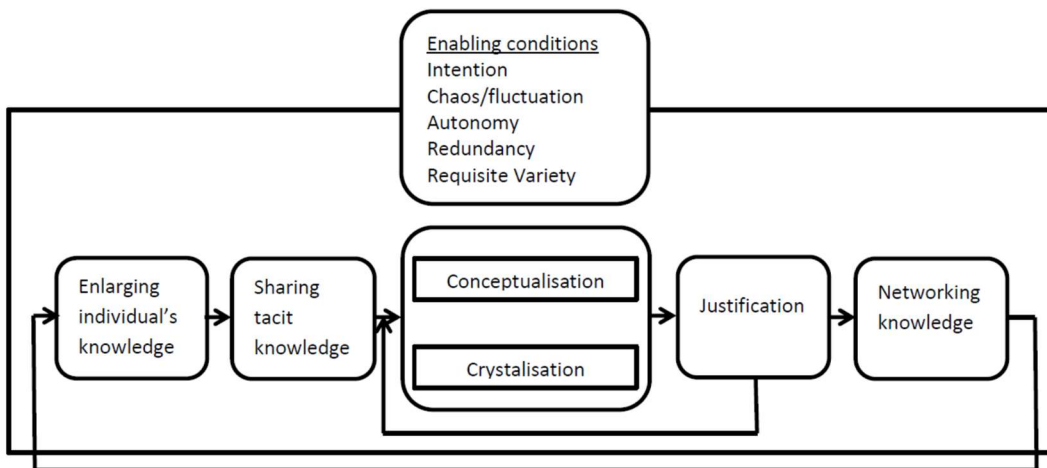
knowledge and this enables them to share this knowledge (Bennet & Bennet, 2008; Joia & Lemos, 2010; Nonaka, 1994). The knowledge creation process described by Nonaka (1994) offers a systematic approach on how these factors can be established. Nonaka (1994) describes four modes of knowledge transfer:

1. from tacit to tacit knowledge: tacit knowledge can be shared by observation, imitation and practice (shared experiences), leading to tacit knowledge by the recipient (*socialisation*);
2. from explicit to explicit knowledge: knowledge exchange through sorting, adding, reconceptualisation of existing knowledge, leading to the creation of new knowledge (*combination*);
3. from tacit to explicit knowledge (*externalisation*);
4. from explicit to tacit knowledge (*internalisation*).

In an organisation, knowledge can be transferred through a continuous exchange between these four modes, also leading to the creation of new knowledge. Nonaka (1994) created a model that explains the process that leads to knowledge creation (figure 2.1).

**Figure 2.1**

*Organisational knowledge creation process*



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First, individual knowledge needs to be *enlarged* by asking an individual to reflect on their tacit knowledge using explicit knowledge, or by reflecting on their actions while putting their tacit knowledge into practice. Then, this tacit knowledge can be *shared* by bringing professionals and other stakeholders inside and outside the organisation together and facilitating them to communicate about their experiences, and so building mutual trust (*socialisation*). By interacting in

this group of mutual trust *conceptualisation* takes place through the process of giving words and meaning to the tacit knowledge (externalisation). These concepts can then be *crystallised* into a concrete form (combination), such as an intervention, which can be evaluated (*justification*) and shared with other stakeholders (*networking knowledge*). Nonaka (1994) shows in the systematic model that the process is continuous, as a justification of the concrete interventions also leads to a more specific understanding of the tacit knowledge, providing new input to the process of *conceptualisation* and *crystallisation*. Furthermore, by sharing the knowledge with stakeholders, professionals are again facilitated to enlarge their own tacit knowledge (internalisation) leading to an iterative process in which the successive cycles lead to a higher understanding of the available knowledge. To promote the formation of new knowledge in an organisation, individual commitment is one of the most important components. This individual commitment can be induced by three factors: *intention*, *autonomy* and a certain level of *fluctuation*. Every professional makes sense of the world and knowledge from their own frame of value judgement, which is *intentionally* gained. A person needs this frame of value judgement to give meaning to information, but this framework also limits the ability to receive and interpret new information in an open way. It is important that an organisation respects the different *intentions* of individuals in the organisation and allows them to act *autonomously* within a wide framework. By doing so, an organisation is more likely to create flexibility in acquiring, relating and interpreting information, which facilitates the formation of new knowledge. Also, *fluctuation* in information is considered as an important factor for creating new knowledge. Knowledge is not only created within an individual, but also through the interaction between other individuals and their environment. When *chaos* or discontinuity in the information occurs, this gives individuals the opportunity to reconsider their knowledge and adapt this knowledge when needed. Other factors that enable the transfer from tacit to explicit knowledge are *redundancy* and *requisite variety*. According to Nonaka (1994), redundant information can help the process of conceptualisation as the sharing of this extra or overlapping information can help in understanding what others try to articulate. Furthermore, the quality of the tacit knowledge of a person is dependent on variety in their tasks and experiences. A *requisite variety* is needed to create new knowledge.

### 2.1.3 Different levels of knowledge

According to De Ronde (2010), different levels of knowledge can be identified in professional practice (as displayed in table 2.1, p. 34). At the level of *personal development*, a professional gains *experienced* and *reflected knowledge* by learning and reflecting with colleagues (which can be identified as tacit knowledge). At the level of *practice-based research*, exchanging the individual knowledge with others creates *methodised* and *evaluated knowledge* (making the transfer to explicit

knowledge). At the level of *theory-oriented research*, through measuring variables and looking for coherences, and then testing these coherences in experiments, *objectified* and *standardised knowledge* can be derived (determining the effectiveness of the way this knowledge is applied in practice).

**Table 2.1**

*Different levels of knowledge described by De Ronde (2010, p. 6)*

<b>Level</b>	<b>Knowledge</b>	<b>Activity</b>
Personal development of professional	Experienced knowledge Reflected knowledge	Learn and reflect
Practice-based research	Methodised knowledge Evaluated knowledge	Exchange and create
Theory-oriented research	Objectified knowledge Standardised knowledge	Measure and test

In this research project, focus will be on transferring tacit knowledge to explicit knowledge. By doing so, the knowledge and experiences of the individual professionals, service users and other stakeholders are transferred from the level of *personal development* of the individual professional to the level of *practice-based research*.

#### 2.1.4 Implications for the current research project

The literature describing the transfer of tacit to explicit knowledge and different levels of knowledge, both show the importance of reflecting on one's own knowledge, becoming aware of this knowledge and sharing this with others. To facilitate this process, mutual trust and understanding is needed. By doing so, knowledge can be exchanged, and can also lead to the creation of new knowledge within individual professionals, but also on an organisational level. To facilitate the transfer from tacit to explicit knowledge within the professionals that will participate in this research project, an environment should be created in which the professionals will feel this freedom and safety to reflect on their own knowledge and share this with others. This will be further elaborated in section 2.3, in which the suitable research design will be discussed.

#### 2.2 Obtaining an explicit description of current care and treatment

To reach the level of practice-based research, the tacit knowledge of professionals needs to be translated into an explicit and well-structured care and treatment approach. This section discusses

the scientific literature that addresses the question of how interventions<sup>1</sup> can be described in a sound way and how this can be used as a starting point for evaluating the effectiveness of care and treatment for adults with VI and SMI in the future.

When providing care and treatment, health care professionals need to justify their clinical decisions. Evidence-based practice is considered to be the best foundation for good clinical reasoning. This is defined by Sackett et al. (1996) as *'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients'* (p. 71). As described in section 1.2, professionals are providing care and treatment that is evidence-based when three important components are integrated in their daily practice: their own clinical expertise, the service user's individual situation and preferences, and the best available external evidence from systematic research (as displayed in figure 1.1, in section 1.2).

To determine the current best available external evidence, the effectiveness of an intervention needs to be evaluated. Within the visual sector in the Netherlands an intervention is defined as:

*'concrete methodical actions, techniques and aids used by a care worker or practitioner – often within a broader scope – to reach a certain goal or change within a person or system'* (VIVIS, 2020, p. 5).

That intervention that has the strongest evidence as to its effectiveness, is widely accepted as the main intervention for a specific condition or problem within a target group (RVS, 2017). Randomised controlled trials (RCTs) are usually considered to provide the highest quality evidence (Margison et al., 2000). However, questions have been raised about the applicability of this type of knowledge in practice (Barkham & Mellor-Clark, 2003; RVS, 2017). This type of research is often seen as too narrow, not reflecting the context in which the health services are provided. The outcomes of an intervention can be influenced by many different factors and this should be considered when an intervention is evaluated.

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<sup>1</sup> As described in chapter 1, the primary aim of this research project was to establish an explicit description of current care and treatment for adults with VI and SMI. This description can then be used as a foundation for the development of more specific interventions. Although the description of current practice will focus more on describing the basic elements in current practice, such as the basic approach within current practice, competencies of professionals and preconditions, the literature about describing and evaluating specific interventions offers important indications for the explicit description of care and treatment in this case and is therefore outlined in this section.

### 2.2.1 Background to theory-driven evaluation

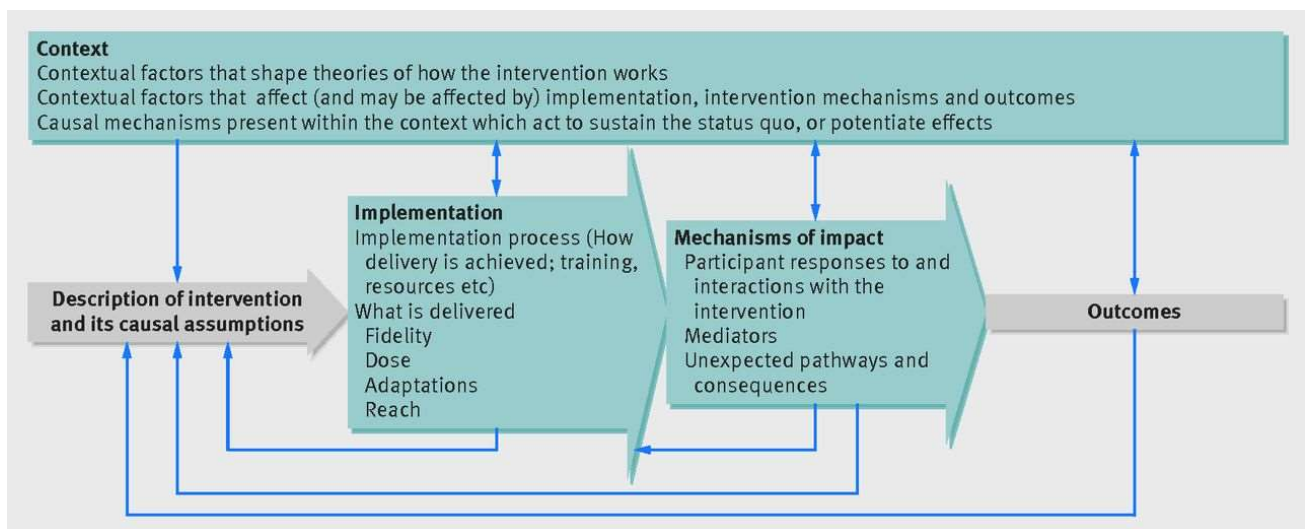
To try to take these other factors into account, alternative research approaches have been developed since the 1980's, which, taken together, comprise 'theory-driven evaluation' (Marchal et al., 2012; Wong et al., 2016). Chen and Rossi (in: Marchal et al. (2012)) were the first to argue that the task of designing an evaluation study can be facilitated by the prior development of a programme theory that explains how, through its implementation, an intervention is expected to achieve its aims (normative theory) along with the underlying assumptions of the programme (causal theory). Another approach is the Theory of Change, introduced by Connell et al. (1995), that uses the development and testing of logic models (see section 2.2.2 for a description) to establish the links between intervention, outcome and context. A theory-driven evaluation approach with a more philosophical foundation and methodology is developed by Pawson and Tilley (1997). They state in their realist evaluation approach that a social intervention arises from (academic) theory. This programme theory is defined as the ideas and assumptions beyond the intervention (units of analysis), that explain why, how and under what circumstances the actions in the intervention lead to change. The effect of an intervention (that is, its outcome) always depends on different mechanisms that are taking place in a specific context. Realist evaluation sees this as context-mechanisms-outcomes configurations (CMOc). The goal in realist evaluation is to develop, test and refine the programme theory about the CMOc of a complex social intervention, gaining insights into the working elements of an intervention, e.g. what works for whom under what circumstances and why (De Souza, 2013; Marchal et al., 2012; Pawson & Tilley, 1997; Wong et al., 2016). These insights can help decision makers to decide whether an intervention is expected to be successful when implemented in another setting. Dalkin et al. (2015) experienced having difficulties in deciding which elements should be indicated as mechanisms and which elements indicated as context. Therefore, they have proposed a refined version of the CMOc, in which a distinction is made between two classes of mechanisms, namely resources and reasoning. They state that *'intervention resources are introduced in a context, in a way that enhances a change in reasoning. This alters the behaviour of participants, which leads to outcomes.'* (p. 4). They expressed this as the alternative formula: M (resources) + C -> M (reasoning) = O, that can help researchers to gain a more detailed picture on how, why and what in the intervention leads to change. Furthermore, Dalkin et al. (2015) propose regarding the 'firing' mechanisms within the theory as elements that operate on a continuous scale, rather than seeing them as a 'switch' that can be turned either on or off.

The UK Medical Research Council (MRC) has developed a framework to guide researchers in the development and evaluation of complex interventions (Moore et al., 2015). A complex intervention is

characterised as an intervention with different interacting components, such as the behaviours required of professionals or service users in the intervention, or which has a number of outcomes. According to the MRC guidance, not only the intervention itself, but also a number of other key functions influence the outcomes of an intervention. These key functions are: the context in which the programme is delivered, the implementation process (what is implemented and how?) and the mechanisms of impact (through which mechanisms is change produced?). In figure 2.2 these key functions are described, and a visual presentation is given of how they are interrelated. To be able to identify the components of influence for each key function, a clear description of the intervention and the causal assumptions is needed.

**Figure 2.2**

*Framework developed by the UK Medical Research Council for the evaluation of complex interventions.*



*Note.* Reproduced from: Process evaluation of complex interventions: Medical Research Council guidance, Moore et al., 350, p.2, 2015, with permission from BMJ Group Ltd.

### 2.2.2 A visual and systematic representation of an intervention: the logic model

Such as clear description and causal assumptions of an intervention can be depicted in the form of a *logic model*. A logic model is defined as ‘a systematic and visual way to present and share your understanding of the relationships among the resources you have to operate your program, the activities you plan, and the changes or results you hope to achieve’ (Kellogg Foundation, 2004, p. 1). By doing so, insight can be gained into the planned work of the intervention (resources and activities) and its intended results (outputs, outcomes and impact). Based on this presentation a theory can then be formulated about how and ‘to what end’ an intervention works (Kellogg Foundation, 2004). A logic model gives insights into the mechanisms and context that influence the outcomes of an

intervention (CMOC) and can inform evaluation methods. The idea was first mentioned in the late 1970s by Wholey and Bennet who developed a forerunner of a logic model (Taylor-Powell & Henert, 2008). Logic models are mainly used in evaluation research, specifically that is referred to as theory-driven evaluation (Bickman, 1987; Chen, 1990) or theory-based evaluation (Weiss, 1997), for measuring causality within a programme and to determine the effectiveness of this causality. By creating a logic model, some of the challenges often faced by evaluators are addressed or reduced, such as the lack of clear goals or objectives for an intervention, the lack of a clear description of the intervention, or the lack of insights into how the intervention was implemented. A number of different variations and types of logic models have been described and developed (American Heart Association, 2006; Kellogg Foundation, 2004; Taylor-Powell & Henert, 2008).

### 2.2.3 The level of evidence of an intervention

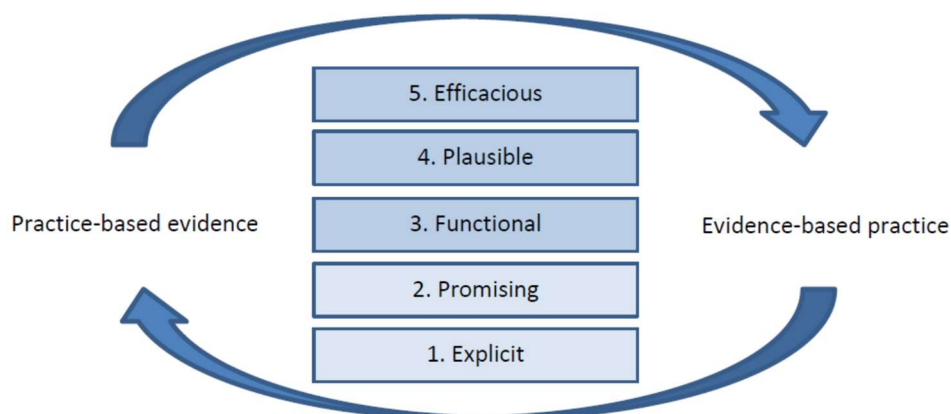
Van Yperen et al. (2017) emphasized the importance of evaluating the effectiveness of an intervention for enabling professionals, researchers and policy makers to make substantial choices about the implementation of interventions for specific problems and/or target groups. They described two routes that can lead to knowledge about the effectiveness of an intervention. In the top-down approach, an evidence-based intervention is implemented in practice where its usability can be further evaluated. The effectiveness of this intervention is determined by following strict criteria in scientific research (such as for randomised-controlled trials). Such an approach is generally known as *evidence-based practice*. On the other hand, in the bottom-up approach, an intervention that is already used in practice is further developed in terms of its clarity and usability, and the resulting real-life data are systematically used to help assess the effectiveness of the intervention. This approach is generally known as *practice-based evidence* (Barkham & Mellor-Clark, 2003). Van Yperen et al. (2017) state that these two routes should not be seen as opposites, but as two approaches that can reinforce each other. They argue for a *result-oriented development*, where the focus lies on describing, theoretically substantiating and monitoring an intervention, and scientifically testing its effectiveness. Van Yperen et al. (2017) state that a large number of interventions are 'intuition-based': in other words, they are mainly present as tacit knowledge in the respective individual professionals, who experience an intervention as effective, but neither the nature of the intervention nor its effectiveness has been made explicit. Either a top-down or bottom-up approach can be used to obtain an explicit description of an intervention and gain insights into its effectiveness. Most importantly, the research approach should connect to the state of development of an intervention. Therefore, Van Yperen et al. (2017) developed a methodological framework that can be used to determine the level of evidence of a specific intervention (see figure 2.3, p. 40). Outside this framework an intervention is considered to be at stage 0, in other words, to exist at the



intuition-based level. In stage 1, an intervention is considered *explicit*: an explicit description of the intervention is present (descriptive instructions). In stage 2, an intervention is termed *promising*: a potential theory is present that provides insights into how and why the intervention produces the expected outcomes (firm theoretical basis). In stage 3, the intervention is *functional*: scientific research shows that service users achieve specific goals and they are satisfied with the result of the intervention (first empirical indications of effectiveness). In stage 4, an intervention is considered *plausible*: it is plausible that the outcomes are a direct result of the intervention (good empirical indications of effectiveness). In stage 5, an intervention is considered *efficacious*: it is *very* plausible that the outcomes are a direct result of the intervention (strong empirical indications of effectiveness).

**Figure 2.3**

*The different levels defined within the methodological framework of Van Yperen et al. (2017) to indicate the level of evidence of an intervention*



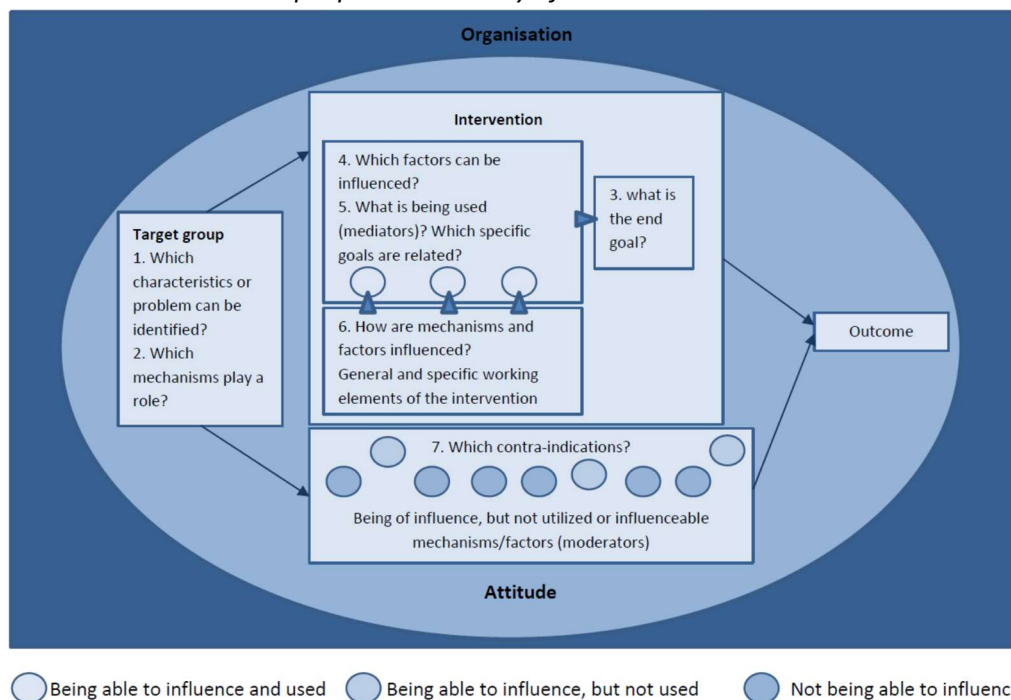
*Note.* Translated by the author from Dutch to English and reproduced from: Zicht op effectiviteit. Handboek voor resultaatgerichte ontwikkeling van interventies in de jeugdsector. [Focus on Effectiveness. Handbook for results-based development of interventions in the youth sector.] Van Yperen et al., p. 77, 2017, with permission from Lemniscaat B.V.

This framework shows the importance of obtaining an explicit description of the essential elements of an intervention (stage 1) and developing a potential theory as to why it should work (programme theory of what, how and why) and with whom (stage 2), before the effectiveness of an intervention can be demonstrated with successively stronger levels of evidence (stages 3, 4 and 5). According to Van Yperen et al. (2017), not only a description of the approach of an intervention and its implementation is needed at the first stage, but also other elements should be clearly described. For example, they stress the importance of a clear description of the target group and the context or other conditional elements that influence the outcomes of an intervention. Also, the name and

origin, goal, executive organisations, similarities with other interventions and its scientific sources should be specified.

An explicit description of these elements forms the basic ingredients for the second stage of the model. Based on these elements, a potential theory as to why and how an intervention should work can be developed. Van Yperen et al. (2017) provide a process model (figure 2.4) that can be used to derive insights about the different mechanisms and factors of influence on a characteristic or problem of a specific target group. These mechanisms or factors differ in the ability to be influenced or used. In the framework, a distinction is made between *mediators* and *moderators*. Mediators are mechanisms and factors that are influenceable and are used to reach a specific goal. Moderators are mechanisms and factors that either are not influenceable, or else which are influenceable but are not used in the specific intervention.

**Figure 2.4**  
*Process model to develop a potential theory of an intervention.*



*Note.* Translated by the author from Dutch to English and reproduced from: Zicht op effectiviteit. Handboek voor resultaatgerichte ontwikkeling van interventies in de jeugdsector. [Focus on Effectiveness. Handbook for results-based development of interventions in the youth sector.], Van Yperen et al., p. 113, 2017, with permission from Lemniscaat B.V.

Figure 2.4 shows that the theory of an intervention starts with the specific characteristics and/or problems of a target group that determine the end goal of the intervention. In these characteristics

and/or problems different mechanisms play a role (moderators and mediators). The intervention focuses on the mechanisms that are influenceable and can be used (mediators), leading to specific goals that provide insights into the way these mechanisms are influenced. The outcome of the implementation of the intervention is not only a result of the intervention itself, but will also be influenced by the mechanisms that serve as moderators. These moderator variables can be indicated as non-influenceable factors that can form a barrier to achieve the desired result and are therefore seen as contra-indications. Furthermore, the attitude of the professional and the organisation can also influence the outcome of the intervention.

### 2.2.4 Implications for current research project

The literature described in section 2.2 shows that, not only the intervention by itself, but also different related factors and mechanisms can influence the outcomes of an intervention, such as the theoretical assumptions underlying the intervention, the context in which the intervention is provided and the way the intervention is implemented (CMOc). These are all factors that have to be described and assessed, when evaluating the effectiveness of an intervention. To gain insights into these factors and how they are related, a logic model of an intervention can be created. This logic model can be used as a starting point, on which improvements can be suggested, the way the intervention can best be implemented described and the effectiveness of an intervention can be evaluated.

By transferring the tacit knowledge of professionals to explicit knowledge and use this knowledge to create a logic model, current practice is transformed from being 'intuition-based' to the level of explicit and promising. By doing so, an explicit description of current care and treatment is made and theories are formed on why and how this current care and treatment is expected to be effective.

### 2.3 Research designs

The literature described in section 2.1 and 2.2 reveal that a research design for this research project should be chosen, in which a safe environment is created for professionals and they are provided sufficient space and possibilities to reflect on their current knowledge and activities and share this with their peers and other important stakeholders. Furthermore, the tacit knowledge that will be revealed by conducting this process has to be transferred to an explicit description of current care and treatment, not only describing the specific activities, but also other mechanisms that can influence the outcomes, such as the theoretical assumptions and the context in which the intervention is provided. In this section, a description of different research approaches is given,

based on this description it is substantiated why a PAR-approach can be used as a suitable research design for this research project.

### 2.3.1 Research fields and methodologies

Different research designs and approaches have been developed within different research fields (Creswell, 2003; Polit & Beck, 2017), according to the subject matter and techniques or methods used to study a subject. According to Creswell (2003) research fields and methodologies differ in their philosophical assumptions about what constitutes knowledge (*knowledge claims*), general research procedures (*strategies of inquiry*) and detailed procedures for data collection, analysis and writing (*method*). He describes four different schools with different perspectives about the construction of knowledge: *post-positivism*, *constructivism*, *advocacy/participatory* and *pragmatism*. In each school, different philosophical ideas about the knowledge claims, strategies of inquiry and method exist:

- In post-positivism a deterministic research philosophy is reflected. This states that a certain cause determines an outcome and therefore their research is prone to search for which cause can be indicated for a specific outcome. This is done by reducing an idea to a small, discrete set of ideas, translating this to a hypothesis about how different variables are connected that can be tested or verified/refined by numeric measures or observations. As a strategy of inquiry, experiments and surveys are used to test hypotheses, and as a method data is collected on predetermined instruments yielding statistical data (quantitative).
- In constructivism individuals seek an understanding of the world in which they live and work and form subjective meanings. These meanings are varied and multiple, needing a research strategy that seeks a complexity of views. Therefore, the goal of research is to understand and capture the participant's view of the situation under study as close as possible. In this search, a researcher takes into account how these views are socially and historically constructed, the specific context of these views and the influence of the researcher's own background on the interpretation of these views. As a strategy of inquiry, different procedures are available, such as ethnography, grounded theory, case studies, phenomenological research and narrative research. In these procedures the method of data collection consists of developing themes out of open-ended, emerging data (qualitative).
- In the advocacy/participatory school, research is focused on creating consciousness and an action agenda of reform that may change the lives of marginalised people. The subjects of study are social issues, such as empowerment, inequality, oppression, domination, suppression, and alienation. Research is conducted in collaboration with the marginalised people under study, giving them a voice in designing questions, data collection and analysis.

Specific research fields give a voice to the position of women (feminism), marginalised or discriminated-against racial or ethnic groups (race studies), lesbians/gays/bisexuals or transgender persons (queer theory), or persons with a disability (disability inquiry); or general studies of the power structures due to society or culture (critical theory). In this school, the same strategies for inquiry and method are used as mentioned for constructivism.

- In pragmatic research the problem is central, and pluralistic approaches can be used to understand the problem. A strategy for inquiry for this school always focuses on the use of a mix of different (sequential, concurrent and transformative) strategies, and the method for data collection consists of both numeric data as well as text (quantitative and qualitative).

### 2.3.2 Qualitative research designs

In the current research project, focus will be on eliciting the participant's view of current care and treatment and understand their reasoning. Therefore, a qualitative research approach can best be conducted gathering open-ended and emerging data. As stated above, qualitative research is mostly conducted within the constructivism and advocacy/participatory school where different strategies of inquiry can be conducted. The following strategies of inquiries are described by Polit and Beck (2017) within research fields that are related to the subject of this study:

- In the field of psychology/philosophy, lived experiences of individuals are studied, either by describing the experiences of individuals within their lifeworld (phenomenology) or by interpreting and giving meaning to individuals' experiences (hermeneutics).
- In the field of psychology, behaviour is observed over time in a natural context (ethology) or behaviour is interpreted as being influenced by the environment (in ecological psychology).
- In the field of sociology, social structural processes within a social setting are studied (grounded theory). These processes can be used to achieve shared agreement in social settings (ethnomethodology) or to make sense of social interactions (semiotics).

A strategy of inquiry that is developed from an advocacy/participatory perspective is the PAR-approach, that focuses on bringing about social change (Polit & Beck, 2017). Within this approach, the focus is on collaboration between researchers and participants in research design and data collection. The researcher participates in the daily practice, and a continuous process of searching, understanding and reflecting is conducted (Glassman & Erdem, 2014; Koch & Kralik, 2006). By using this approach, awareness is created among all participants (including the researchers) leading to insights into the activities and underlying assumptions in daily practice and into how these can be improved.

### 2.4 Implications for research approach

The organisational knowledge creation process of Nonaka (1994), provides a concrete framework to facilitate the knowledge transfer from tacit to explicit knowledge. In this framework, professionals are asked to enlarge their tacit knowledge and share this with their peers and the researcher. Through the process of sharing, according to this process, conceptualisation of the tacit knowledge takes place, which can then be crystallised in an explicit description of current care and treatment that can be justified and shared with stakeholders. The process of enlarging knowledge and sharing can be facilitated by using a qualitative research approach, in which the focus is on creating consciousness in the primary stakeholders (professionals and service users). An advocacy/participatory approach and the collection of open-ended emerging data can be an appropriate approach for facilitating this process in which the PAR-approach (Glassman & Erdem, 2014; Koch & Kralik, 2006) can be used as a strategy of inquiry. By using this approach, participants are guided through different cycles of sharing and reflecting, creating awareness among the participants and researcher. Through this process, it is hypothesised that the individual tacit knowledge and experience of professionals regarding current care and treatment can be transferred from being intuition-based to providing an explicit description of current care and treatment and a potential theory of the working elements in the intervention, as described in the first two stages (explicit and promising) of the methodological framework of Van Yperen et al. (2017). This is a prerequisite of practice-based research (De Ronde, 2010). Moore et al. (2015) advise researchers to establish a logic model of an intervention, providing insights into the programme theory and the elements that influence the outcomes. Van Yperen et al. (2017) also offer a framework that can be used to establish a programme theory of an intervention that has a greater focus on the specific activities within an intervention. In the current study, the focus will be on obtaining insights into the key elements of the approach, its general aims, and the requirements that need to be met to optimally support the service users. Therefore, a logic model (Kellogg Foundation, 2004) will be developed to describe the programme theory, expressing how the resources within current care and treatment are used within a specific context, enhancing the reasoning of participants, and, as a result, how the programme influences outcomes.

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## CHAPTER 3: RESEARCH DESIGN, GENERAL PROCEDURE AND QUALITY CRITERIA

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In this chapter, the research design and processes are presented. Furthermore, in section 3.3 the standards for good evidence within qualitative research are discussed and an explanation is given of how these standards were met within the current research project. In this chapter, the activities to be undertaken across the overall research project are described; each of these activities will be described in a more detailed fashion in the appropriate subsequent chapter.

### 3.1 Research design

The project was conducted using a PAR-approach, with the use of qualitative methods. Within this approach, the focus is on collaboration between researchers and participants in research design and data collection. During the study a continuous process of searching, understanding and reflecting was followed (Glassman & Erdem, 2014; Koch & Kralik, 2006).

This PAR-approach was developed and implied at the instigation and with the input of various actors:

- The study was initiated by the CEO of the RCF, who felt a need for her organisation to be an advocate for adults with VI and SMI and a responsibility to provide adults with VI and SMI with the latest expertise in their care and treatment (as already outlined in section 1.1.3). To achieve this aim, more clarity about the specific approach of the RCF was needed. This need and importance was also felt by the PhD researcher. Before the start of the study, the researcher was employed as a behavioural scientist at the RCF and experienced in her care and treatment for adults with VI and SMI that her approach seemed to fit the need of her service users, but had difficulties in providing an explicit description of this approach. She felt a need for more explicit guidelines and uniformity in her practice.
- The study was designed by the PhD researcher in close collaboration with the advisory board of the study. Furthermore, during the study several reflective meetings would be held with the advisory board. In these meetings the board was updated about the progress and the findings of the study and based on this information the members reflected on how these findings relate to the vision of the RCF and relate to its current protocols used in the care and treatment. Furthermore, the board was asked to provide advice and agreement on the next steps of the study. The board consisted of the following members:
  - CEO of the RCF;

- The manager of healthcare-related care and treatment of the RCF, who was also a member of the team of behavioural scientists of the RCF (see below for further description);
  - the advising psychiatrist of the RCF, who is employed as a physician director/psychiatrist of the mental health care organisation Reinier van Arkel Group;
  - the first supervisor of the PhD candidate from the University of Sheffield, United Kingdom;
  - the co-supervisor who is employed at Zuyd University of Applied Sciences, Heerlen, The Netherlands.
- During the phase of data collection and interpretation, the participants of the study (a group of professionals and a group of service users) would be closely involved in the study and regularly informed of progress, and asked to provide their opinions about the way data was collected, the output of the meetings and the interpretation of the data.
  - Within the RCF, a team of behavioural scientists is present. Next to being a member of this team, each member is also involved with one or more of the residential care teams, outreach care teams and/or teams for day-care activities. Furthermore, they have an important role in other activities of the RCF, such as intake of (possible) new service users, applying for the eligibility for care and treatment of a person at the CIZ, advising role to management about policy, and being involved in expertise activities of the RCF and/or the consortium 'visual'. Therefore, these persons have a broad representation within the RCF and can take a 'birds-eye view' on the care and treatment provided for adults with VI and SMI. This makes them an important source for this research project. The behavioural scientists of the RCF would be regularly updated about the progress of the study and asked to provide their input.

By using this approach, it was intended that awareness would be created among all participants (including the researcher) and that through the close involvement of these different groups an explicit description of current care and treatment would be arrived at. This description would then be further supplemented with and validated against the current external evidence and other resources available within the RCF, such as the records of service users. During the study, different exercises of sharing and reflecting on knowledge with different participants would be performed, in which daily practice was shared with the researcher and participants were asked to reflect on this. By undergoing these episodes of sharing and reflecting, participants would be encouraged to become aware of their tacit knowledge and to progress through the stages of the knowledge creation process (Nonaka, 1994) as described in section 2.1.2. In the current study, the participants and researcher would



together be following an iterative process of inquiry, consisting of individual in-depth interviews and participatory group meetings (see section 3.2.4 for a more detailed description). By following this process, it was intended that mutual trust and equality would be facilitated and, as a result, that participants and researcher would be better able to build a mutual language.

### 3.2 Procedure

In this section, information about the general overall procedure of the study is presented, by describing the context in which the study was conducted, its ethical issues, the participatory groups who took part in the iterative process and other resources that were used for data collection. Furthermore, the activities that were conducted and methods used for data collection will be described and presented in a flowchart.

#### 3.2.1 Context

Main focus of the study was on current care and treatment as it is provided within the residential care facilities of the RCF. The study would involve consulting professionals providing care and treatment and service users receiving care and treatment in those facilities. In addition, professionals from two other care organisations within the visual sector (Bartiméus and Royal Dutch Visio) and one representing an organisation for general mental health care (Reinier van Arkel Group) were included in the consultations. By including participants from different organisations, it was intended that insights into the specific features of care and treatment provision for adults with VI and SMI in their respective organisations would be obtained.

#### 3.2.2 Ethical issues

Ethical approval for the conduct of the research project was obtained in the Netherlands at the Medical Ethical Review Committee (METC in Dutch) Zuyderland – Zuyd on 21<sup>st</sup> February 2017 (number 17-N-42). The committee stated that the Dutch Medical Research Involving Human Subjects Act (WMO) did not apply to the study, because there is no indication that persons are subordinate to specific acts or forced to perform specific actions. The committee had no objections to the conduct of the study, assuming the code for good clinical practice and the personal data protection act (WBP) were observed.

The ethical approval and ethics process of METC Zuyderland – Zuyd was also presented to the School of Health And Related Research (SchARR) research ethics committee of the University of Sheffield and was acknowledged on 6<sup>th</sup> March 2019. In appendix 3 a full overview of the admission and the approval is provided.

Each participant received an information letter describing the purpose and activities of the study. Before participation they were asked to provide their informed consent by signing the consent form (added in the information letter in appendix 3). All information about the study was stored on a secure place that could only be accessed by the persons involved in the research. Each participant was given an individual code, which was used to store the data of that specific person or to refer to information of that specific person in a group meeting. A key file with an overview of the codes for the specific persons was stored separately.

### 3.2.3 Participatory groups and additional resources

As outlined in section 3.1, the members of the advisory board were to be regularly informed and consulted during all phases of the research project and were to constitute an important partner during the study. Furthermore, the team of behavioural scientists were to be consulted. Additionally, the following participatory groups were constituted for the phase of data collection and interpretation:

- Professionals from three low-vision organisations (RCF, Bartiméus and Royal Dutch Visio) and a mental health organisation (Reinier van Arkel Group) in the Netherlands who are experienced in providing care and treatment for adults with VI and SMI in a variety of roles and with various years of experience;
- Service users with VI and SMI who obtain care and treatment in one of the residential care facilities of the RCF;
- Members of an online community of practice called Psyvisnet, which has its home on a digital platform of the same name that has been developed by the RCF (Teunissen et al., 2017). Professionals from different organisations in Dutch health care can subscribe to this platform. Through Psyvisnet members are able to share experiences about the care and treatment of persons with VI and comorbid mental illness. Professionals can share or read information, such as useful procedures, interventions or scientific evidence; they can consult the other members by asking specific questions about a case; they can access an overview of the members and their specific knowledge; and can share news of relevant activities such as congresses, training sessions or workshops. The aim of this platform is to bring professionals together and to enable them to share knowledge about the care and treatment for persons with VI and comorbid mental illness.

In table 3.1 (p. 50) an overview of the characteristics of each group is given.

The following additional resources would also be used for data collection:

- Records of the service users in the residential care facilities;
- The current available research evidence relevant to the care and treatment of adults with VI and SMI.

**Table 3.1**

*Overview of the characteristics of each participatory group.*

<b>Involvement</b>	<b>Group</b>	<b>Participants</b>	<b>Role</b>	<b>Organisation</b>
Data collection and interpretation	Professionals	Professionals with knowledge and experience of providing care and treatment for adults with VI and SMI	- Psychologist - Educationalist - Psychiatrist - Care coordinator - Care worker	- RCF - Royal Dutch Visio - Bartiméus - Reinier van Arkel Group
	Service users	Service users with VI and SMI receiving care in a residential care facility		RCF
	Psyvisnet	Members of online platform for care professionals who are, in some form, providing care and treatment to persons with VI and comorbid mental illness	- Psychiatrist - Psychologist - Social/ care worker - Nurse - Therapist (such as occupational therapist or physiotherapist)	Different organisations in the Netherlands (mental health, disability care, nursing homes)
Consultation/ reflection	Advisory board	Different members who are involved in the research project and have an advising role about the design of the study and the interpretation of the outcomes	- Members of the strategic team of the RCF - Psychiatrist - Researchers	- RCF - Reinier van Arkel group - University of Sheffield - Zuyd University of applied sciences
	Behavioural scientists	Members of the team of behavioural scientists at the RCF	- Psychologists - Pedagogical scientists	RCF

By consulting different participatory groups, a representative set of the total group of professionals and service users would be involved in the research. After each session with a participatory group, the data and the model of current care and treatment would be checked by the participants. In

addition, the results of the sessions would also be presented and discussed with the advisory board of the study. Furthermore, the behavioural scientists of the RCF would be regularly updated about progress and asked to provide input.

### 3.2.4 Activities

In figure 3.1 (p. 52), a flowchart of the specific activities during the different phases of the study is presented showing that the study was divided into four phases.

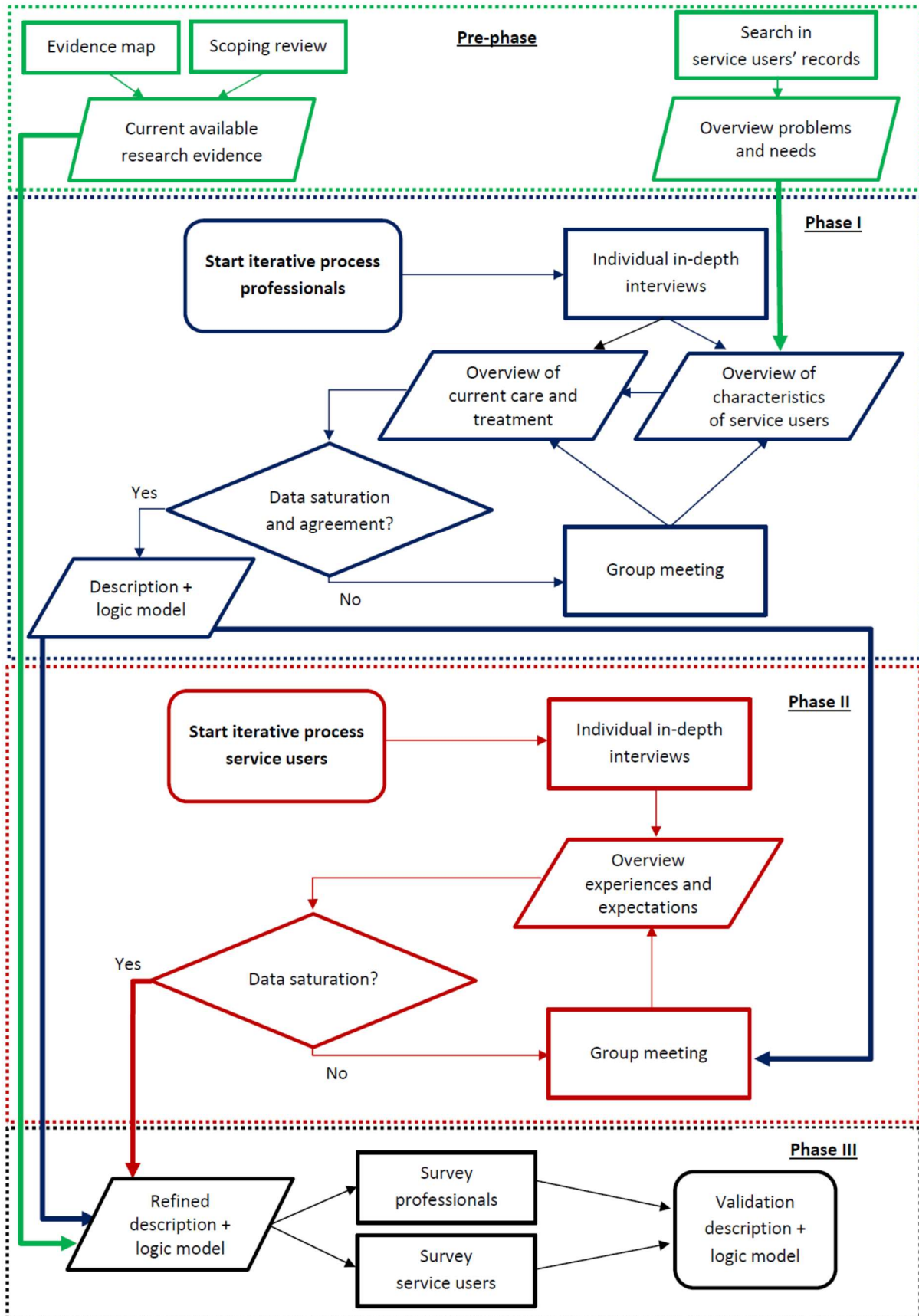
As a pre-phase, the current available research evidence relevant to the care and treatment of adults with VI and SMI would be explored by conducting a scoping review (Arksey & O'Malley, 2005) and constructing an evidence map of the evidence (Colquhoun et al., 2014) (see chapter 6 for a more detailed description). This map would provide an overview of the current scope of the research in the field of VI and SMI, and of how this group is represented in the literature compared to the study of other comorbid problems in VI. Also, a scoping review (Arksey & O'Malley, 2005) (see chapter 7 for a more detailed description) would be conducted to gain insights into the available published evidence for care of adults with VI and SMI, including highlighting gaps in the evidence. These insights would be used to compare the logic model derived in phase I of the study to identify its similarities to and differences from the available research evidence.

Additionally, in chapter 5 a search would be made of service users' records to make an inventory of the problems and needs described and/or diagnosed for the service users at the residential care facilities.

In phase I, an iterative process together with a group of professionals would be started, in which the professionals would be stimulated to become aware of their own actions and assumptions guiding these actions (what they do, why they do it) and share this with the researcher and other professionals. By conducting in-depth individual interviews (Polit & Beck, 2017), professionals would be prompted to *enlarge* their own tacit knowledge and *share* this with the researcher as described in the first two stages of the knowledge creation process of Nonaka (1994). Based on these interviews and the search in the service users' records within the residential care facilities, a first overview of the problems and needs that characterise adults with VI and SMI (research question 1) and their current care and treatment (research question 3) would be made by the researcher. These overviews would be presented in a group meeting (Polit & Beck, 2017) with the professionals and would form the starting point for a discussion regarding the characteristics of adults with VI and SMI and their

**Figure 3.1**

*Flowchart of the phases, activities and methods used for data collection and processing*



current care and treatment, facilitating the professionals to *share* their knowledge and *conceptualise* this in words and meaning (Nonaka, 1994). Based on this discussion, the overviews would be adapted, which in turn would form the basis for the next group meeting. Through their involvement in this process, the professionals would be undergoing several cycles of sharing and modelling, with each cycle seeking to bring them to a higher level of understanding and greater ability to explain their own actions and assumptions in concordance with a PAR-approach (Koch & Kralik, 2006) and the knowledge-creation process (Nonaka, 1994). These cycles would end only once the professionals and the researcher agreed on the description of current care and treatment, and data saturation had been reached. These preliminary overviews were then *crystallised* by the researcher into an explicit description of the problems and needs that characterise adults with VI and SMI. Furthermore, based on the overviews, a logic model of current care and treatment would be established, describing the theory behind current care and treatment, important contextual factors, current activities in care and treatment, and the intermediate and final outcomes.

In phase II, a similar iterative process would be conducted with service users. They would be invited to share their experiences and expectations about the care and treatment they receive in an in-depth individual interview (Polit & Beck, 2017) and then the outcomes of these interviews, together with the outcomes of the iterative process with professionals, would be presented in a group session (Polit & Beck, 2017). In this session, the service users would be asked to discuss these findings. This resulted in a description of the experiences of service users of their current care and treatment, and of what they define as the key elements. These outcomes would be compared to the logic model, and the logic model would be adapted accordingly.

In phase III, the description of the problems and needs that characterise adults with VI and SMI, their current care and treatment, and the draft logic model would be shared with a larger group of professionals and service users for validation. These professionals were recruited in two ways:

1. All professionals who are active in practice as a care worker, care coordinator, behavioural scientist or manager in outreach care, residential care or day care within the RCF, would be approached by email and asked if they were willing to participate in the last phase of the study.
2. A special edition of the Psyvisnet newsletter would be send to all Dutch members of Psyvisnet, in which they would be invited to participate.

These persons could agree to participate by clicking the link in the e-mail, they would then be asked to complete an e-learning course presenting the explicit description of the problems and needs that characterise adults with VI and SMI, a description of current care and treatment, and the draft logic model. This e-learning course was created using the e-learning online course creation web app *Rise 360* of Articulate Global, Inc.. After following the e-learning course, participants would be asked to fill in a short questionnaire afterwards.

Service users would be selected and recruited in collaboration with the care coordinators of the residential care facilities. After receiving informed consent, an accessible Microsoft Word version of the e-learning course would be shared and service users would be asked to read this description and provide their response to a short questionnaire afterwards.

Based on the outcomes of these questionnaires, it would be possible to determine if the logic model could be validated as an accurate representation of current practice.

### 3.3 Standards for good evidence in qualitative research

Within qualitative research, different quality criteria are formulated to assess if the standards for good evidence are applied in the study. Quality criteria are established to ensure the credibility (trustworthiness and believability), transferability, dependability (consistency) and 'confirmability' (being conscious of the influence of personal biases) of the study (Frambach et al., 2013). In the following sections a short introduction to the sort of activities that can be used to meet these quality criteria is given and, more specifically, how these activities would be performed in the current research project.

#### 3.3.1 Credibility

Credibility refers to the trustworthiness and believability of a study. This can be enhanced by 'triangulation' of the data: that is, using multiple data sources, methods, researchers and theories for corroboration. Other activities that can enhance the credibility of a study are spending sufficient time in the field to understand the phenomenon of research (prolonged engagement), and asking participants to give feedback on the data and on the interpretation of the data (member checking) (Frambach et al., 2013).

Within the current study, data triangulation would be achieved by consulting different groups (professionals and service users) during different phases of the study and by comparing the outcomes of these consultations with data from other data sources, such as the records of service

users and the current available external evidence. Also, different qualitative methods were to be applied during the study, namely individual interviews, group meetings and questionnaires. The process of data collection and analysis was to be conducted by the PhD-researcher and the co-supervisor who continuously sought mutual understanding and agreement. Furthermore, the reviews would be performed in collaboration with a junior researcher. In data-analysis different theoretical schemes were to be applied (framework of the ICF and generally accepted phases in a care process), in which the data of the interviews could be structured. No other theories were used for data interpretation, as it was important to be open and neutral with respect to this data.

By conducting an iterative process, data would be collected over an extended period of time to gain a sufficient understanding of current practice and after each session a member check would be performed by asking participants to give feedback on the data and its interpretation, as is shown in the flowchart (figure 3.1) in section 3.2.4.

### 3.3.2 Transferability

Transferability refers to the extent to which the findings of the study can be transferred and applied to other settings. It can be enhanced by providing a detailed description of the findings, to make them meaningful and understandable for others ('thick' description), by explaining the sampling strategy and by discussing the similarities and differences between the findings and existing external evidence (Frambach et al., 2013).

In the current study, a thick description would be provided for the findings resulting from the iterative process with professionals and service users. For the recruitment of professionals and service users a purposive sampling strategy (Polit & Beck, 2017) would be used in consultation with the stakeholders of the study: professionals and service users were to be purposively selected by using clear and explicit inclusion criteria (see chapter 4 for a more detailed description of this procedure). By conducting a mapping and scoping review as described in section 3.2.4, the current evidence would be identified and its alignment with the findings of the study assessed and discussed.

### 3.3.3 Dependability

Dependability refers to the consistency of the findings in relation to the context in which they were generated. This can be enhanced by applying data saturation, i.e. collection of data continues until no new themes emerge. Also, conducting an iterative process in data collection and analysis, in which analysing and interpreting the data is a continuous process and new information or insights leads to the next steps in data collection and a re-interpretation of the data, can enhance the



dependability of a study. Therefore, it is important as a researcher to be flexible and open towards the process and topic of the study (Frambach et al., 2013).

The iterative process of inquiry for the study, as described in section 3.2.4, should serve to enhance the dependability of the study. Different cycles of data collection, analysis and sharing would be conducted, in which each cycle would inform the content and interpretation of data collection and analysis for the next cycle. By continuously discussing the process of data collection and interpretation with the different participatory groups (see table 3.1), the researcher would be helped to keep a flexible and open attitude towards the data. By conducting a series of cycles, opportunities would be provided to allow new themes to emerge and, ultimately, to decide, together with the participants, that data saturation had been achieved.

### 3.3.4 Confirmability

Confirmability refers to the extent to which the findings are a consistent representation of the input from the participants. Findings which have been influenced unduly by the researcher's biases show poor confirmability. To mitigate against this, it is important to search for evidence or data that (dis-)confirms the findings, to discuss the research process and findings with peers and/or experts (peer debriefing), to keep a diary to reflect on the process and the researcher's role and influence, and to document the steps and decisions taken in the process (audit trail) (Frambach et al., 2013).

During the iterative process, participants would be not only asked to confirm the findings, but also to share data or experiences that disconfirm the findings or show that data was missing. Also, the findings were to be compared to the available scientific evidence and to the experiences and expectations of service users. Furthermore, not only would professionals from the RCF be involved in the study, but also professionals from other care organisations in the visual sector. By doing so, insights would be gained into the differences between these organisations, thereby providing a more detailed understanding of the specific context within the RCF.

As can be seen from the description in section 3.2.4, peer debriefing was to play a substantial role in the iterative process, during which participants would be asked to reflect on and discuss the findings of the study. Furthermore, different reference groups would be consulted to discuss the research process and the findings. Every four months a meeting with the advisory board (see section 3.1) would take place to discuss the research process and reflect on the findings. Also, the behavioural scientists of the RCF would be kept up to date on the findings of the study and asked to provide

feedback. The supervisors of the study would be debriefed every three weeks, with important decisions about the research process discussed along with the findings during these meetings. Each meeting would be documented in the form of a report that would then be sent to the participants of the meeting for a member check. Furthermore, the researcher would regularly reflecting on her own role and influence during the research process and in the interpretation of the data. In the following section, this role and possible influence is further clarified.

### Researcher's characteristics and reflexivity

Within qualitative research it is important to be aware of the researcher's effect on the collection, analysis and interpretation of the data (Polit & Beck, 2017). A researcher should be aware of her own background, set of values, and social and professional identity, and how these can affect the research process. Within the PAR-approach, cycles of 'look, think and act' are executed by the researcher, in which the researcher's own beliefs and relations with the participants may influence the research process and results (Koch & Kralik, 2006).

The activities for the study would be conducted by the PhD researcher as part of her employment at the RCF. These activities were partly funded by a two-year grant from the Dutch Program Council for the Visual Sector, which assigns funding received from the Dutch Government to enable organisations in the visual sector to maintain and enlarge their expertise in providing care and treatment. The members of the steering group of this council represent the three different health care organisations for persons with a VI (Bartiméus, Royal Dutch Visio and the RCF) and the Eye Association Netherlands. The activities within the study that were not covered by the funding and additional study costs were covered by the RCF. Although the conduct of the study was facilitated by the RCF, which could lead to possible conflicts of interest, the responsibility for and justification of the study would reside at the University of Sheffield. Decisions about the activities and reporting of the study would be taken together with the supervisors of the study, who did not have any affiliation with the RCF.

At the start of the study, the researcher had nine years of experience in providing care and treatment to adults with VI and SMI in residential care facilities as a care worker and behavioural scientist employed by the RCF. Therefore, the researcher could use her own tacit knowledge as a basis and would be able to connect with the professionals and service users who participated in the study. This would serve to facilitate mutual trust and understanding, as the participants could consider the researcher to be 'one of their own'. This would encourage participants to be open, as the researcher could relate to the subject matter participants were asked to discuss with the researcher. However,

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this close connection to the participants and the study subject matter could also prejudice the neutrality of the evidence if the researcher were unable to maintain sufficient objective distance from the subject matter. This possibility would be mitigated by analysing the data of the individual in-depth interviews and group meetings in collaboration with a second researcher, who had no experience in providing care and treatment to adults with VI and SMI. This second researcher would also join the group meetings, and would be able to ask for clarification or to take a more objective position. Furthermore, it would be expected that discussing the data with the supervisors of the study, who would be able to take a more critical and neutral view, would help the researcher to maintain an open and critical attitude towards the data.

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## CHAPTER 4: AN OVERVIEW OF THE PROBLEMS AND NEEDS THAT CHARACTERISE ADULTS WITH VI AND SMI

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### 4.1 Introduction

Currently, the care and treatment of adults with VI and SMI as provided by the RCF can be considered to be 'intuition-based'; an explicit description of the care and treatment is needed to work towards evidence-based practice in the future (Van Yperen et al., 2017). An important condition for creating this explicit description is the possession of a clear overview of the characteristics of the target group for whom the care and treatment is assumed to be effective (Van Yperen et al., 2017; VIVIS, 2020). At the outset of this study, no specific information was available about the problems and needs that characterise adults with VI and SMI. So, before an explicit description of current care and treatment could be created a clear overview of the problems and needs that characterise adults with VI and SMI was required.

According to Van Yperen et al. (2017), a clear overview of a target group requires a description of the demographic characteristics (such as age, gender and ethnic origin) and a description of the characteristics and related factors that will be the main target for change in an intervention. This can be done by describing the typical characteristics of a target group (indications) and the characteristics that exclude persons from an intervention (contraindications) (Van Yperen et al., 2017). Furthermore, a detailed understanding of the characteristics within the target group that lead to the complexity of their problems helps to identify and understand the working elements of an intervention, as these are implicated in the mechanisms that will be targeted by an intervention. An overview of these characteristics in adults with VI and SMI can be obtained by consulting professionals about what they identify as the problems and needs of these adults. Based on their stories, insights can be gained into the characteristics underlying the problems and needs of adults with VI and SMI and how these problems and needs have evolved due to service users' life histories and (missing) competencies. Furthermore, based on these insights, the underlying theories of professionals can be identified about how these problems and needs may guide their current activities and decisions taken in the care and treatment of adults with VI and SMI.

By conducting a PAR-approach in collaboration with professionals and using qualitative measures, an answer will be obtained to the research question *'Which problems and needs and general characteristics do professionals identify in adults with VI and SMI?'*

## CHAPTER 4

This research question was further specified as follows:

- Do professionals acknowledge the definition for SMI (as outlined in section 1.1.1) as an accurate representation of the mental health problems experienced in adults with VI and SMI?
- Which problems and needs do professionals identify in adults with VI and SMI?
- Which theories have professionals, based on their own knowledge and experiences, constructed about how these problems and needs develop?

### 4.2 Method

In this section the design of the study is presented. Furthermore, a description is given of how the participants were recruited and how data collection and analysis was executed.

#### 4.2.1 Design

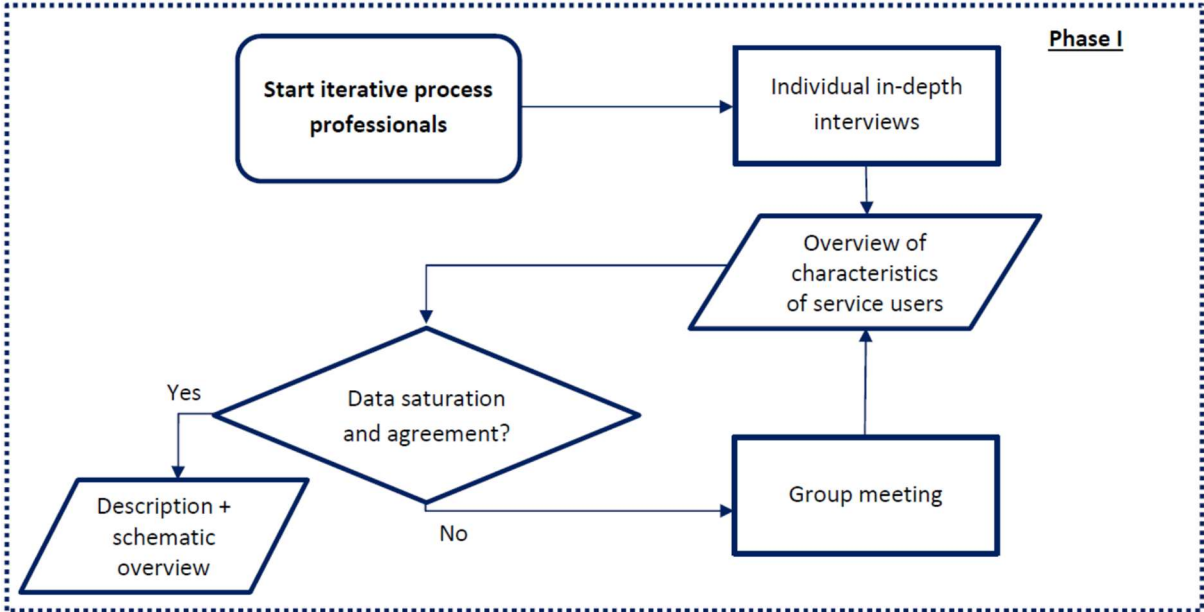
As described in section 3.1, a qualitative study using a PAR-approach was conducted. In the research described in this chapter, the focus was on obtaining a description of the problems and needs that characterise adults with VI and SMI and that shape their care and treatment. To arrive at this description, individual in-depth interviews with professionals were used to *enlarge* and *share* knowledge. These interviews were transcribed and analysed, resulting in a first overview of the characteristics of adults with VI and SMI. This overview formed the input for a group meeting with professionals, in which professionals were facilitated to *share* their knowledge and *conceptualise* this in words and meaning. Based on these activities the knowledge was *crystallised* into a description by creating a schematic overview of the problems and needs that describe adults with VI and SMI. In figure 4.1 (p. 61) a flowchart of the design of this phase of the study is presented.

#### 4.2.2 Participants

Participants were recruited based on their experience and ability to reflect on their own actions and assumptions (purposive sampling) (Fawcett & Garity, 2009; Polit & Beck, 2017). Participants needed to meet all the following criteria:

- a minimum of 3 years' experience of providing care and treatment to adults with VI and SMI;
- active in daily practice with regular contact with service users;
- willing to share his or her knowledge and experiences with the researcher and group members, and to reflect on these.

**Figure 4.1**  
*Flowchart of the procedure used for the PAR approach to obtain an explicit description of adults with VI and SMI*



To try to ensure that the participants would be a representative group of professionals, participants were recruited from three organisations that provide care and treatment to persons with VI in the Netherlands (RCF, Royal Dutch Visio and Bartiméus) and a mental health care organisation (Reinier van Arkel Group). The participants were asked to participate in individual in-depth interviews held in May and June 2017, and in a group meeting held in October 2018.

To identify potential participants from RCF, a purposive sampling strategy was used to select professionals who were thought likely to contribute to the study, and who as a whole constituted a group that varied in roles, ages, and years of experience in providing care and treatment to adults with VI and SMI (maximum variation sampling) (Polit & Beck, 2017). The researcher first composed a list of professionals who met the selection criteria. At that time, the researcher had nine years’ experience in providing care and treatment to adults with VI and SMI in their residential care facilities, being employed at the RCF as a care worker and behavioural scientist, and was therefore able to make this first assessment. This list was discussed with the advisory board of the study and, based on their input, a selection of three professionals was made by the researcher taking into account a variation in role and years of experience. For Bartiméus and Royal Dutch Visio, the research coordinator for each organisation was asked to send a request to the behavioural scientists in their organisation to recruit two professionals for each organisation who met the criteria. The mental health care perspective was represented by a psychiatrist of the Reinier van Arkel Group.

Therefore, the advising psychiatrist of the RCF (who was also a member of the advisory board) was asked to participate in the interviews.

The identified professionals were asked to participate in the study by sending them an information letter by email. This letter gave information about the purpose of the study, what would be expected of a participant and contact persons for more information or complaints. The researcher contacted the potential participants by telephone one week after sending the letter. During this conversation they were able to ask more questions about the study and the nature of participation, after which they were asked if they agreed to participate in the study. If so, an appointment was then made to conduct the individual in-depth interview.

All professionals who were asked for this phase agreed to participate and provided informed consent at the start of data collection, acknowledging that they were fully informed and had had adequate opportunity to ask questions, that they participated voluntarily, that they would provide information and that this information could be used for the specific aims of the study, and that they would keep information that is shared during group meetings confidential. Furthermore, the researcher affirmed that all data would be handled according to the European Law on Data Protection and the Dutch Central Committee on Research Involving Human Subjects (CCMO in its Dutch abbreviation), with all information collected and shared confidentially and anonymously.

### 4.2.3 Activities and instruments for data collection

Data for the total of phase I was collected by conducting individual in-depth interviews and three group meetings. Part of the data collected in the individual in-depth interviews and the first group meeting were used for the description of the problems and needs that characterise adults with VI and SMI. In this section the content and instruments used during these activities are elaborated.

#### Individual in-depth interviews

Professionals were asked to describe characteristics of service users during an in-depth one-to-one semi-structured interview (Polit & Beck, 2017) with an average duration of one hour (designated hereafter as an “individual interview”). For this individual interview, the participants were asked to select two cases, each involving a person who was officially diagnosed with VI and a mental disorder that was present for longer than two years (in line with the criterium used for SMI as specified by Ruggeri et al. (2000)). With regards to the purposes of this chapter, the individual interviews were used to collect data about the overall characteristics of service users. (The same interview was also used to collect data about current care and treatment; these activities will be further elaborated in

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chapter 8.) Here, the first question of the interview guide was most relevant. In this first question the professionals were asked to give a short description of the service users in their selected cases in terms of their life history, diagnoses, problems and needs. The interview guide for the whole interview is enclosed in appendix 4.

All interviews were recorded digitally and transcribed verbatim. The transcripts of the interviews were sent to the participants for a first member check.

### Group meeting

All the participants who were interviewed were invited to join a group meeting. Due to personal circumstances (maternity leave, retirement, long-term illness, change of work, or simply not being able to attend the meeting) not all participants were able to take part in this meeting and new participants were invited using the recruitment strategy described in section 4.2.2 (in the results section a more specific overview is provided).

Based on the descriptions provided by the participants in the individual in-depth interviews, an overview of the characteristics of each case was made, structured by the framework of the ICF (WHO, 2001a). This overview was sent in advance to the participants of the group meeting and they were asked to study this before the start of the group meeting (Polit & Beck, 2017). At the start of the group meeting, participants were informed about the specific definition used to describe the SMI of service users (as defined in section 1.1.1). After this presentation, a discussion took place, based on the overview of the characteristics of adults with VI and SMI, about the problems and needs that characterise adults with VI and SMI, guided by the following questions:

- Do the characteristics in the overview accurately describe the service users?
- Which characteristics shape the care and treatment of adults with VI and SMI?

The group meeting was recorded digitally and based on this record a report was made. This report was sent to the participants for a member check. Based on this report a first description and schematic overview of the characteristics of the service users and their care needs was made.

### Validation

The description and schematic overview of the characteristics of the service users were presented to the behavioural scientists of the RCF. They were asked if this overview accurately represented the characteristics of the service users and to provide feedback.



### Reflection

The advisory board of the study was regularly updated about the progress and outcomes of the different steps of data collection. During these meetings, the outcomes were presented and the board was asked to reflect on these outcomes by considering how these outcomes are related to the vision of the RCF, the protocols used for care and treatment and different care programs of the RCF. Based on these reflective discussions, the outcomes could be further refined. These meetings were recorded digitally and based on these records reports were made.

The input of the behavioural scientists and advisory board on the description and schematic overview were used to refine the models. This was then sent to the participants for a last check for validation.

#### 4.2.4 Data processing and analysis

In this section the processing and analysis of the data that were derived from the individual in-depth interviews and group meeting is described.

#### Individual in-depth interviews with professionals

The interview transcripts were analysed by two researchers using a *qualitative content analysis* approach. This approach aims to identify themes and patterns in a narrative source by condensing the words of a text into smaller content categories (Mayring, 2014; Polit & Beck, 2017). Based on the analysis procedure described by Mayring (2014), the transcripts of the individual interviews and group meetings were used to search for phrases that are in line with the subject of study. These phrases were categorised into themes based on their content. Mayring (2014) describes two methods within qualitative content analysis: *deductive category assignment*, in which phrases are structured according to categories formulated in advance based on theory; and *inductive category formation*, in which categories are formulated based on the content of the phrases.

For the study phase in this chapter, a deductive category assignment was used, in which the framework of the ICF (WHO, 2001a) was used to categorise the phrases. The framework of the ICF is a classification tool that was established to offer health workers worldwide a common language of terms from health and health-related domains to describe the functioning of a person. This framework is officially endorsed by all WHO member states as the international standard to describe and measure health and disability. The phrases referring to the characteristics of the service users were categorised according to the following ICF categories:

- Health condition (disorder or disease)
- Affected body functions & structures

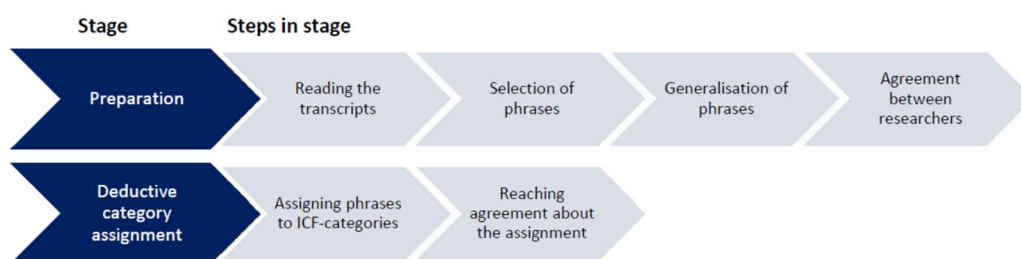
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- Activities & participation
- Environmental factors
- Personal factors

In figure 4.2 a schematic overview of the analysis procedure is provided. After reading the transcripts line by line, phrases were selected and copied to a Microsoft Excel spreadsheet, with each phrase representing one row in the spreadsheet. According to the deductive category assignment process, each phrase was generalised to a more abstract level by each researcher separately. These more general phrases were then categorised according to the domains of the ICF framework by one of the researchers. The categorisation was checked by the second researcher.

**Figure 4.2**

*Schematic overview of the analysis procedure*



### Group meeting 1

Based on the recording of the group meeting, a detailed report was made. The content of this report was analysed using the qualitative content analysis procedure described above and, based on this analysis, a schematic overview and a description of the problems and needs that characterise adults with VI and SMI and that shape their care and treatment was made.

### 4.3 Results

In this section the results of the study are presented, divided into an overview of the characteristics of the participants that provided information during an individual interview and/or group meeting, and a description of the problems and needs identified by professionals in adults with VI and SMI. To substantiate these results, quotations are provided derived from the individual interviews and the group meeting. These meetings were held in Dutch and the quotations provided in this section are translated from Dutch into English by the researcher.

## 4.3.1 Participants

A total of six, instead of eight, professionals participated in the individual in-depth semi structured interviews. This number was lower than planned as only one participant was appointed to participate representing Bartiméus and the participant of Reinier van Arkel group did not have direct contact with the service users and was therefore not able to join an interview that was structured around cases. As mentioned above, not all participants who participated in the individual in-depth interviews were able to attend the group meeting and additional participants were recruited. Therefore, the total number of participants overall was higher than expected (12 instead of 8). In table 4.1 an overview of the participants' employer organisations and their roles is given. To prevent the inadvertent identification of participants based on their characteristics no additional information is given. Instead information about age and years of experience (YoE) of the participants is given by providing the mean and range of these characteristics for the total group in table 4.2 (page 67). In this table, the number of participants and the mean and range for age and years of experience is also specified for the individual in-depth interviews and group meeting separately.

During the interviews and group meeting a pleasant atmosphere was created, and that was considered to facilitate the sessions. Professionals expressed the opinion that they really enjoyed the discussions and felt an atmosphere of trust and understanding among each other.

**Table 4.1**

*Characteristics of professionals participating in interviews and group meetings*

<b>No.</b>	<b>Organisation</b>	<b>Role</b>
P1	Royal Dutch Visio	Behavioural scientist
P2	Royal Dutch Visio	Psychologist
P3	Robert Coppes Foundation	Care coordinator
P4	Robert Coppes Foundation	Coordinator of day activities
P5	Robert Coppes Foundation	Mental health psychologist
P6	Bartiméus	Behavioural scientist
P7	Bartiméus	Psychologist
P8	Reinier van Arkel Group	Psychiatrist/director
P9	Bartiméus	Behavioural scientist
P10	Robert Coppes Foundation	Care coordinator
P11	Robert Coppes Foundation	Care coordinator
P12	Royal Dutch Visio	Social worker

**Table 4.2***Number of professionals, age and years of experience for each meeting*

Meeting (N)	Organisation (N)	Participant (no.)	Age	YoE
Overall (12)	RCF (5)	P3, P4, P5, P10, P11	51 (28-64)*	16 (4-34)*
	Royal Dutch Visio (3)	P1, P2, P12		
	Bartiméus (3)	P6, P7, P9		
	Reinier van Arkel Group (1)	P8		
Individual in-depth interviews (6)	RCF (3)	P3, P4, P5	47 (28-64)*	8 (4-22)*
	Royal Dutch Visio (2)	P1, P2		
	Bartiméus (1)	P6		
Group meeting (8)	RCF (3)	P3, P10, P11	53 (27-61)*	15 (5-34)*
	Royal Dutch Visio (2)	P1, P12		
	Bartiméus (2)	P7, P9		
	Reinier van Arkel Group (1)	P8		

\*mean (range)

#### 4.3.2 Problems and needs of adults with VI and SMI

In this section an overview is given of in how far the participants acknowledged the definition of SMI as accurate for describing the mental health problems of adults with VI and SMI, and of the professionals' views about the problems and needs that characterise adults with VI and SMI.

##### Definition of SMI

The participants acknowledged that the definition of SMI represented the mental health problems they experienced in their service users, who met the criteria formulated for SMI by Delespaul and Consensusgroep EPA (2013):

*'...a person [who] experiences a mental disorder in need of treatment or support; involving serious impairments in social and/or societal functioning; this is structural and over a longer period of time. The impairment is caused by and a consequence of the mental disorder and coordinated care from professionals in care networks is needed to realise a treatment plan.'*  
(p. 429-430, translated by the author).

##### Problems and needs of adults with VI and SMI

Presented in separate tables in appendix 5 are the characteristics indicated for health condition, affected body functions and structures, problems experienced in daily functioning, environmental factors and personal factors of the service users who were selected as cases by the professionals in the individual interviews. To prevent the possibility that the description of the characteristics can identify individual persons, a general overview of the characteristics is presented in the appendix. This overview is the result of the qualitative content analysis of the transcripts of the individual

interviews and formed the main input to the discussion in the group meeting. During the group meeting an overview of the characteristics of each case was presented. All cases were identified as experiencing mental health problems over a longer period of time, with a high impact on their daily functioning. The following mental disorders (or suspicion of) were indicated: (borderline) personality disorder, depression or mood disorder, anxiety disorder, post-traumatic stress disorder, psychosis, adaptation disorder, conversion disorder, autism, stress disorder.

Based on the analysis of the cases described during the individual interviews and the discussion during the group meeting, five important mechanisms could be identified, that seem to underlie the problems and needs of adults with VI and SMI and that shape their care and treatment. Professionals indicated that adults with VI and SMI who are in need of care and treatment are vulnerable, and their problems can be described as complex. Service users often experience problems in forming a safe attachment, lack basic feelings of safety and have a fragile sense of trust in themselves and others. In table 4.3 an overview of quotations is given that represent these different conditions.

**Table 4.3**

*Quotations from participants that illustrate the factors of vulnerability, problem complexity, fragile trust, lack of basic safety and problems in attachments.*

<b>Factor</b>	<b>Quotation</b>	<b>Source</b>
Vulnerability	<i>'...that it is due to that VI that you are more vulnerable and therefore the psychological problems arise.'</i>	P11, group meeting
Problem complexity	<i>'It's not one condition. Someone is not only depressed or psychotic, but especially when there are certain multiple factors that play a role. Then you cannot just get away with a diagnosis. People find it difficult to be categorised, especially in people where so much is going on. This is complex and you have to enjoy it [the categorisation task] to unravel what is going on.'</i>	P8, group meeting
Fragile trust	<i>'... not having any trust in the right to be there does seriously hamper the development tasks they face.'</i>	P1, group meeting
Lack of basic safety	<i>'There was a lot of overlap. When looking at the overview, I thought for almost all service users the lack of basic safety. Can I be there? Will I be supported if I have a problem? That's the cornerstone of this group.'</i>	P1, group meeting
Problems in attachment	<i>'I often experience that in the service users I see at the RCF, they all lack a safe attachment.'</i>	P8, group meeting

Furthermore, the discussion of the problems and needs of service users revealed four domains that can be used to describe adults with VI and SMI and that seem to be important factors that explain the mechanisms described above:

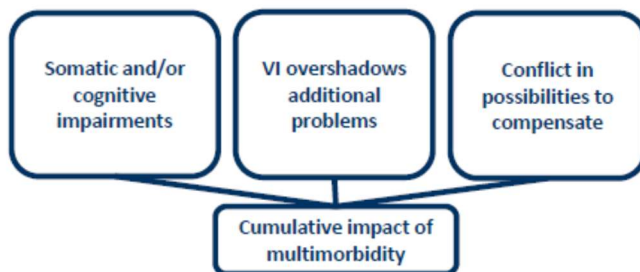
1. Cumulative impact of multimorbidity
2. Life history
3. Development
4. Personal and external factors

1. Cumulative impact of multimorbidity

In figure 4.3 an overview is given of the themes indicated by professionals as being related to the service users experiencing a cumulative impact of their multimorbid problems.

**Figure 4.3**

*Overview of themes in the cumulative impact of multimorbid problems experienced in service users with VI and SMI*



Due to their VI, a service user experiences functional restrictions in their daily life. For example, they experience difficulty with recognising someone's face or their facial expressions, leading to problems in social interaction. Also, they can experience restrictions in reading text, this imposes restrictions on many daily activities, such as the possibility to follow guidelines or learn. Another restriction can be the possibility to orientate in a space and/or independent mobility, making a person dependent of aids or others to visit places.

The professionals indicated that service users with VI and SMI often have additional somatic or cognitive problems, such as diabetes, acquired brain injury, mild intellectual disability, hormonal diseases or syndromes (for example Alström, Bardet-Biedl). For all different problems (VI, SMI and somatic or cognitive problems) there is a wide variety in diseases, causes, manifestations and types of impairments. Professionals emphasize that no two service users are the same. The problems of each service user are interrelated and generally reinforce each other, making it difficult to obtain a detailed understanding of the problems and needs. As participant P1 observed in the group meeting:

*'There are a whole range of conditions, such as Wolfram's or Alström's disease, of which the consequences are both somatic and mental. In these diseases, a very large number of people often have mental health problems. It is important that you know that, that you are*

*apprehensive about the things that can happen. Look at Alström. Then there can be so much somatic deficiency. You must keep an eye on that and the interaction of all those things. Bardet-Biedl is also part of that, you also see mental health problems.'* (P1, group meeting).

Furthermore, professionals note that many problems a person experiences are easily linked to a VI, making it difficult to identify additional impairments. In other words, the VI seems to overshadow these additional impairments, as is demonstrated in the following quotation:

*'Then you can confront him: you are fifty and you are not happy, no job, no friends and your house does not look nice. But he then says, I don't see well. He has an escape....'* (P5, individual interview).

Due to this cumulative impact of multimorbid problems, there can be a conflict in the possibilities to compensate for their impairments. What can be used as a compensating strategy for one impairment can be a restriction for the other impairment, as a participant stated in an additional individual interview that was held with one of the participants who was not able to participate in the group meeting:

*'there is a conflict in the possibilities to compensate. ... one [possibility] cannot be used because that access [to that possibility] is also hampered by another [possibility].'* (P1, additional interview).

## 2. Life history

In figure 4.4 an overview is provided of the problems experienced by service users during their life histories, as identified by professionals.

**Figure 4.4**

*Overview of problems experienced by service users during their life histories*



The life history of the service user is described by professionals as being disrupted due to their VI or early psychosocial problems. Because of their impairments or problems they are at risk of developing mental health problems. In childhood, service users will have experienced different challenges that have influenced their development. For example, meeting the needs of a child with a congenital VI is difficult for parents, as to communicate their needs their infant expresses different signals compared to an infant without VI and/or parents can be overprotective. Furthermore, a large number of service users have been placed outside their homes from a young age, due to receiving institutional education or lengthy hospital admissions. As a result of these situations, service users can have their basic needs neglected. This may have resulted in difficulties trusting others, feelings of lacking basic safety and problems in attachment.

*'...or ended up in the hospital at a very young age. That is, a bit neglected, as if nothing is wrong, but that is something. A 2- or 3-year-old kid who has had yet another operation.'* (P8, group meeting).

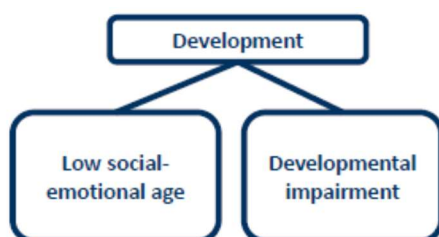
Furthermore, major life events, such as traumatic experiences, experiences of failure, or loss of support structures, may have influenced the course of their lives and which present challenges to a normal development.

### 3. Development

In figure 4.5 an overview is displayed of the developmental challenges faced by service users with VI and SMI.

**Figure 4.5**

*Overview of developmental challenges experienced by service users*



Professionals recognise that service users experience an impact of their VI on their development. For example, due to missing important facial expressions or having an overview over a situation, they experience difficulties with participating in social situations. This could lead to delays in their general



developmental delay or their socio-emotional level in comparison with their calendar age, as is expressed by participant 8 in the group meeting:

*'What you also see often is a developmental delay due to all the traumas and other experiences they have gone through. They may be 24/26, but what is their emotional age?'* (P8, group meeting).

#### 4. Personal and external factors

In figure 4.6 an overview is displayed of the personal and external factors in the problems encountered by adults with VI and SMI.

Professionals mention that service users experience an imbalance in, on the one hand, the number of stressing factors and, on the other, their resilience in coping with these factors. A service user with VI and SMI has limited resources or facilitating factors to cope with the stressing factors in their lives. Service users use dysfunctional ways of coping and they have an extremely small or no social network. Therefore, they are easily knocked off balance when faced with a stressing life event or problematic phase in their lives and lack a social network that could help them cope. This was illustrated by participant 1 in the group meeting:

*'...the lack of the support structure. There is no mother or aunt who looks after them. Where they could always go to. These kinds of things are just making the balance even more skewed than it already is.'* (P1, group meeting).

**Figure 4.6**

*Overview of personal and external factors in the problems experienced by service users*

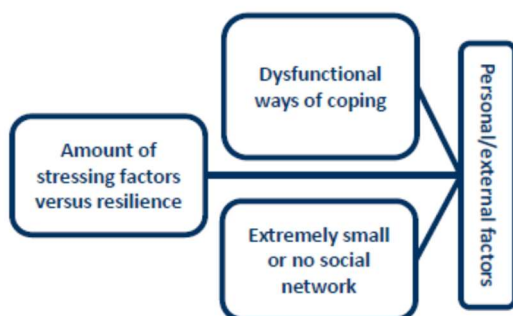
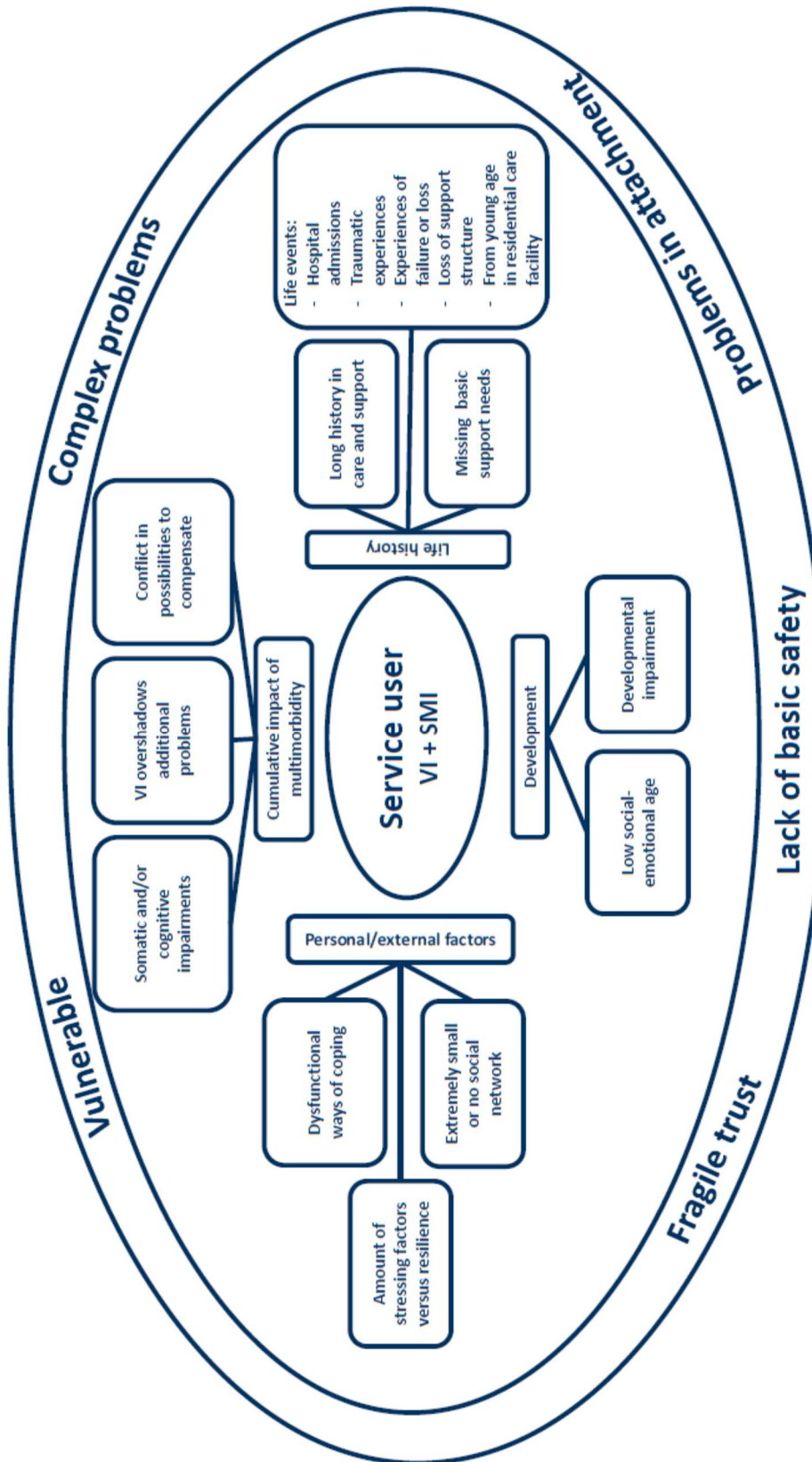


Figure 4.7 (p. 73) gives a complete overview of the discussed problems and needs that characterise adults with VI and SMI and that shape their care and treatment.

**Figure 4.7**

*Schematic overview of the problems and needs that characterise adults with VI and SMI and that shape their care and treatment*



## CHAPTER 4

### 4.4 Discussion

In this section the main findings of the study are presented by answering the research questions formulated in section 4.1 and by comparing the outcomes to the existing literature. Furthermore, the strength and limitations of the study are discussed, resulting in the main conclusion.

#### 4.4.1 Main findings

A PAR-approach was used to gain more insights into the problems and needs that characterise adults with VI and SMI. Professionals identified different problems in their service users and have developed underlying theories on how these problems have developed. Professionals acknowledged that the definition for SMI as formulated by Delespaul and Consensusgroep EPA (2013) accurately represented the mental health problems their service users experienced. In addition, professionals emphasized the complex picture of adults with VI and SMI, and indicated that service users were experiencing a cumulative impact of their multimorbid problems, showing comorbid somatic or cognitive problems alongside their VI and SMI. Their VI seems to overshadow these other comorbid problems and this leads to conflicts in their possibilities to compensate. Furthermore, experiences in their life history, due to their VI or psychosocial difficulties, can have a large impact on their current daily functioning. Professionals note that their service users were faced with different (traumatic) life events, long histories of care and treatment, and their basic needs were not (sufficiently) fulfilled. Professionals state that, due to their challenges in life and the cumulative impact of their multimorbid problems, development can be delayed, especially in respect to their socio-emotional development. These problems can also explain their current challenges, presented as the personal and external factors in the schematic overview. In terms of these factors, professionals indicate that service users use dysfunctional ways of coping and lack a support network. Therefore, service users experience a continuous imbalance in the number of stresses they are challenged with and an insufficient resilience to those stresses.

Based on the combination of these factors, professionals described their service users as vulnerable and having complex problems. Due to the problems described in the different domains and how these problems have developed, service users have a fragile sense of trust in themselves and in others, they lack basic feelings of safety and show problems in attachment. Professionals indicate that these five mechanisms as the factors in their service users that shape their care and treatment.

A study by Teunissen et al. (2020) on the impact on daily life of a combination of VI and mental problems showed comparable outcomes. Through a Delphi study, professionals indicated that adults

with VI and SMI experience feelings of anxiety, depression or loneliness, have low self-esteem and resilience, and a strong dependence on others. They have difficulties accepting their VI, trusting others and judging who can be trusted, and building social relationships or support networks. They are unable to manage their time adequately and lack a feeling of being part of society.

In the current study and the study by Teunissen et al. (2020) professionals indicate a fragile sense of trust, lack of feelings of safety and problems in attachment of their service users as important mechanisms that shape current care and treatment. The process of attachment is known to be frail in some persons with VI (Dekker-van der Sande & Janssen, 2009; Fraiberg, 1977; Sterkenburg, 2019). Attachment can be defined as the ability to develop an affective connection with a primary caregiver and to find comfort in the connection with this caregiver in times of stress (Zaal et al., 2009). Establishing a 'safe' attachment to a primary caregiver is important for a child to be able to develop a feeling of trust and of basic safety (Dekker-van der Sande & Janssen, 2009; Zaal et al., 2009), showing that these factors are interrelated. Studies on the development of attachment in children with VI report that these children show attachment signals that differ from those of sighted children (Fraiberg, 1977). To be sensitive and responsive to these signals requires parents to have greater than average skills (Sterkenburg, 2019). Therefore, these studies conclude that children with VI are at greater risk of developing problems in attachment. On the contrary, other studies have reported finding good attachment patterns in blind children (Urqueta-Alfaro et al., 2019) or in adults who were blind from birth (Ardito et al., 2004). However, these studies were conducted among persons without comorbid problems. Dekker-van der Sande and Janssen (2009) indicate different risk factors for developing unsafe attachment patterns in children with VI; these include: difficulties faced by the parents in accepting the VI in their child and who therefore are not able to be responsive to the child; neurological or cognitive disabilities in the child; difficulties experienced by the child in receiving and expressing attachment behaviour because of the VI; and the child being placed in a residential care facility at a young age. Developing a safe attachment style is important in order to learn to cope with stress and be able to regulate stress and emotions on your own (Dekker-van der Sande & Janssen, 2009; Zaal et al., 2009). Also, a correlation between attachment problems and mental health problems has been reported. Dekker-van der Sande and Janssen (2009) state that a child who does not develop a safe attachment to their caregiver is more vulnerable to developing mental health problems such as mood, anxiety and personality disorders, their socio-emotional development is affected, and they display more problematic relationships with their peers. A correlation between unsafe attachment and SMI has also been found in a literature review (Pearse et al., 2020). This shows the interrelations among the different domains in which professionals identify problems in

adults with VI and SMI. Based on the literature, it could be hypothesised that problems in attachment play a central role in the development and experience of other problems and needs.

### 4.4.2 Strengths and limitations

By using a PAR-approach with qualitative measures, professionals were invited to become aware of their tacit knowledge and experiences that shape their views on the problems of their service users and shape their underlying theories about how these problems have developed over time. By combining an individual interview and a group meeting professionals were given the safety and space to enlarge their individual knowledge and share this with others (in line with the knowledge creation process described by Nonaka (1994)) and were able to create a mutual understanding and conceptualise their individual knowledge. The credibility of the study was enhanced by the use of multiple data sources (individual interview and group meeting), and by collecting data over an extended period of time. Furthermore, the data were analysed by two researchers, who searched for points of mutual agreement. And after each session a member check was conducted by asking participants to give feedback on the data and its interpretation. Transferability of the study was enhanced by providing a thick description of the data and being clear about the sampling method. By conducting an iterative process and involving the participants in the interpretation of data and asking participants if items or elements were missing from the description (data saturation) the dependability of the study was enhanced. Finally, the confirmability of the study was enhanced by continuously probing the data and its interpretation with different resource groups and discussing the findings in these groups so as to keep an open and objective view on the data.

Although the approach can be seen to satisfy the different quality criteria, limitations to the study can still be identified. The overview and description of characteristics is based on the knowledge and experiences of a small number of professionals who provide daily care and treatment to adults with VI and SMI. This has been mitigated by using a maximum variation sampling technique, in which the professionals who were selected were diverse in terms of employer organisation, age, years of experience and role. However, these professionals were purposively selected based on their ability to provide useful information for this study, which may have led to sampling bias. Therefore, validation of the outcomes by other resource groups is required. This was partly achieved in the current study by discussing the outcomes with the advisory board of the study and the behavioural scientists of the RCF. Nonetheless, the outcomes should also be presented to a larger number of professionals to confirm that these outcomes represent an adequate presentation of reality.

Another limitation of the study could be that service users were not consulted on their own experiences of their problems and needs in this study, which would provide another perspective on

these questions. This was a deliberate choice: here the focus of the study is on translating the tacit knowledge of professionals to explicit knowledge, and as such professionals represent the main source for the description of the problems and needs of adults with VI and SMI. Furthermore, due to the vulnerability and the low capacity of the service users, the sort of interviews about their life histories and needs used in this phase could be stressful or distressing. To account for this limitation, the service users would be consulted and their responses used to validate this description, as will be described in chapters 9 and 10.

### 4.4.3 Conclusion

As discussed in the introduction of this chapter, Van Yperen et al. (2017) provide different criteria for the description of the target group, such as the demographic characteristics, indications and contra-indications. Based on the outcomes reported in this chapter, a first description can be made of the target group for whom the care and treatment that will be described in chapters 8-10 is assumed to be effective. Adults with VI and SMI can be indicated as aged 18 and over, with a variation in gender and ethnic origin. In addition to being diagnosed with a VI (as described in section 1.1.1), the definition described in section 1.1.1 for SMI can be used as an indicative criterion for including persons in this group. However, adults who experience mental health problems for a longer period of time without having a diagnosis for a mental illness can also be included, as professionals indicate that establishing a proper diagnosis is a challenge. Furthermore, adults may have other comorbid problems existing alongside their VI and SMI. Contra-indications can be formulated for age (younger than 18) and experience of comorbid mental health problems for a short period of time.

More importantly, by describing and providing an overview of the problems and needs that characterise adults with VI and SMI, greater insight could be gained into the theories developed by professionals to guide their activities and decisions in current care and treatment. This showed that, according to professionals, these adults are faced with complex problems. Due to problems in attachment and difficult life histories, they have a fragile sense of trust in themselves and others, and lack a basic feeling of safety. These factors seem to influence their abilities in daily life, and contribute to an imbalance between the stresses they experience and their resilience in coping with those stresses, which in turn makes them vulnerable. These (complex) problems and needs shape the way these service users can best be provided care and treatment. In this manner, this overview forms an important input for the logic model in providing an underlying theory. In chapter 8, this care and treatment will be further elaborated.

## CHAPTER 4

Finally, based on the existing literature, it can be concluded that problems in attachment may play a central role in the development of other problems and needs. Greater insight into the attachment patterns of adults with VI and SMI could provide a better understanding of how these aspects are interrelated. This falls outside the scope of this study, but it is recommended that future research explores attachment and how this influences daily functioning in adults with VI and SMI.

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## CHAPTER 5: AN OVERVIEW OF SPECIFIC DISORDERS, AFFECTED BODY FUNCTIONS AND PROBLEMS IN DAILY FUNCTIONING IN ADULTS WITH VI LIVING IN A RESIDENTIAL CARE FACILITY

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### 5.1 Introduction

In the previous chapter, an overview of the problems and needs that characterise adults with VI and SMI and that shape their care and treatment was obtained. According to professionals, one of the characteristics of adults with VI and SMI is the wide variety of problems that afflict them: while they have their VI and SMI in common, there is a variety among service users in specific types of VI and specific mental disorders that can be indicated as the cause of their VI and SMI. Furthermore, professionals indicated that their service users experience comorbid somatic and/or cognitive problems along with their VI and SMI.

Until now, no overview has been available of the different types of VI, the different mental disorders that are part of a SMI, and the specific comorbid somatic and/or cognitive problems that are experienced by service users of the RCF. In the research presented in this chapter, the aim was to gain insights into the specific problems and needs experienced by the service users, and to use this overview to further refine and validate the description of the problems and needs of adults with VI and SMI. Therefore, the following research question will be answered: *Which comorbid problems and needs are reported in service users' records in the residential care facilities of the RCF?*

The research question was further elaborated by the following sub-questions:

- Which specific diseases and/or disorders are reported for the service users receiving care and treatment in the residential care facilities of the RCF?
- Which problems are reported for the service users on the level of affected body functions and structures, and in daily functioning?

### 5.2 Method

In this section the design of the study is presented. Furthermore, a description is given of the instruments used for data collection, the units of study and the procedure used to collect this data.

#### 5.2.1 Design

To be able to obtain an overview of the specific disorders, affected body functions and problems in daily functioning of adults with a VI and SMI, a descriptive study using quantitative data would be



conducted. The records of the service users who are currently living in a residential care facility of the RCF would form the main source for data collection, and were to be collected and reviewed by a master's degree student from Radboud University, Nijmegen, The Netherlands. The student used the collected data to write her Master's thesis titled '*Clënten met een visuele beperking en bijkomende problemen nader bekeken*' [Service users with a visual impairment and additional problems in closer look]. Based on these records, the reported health conditions (disorder or disease), the affected body functions and structures, and the assessed daily functioning (activity and participation) as defined by ICF (WHO, 2001a) would be listed for each service user.

### 5.2.2 Instruments

The main documentary source for data collection was the official form that is used for the application for long-term care according to the Long-Term Care Act (Rijksoverheid, 2014), as assessed by the Care Assessment Centre (CIZ, in its Dutch abbreviation) in the manner described above in section 1.1.4. This form is structured according to the ICF-model, providing an overview of the disorders and diseases (with the official medical diagnosis), their affected body functions and structures, and daily functioning. In the following sections, these ICF-terms are further specified.

#### Diseases and/or disorders

In table 5.1 an overview is given of the categories in which the CIZ has divided the specification of different diseases and/or disorders.

**Table 5.1**

*Overview of categories for disease or disorder as specified in the application form for long-term care*

ICF term	Categories
Disease or disorder	1. Somatic/physical 2. Psycho-geriatric 3. Intellectual 4. Visual/auditory 5. Mental

A total of five different categories were formulated to structure the different diseases and disorders (CIZ, 2011). In the first category, two different kinds of conditions are listed. A somatic condition is defined as a somatic illness not caused by disorders in the nervous system or locomotor system and that is mainly stable or can be cured or treated when aggravation is present. A physical condition is defined as an illness that leads to ailments in the nervous system or locomotor system and for which no functional improvement is possible. In the second category, psycho-geriatric disorders, are listed referring to brain conditions that result in a deterioration in psychiatric, physical or social functioning

(for example, dementia). In the third category, intellectual disability is listed, the classification used is that of the DSM-IV-TR (American Psychiatric Association, 2013) (see table 5.2).

**Table 5.2**

*Categories of intellectual disability as defined by the DSM-IV-TR (American Psychiatric Association, 2013).*

Category	IQ
No intellectual disability	>70
Mild intellectual disability	69-50
Moderate intellectual disability	49-35
Severe intellectual disability	34-20
Profound intellectual disability	<20

In the fourth category, sensory impairments are listed, divided into VI and auditory impairment. For VI, a person can receive care and treatment when the visual acuity is lower than 0.3. The visual acuity is based on the best eye and is registered using the classification as formulated in the most recent version of the ICD-11 (WHO, 2018). In table 5.3 an overview of the different categories and the corresponding visual acuity is provided.

Not only the visual acuity of a service user is registered, but also the cause of the VI as is indicated by an ophthalmologist. An auditory impairment is registered when hearing loss is noted, and is measured in decibels. In the fifth category, mental disorders are listed, defined as a mental disorder diagnosed with the use of the DSM-IV-TR or DSM 5, and associated with suffering or social dysfunctioning in daily life.

**Table 5.3**

*Categories of VI as defined by the WHO in the ICD-11 (WHO, 2019).*

Category	Worse than	Equal to or better than:
0. No VI		6/12
		5/10 (0.5)
		20/40
1. Mild VI	6/12	6/18
	5/10 (0.5)	3/10 (0.3)
	20/40	20/70
2. Moderate VI	6/18	6/60
	3/10 (0.3)	1/10 (0.1)
	20/70	20/200
3. Severe VI	6/60	3/60
	1/10 (0.1)	1/20 (0.05)

Category	Worse than	Equal to or better than:
	20/200	20/400
4. Blindness	3/60	1/60
	1/20 (0.05)	1/50 (0.02)
	20/400	5/300 (20/1200) or count
	Light perception	finger (CF) at metre
5. Blindness	1/60	Light perception
	1/50 (0.02)	
	5/300 (20/1200)	
6. Blindness	No light perception	

#### Affected body functions and structures

In table 5.4 an overview is given of the categories into which the CIZ has divided the specification of different affected body function and structures.

**Table 5.4**

*Overview of categories for body functions and structures as specified in the application form for long-term care.*

ICF term	Category
Affected body functions and structures	Orientation disorders
	Mental functioning
	Physical functioning
	Problem behaviour
	Addictive problems
	Psychosocial well-being

A total of six different categories are formulated for the affected body functions and structures. The first category refers to orientation disorders, subdivided into a lack of awareness of time (knowing which day it is); place (knowing where you are); space (finding the way in the environment); and person (knowing who you are). In the second category, problems in mental functioning are registered, subdivided into problems with concentration; memory and thinking; perception of the environment; and motivation. The third category refers to physical functioning, subdivided into problems in the use of arms; hands; legs; feet; head; and in postural control. The fourth category registers problem behaviour, which can be indicated if a person shows (self)destructive; obsessive; manipulative; aggressive; or sexually excessive behaviour. The fifth category relates to addictive problems, where an addiction to alcohol; gambling; soft or hard drugs; or other can be indicated. The sixth category refers to problems in psychosocial well-being, subdivided into anxious or depressive complaints; absence of personal relations; absence of social identification roles; and lack of involvement with and interest in others. For each item, a score is given for the proposition 'In need of

*support or supervision'*, representing the extent of this need: 0. *None*, 1. *Occasionally*, 2. *Often*, 3. *Continuously*. For this study, body functions and structures were considered to be affected when a service user was given a score of 2 or 3 for an item.

### Daily functioning

In table 5.5 an overview is given of the categories into which the CIZ has divided the specification of problems in daily functioning.

**Table 5.5**

*Overview of categories of daily functioning as specified in the application form for long-term care.*

<b>ICF term</b>	<b>Categories</b>
Daily functioning	1. Social functioning 2. Mobility 3. Self-care 4. Domestic life 5. Social relationships and participation in community life 6. Participation in labour activities

Daily functioning is categorised as formulated by the CIZ and is based on the categories found in the ICF for activities and participation. See table 5.6 for the categories as formulated by the ICF and their translations for use in the CIZ. For each item within the categories, scale scores were given indicating at which level problems were experienced: 0. *Can perform activity independently, no support needed*; 1. *Can perform activity independently, but someone provides supervision*; 2. *Has difficulty performing activity independently, someone else needs to provide support*; 3. *Cannot perform activity independently, someone else has to take over*. For this study, problems in daily functioning for each item were registered when a service user was given a score of 2 or 3.

**Table 5.6**

*Overview of domains within ICF and how these domains are translated for use by the CIZ.*

<b>Function</b>	<b>ICF domain</b>	<b>Translation to CIZ category</b>
Activities	Learning and applying knowledge	Social functioning
	General tasks and demands	
	Communication	
	Mobility	Mobility
Participation	Self-care	Self-care
	Domestic Life	Domestic Life
	Interpersonal interactions and relationships	Social relationships and participation in community life
	Major life areas	
	Community, social and civic life	Participation in labour activities

### 5.2.3 Units of study

The records of service users receiving care and treatment in one of the residential care facilities of the RCF would constitute the units of study. A record would be included if it contained a completed paper application form for long-term care.

### 5.2.4 Procedure

The records of service users were reviewed by a master's degree student in the period between September 2017 and June 2018. For each service user whose record contained the paper application form for long-term care, data about their reported diseases and/or disorders, affected body functions and structures, and daily functioning were extracted and anonymously registered using SPSS version 25. The details registered for each service user were checked by the behavioural scientist responsible for the coordination of the care and treatment of the service user. Based on the registered data general overviews were generated showing the characteristics of service users.

## 5.3 Results

A complete long-term care application form was present in the records of a total of 63 service users and therefore their details were included in the study. For the total group an age range of 28 to 75 years was reported with a mean age of 50 years. In the following sections, tables provide an overview of the number of service users diagnosed with a specific disorder or disease, indicated as having affected body functions and structures, or noted to be experiencing problems in daily functioning. These tables are followed by a descriptive overview of the prevalence among the service users for each category.

### 5.3.1 Disease or disorder

An overview of the prevalence among the service users is given for somatic disorders and/or physical symptoms, psycho-geriatric disorders, intellectual functioning, mental disorders and sensory disorders.

#### Somatic disorder and/or physical symptoms

A total of 21 different somatic and/or physical conditions were recorded. In table 5.7 (page 85) an overview of the conditions and their prevalence is listed.

**Table 5.7***Somatic and physical conditions diagnosed among service users of the RCF (n=63).*

<b>Somatic/physical condition</b>	<b>Number of service users (n)</b>
Being overweight	20
Epilepsy	11
Diabetes mellitus	7
Allergy, not specified	6
Hydrocephalus	5
Laurence-Moon-Bardet-Biedl syndrome	4
Spasm	4
Hypopituitarism	3
Acquired brain impairment	3
Asthma	3
Metabolic Disorder, not specified	3
Paralysis of parts of the body	3
Arthrosis	2
Sleep apnoea	2
Stomach problems	2
Crohn's disease	1
Scheuermann's disease	1
Subdural bleeding caused by birth trauma	1
Clubfeet	1
Tremor (as a consequence of drug use)	1
Parkinsonism	1
Charles Bonnet Syndrome	1

*Note.* A service user can have multiple diagnoses.

The comorbid conditions with highest reported prevalence among service users were being overweight (n=20), epilepsy (n=11) and diabetes mellitus (n=7). Other somatic conditions reported by more than one service user were allergy (n=6), hydrocephalus (n=5), Laurence-Moon-Bardet-Biedl syndrome (n=4), spasm (n=4), paralysis of parts of the body (n=3), hypopituitarism (n=3), acquired brain impairment (n=3), asthma (n=3), metabolic disorder (n=3), sleep apnoea (n=2), stomach problems (n=2) and arthrosis (n=2). Conditions reported in only one service user were Crohn's disease, Scheuermann's disease, subdural bleeding caused by birth trauma, club feet, tremor (as a consequence of drug use), Parkinsonism and Charles Bonnet syndrome.

#### Psycho-geriatric disorders

No records were found in which psycho-geriatric disorders were reported among service users.

Intellectual functioning

In table 5.8 an overview is given of the intellectual functioning of service users.

**Table 5.8**

*Intellectual functioning of service users of the RCF (n=63).*

<b>Intellectual functioning</b>	<b>Number of service users (n)</b>
No intellectual disability	21
Mild intellectual disability	39
Moderate intellectual disability	3

A total of 21 service users were reported having no intellectual disability; a mild intellectual disability was reported in a total of 39 service users; and 3 service users were reported having a moderate intellectual disability. No service users were reported to have a severe intellectual disability.

Mental disorders

In table 5.9 an overview is given of the reported mental disorders and the number of service users recorded as having each of these disorders.

**Table 5.9**

*Mental disorder indicated for service users of the RCF (n=63).*

<b>Mental Disorder</b>	<b>Number of service users (n)</b>
Personality disorder	12
Pervasive development disorder	10
Depression	9
Psychotic disorder	8
Post-traumatic stress disorder	5
Anxiety disorder	5
Schizophrenia	2
Adjustment disorder	2
Attention deficit hyperactivity disorder	2
Obsessive compulsive disorder	1
Social phobia	1

*Note.* A service user can have multiple diagnoses.

A diagnosis according to the DSM-(IV-TR or 5) of one or more mental disorders was indicated for 35 service users. A total of 11 different disorders were diagnosed. In order of highest to lowest prevalence, the diagnoses were: personality disorders (n=12), pervasive development disorder (n=10), depression (n=9), psychotic disorder (n=8), post-traumatic stress disorder (PTSD) (n=5),

anxiety disorder (n=5), schizophrenia (n=2), adjustment disorder (n=2), attention deficit hyperactivity disorder (n=2), obsessive compulsive disorder (n=1) and social phobia (n=1). For 28 service users no (official) diagnosis of a mental disorder was registered.

In table 5.10 an overview is given of the distribution of diagnoses among service users. A total of 18 service users were diagnosed as having one mental disorder, 12 service users were diagnosed with two mental disorders, 4 were diagnosed with three mental disorders, and 1 service user was diagnosed with four mental disorders. The combinations of mental disorders with the highest prevalence were a personality disorder with depression and with a psychotic disorder. Autism was diagnosed combined with a personality disorder, with a psychotic disorder and with depression; and PTSD was diagnosed along with a psychotic disorder.

**Table 5.10**

*Distribution of mental disorders diagnoses among service users of the RCF (n=63).*

<b>Number of mental disorders indicated for a service user</b>	<b>Number of service users (n)</b>
No mental disorder	28
1 diagnosis of a mental disorder	18
2 diagnoses of mental disorders	12
3 diagnoses of mental disorders	4
4 diagnoses of mental disorders	1

Among those diagnosed with 3 mental disorders, two service users were diagnosed with a combination of a personality disorder, anxiety disorder and PTSD; one service user was diagnosed with a personality disorder, anxiety disorder and a psychotic disorder, and one service user was diagnosed as having a personality disorder combined with autism and depression. One service user was diagnosed with four mental disorders, namely a personality disorder, depression, PTSD and a psychotic disorder.

#### Sensory disorders

Low vision was measured among 36 service users, divided into mild low vision (n=23), moderate low vision (n=8) and severe low vision (n=5). A total of 27 service users were reported as being blind, divided into light-only perception (n=5) and total blindness (n=22).

In table 5.11 (p. 88) an overview is given of the different visual disorders diagnosed in service users. Retinitis pigmentosa was indicated as the most prevalent cause of a VI (n=16), followed by congenital nystagmus (n=9). Other causes that were indicated in two or more service users were lens removal as



a consequence of cataract (n=6), congenital glaucoma (n=6), retinal detachment (n=5), optic nerve atrophy (n=3), nystagmus as a consequence of cataract (n=3), retinoblastoma (n=2), and aniridia as a consequence of nystagmus (n=2). Each of the following visual disorders was reported in one service user: aniridia as a consequence of glaucoma, papillae atrophy, optic nerve hypoplasia, retinopathy, diabetic retinopathy, cataract as a consequence of retinal detachment, amblyopia and cone dystrophy.

A total of 13 service users were reported as having hearing loss.

**Table 5.11**

*Visual disorders indicated for service users of the RCF (n=63).*

<b>Visual disorder</b>	<b>Number of service users (n)</b>
Retinitis pigmentosa	16
Congenital nystagmus	9
Lens removal as a consequence of cataract	6
Congenital glaucoma	6
Retinal detachment	5
Optic nerve atrophy	3
Nystagmus as a consequence of cataract	3
Retinoblastoma	2
Aniridia as a consequence of nystagmus	2
Aniridia as a consequence of glaucoma	1
Papillae atrophy	1
Optic nerve hypoplasia	1
Retinopathy	1
Diabetic retinopathy	1
Cataract as a consequence of retinal detachment	1
Amblyopia	1
Cone dystrophy	1

*Note.* A service user can have multiple diagnoses.

### 5.3.2 Affected body functions and structures

With regards to affected body functions and structures, the most common area in which problems were reported was psychosocial well-being (table 5.12, page 89): lacking personal relations (n=47); lacking acknowledged social identification roles (n=43); anxiety (n=41); depressive feelings (n=38); and a lack of interest in and involvement with others (n=38).

**Table 5.12***Number of service users experiencing a problem of psychosocial well-being.*

<b>Psychosocial well-being</b>	<b>Number of service users (n)</b>
Lack of personal relations	47
Lack of acknowledged social roles	43
Being anxious	41
Depressive	38
Lack of interest in and involvement with others	38

*Note.* A service user could be recorded as having multiple problems.

A high prevalence of problems was also reported in mental functioning (table 5.13), in which problems were reported in concentration (n=49), memory (n=49), motivation (n=45) and perception of the environment (n=39).

**Table 5.13***Number of service users experiencing a problem of mental functioning*

<b>Mental functioning</b>	<b>Number of service users (n)</b>
Concentration	49
Memory	49
Motivation	45
Perception of the environment	39

*Note.* A service user could be recorded as having multiple problems.

Also, a high prevalence of orientation disorders was reported (table 5.14), involving having problems with orientation in place (n=39); with orientation in space (n=35); with orientation in time (n=22); and with awareness of persons (n=19).

**Table 5.14***Number of service users experiencing a problem of orientation*

<b>Orientation disorders</b>	<b>Number of service users (n)</b>
Orientation in place (know where you are)	39
Orientation in space (finding the way in the environment)	35
Orientation in time (knowing which day it is)	22
Orientation in person (knowing who you are)	19

*Note.* A service user could be recorded as having multiple problems.

The records also indicated that service users experienced problem behaviours (table 5.15), namely manipulative (n=35); compulsive (n=31); self-harming (n=23); verbally aggressive (n=18); problematic sexual (n=10); destructive (n=8); and physically aggressive behaviours (n=3).

**Table 5.15**

*Number of service users experiencing problem behaviour/safety problems*

<b>Problem behaviour</b>	<b>Number of service users (n)</b>
Manipulative behaviour	35
Compulsive behaviour	31
Self-harming behaviour	23
Verbally aggressive behaviour	18
Problematic sexual behaviour	10
Destructive behaviour	8
Physically aggressive behaviour	3

*Note.* A service user could be recorded as having multiple problems.

Addictive problems were reported among service users related to alcohol (n=12); gambling (n=5); soft drugs (n=2); and hard drugs (n=1) (table 5.16).

**Table 5.16**

*Number of service users experiencing a problem of addiction*

<b>Addiction</b>	<b>Number of service users (n)</b>
Alcohol	12
Gambling	5
Soft drugs	2
Hard drugs	1

*Note.* A service user could be recorded as having multiple problems.

Finally, problems in motor function that were reported in service users (table 5.17, page 91) encompassed problems with control of hands (n=8); arms (n=6); feet (n=6); legs (n=5); problems of head control (n=2); and problems of postural control (n=2).

**Table 5.17***Number of service users experiencing a problem of motor function*

<b>Motor function</b>	<b>Number of service users (n)</b>
Hands	8
Arms	6
Feet	6
Legs	5
Head control	2
Postural control	2

*Note.* A service user could be recorded as having multiple problems.

### 5.3.3 Daily functioning

On the level of daily functioning problems were recorded in all domains and for a large number of service users. Tables 5.18 to 5.23 show that main problems are related to managing life, performing complex tasks, interpersonal relationships and being part of society. Fewer difficulties or needs were recorded in performing simple tasks and less nursing care was required.

**Table 5.18***Number of service users experiencing a problem of social self-reliance*

<b>Social self-reliance</b>	<b>Numer of service users (n)</b>
Carrying out administrative tasks by themselves	62
Solving problems, making decisions and assessing the consequences	62
Initiating and performing complex tasks	61
Coordinating daily routine: bringing structure to the day	58
Daily activities: planning activities and structuring the day	57
Managing finance by themselves	53
Initiating and performing simple tasks	52
Managing themselves in shops, postal office, etc.	52
Managing themselves when using public transport	49
Reading, writing and maths	46
Having a conversation	42
Using communication aids	39
Understanding what others tell you	39
Making themselves understandable for others	36

*Note.* A service user could be recorded as having multiple problems.

**Table 5.19***Number of service users experiencing a problem in personal care*

<b>Personal care</b>	<b>Number of service users (n)</b>
Taking care of their own personal health	53
Taking care of own teeth, hair, nails and skin	33
Eating and drinking	14
Washing	14
Dressing	12
Getting into and out of bed	8
Moving themselves to lying or seating position	5
Going to the toilet and cleaning themselves	5

*Note.* A service user could be recorded as having multiple problems.

**Table 5.20***Number of service users experiencing a problem of mobility*

<b>Mobility</b>	<b>Number of service users (n)</b>
Moving themselves outside the house (>1km)	55
Using own form of transport	53
Making use of public transport	45
Walking short distances	37
Moving themselves with the use of aids	36
Lifting and carrying heavy objects	30
Going up and down the stairs	25
Moving themselves inside the house	16
Making coordinated movements with legs and feet	16
Performing fine hand movements	12
Performing gross hand movements	7
Lifting and carrying light objects	6
Changing body posture	4
Maintaining body posture	3

*Note.* A service user could be recorded as having multiple problems.

**Table 5.21***Number of service users experiencing a problem in domestic life*

<b>Domestic life</b>	<b>Number of service users (n)</b>
Daily managing of household	60
Cleaning the entire house	59
Preparing meal: hot meal	54
Helping others in household with self-care	53
Helping others with preparing a meal	52
Managing domestic matters	51

<b>Domestic life</b>	<b>Number of service users (n)</b>
Using household appliances	47
Doing grocery shopping	45
Performing light cleaning tasks in the house	45
Washing clothes and linen	44
Preparing meal: bread-based	20

*Note.* A service user could be recorded as having multiple problems.

**Table 5.22**

*Number of service users experiencing a problem of social relations and societal life*

<b>Social relations and societal life</b>	<b>Number of service users (n)</b>
Creating contacts with others independently	55
Engaging in leisure activities outside the house: sports, café, etc.	55
Participating in clubs or associations	54
Maintaining social contacts independently	53
Visiting general facilities independently	50
Maintaining relations with family	36

*Note.* A service user could be recorded as having multiple problems.

**Table 5.23**

*Number of service users experiencing a problem in performing labour activities (score of 2 or 3 = has difficulty performing or cannot perform given activity independently).*

<b>Performing labour activities</b>	<b>Number of service users (n)</b>
Searching for and getting a job	62
Performing a full-time job	61
Performing a part-time job	61
Performing a day job, keeping a work routine	55
Volunteering	54

*Note.* A service user could be recorded as having multiple problems.

## 5.4 Discussion

In this section the main findings of the study are presented by answering the research questions formulated in section 5.1 and comparing the outcomes to the existing literature. Furthermore, the strengths and limitations of the study are discussed, leading to the main conclusions to be drawn from this chapter.

### 5.4.1 Main findings

The records of the service users in the residential care facilities of the RCF were studied to gain greater insight into the comorbid problems that are diagnosed/reported in its service users. A search

for specific diseases and/or disorders reported in service users' records revealed that half of the service users were diagnosed as having one or more mental disorders, including personality disorders, pervasive development disorder, depression, psychotic disorders, PTSD and anxiety disorder. Comorbid somatic disorders and/or physical symptoms with a high prevalence were being overweight, epilepsy, diabetes mellitus, allergies and hydrocephalus. Furthermore, two-thirds of the service users were reported as having either a mild (the most prevalent) or a moderate intellectual disability. All service users were reported as having VI, with an equal distribution between having low vision and being blind. Retinitis pigmentosa was indicated as the most prevalent VI, followed by congenital nystagmus. Other prevalent causes were congenital glaucoma, ablatio retinae and cataracts. Around one-fifth of service users were reported as having hearing loss. No comorbid psycho-geriatric disorders were found in the records of service users.

The inventory into the problems experienced by service users in terms of affected body functions and structures revealed that service users were experiencing problems in the following domains: mental functioning, psychosocial well-being, orientation disorders and problem behaviour. Some service users were reported as having problems with motor function or addiction. On the level of daily functioning problems were indicated in all categories. In most service users, problems were reported in items that referred to activities related to managing life, completing complex tasks, establishing and maintaining interpersonal relationships, and being part of society. Problems in performing simple tasks of self-care or domestic life were less prevalent. In terms of participation, problems were reported in all categories for the majority of the service users, showing the difficulties these persons experience in participating on an equal level in society.

In this study, an overview has been obtained of the specific diseases and/or disorders, affected body functions and structures, and problems of daily functioning reported in the service users within the residential care facilities of the RCF. When compared to the problems expressed by professionals for adults with VI and SMI similarities are found in the multimorbid problems experienced in service users. The study reveals that over half of the service users were diagnosed with at least one mental disorder alongside their VI, and of those almost half were diagnosed with two or more mental disorders. Furthermore, different comorbid somatic problems were indicated within the service users of the RCF. Mild intellectual disability was a common comorbid cognitive problem, being reported among more than half of the service users. Other comorbid cognitive problems seem to be less prevalent among the service users. Only three service users were reported as having acquired brain injury and no reports of psycho-geriatric disorders were found.

With regard to affected body functions and structures and daily functioning, problems were commonly encountered in mental functioning and psychosocial well-being, managing life, performing complex tasks, interpersonal relationships and participating in society. These problems seem to be related to the problems recognised by professionals in the form of personal and external factors in a service users' live. Professionals indicated that their service users lack a social network, use dysfunctional ways of coping and experience an imbalance in the amount of stress and their resilience to cope with this. These difficulties could be the result of the problems experienced by service users as a result of affected body functions and structures and in daily functioning. Specific research is needed to determine how the service users' experienced difficulties in their personal and external factors and their problems experienced in daily functioning can be related.

With this overview in hand, some differences and similarities compared to the existing literature can be discussed. In the current study, the most prevalent causes for a VI were found to be retinitis pigmentosa and congenital nystagmus. This is not in line with the most prevalent causes for a VI (cataract and macular degeneration) indicated by Limburg and Keunen (2009). Within the study of Limburg and Keunen (2009), the majority of the population was elder persons, as these persons can be identified as a group with a high prevalence of VI. Cataract and macular degeneration are causes for VI that develop in persons due to ageing. Therefore, these causes were identified as most prevalent within the total Dutch population. Limburg (2007) studied the most prevalent causes of VI for different age groups. Based on studies conducted in Scandinavian countries and the United Kingdom he concluded that for children between 0-14 years of age, refractive errors, congenital cataract and congenital glaucoma were the most prevalent causes for VI. For persons between 15-49 years of age, an estimation of the most prevalent causes could be made based on the Copenhagen Eye study. They indicated the following VIs as most prevalent within this age group: refractive errors, cataract, glaucoma, diabetic retinopathy, macular degeneration and myopia. In this study, the causes of VI found in the service users are more in accordance with the prevalent causes in younger age groups. However, the high prevalence of retinitis pigmentosa under the service users of the RCF is not recognised in related studies.

Similarities with the existing literature can be found in the reported problems of service users in terms of psychosocial functioning, wellbeing and problem behaviours. In more than half of the service users problems were reported in these domains. This is in line with the study of Teunissen et al. (2020) who state that adults with VI and comorbid mental illness were thought, according to professionals, to experience feelings of anxiety, depression or loneliness, to have low self-esteem and resilience, and to have a strong dependence on others. They have difficulties accepting their VI,



trusting others and judging who can be trusted, and building social relationships or support networks. They are unable to manage their time adequately and lack a feeling of being part of society. It seems that these problems cannot be explained by their VI solely and it might be expected that mental health problems are under-diagnosed in service users. This susceptibility to mental health problems is in line with the susceptibility in adults with VI to developing mental health and psychosocial problems reported in other studies, in which they show a higher risk for developing difficulties in attachment (Dekker-van der Sande & Janssen, 2009; Sterkenburg, 2019), difficulties in building a social network (Kef, 2002; Kef & Dekovic, 2004) and a higher proclivity to depressive and/or anxious feelings (Adams et al., 1971; Berman & Brodaty, 2006; Casten & Rovner, 2008; Horowitz et al., 2005; Stewart et al., 1998; Watkinson, 2011).

### 5.4.2 Strengths and limitations

In this study a broad overview of the reported problems for the service users of the RCF has been obtained. The basis for this overview was the CIZ form used for the application for and assessment of the suitable amount of long-term care. The contents of this form provided descriptive statistics of diseases/disorders, affected body functions and structures, and daily functioning. This form is composed using the ICF classification as a reference. By using this form for data collection a systematic inventory could be executed, in which the data for each service user was based on the same (and worldwide-accepted) categorisation, and so helping to make the outcomes transferable and generalisable. However, a limitation in the use of the form could also be that, as the information in this application form was based on a snapshot at admission or when changes in the care and treatment were indicated. So, this is not a representation of the current situation of the service users, but gives a clear overview of the initial state of service users when applying for care and treatment. Furthermore, not all service users in the residential care facilities could be included as a paper version of the application form was not available for all. However, this form was experienced as the most representative form providing an overview of the problems and needs of service users. It seems that no such a clear overview of the current situation of a service user is present within the RCF. It could be considered that having annual clear assessment of the problems and needs of a service user can improve the quality of care for service users. Another limitation for this study is that no specific analysis was made of the comorbid disorders and diseases, affected body functions and structures, and problems in daily functioning for those service users diagnosed with a mental disorder. Going further, it is not clear to what extent the reported problems are specific for adults with VI and SMI, the particular subjects of this research. Performing such an analysis would have been problematic for two reasons. On the one hand, while (35/63=) 55% of the included service users had recorded an official diagnosis of a mental disorder, it was not clear to what extent service

users without an official diagnosis were experiencing mental disorders. On the other hand, no specific diagnosis for SMI was recorded. Therefore, any attempt to provide this specific analysis based on the available records could lead to results that might well not be internally valid. Before this is attempted, more structured assessments should be conducted among the service users for the diagnosis of mental disorders and concurrent SMI.

### 5.4.3 Conclusion

In this chapter an overview of the reported problems for the service users of the RCF has been provided to gain insights into the specific disorders underlying their VI and SMI and other comorbid problems. Based on this overview, the indications and contra-indications for adults with VI and SMI as formulated in chapter 4 can be further refined. The study in this chapter shows that prevalent causes for a VI among service users were retinitis pigmentosa, congenital nystagmus, congenital glaucoma, ablatio retinae and cataracts. Prevalent mental disorders among service users include personality disorders, pervasive development disorder, depression, psychotic disorder, PTSD and anxiety disorder. The experienced multimorbid problems in service users as described in chapter 4 can be further specified, as the results show that of those service users with at least one diagnosed mental disorder, almost half have been diagnosed with two or more mental disorders. Comorbid somatic disorders and symptoms are present within the service users and to some extent comorbid cognitive disorders are reported. The service users' problems reported on the level of daily functioning, such as activities related to managing life, conducting complex tasks, establishing and maintaining interpersonal relationships and being part of society, show that their problems lead to serious impairments in social and/or societal functioning. Together with the multimorbid problems experienced in service users, this underlines their complexity of problems and it can be seen as one of the aspects that shape the current care and treatment of adults with VI and SMI.

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## CHAPTER 6: AN EVIDENCE MAP OF RESEARCH INTO ADULTS WITH VI AND COMORBID MENTAL, COGNITIVE AND/OR SOMATIC PROBLEMS

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### 6.1 Introduction

This and the following chapter identify core areas in the available scientific evidence related to the care and treatment of adults with VI and SMI. In this chapter, the results are presented of a mapping review that has been conducted to gain insights into how this group is represented in the literature compared to research involving people with VI and other comorbid problems, such as cognitive/intellectual and physical/somatic conditions. Chapter 7 will provide an overview of the available published evidence describing specific interventions or implications for practice relevant to the care and treatment for adults with VI and SMI.

For this mapping review a broader focus was chosen to represent the total population of service users in the RCF, namely adults with VI and complex multimorbid problems. Professionals indicate that their service users can be described as a diverse group with a wide variety of disorders or diseases, and who experience problems of mental, cognitive or somatic functioning. Adults with such characteristics seem to be underrepresented in the scientific literature (Boessen et al., 2016). As such, taking a wide overview of the comorbid problems addressed in adults with VI in the scientific evidence is important if potentially relevant evidence is to be identified. This overview would provide insights into the current scope of the research field, where possible gaps in the research can be identified and how these could be interpreted when compared to the total research field. Furthermore, insight can be gained into the specific comorbid problems that receive high attention in the literature and how this activity relates to research within the scope of comorbid SMI.

When taking a closer look at the research activity in the Netherlands, different groups with comorbid problems are acknowledged in the literature. For example, different academic chairs for persons with VI and specific co- or multimorbidities have been established in the Netherlands, such as for persons with profound intellectual and multiple disabilities (PIMD) or deafblindness (VGN, 2019b).

Furthermore, different programmes are available that provide funding for research for persons with VI. The programme '*Uitzicht*' is a cooperation between several Dutch funds for persons with VI and provides funding for scientific research that is specifically focused to the origins, prevention and treatment of diseases of the eye. The programme '*Inzicht*' is coordinated by the Netherlands Organisation for Health Research and Development (ZonMw, according to its Dutch abbreviation) and offers funding for research oriented to the care, employment, education and rehabilitation of

persons with VI. They have funded a total of 80 projects since 1998. Among these projects, there is one that focused on VI and comorbid mental health problems by studying the effectiveness of a stepped-care programme to reduce depression and anxiety in older persons with VI. Other projects have focused on subjects related to the study of adults with VI and SMI, such as loneliness and fatigue. Related subjects have also been studied in persons, or more specifically children, with VI and an intellectual disability, such as separation anxiety, attachment or autism. In 2017, ZonMw coordinated a specific call in which they invited researchers to submit projects focused on optimising the diagnostic process and/or interventions for persons with VI and mental health problems or a mental disorder. This call resulted in funding for two projects focusing on the diagnosis and treatment of post-traumatic stress disorder in adults with VI (Van der Aa, 2017) and the development of a mentalisation-based treatment programme for adults with VI and psychological and/or psychiatric problems (Sterkenburg, 2017). It is possible, however, that studies may have been conducted in other research fields or countries. It is important, therefore, to search the literature systematically and widely to identify all research into comorbid problems in adults with VI.

In this chapter, an answer will be obtained to the following research question: *'How is SMI as a comorbid problem in adults with VI represented in the literature when compared to the study of other comorbid problems in persons with VI?'*

This sub question was further specified by the following questions:

- Which comorbid problems in adults with VI have been addressed in the literature?
- Which topics are addressed in these studies?

### 6.2 Method

In this section the design of the study is presented. Furthermore, a description is given of the search strategy and the procedure that would be applied for the review.

#### 6.2.1 Design

An evidence map of the evidence for adults with VI and comorbid problems would be created by conducting a scoping study (Arksey & O'Malley, 2005). A scoping study is defined by Colquhoun et al. (2014) as:

*'a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge.'* (pp. 1292 and 1294).

By conducting a scoping study, coverage of the available literature can be assessed, identifying the extent, range and nature of research in the field, determining the value of undertaking a systematic review, summarising and disseminating research findings, and identifying possible research gaps (Arksey & O'Malley, 2005). The results of a scoping study can be presented in a table, creating an *evidence map*, that offers a 'user-friendly' and digestible overview of the literature (Miake-Lye et al., 2016). For this scoping study, the procedure as described by Arksey and O'Malley (2005) and enhanced by Levac et al. (2010) would be applied. In their framework a total of six stages are described:

1. Identifying the research question;
2. Identifying relevant studies;
3. Study selection;
4. Charting the data;
5. Collating, summarising and reporting the results;
6. Consultation with stakeholders.

### 6.2.2 Search strategy

A search strategy was established based on the first sub question as stated in the introduction of this chapter: '*which comorbid problems in adults with VI have been addressed in the literature?*' Based on this research question, a search strategy describing the population, concept and context (PCC) was formulated. A search in the following three databases would be conducted: Pubmed, CINAHL and PsycINFO. Pubmed was chosen as a database because it is one of the largest databases in the world comprising literature in biomedical research. CINAHL and PsycINFO were added as databases for their specific focus on nursing/paramedical research and psychology. By choosing these three databases a combination of a broad search in biomedical research, and a more specific focus on nursing, paramedical and psychology would be achieved. The search strategies for these databases specifically focused on the description/definition of adults with VI and comorbid problems, and had a broad scope. A difference was made between three categories of comorbid conditions, namely 1) mental, 2) cognitive/intellectual, and 3) physical/somatic. Different search terms, including MeSH and free-text terms (in the full study or more specifically in title and abstract only [tiab]), were combined within each category using the Boolean operator "OR". Subsequently, the results for each comorbid condition were combined with the search terms for VI using the Boolean operator "AND". Furthermore, the relevant characteristics of comorbidity and age, using separate search terms, were included. In table 6.1 (page 101) the search strategy for PubMed is presented as an example.

**Table 6.1***Search strategy used for the search in PubMed.*

Search category	Search term	“OR”	“AND”
Visual	#1. Visually Impaired Persons [Mesh]	<b>#106</b>	<b>#112</b>
	#2. Blindness [Mesh]	Search item 1-6 combined with OR	106 AND 107 NOT
	#3. Vision, Low [Mesh]		111
	#4. visual impair*[tiab]	<b>#113</b>	106 AND 107 AND 108 NOT 111
	#5. visually impair*[tiab]		
	#6. blindness [tiab]		
#7. Mentally Ill Persons [Mesh]			
Mental	#8. Anxiety disorders [Mesh]	<b>#107</b> Search items 7-35 combined with OR	106 AND 107 AND 108 NOT 111
	#9. Bipolar and related disorders [Mesh]		
	#10. Feeding and eating disorders [Mesh]	<b>#114</b> 106 AND 107 AND 109 NOT 111	
	#11. Mood disorders [Mesh]		
	#12. Anxiety, separation [Mesh]		
	#13. Attention deficit and disruptive behavior disorders [Mesh]		
	#14. Child development disorders, pervasive [Mesh]		<b>#115</b> 106 AND 108 AND 109 NOT 111
	#15. Communication disorders [Mesh]		
	#16. Mutism [Mesh]		<b>#116</b> 106 AND 110 NOT 111
	#17. Reactive attachment disorder [Mesh]		
	#18. Schizophrenia, childhood [Mesh]		
	#19. Stereotypic movement disorders [Mesh]		
	#20. Tic disorders [Mesh]		
	#21. Neurotic disorders [Mesh]		
	#22. Personality disorders [Mesh]		
	#23. Schizophrenia spectrum and other psychotic disorders [Mesh]		
	#24. Sexual dysfunction, psychological [Mesh]	<b>#108</b> Search items 36-48 combined with OR	
	#25. Sleep wake disorders [Mesh]		
	#26. Somatoform disorders [Mesh]		
	#27. Trauma and stressor related disorders [Mesh]		
	#28. psychiatric disabilit*		
	#29. psychiatric impairment*		
	#30. psychiatric disorder*		
#31. mental disorder*			
#32. mental ill*			
#33. psychological disorder*			
#34. psychological disabilit*			
#35. psychological impairment*			
Cognitive/ intellectual	#36. Mentally Disabled Persons [Mesh]	<b>#109</b>	
	#37. Intellectual Disability [Mesh]		
	#38. Learning Disorders [Mesh]		
	#39. Neurocognitive disorders [Mesh]		
	#40. Developmental disabilities [Mesh]		
	#41. Dementia [Mesh]		
	#42. intellectual disab*		
	#43. intellectually disab*		
	#44. cognitive disabilit*		
	#45. cognitive impair*		
	#46. mental disabilit*		
	#47. “mentally retarded”		
	#48. “mental retardation”		
Physical/somatic	#49. Mobility Limitation [Mesh]		

Search category	Search term	"OR"	"AND"
	#50. Dependent Ambulation [Mesh]	Search items 49-87 combined with OR	
	#51. Motor Disorders [Mesh]		
	#52. Motor Skills Disorders [Mesh]		
	#53. Endocrine system disease [Mesh]		
	#54. Syndrome [Mesh]		
	#55. skin diseases [mesh]		
	#56. respiratory tract diseases [mesh]		
	#57. musculoskeletal diseases [mesh]		
	#58. digestive system diseases [mesh]		
	#59. cardiovascular diseases [mesh]		
	#60. Akinetic mutism [Mesh]		
	#61. Auditory diseases, central [Mesh]		
	#62. Parkinsonian disorders [Mesh]		
	#63. Brian abscess [Mesh]		
	#64. Brain damage, chronic [Mesh]		
	#65. Brain diseases, metabolic [Mesh]		
	#66. Brain edema [Mesh]		
	#67. Brain injuries [Mesh]		
	#68. Brain neoplasms [Mesh]		
	#69. Cerebellar diseases [Mesh]		
	#70. Diffuse cerebral sclerosis of schilder [Mesh]		
	#71. Encephalitis [Mesh]		
	#72. Encephalomalacia [Mesh]		
	#73. Epilepsy [Mesh]		
	#74. Headache disorders [Mesh]		
	#75. Hydrocephalus [Mesh]		
	#76. Hypothalamic diseases [Mesh]		
	#77. Hypoxia, brain [Mesh]		
	#78. Intracranial hypertension [Mesh]		
	#79. Intracranial hypotension [Mesh]		
	#80. Neuroaxonal dystrophies [Mesh]		
	#81. Sepsis-associated encephalopathy [Mesh]		
	#82. Subdural effusion [Mesh]		
	#83. Thalamic diseases [Mesh]		
	#84. physical disabilit*		
	#85. physical impairment*		
	#86. physical limit*		
	#87. equilibrium disorder*		
Comorbidity	#88. Comorbidity [Mesh]	<b>#110</b>	
	#89. multimorbidity	Search items 88-101 combined with OR	
	#90. multimorbidities		
	#91. "multi morbidity"		
	#92. "co morbidity"		
	#93. "multi morbidities"		
	#94. "co morbidities"		
	#95. comorbidity		
	#96. comorbidities		
	#97. multiple disab*		
	#98. multiple disorder*		
	#99. multiple impairment*		
	#100. associated disorder*		
	#101. associated impairment*		
Age < 18 years	#102. Child [ti]	<b>#111</b>	
	#103. Children [ti]	Search items 102-105 combined with OR	
	#104. Infant [ti]		
	#105. Infants [ti]		

Inclusion criteria scoping review

A study would be included only if all the following criteria were met:

- The study subjects are adults (aged 18 or over) with a VI and comorbid problems, with a main focus on those comorbid disorders that are mentioned in the search strategy: mental disorders, cognitive/intellectual conditions and physical/somatic conditions;
- It describes any type of study, including systematic reviews, RCTs, observational studies, and qualitative studies;
- It has been published in a (peer-reviewed) journal, or as part of (peer-reviewed) conference proceedings, as a book or book chapter, or as a treatment protocol.
- It was published in English, German or Dutch;
- It had been published from 1990.

This last inclusion criterion was added, due to the broad focus of this review. Therefore, a large amount of titles were found to be assessed. To prevent that the search would become too time consuming, an overview of studies published from 1990 was considered as sufficient.

6.2.3 Procedure

A flowchart of study selection is presented in figure 6.1 (p. 104). The search strategy was established by the PhD researcher in collaboration with a junior researcher (with a Master's degree). A search was conducted in June 2016 by the junior researcher using the search strategies for the three databases (PubMed, CINAHL and PsychINFO). A total of 6735 references were found; after deleting duplicates, 4606 references remained. Of these references all publications from 1990 to 2016 (n=3540) were included. Their titles were independently examined for their relevance by three researchers, namely the PhD researcher, the junior researcher and a senior researcher who was involved as a co-supervisor of the study. In the next step the abstracts of the remaining articles (n=1096) were read and assessed using a scoring system that is enclosed in appendix 6. Internal agreement between the three researchers was measured using Cohen's kappa (Landis & Koch, 1977). As the scoring system describes, articles were included when two or more researchers indicated the study as being relevant. When a different score was given by all three researchers, a definite score was given based on a subsequent discussion of the paper to arrive at a consensus among the three researchers.

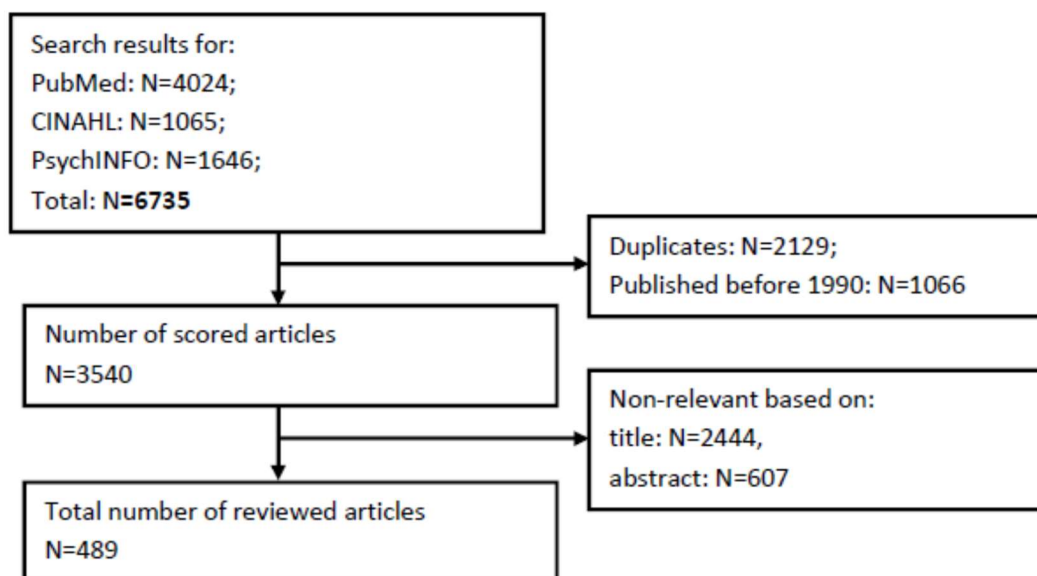
The remaining relevant articles (n=489) were not fully read, but an evidence map was made, based on their abstracts. The articles were charted based on the comorbid condition they dealt with (mental, cognitive/intellectual, or physical/somatic). Also, based on the specific conditions described



as the focus of the research in the abstracts, different topics were formulated. For each comorbid condition the studies were structured by these topics as follows: intervention/implications for practice; incidence/prevalence; studies that investigated the relationship between VI and the comorbid condition in question (designated hereafter as ‘*association*’); aetiology; diagnostics/assessment; case report (without description of an intervention); and other. Based on this charting process, the outcomes were collated and summarised by creating an ‘evidence map’ (three in total) for each class of comorbid condition (mental, cognitive/intellectual, or physical/somatic). Each evidence map consisted of a table showing the number of articles per type of comorbid disorder or condition and the topic the article focused on.

**Figure 6.1**

*Flowchart of the steps taken for study selection.*



### 6.3 Results

Cohen’s kappa varied from 0.39 – 0.56 between the three researchers, indicating a moderate agreement in coding (Landis & Koch, 1977).

In tables 6.2 to 6.4 the number of articles is presented categorised by the different comorbid disorder or condition and the topics addressed. A separate table is presented for each comorbid condition: mental in table 6.2, cognitive/intellectual in table 6.3 and physical/somatic in table 6.4.

**Table 6.2**

*Number of articles on mental comorbidity categorised by type of mental disorder and topic*

<b>Topic</b>	<b>Depression/ anxiety</b>	<b>Psychiatry/ psychosocial</b>	<b>Psychosis</b>	<b>Autism</b>	<b>Psychiatric symptoms in Wolfram</b>	<b>Alcohol/ drugs</b>	<b>Eating disorders</b>	<b>Other</b>	<b>Total</b>
Intervention/ implications	14	2	-	3	-	3	3	3	28
Incidence, prevalence	50	15	7	5	4	6	3	-	90
Association	-	3	4	1	-	-	2	4	14
Aetiology	-	4	1	4	-	1	-	-	10
Diagnostics/ assessment	10	2	2	-	-	-	-	1	15
Case report*	-	1	-	-	7	1	-	1	10
Other	-	3	-	-	-	-	-	-	3
<b>Total</b>	<b>74</b>	<b>30</b>	<b>14</b>	<b>13</b>	<b>11</b>	<b>11</b>	<b>8</b>	<b>9</b>	<b>170</b>

\* without the description of an intervention

## CHAPTER 6

Within the category of mental comorbidity, a total of 170 studies were found, which focused on: comorbid depression and/or anxiety (n=74); psychiatry/psychosocial problems, not further specified (n=30); psychosis (n=14); autism (n=13); problematic alcohol and/or drug use (n=11); and eating disorders (n=8). A category related to psychiatry was found referring to psychiatric symptoms in Wolfram syndrome (n=11). Furthermore, the category 'other comorbid mental health conditions' was established, categorised into which were studies referring to a range of comorbid mental disorders that were subject of only one or two studies (n=9). Most common were articles that studied comorbid depression and/or anxiety in adults with VI, with many having a focus on incidence or prevalence (n=50), along with articles concerning the description of interventions/implications for practice (n=14) and diagnostics/assessment (n=10). Another relatively common focus was on the incidence or prevalence of unspecified psychiatric or psychosocial problems in adults with VI (n=15). Studies that were less prevalent were those that focused on a comorbid psychosis (n=14), autism (N=13), problematic alcohol/drugs use (n=11) and eating disorders (n=8). In most of these studies the incidence or prevalence of this comorbid disorder among persons with VI was studied. Within studies related to Wolfram Syndrome, the prevalence/incidence of psychiatric symptoms (n=4) and case studies describing these symptoms among persons diagnosed with this syndrome (n=7) formed the main topics of study. In the category referring to other comorbid mental disorders the following disorders were studied: sleeping disorders, attention deficit hyperactivity disorder, chronic mental health conditions not further specified, obsessive-compulsive disorder and dissociative identity disorder. The main topic within these studies was the association of the comorbid disorder with VI.

Within the category of cognitive or intellectual comorbidity a total of 75 studies were found (table 6.3, p. 107), which focused on comorbid intellectual disabilities (n=50), dementia (n=14) and cognitive functioning not further specified (n=11). Most common among articles studying comorbid intellectual disabilities were those focusing on association (n=13) and diagnostics/assessment (n=11). For studies involving dementia and cognitive functioning, a main focus was on the topic of the association between VI and the comorbid disorder in question.

**Table 6.3**

*Number of articles on cognitive/intellectual comorbidity categorised by type of disorder and topic.*

<b>Topic</b>	<b>Intellectual disabilities</b>	<b>Dementia</b>	<b>Cognitive functioning</b>	<b>Total</b>
Intervention/implications	8	2	3	13
Incidence, prevalence	7	-	-	7
Association	13	6	7	26
Aetiology	4	2	1	7
Diagnostics, assessment	11	1	-	12
Case report*	4	3	-	7
Other	3	-	-	3
<b>Total</b>	<b>50</b>	<b>14</b>	<b>11</b>	<b>75</b>

\* without the description of an intervention

Within the category physical/somatic comorbidity a total of 244 studies were found (table 6.4, p. 108). These focused on deafblindness (n=79), different diseases (n=56), different syndromes (n=50), diabetes (n=30), the sleep-wake cycle (n=13), multiple disabilities (n=13), and hip fractures due to falls (n=3) within adults with VI. Most common were articles that studied the association between VI and deafness (n=24) or with different diseases (n=33), and those focusing on the aetiology of syndromes (n=34). In addition, other topics with a prevalence of ten or more studies were found in deafblindness: studying interventions/implications based on communication systems that can be used to facilitate the communication for these persons (n=16); or diagnostics/assessment of deafblindness (n=12). Furthermore, ten or more studies focused on the association between VI and diabetes (n=10); and to the association between VI and the sleep-wake cycle (n=13). In the categories addressing multiple disabilities or hip fractures due to falls a handful of studies were found, with a main focus on the topics interventions or implications for practice (n=7) and the topic association (n=3).

**Table 6.4**

*Number of articles on physical/somatic comorbidity categorised by type of disorder and topic.*

<b>Topic</b>	<b>Deaf-blindness</b>	<b>Diseases</b>	<b>Syndromes</b>	<b>Diabetes</b>	<b>Sleep-wake cycle</b>	<b>Multiple disabilities</b>	<b>Hip fractures due to falls</b>	<b>Total</b>
Intervention/implications	16	3	1	1	-	7	-	28
Incidence, prevalence	8	1	1	9	-	-	-	19
Association	24	33	2	10	13	-	3	85
Aetiology	2	9	34	-	-	-	-	45
Diagnostics, assessment	12	1	5	7	-	2	-	27
Case report*	5	9	6	1	-	-	-	21
Other	12	-	1	2	-	4	-	19
<b>Total</b>	<b>79</b>	<b>56</b>	<b>50</b>	<b>30</b>	<b>13</b>	<b>13</b>	<b>3</b>	<b>244</b>

\* without the description of an intervention

To provide more insight into the nature of the diseases and the syndromes that were addressed in the included studies related to physical/somatic conditions, these are categorised and listed by frequency in tables 6.5 and 6.6 respectively.

**Table 6.5**

*Diseases addressed in the included studies, listed by category and number of studies related to each listed disease.*

<b>Disease</b>	<b>No. of studies of each disease</b>
Chronic multi-morbidity; comorbidities; illness; and health conditions	9
Stroke	5
Systemic illness and anomalies; Wernicke's encephalopathy; HIV-AIDS; Parkinson's disease	3
Acute pancreatitis; multiple sclerosis; heart failure/disease; Creutzfeldt-Jakob; muscle-eye-brain disease	2
Cancer; leprosy; functional disability; ectodermal dysplasia; inflammatory bowel disease; obstructive sleep apnoea; tuberculosis; myopathy; traumatic brain injury; heroin withdrawal; vitamin A deficiency; temporal lobectomy for drug resistant epilepsy; and hereditary endotheliopathy with: retinopathy; nephropathy; neuromuscular impairment; and stroke	1

**Table 6.6**

*Syndromes addressed in the included studies, listed by category and number of studies concerning each listed syndrome.*

<b>Syndrome</b>	<b>No. of studies of each syndrome</b>
Norrie's	17
Bardet-Biedl	10
Dide-Botcazo; Usher	3
Leukoencephalopathy; CHARGE; Anton's; Lowe	2
Alström; Arima; Prader-Willi; Moebius; Spielmeyer-Vogt; MELAS; Mohr-Tranebjaerg; Good's; Senior-Loken; osteoporosis-pseudoglioma; congenital syndrome	1

## 6.4 Discussion

In this section the main findings of the study are presented by answering the research questions formulated in section 6.1. Furthermore, the strengths and limitations of the study are discussed, and finally some conclusions are drawn.

### 6.4.1 Main findings

By conducting a scoping review and presenting the results in tables for comorbid mental, cognitive/intellectual and physical/somatic conditions, insights were gained into the different

comorbid problems in adults with VI that have been addressed in the literature and the particular topics addressed in these studies. The largest number of studies were found to address comorbid physical/somatic conditions, with a high attention paid to persons with deafblindness, and specifically describing the association between a VI and hearing impairment or interventions to facilitate communication. Also, prominent objects of research have been the association between a VI and diabetes, and the aetiology of different syndromes and diseases in persons with VI.

Compared to other comorbid conditions, relatively little attention has been given to comorbid cognitive/intellectual conditions in adults with VI. Within this category, the greatest number of studies have addressed the association of VI and a comorbid intellectual disability and the diagnostics or assessment within persons with VI and intellectual disability.

When taking a closer look at the attention paid to comorbid mental disorders, the greatest number of studies focus on the prevalence or incidence of depression and/or anxiety in persons with VI, followed by interventions for and diagnosis/assessment of this particular disorder. This is an area that receives a great deal of attention in the literature, and is therefore also accounting for the high number of studies found in total in this class of comorbid condition. The attention paid to other comorbid mental disorders in persons with VI is much lower. The only other combination of topic and disorder to be the subject of more than ten studies is the prevalence or incidence of unspecified psychiatric or psychosocial problems among persons with VI. Furthermore, fewer than fifteen studies were found to address each of the other comorbid mental disorders (psychosis, autism, problematic alcohol and/or drugs use, eating disorders, sleeping disorders, attention deficit hyperactivity disorder, obsessive-compulsive disorder and dissociative identity disorder) in persons with VI. In these studies focus was mainly on the incidence/prevalence of the disorder among persons with VI and on the association of the disorder and VI. A specific topic in the literature concerns the psychiatric symptoms in Wolfram syndrome. Most of the studies in this area refer to the prevalence of these symptoms, describe cases without an intervention or implications for practice. No studies were found that specifically address a comorbid SMI in persons with VI, although a psychosis is often indicated as being an SMI. Also, a severe depression/anxiety can be identified as an SMI. However, the studies found in this review addressing depression and/or anxiety mainly focus on the prevention of these disorders in persons with VI or refer to (sub-threshold) symptoms of depression or anxiety related to vision loss. Furthermore, a total of 28 studies were found that focus more specifically on interventions or implications for practice for VI and a comorbid mental condition. These studies will be further addressed in chapter 7.

### 6.4.2 Strengths and limitations

A scoping review with a broad scope was conducted using a clear methodology to obtain an overview of the current research concerning scope for adults with a VI and comorbid mental, cognitive and/or physical/somatic problems. This overview was intended to provide insights into the subjects that are most commonly addressed in the literature, and into the gaps in research into comorbid problems and specifically into comorbid mental disorders in adults with VI. A concise search was conducted, in which the analysis and selection of articles was executed by three researchers and mutual agreement was sought for each selection stage. A limitation of the study could be that the overview was based on the abstract only of each included study, and this may not have provided sufficient information compared to a full assessment of the study. This should be taken into account when interpreting the results of this review. However, the evidence map is mainly built based on the goal of the studies, an aspect that should be indicated in an abstract. Therefore, it is not unreasonable to consider that the overview of studies provides an accurate indication of the areas that have received interest within the field of research into comorbid problems in adults with VI. Another limitation could be that no specific search term for SMI was used in the search strategy. However, the search included such terms as “mental ill\*”, “mental disorder\*” and “mentally ill persons”, based on which it would be expected that studies focusing on SMI would have been retrieved in the search.

### 6.4.3 Conclusion

In relation to the present study, the areas of deafblindness and depression and/or anxiety have received most attention in the field of research into VI and different comorbid problems. Intellectual disabilities is another frequently addressed comorbid condition in the literature. However, most of these studies focus on other topics than the description of an intervention or implications for practice. In the following chapter, the studies that do address this topic are analysed more closely.

The results of this review indicates that there is still a gap in the literature, especially when referring to comorbid mental disorders and SMI. The topic of comorbid SMI has not specifically been addressed in the literature and therefore no specific implications can be drawn from it with regards to the present study.



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## CHAPTER 7: SCOPING REVIEW OF THE AVAILABLE EVIDENCE RELEVANT TO THE CARE AND TREATMENT FOR ADULTS WITH VI AND SMI

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### 7.1 Introduction

In chapter 6, an evidence map has been presented that reveals the scope of research for adults with VI and mental illness. This map shows that the availability of evidence regarding the care and treatment of adults with VI and SMI is scarce. A total of 170 studies were found addressing a comorbid mental illness in adults with VI. Of these studies, 28 focused on describing a specific intervention or implications for practice. Based on the abstracts of these studies it can be concluded that attention is mainly paid to the treatment of depressive and/or anxious symptoms in adults with acquired VI. This is a different focus from that of this research project, in terms of both the target group and nature of care and treatment. The few studies that focus on other comorbid mental disorders do not describe or evaluate a specific intervention, but are case reports, (narrative) reviews or qualitative studies, which may lead to implications for practice.

However, these studies may provide findings that can be transferred to the care and treatment of adults with VI and SMI. To identify such findings a more specific review of this evidence is needed, in which the studies are read in full and summarised based on the research designs and methods used and the specific outcomes. As few studies seem to have used a specific design that would lead to insights into the effectiveness of a specific intervention, a scoping review is most suitable for gaining an overview of the available evidence. This review provides insights into the best research evidence that is available relevant to the care and treatment of adults with VI and SMI; such evidence is identified as one of the three important components for providing evidence-based practice by Sackett et al. (1996) as outlined in sections 1.2 and 2.2.1. The implications drawn from these studies can then be integrated with the two other components (clinical expertise and service users' values), by identifying their similarities to and differences from the logic model describing the care and treatment for adults with VI and SMI provided by the RCF (which will be the result of the iterative process of inquiry with a group of professionals (chapter 8) and a group of service users (chapter 9)).

In this chapter, an answer will be gained to the central research question: *'What published evidence is available relevant to the care and treatment for adults with VI and SMI?'*

### 7.2 Method

A scoping review was to be conducted, with a broad scope based on a PCC (population, concept and context) search strategy (Peters et al., 2015). A scoping review can be undertaken when an examination of the extent, range and nature of research activity is needed in order to summarise and disseminate research findings (Arksey & O'Malley, 2005). This strategy was chosen since the aim of the research project is to arrive at an explicit description of current care and treatment for adults with VI and SMI in general, and as such no specific intervention could be formulated on which to conduct a specific search by defining the Population, Intervention, Comparison and Outcome (PICO search strategy). Furthermore, the review conducted in chapter 6 revealed only a few studies that specifically describe the effectiveness of an intervention, with more studies describing more general implications concerning the care and treatment for adults with VI and a comorbid mental disorder. Therefore, it was expected that a systematic review would not yield the desired results and a scoping review was more suitable.

#### 7.2.1 Search strategy

Based on the abstracts of the studies that were found in the review described in chapter 6, a total of 28 studies were expected to describe an intervention or implications for practice of treatment for adults with VI and a comorbid mental disorder and were therefore selected for full text reading in this review. Furthermore, the scope of the search would be widened to include studies published before 1990 and after June 2016. These search periods were included to identify all research relevant to the care and treatment for adults with VI and SMI, as this subject could have been more addressed in a specific period. The titles of the studies that were excluded based on their publication date (published before 1990) in the review described in chapter 6 would be included for this new review. To include studies published after June 2016, an additional search would be conducted in the three databases (PubMed, CINAHL, PsycInfo) in December 2018. For this additional search, the search strategy as used for the review in chapter 6 (see figure 6.1) would be narrowed to the focus of this specific study. In the original search strategy, search terms were formulated for the following categories: visual, mental, cognitive/intellectual, physical/somatic, comorbidity and age >18. As the focus for this review was on comorbid mental disorders, the search terms related to the categories cognitive/intellectual and physical/somatic were to be omitted from the additional search.

#### Inclusion criteria scoping review

A study would be included only if all the following criteria were met:

- The study subjects are adults (aged 18 or over) with VI and comorbid mental disorder;

- The study describes the effectiveness of an intervention or a study of the effectiveness of an intervention, or else describes implications for practice;
- It describes any type of study, including systematic reviews, RCTs, observational studies, and qualitative studies;
- It was published in a (peer-reviewed) journal, or as part of (peer-reviewed) conference proceedings, as a book or book chapter, or as a treatment protocol;
- It was published English, German or Dutch.

A study would be excluded if any of the following criteria were met:

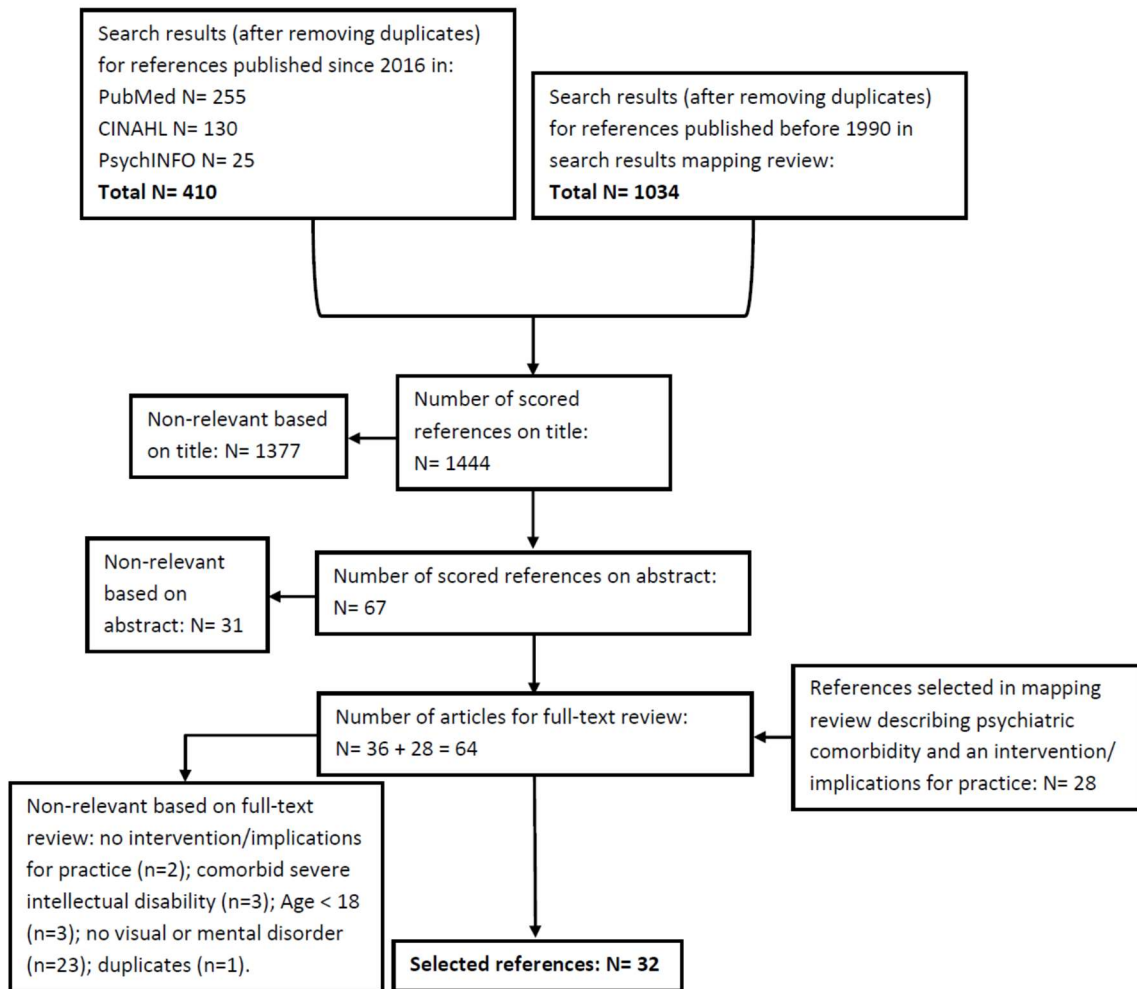
- It included participants with a comorbid severe intellectual disability;
- It concerns a medical or surgical treatment.

### 7.2.2 Procedure

In figure 7.1 (p. 115) a flowchart is presented of the search procedure. By conducting an additional search in the three databases, a total of 410 references that were published after 2016 were found. Furthermore, a total of 1034 references (after removing duplicates) that were published before 1990 were found in the search results derived by the search conducted as described in chapter 6. The titles of both old and new publications (1444 in total) were independently examined for relevance, using a scoring system, by two of the three researchers who were described in chapter 6 (the PhD researcher and co-supervisor of the research project). In the next step the abstracts of the remaining 67 articles were read and assessed using a more specific scoring system. Both scoring systems are enclosed in appendix 7. A total of 36 studies were selected based on this scoring procedure. The 28 studies that were identified in the review described in chapter 6 were added to these results. This resulted in a total of 64 studies, whose texts were then read in full. Articles that were found, after reading the full text, to meet one of the exclusion criteria or which did not satisfy all the inclusion criteria were excluded. Internal agreement between the two researchers for the two additional searches was measured using Cohen's kappa (Landis & Koch, 1977). A total of 32 articles remained, each of which were categorised based on the specific mental disorder they describe. For each category a table was made, displaying the authors, the target group (by specifying the age, number of participants, specific VI and comorbid mental disorder), setting and design of the study. Furthermore, the results of the study and important implications for practice based on those results were summarised.

**Figure 7.1**

*Flowchart of the steps taken in the scoping review procedure.*



### 7.3 Results

Cohen's kappa was 0.35 for the screening of the titles and 0.54 for the screening of the abstracts, indicating moderate agreement between the two reviewers (Landis & Koch, 1977). A total of 32 articles were found that describe interventions or implications for practice for adults with a VI combined with depression and/or anxiety (n=17); an eating disorder (n=3); problematic alcohol and/or drug use (n=4); dementia (n=3); PTSD (n=1); mental disorders not further specified (n=3); or personality disorder (n=1). At the end of the results section an overview of the subject and results of the studies is provided in separate tables for each comorbid mental disorder (tables 7.1 to 7.7). These results are further described in the following sections.

### 7.3.1 Depression and/or anxiety

In table 7.1 the studies addressing interventions for comorbid depression and/or anxiety are summarised. The table shows that the following research designs were applied in the studies: meta-analysis (n=1), systematic review (n=1), (literature) review (n=5), longitudinal study (n=1), RCT (n=2), randomised control pilot study (n=1), pre-test post-test study (n=2), study using an experimental and control group without randomisation (n=1), multiple case study (n=1), qualitative study (n=1) and the description of a treatment protocol (n=1). In the table 7.1 the articles are starred, when they are also part of one of the reviews. The focus of this review is on gathering the important aspects relevant to the care and treatment for adults with VI and SMI, therefore it is expected that this will not influence the outcomes of this study.

Different studies describe the application or the effectiveness of a specific intervention that is intended to help adults with VI in reducing comorbid depressive symptoms. Studied interventions are: cognitive behavioural therapy (CBT) or self-management programmes based on CBT (Berman & Brodaty, 2006; Casten & Rovner, 2008; Watkinson, 2011); problem-solving treatment (PST) (Casten & Rovner, 2008; Nollett et al., 2016); stepped-care programme (Van der Aa, van Rens, et al., 2015); counselling and interpersonal therapy (Watkinson, 2011); social skills training with an emphasis on assertiveness (Donohue et al., 1995); job-coaching for employment or volunteer work (McDonnall, 2011; Nyman et al., 2010); and general rehabilitation training (Casten & Rovner, 2008; Horowitz et al., 2005; Mielke et al., 2013; O'Donnell, 2005). Based on the results of these different studies as summarised in table 7.1, different treatment programmes can be designated as effective in reducing depressive symptoms for persons with vision loss.

Three studies prove the effectiveness of a PST (Nollett et al., 2016) and a stepped-care programme on major depressive dysthymic and/or anxiety disorders in older persons with VI (Van der Aa, Krijnen-de Bruin, et al., 2015; Van der Aa, van Rens, et al., 2015) by conducting a RCT or meta-analysis. Nollett et al. (2016) showed a greater decrease of depressive symptoms in persons receiving a PST compared to a control group or to referral to a GP. However, the differences between the groups were small. The stepped-care programme of Van der Aa, van Rens, et al. (2015) consisted of successive steps, in which participants proceeded to the next step if their depressive and/or anxiety complaints did not sufficiently decrease. The programme started with a period of 'watchful waiting', followed by a supported self-help therapy based on CBT, the next step being PST provided by an outreaching care worker and at last referral to a GP for more intensive treatment. To fit the needs of persons with VI, specific adjustments in the self-help therapy and PST were made. These adjustments

were in the form of the addition of specific themes based on the physical and psychological consequences of VI (such as grief about their vision loss, fatigue and psychosocial adjustment) that could lead to feelings of depression and anxiety, and by altering the exercises and examples or the presentation type of the materials (for example, using audio or Braille versions of written documents). The results of the RCT suggests that the stepped-care programme was associated with a reduced incidence of depression and anxiety and the programme could lead to a more standardised approach of the treatment of depression and anxiety in persons with VI.

Other important outcomes could also be described based on the information provided in the studies that describe (the effectiveness of) a specific intervention or implications for practice. Different studies emphasize the high rates of comorbidity (Adams et al., 1971; Berman & Brodaty, 2006; Casten & Rovner, 2008; Horowitz et al., 2005; Stewart et al., 1998; Watkinson, 2011) and the importance of treatment in reducing these comorbid symptoms (Adams et al., 1971; Stewart et al., 1998; Van der Aa et al., 2016). Also, the lack of awareness in professionals of this comorbidity in adults with VI is addressed in different studies (Berman & Brodaty, 2006; Casten & Rovner, 2008; Stewart et al., 1998; Van der Aa, van Rens, et al., 2015; Watkinson, 2011). These same studies also emphasize the importance of the inclusion of psychosocial programmes during rehabilitation, and this is also mentioned in two other studies (Adams et al., 1971; Horowitz et al., 2005). Casten and Rovner (2008) stress the importance of educating vision care providers in the provision of psychosocial interventions, mainly because of the interplay of the combination of impairments and the effects that combination has on functioning. Professionals need to be aware of this interplay and be able to adapt their psychosocial interventions. Furthermore, two studies discussed the importance of being able to differentiate between the symptoms resulting from the VI and depressive complaints (Stewart et al., 1998; Whitson et al., 2011). Other important implications were discussed by O'Donnell (2005), who indicates the importance of a client-centred and holistic approach with awareness of and more attention paid to the relation between VI and depression, as well as the importance of showing respect, a suitable use of language and engaging in multidisciplinary collaboration.

### 7.3.2 Eating disorders

In table 7.2 the studies addressing comorbid eating disorders are summarised: three case reports were found describing the treatment of an eating disorder in a person with VI (Chapman et al., 1998; Fernandez-Aranda et al., 2006; Thomas et al., 2012). All studies conclude that treatment of an eating disorder is possible when the treatment is adjusted to the needs of a VI. Furthermore, Chapman et al. (1998) emphasize the importance of an intensive focus on building a trusting relationship, using

alternative communication methods, and adjusting the number and place of treatment sessions. This makes it difficult to involve the service user in the general programme and therapists showed anxiety in treating a person with VI. Fernandez-Aranda et al. (2006) conclude that an approach oriented at the causes and not the symptoms seems to be effective.

### 7.3.3 Problematic alcohol and/or drug use

In table 7.3 the studies addressing problematic alcohol and/or drug use are summarised. Three studies were found: a review; a needs assessment based on a review of existing data, a survey and focus groups; and a case report. Greenleaf (1971) describes in his case report, concerning a patient with problematic alcohol use and vision loss due to blindness in one eye and vision loss in the other eye without a physical reason, that a treatment by hypnosis with a duration of two years, helped the patient to regain his sight in one eye and gain control over his alcohol consumption. The therapist experienced the treatment as an intermittent process: going back and forward in steps and taking the possibilities of the service user at that moment into account. Furthermore, an emphasis is placed by the therapist on the following aspects: the importance of trust and acceptance between therapist and patient, taking time, talking about traumatic life events and not being judgemental. The authors of the two other studies conclude that in both sectors (visual and mental health) knowledge is lacking for effective treatment; they advocate an interdisciplinary approach to achieve effective outcomes in persons with VI and problematic alcohol and/or drug use (Koch et al., 2002; Koch et al., 2005).

### 7.3.4 Dementia

In table 7.4 the studies addressing comorbid dementia are summarised, comprising a literature review (Bowes et al., 2016) and two qualitative studies (Evans & Bray, 2016; Nyman et al., 2017). The importance of collaboration between different sectors is also emphasized in these studies. Furthermore, Bowes et al. (2016) describe in their literature review how a focus on one single condition is taken when designing a safe environment for elderly with VI and dementia, and stress the importance of a person-centred approach when adapting the environment for these persons. Nyman et al. (2017) describe in their qualitative study with semi-structured interviews the impact of dementia on the ability to cope with VI and the difficulties encountered in using VI aids or technology.

### 7.3.5 PTSD

In table 7.5 a study addressing comorbid PTSD is summarised. Brunet et al. (2019) conducted a systematic review regarding the stress reactions of persons with VI to traumatic events. They conclude that different reactions can occur in persons with VI (physical, behavioural, emotional and

cognitive) and this has an impact on their mental health. Based on their findings, they suggest that more attention should be paid to the presence of mental health problems in persons with VI who experienced a traumatic event and to the need for treatment of these problems. This treatment should be adjusted to the needs of a person with VI.

### 7.3.6 Mental disorders, not further specified

In table 7.6 the studies addressing unspecified comorbid mental disorders, are summarised. These studies describe: a pre-test post-test study; a review; an intensive rehabilitation programme; and a manual arts workshop in combination with a specific case report. Needham et al. (1992) found in their pre-test post-test study that persons with previous or existing symptoms of psychological problems showed more distress due to vision loss, but based on staff ratings no differences were found between these service users and service users without psychological problems at the beginning and end of a rehabilitation program for VI, both groups showing a significant improvement in terms of skills, attitude and overall adjustment. They concluded that persons with comorbid psychological problems should not be excluded from rehabilitation training. The two studies describing interventions show that these interventions can be applied for persons with VI and comorbid mental health problems and lead to improvements in psychosocial functioning (Browne et al., 1968; Leddy, 1974). Leddy (1974) emphasizes the importance of being flexible and establishing trust. A review study by Kelley and Tedder (1993) indicates that persons with VI and unspecified mental disorders experience stigma and problems in adjusting to society. They emphasize the importance of collaboration with mental health care.

### 7.3.7 Personality disorder

In table 7.7 a study addressing comorbid personality disorder is summarised. A case report described by Adams (1980) shows that it takes longer for a person with VI and a personality disorder of a passive-aggressive type to establish a therapeutic relationship, and that the therapist needs to play a more active role to forge this relationship. This can be established by adopting VI-related behaviours, such as announcing your presence, touching the service user and allowing oneself to be touched by the service user, interpreting the service user's non-verbal behaviour, providing verbal cues and explaining the environment.



**Table 7.1**

*Overview and summary of the studies that focus on interventions or implications for practice of treatment for adults with VI and comorbid depression and/or anxiety.*

<b>Study</b>	<b>Target group</b> N, age		<b>VI</b>	<b>Comorbid condition</b>	<b>Setting</b>	<b>Design</b>	<b>Results</b>	<b>Implications</b>
<b>Berman and Brodaty (2006), Australia</b>	Elderly	Age-related macular degeneration (AMD)	Age-related macular degeneration (AMD)	Psychosocial problems, e.g. depression, suicidal complaints, worries, somatisation and anxiety.		Literature review to the psychosocial effects of AMD (MEDLINE, PsycINFO, CINAHL) Keywords: depression, psychosocial, functional impairment, blindness, psychosis, Charles Bonnet syndrome and AMD, associated with elderly or old age.	Associations were found for AMD with depression, anxiety and Charles Bonnet syndrome. Other sequelae associated to AMD were functional impairment, decreased quality of life, psychosocial dysfunction and distress.  A self-management program based on cognitive behavioural therapy (CBT) seems to be effective in preventing psychosocial problems due to depressive symptoms.	Therapists should be aware on the psychosocial effects and social damage that are associated with AMD, but also other VIs. Patients who have accepted their VI seem to best manage their social adjustments.
<b>Casten and Rovner (2008), USA</b>	Elderly	AMD	AMD	Depression		Narrative review (discussion article) on the extent of depression	People with AMD are more sensitive to develop a depression. This combination of impairments reinforces each other, as a result	It is important to develop interventions that incorporate the management of depression in rehabilitation programs, because of the relation

					among AMD patients, the effect of depression on vision-related disability, suggestions for treating and preventing depression.	treatment is more difficult. Interventions using CBT, problem solving, and rehabilitation seem to be effective to avert the onset of depressive symptoms in people with AMD. It is important that more attention is paid to the screening of depressive symptoms in people with AMD and professionals are specifically educated.	between depression and AMD. Professionals need to be educated in psychosocial interventions, mainly because of the interplay of the combination of impairments and the effects they have on functioning.
<b>Donohue et al. (1995), USA</b>	Elderly	VI	Depression	Policlinical	Treatment manual	Description of a social skills training for elderly with VI who are depressive, consisting of three components: negative assertion, requests for assistance, and requests for social involvement.	Training has an emphasis on social skills and assertiveness. Because elderly persons with VI need higher levels of assertiveness, due to a weakening of the social support structure (natural process for elder persons) and an increased dependence because of the vision loss.
<b>McDonnall (2011), UK</b>	n=2688 (1380 with Dual sensory loss (DSL) and	Dual sensory loss	Depressive symptoms		Used data of a longitudinal study to determine the effect of productivity activities (employment,	The results indicate that all three indicators, i.e. employment, volunteer work or informal help, were associated with lower levels of depression for both persons with VI and	Volunteering seems to be a suitable option to prevent depressive symptoms in this population; this can be more difficult when a person is in bad health; volunteering can be facilitated by providing

	1308 without DSL) Elderly			volunteer work or informal help) on depressive symptoms (measured by shortened CES-D) in older persons with VI compared to older persons without VI.	without, but only volunteering acted as a moderator of depressive symptoms for persons with vision loss.	information about volunteering, facilitating travel and preparing a person on the job by training (comparable to supported employment).
<b>Mielke et al. (2013), Germany</b>	65-85 n=20 (9 in treat- ment group, 11 in control group)	AMD	Secondary depression	Randomized, controlled pilot study in which the effect of a rehabilitation training for VI is measured on emotional status (GDS, ADS-L), cognitive delay (MMS, DemTecT) and quality of life (NEI-VFQ 25) for AMD- patients.	Clients who receive rehabilitation training for their VI are less likely to develop depressive complaints; there is an increase in cognitive and social skills; the results of the control group was the other way round.	The effects have to be confirmed in future studies with more patients and a longer observation period.

<b>Van der Aa, Krijnen-de Bruin, et al. (2015), The Netherlands/Belgium</b>	n=265 (baseline); n=246 (after watchful waiting) 50+. Average age: 73.7 (12.3)	46% macular degeneration; 17% glaucoma; 17% cataract; 5.7% cerebral bleeding; 3.4% diabetic retinopathy; 3.6% other	Depression/anxiety: no symptoms 34.1%; subthreshold symptoms 47.6%; disorder 18.3%	Policlinic rehabilitation for persons with VI	Pre-test/post-test study with the following outcome measures: subthreshold depression and anxiety (CESD and HADS-A), and depressive and anxiety disorders (Mini International Neuropsychiatric Interview).	A watchful waiting period is a sufficient first step for persons with VI and mild depression and anxiety complaints. A significant decrease of symptoms was found after 3 months of watchful waiting. This intervention is less effective for women, people who show more symptoms of depression or anxiety in their history or people with more adjustment difficulties to their VI. These persons may take advantage of a higher intensity or shorter period of watchful waiting.	
<b>Van der Aa, van Rens, et al. (2015), The Netherlands</b>	n=265 73,65	Low vision	Depression and/or anxiety	Rehabilitation for persons with VI, outreaching	RCT of a stepped care program on the 24 months cumulative incidence for major depressive dysthymic and/or anxiety disorders (primary outcome) and	A stepped-care intervention (watchful waiting, supported self-help therapy, problem solving treatment, GP) adjusted to the needs of persons with VI by referring to specific themes based on physical and psychological consequences of VI (such as bereavement,	Patients with subthreshold symptoms can benefit from the (low intensity) psychological services offered in the stepped-care programme that can be integrated in low-vision rehabilitation care. More awareness is needed on the detection of subthreshold symptoms of depression and anxiety in older persons with VI.

				change in symptoms of depression and anxiety, vision-related QoL, health-related QoL, and adaptation to vision loss over time up to 24 months' follow-up (secondary outcomes)	fatigue, psychosocial adjustment) that could lead to feelings of depression and anxiety; and by altering exercises and examples, and the presentation type of the materials (for example, audio and Braille version of written documents). The intervention had a significant effect on the onset of depression or anxiety disorders over two years in elderly persons with VI. These persons showed a significant decrease of depressive and anxious symptoms and an improved visual related quality of life. Prevention of depression and anxiety can have positive effects on the life of clients and lead to cost reductions in care.	
<b>Watkinson (2011), UK</b>	-	VI	Depression	Literature review (Qualitative)	Different treatment options are discussed for mild depressive symptoms in persons with VI, such as Cognitive Behaviour Therapy (CBT), counselling,	The primary challenge remains the effective delivery of psychosocial care in recognising the signs of depression and

						and Interpersonal Therapy (IPT) in combination with antidepressants if the symptoms are more persistent. The review emphasizes the importance of paying specific attention to symptoms of depression in persons with VI.	providing the necessary help and emotional support with a view to further assessment and treatment. Accessing services for professional advice and continuing support will help to provide the basis for regaining better general and visual functioning and quality of life in the longer term.
<b>Nollett et al. (2016), UK</b>	n=85 70,4	Low vision	Depression	Rehabilitation for persons with VI	RCT for PST compared to referral to a GP or waiting list. Outcome: change in depressive symptoms on BECK depression inventory (6 months after baseline)	Symptoms of depression showed a greater reduction in persons receiving a Problem-Solving Treatment (PST) compared to referral to a GP or a control group; the differences between the groups were small. It is important to refer persons to a GP and stepped care is recommended.	
<b>Horowitz et al. (2005), USA</b>	n=95 65-89 (average 76,9)	VI	Depression, hearing- and cognitive impairments (multiple comorbidity; e.g. arthritis, high blood	Rehabilitation setting	Pre-test/post-test study (after two years) on the effect of specific vision rehabilitation services	Results of services for people with VI (such as assessment of residual vision, prescription of aids, skills training, support/advice/providing information and use of aids) show that depression	The results show the importance of a psychological approach in the rehabilitation of elderly people. Elderly with VI often deal with emotional consequences after diagnosis. It is important to

			pressure, heart problems and diabetes)	on change in depression (CES-D) in older adults with VI.	is often acknowledged in elder persons with VI. Rehabilitation focusing on supporting/informing persons and offering services for persons with VI seem to facilitate a decrease in depression. Training skills and adaptation of aids did not lead to a decrease in depression.	give hope. Not focussing on repairing the vision, but enabling a person to keep performing important activities with the use of devices.
<b>Nyman et al. (2010), UK</b>	18-64	VI	Psychosocial causes	Systematic review of quantitative studies (English, from 2001 to July 2008) that measured depression/ mental health, anxiety, quality of life, social functioning or social support.	Working-age adults with VI were significantly more likely to report lower levels of mental health, social functioning and quality of life. Three studies focused on psychosocial outcomes of rehabilitation and interventions. An elaborated program for jobs leads to more satisfaction and empowerment/ independence.	More research is needed to gain insights on the impact of VI on depression in working-age adults to clarify if depression and anxiety are more prevalent in working-age adults with VI, explore whether working-age adults report higher levels of perceived social support than older people, test the effectiveness of interventions to improve psychosocial wellbeing directly through counselling/peer support or indirectly through employment programmes.

<b>O'Donnell (2005), USA</b>	Elderly	VI	Depression		Narrative review		Client-centred approach; VI-aids should be placed in the context of meaningful activities; an approach based on respect, suitable use of language; multidisciplinary collaboration; screening tool for depression; awareness and more attention for the relation between VI and depression; holistic approach; attention to physical and mental impairments, attention to health and environment; rehabilitation adjusted on the elderly client.
<b>Stewart et al. (1998), USA</b>	-	VI	Depression	Rehabilitation for persons with VI	Narrative review	Needed skills for professionals: differentiate and be able to assess the different impairments; be able to react to difficulties in the rehabilitation process involving the mood of the client; provide suitable mental health care. The assessment of depression in persons with VI is problematic: depressive symptoms show similarities with behaviour	Too little attention is paid to assessment of depression in persons with VI; a coordinating role in a multidisciplinary team; treatment: outreaching in case of mild symptoms of depression (advice). Psychotherapy and (when needed) anti-depressants; also in a severe depressive episode, outreaching support is possible, when there is no indication of



after loss of vision. Social isolation and restricted mobility can lead to coping strategies that mask depressive symptoms; if the VI is due to getting older, the depression could also be part of this process.

suicidal thoughts and a supportive environment is present; in case of recurring episodes: strategies to decrease stress. Different forms of psychotherapy, including insights into negative feelings, determine causes, enlighten symptoms, develop strategies to prevent negative episodes in the future; cognitive therapy (identify and change cognitive images), behavioural therapy (change in behaviour and environment); psychoanalysis (change personality structure and decrease vulnerability); group therapy (participants feel less isolated, peer contact, social skills, problem solving ability); intramural treatment when depression is very severe. Assessment of depressive complaints should standard be part of rehabilitation for people with VI.

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<b>Trozzolino et al. (2003), USA</b>	n=48 Adult clients; 62,4 ± 9,8	VI	Diabetes, depression	VI rehabilitation centre	Experimental and control group, outcomes: depressive symptoms (BDI), knowledge of diabetes (DKT), and diabetes-related psychosocial stress (PAID).	The treatment program Vision Maximizer (10 sessions of group therapy with CBT-like interventions) seems to be effective for clients in controlling their gluco-values and therefore prevent diabetic retinopathy. Persons with improvement in depressive complaints gained better control over their gluco-values.	Professionals should screen their clients with diabetes for depression.
<b>Whitson et al. (2011), USA</b>	n=98 average 80,4 ± 7,8	Different conditions of the macula, such as macular degeneration	Depression and cognitive impairments ; auditive impairment, anxiety disorder, diabetes, lung illness, fall incidents, arthritis	Outreaching rehabilitation	Semi-structured interviews that elicited perceptions about barriers and facilitators of successful program participation.	Impact of comorbidity on rehabilitation → 5 themes: 1) Good days, bad days 2) restrictions in communication 3) Feeling overwhelmed 4) delay 5) importance of a buddy/support	Implications for practice: 1) flexible planning of appointments; same-day options, material to take home or is available on the internet; routine assessment during every appointment and suitable individual service 2) calm space; less distraction; training of professionals in conversation skills; wearable sound amplifiers; multimodal: graphic, audio, video, oral. 3) tuning with other service providers; visit clients at home; transport provision;

							guidelines and protocols to provide information about problems caused by comorbidity; support groups
<b>Van der Aa et al. (2016)</b>	Adults (≥18)	VI	Depression, anxiety, psychological stress, psychological well-being, fatigue, loneliness		Systematic review and meta-analysis of psychosocial interventions to improve mental health (depression, anxiety, mental fatigue, loneliness, psychological stress and psychological well-being)	In the last decade recognition has grown of the need to address psychological consequences when having a VI. A meta-analysis of studies of the effect of interventions on indicated symptoms shows no significant overall effect on these symptoms after removing outliers. No differences were found in specific eye condition or setting. An older age seems to negatively influence the outcome on psychological well-being.	Well-designed high-quality studies about the effect of interventions on psychological symptoms (especially anxiety, stress, fatigue and loneliness) in adults with VI are needed. These studies should also include the cost-effectiveness of the intervention. More attention is needed on an effective intervention for increasing psychological well-being in the elderly.
<b>Adams et al. (1971)</b>	Adults (n=3), 30, 31, 28	Loss of vision (glaucoma, visual field loss, due to CVA & retinitis pigmentosa)	Emotional stress	Outpatient	Description of different ways in which persons can respond to vision loss, by describing typical case histories.	Generally, 3 different reactions to late onset VI can be observed: acceptance, denial or depression, with or without anxiety.	Denial requires attention if it persists and clients do not take action to cope with their VI, i.e. consultation of a psychiatrist; depression can occur in various degrees of severity, with psychotic episodes and risk of suicide; care can vary

accordingly from psychiatric consultation to short- or long-term psychiatric therapy (psychotherapy, medication etc.).

**Table 7.2**

*Overview and summary of the studies that focus on interventions or implications for practice in treatment for adults with VI and comorbid eating disorder*

Study	Target group N, age	VI	Comorbid condition	Setting	Design	Results	Implications
<b>Fernandez-Aranda et al. (2006), Spain</b>	n=1 47	Blind	Eating disorder (bulimia nervosa), psycho-social stress, anxiety and depressive symptoms, allergic asthma	Policlinical rehabilitation	Case report of a single diagnosed and treated case of bulimia nervosa in a blind, 47-year-old Spanish woman.	The disappearance of binge eating and throwing up (even after follow-up) was reported, after treatment of most important triggers: individual shortcomings and interpersonal reactions of family members. It seems that the eating disorder was a consequence of inadequate skills to manage stress.	An eating disorder is not always a consequence of poor body image. An approach oriented to the causes and not the symptoms seems to be effective.
<b>Thomas et al. (2012), USA</b>	n=1 19	Blind from birth	Anorexia nervosa	Intramural; centre for the treatment of eating disorders	Case report	CBT-like interventions (selfmonitoring, response prevention, mirror exposure therapy, intensive outreach therapy, nutrition advice and medication) that are	If adjusted to the needs of clients with a VI, CBT can be a relevant and acceptable treatment for persons with VI.

						adjusted to the needs of a client with VI (for example feeling the body instead of checking with the eyes) seem to be relevant and acceptable for the treatment of persons with VI.	
<b>Chapman et al. (1998), England</b>	n=1 34 (woman )	Retinitis pigmentosa	Usher's syndrome (deaf) and eating disorder (anorexia).	Clinical setting	Case report	The complexity of the problems makes it difficult to involve the client in the general programme. Individual adjustments had to be made by placing an intensive focus on building a trusting relationship, mainly individually focused, using alternative communication methods and adjustments in the number and place of treatment sessions. Furthermore, therapists showed an anxiety in treating a person with chronic impairments.	In persons with complex problems it is important that a relation is based on trust. Furthermore, more attention should be paid to aetiology and the restricted factors of the disability that influence the treatment.

**Table 7.3**

*Overview and summary of the studies that focus on interventions or implications for practice in treatment for adults with VI and problematic alcohol and/or drug use.*

<b>Study</b>	<b>Target group</b> N, age VI		<b>Comorbid condition</b>	<b>Setting</b>	<b>Design</b>	<b>Results</b>	<b>Implications</b>
<b>Koch et al. (2002), USA</b>	-	VI	Alcohol and drug use	-	Narrative review	Support staff should realise that people with a VI combined with alcohol/drug abuse (AODA) experience extra stigma. These people do not fit in one specialised care system. In both sectors knowledge about the other impairment is missing and the effect of the interaction of the impairments is insufficiently integrated. Traditional AODA treatments provide general approaches that do not recognise individual differences. This is not effective for this target group. The most important premise for an effective treatment is strengthening the relationship between different professional service delivery cultures.	It is important that professionals from the visual sector as well as AODA collaborate. A single general approach is not suitable for the specific combination of disabilities of this target group.

<p><b>Koch et al. (2005), USA</b></p>	<p>-</p>	<p>Blind or low vision</p>	<p>Alcohol and drug use</p>	<p>Needs assessment by a review of existing data, survey regarding the definition of clients served and description of the referral process; focus groups with key stakeholders.</p>	<p>“Train the trainers” is advocated focusing on 1) attitudinal exercises on stereotypes of both addiction and disability; (b) identification of motivational strategies to address clients who are in “denial” or who are “resistant”; (c) screening and identification tools; (d) identification of community resources and systems overviews targeted at facilitating effective referral and case management as well as with the end-goal of developing a service delivery model within each individual community; (e) methodologies for accessibility and accommodations individualizing programmatic interventions for the specific needs of this population; and (f) identification of national resources providing accessible treatment materials.</p>	<p>More emphasis is needed on an interdisciplinary approach for persons with VI and AODA.</p>
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CHAPTER 7

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<b>Greenleaf (1971), USA</b>	Adult (n=1)	Hysterical blindness; left eye: blind (glass), right eye: no sight (without physical reason)	Conversion , heavy drinking, difficulty controlling his anger.	Clinical (closed psychiatric ward) and ambulant psychiatric setting	Case report	After hypnosis treatment of almost two years (with intermitting phases) the patient has gained sight in his right eye and managed to get control over his heavy drinking and anger.	The case report describes the treatment as an intermittent process, in which the following aspects are described: The importance of trust and acceptance between hypnotist and patient; Taking time; Talking about traumatic life events and processing these events; Not being judgemental; Stay close to the things in life that are important for the client.
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**Table 7.4**

*Overview and summary of the studies that focus on interventions or implications for practice of treatment for adults with VI and dementia.*

Study	Target group		Comorbid condition	Setting	Design	Results	Implications
	N, age	VI					
<b>Nyman et al. (2017), UK</b>	Elderly, n=26, 58-96	VI	Dementia	-	Qualitative, semi-structured interviews with persons with VI and dementia or their family/paid carers.	Dementia has an impact on the ability to cope with the VI, becoming more dependent and prone to lack of daily stimulation. The combination makes the use of VI aids or use of technology difficult. A familiar living environment and familiar paid carers are seen as facilitators for independence.	More familiarity with the support needs for dementia on the part of professionals working with persons with VI is needed, and vice versa for professionals working with persons with dementia.
<b>Evans and Bray (2016), UK</b>	Elderly aged 75 and older, n=47 (being professionals providing care to this target group)	VI	Dementia		Qualitative study by conducting focus groups and 1-to-1 interviews with professionals discussing the experiences of people with dementia and sight loss who use services; the current care; relevant	Effectiveness and availability of services is limited due to the focus on one condition. Support needs depend on the order in which the conditions are developed. A focus on carrying out tasks and meeting targets has a negative influence on quality of care.	Knowledge of both conditions, and joint working and information sharing is needed.

organisational policies and procedures; experiences of the internal and external built environment; experiences of the social environment and social interaction; facilitators and barriers

**Bowes et al. (2016), UK**

Elderly

VI

Dementia

Structured literature review

A wide range of design issues for the environment are considered in the literature. Research is mainly focused on small issues of context and single conditions, not on the whole person. There is a contrast in the approach taken with regard to design issues. For persons with dementia design is focused on controlling the environment; for persons with VI design is focused on supporting independence.

The researchers advise service providers to adopt a person-centred approach in designing the environment, taking into account the individual needs of that person. Research should focus on how to deliver these person-centred designs.

**Table 7.5**

*Overview and summary of a study that focuses on interventions or implications for practice in treatment for adults with VI and PTSD*

<b>Study</b>	<b>Target group</b>		<b>Setting</b>	<b>Design</b>	<b>Results</b>	<b>Implications</b>
	<b>N, age</b>	<b>VI</b>	<b>Comorbid condition</b>			
<b>Brunes et al. (2019), Norway</b>	Adults	VI	Post-traumatic stress reactions	Systematic review	Persons with VI experience multiple types of stress reactions to traumatic events, such as physical, behavioural, emotional, and cognitive and this has an impact on their mental health.	Due to the possible link between traumatic experiences and mental adversities in persons with VI, more attention should be paid to the need for mental health care of persons with VI, and rehabilitation should meet the needs of traumatised individuals with VI.

**Table 7.6**

*Overview and summary of the studies that focus on interventions or implications for practice in treatment for adults with VI and mental disorders not further specified.*

<b>Study</b>	<b>Target group</b> N, age VI		<b>Comorbid condition</b>	<b>Setting</b>	<b>Design</b>	<b>Results</b>	<b>Implications</b>
<b>Needham et al. (1992), USA</b>	n=45,	Blind	Mental disorders, not further specified		Pre-test/post-test	On admission to a residential rehabilitation programme, blind clients with previous psychiatric diagnoses or psychiatric/psychological treatment had more symptoms of distress than did those without such histories. However, staff ratings at the beginning and end of rehabilitation indicated no differences between these groups in skill, attitude, and overall adjustment, and all clients improved significantly during rehabilitation.	Neither a history of psychological disorder nor test scores indicating severe emotional discomfort should exclude participation in residential rehabilitation for blind people, provided that the programme includes adequate psychological services.
<b>Browne et al. (1968), USA</b>	Adults (n=9), 40-77	Blindness (1-41 years)	Psychiatric problems; chronic brain syndrome, schizophrenic reaction	Special ward of a hospital	Description of intensive rehabilitation programme ADL, self-care, mobility	Behaviour improvements (better oriented, more sociable, home visits); several clients could be discharged.	Better screening for VI is needed; rehabilitation for more independence leads to overall improvement and more social interest

<b>Leddy (1974), USA</b>	50 years (n=1)	Blind	Psychiatric problems (schizophrenic)	Manual arts workshop	Description of the workshop and case report	A manual arts workshop is described as an effective stage in the rehabilitation process for blind, psychiatric veterans. By working through a set of tasks, they gain self-confidence, learn new skills and build a positive self-concept. This is illustrated in a case report.	Different important factors for successful outcomes are described: Flexibility and sensitivity When trust and confidence is established, veterans become more open. By accomplishing different tasks clients learn different skills for daily living and work.
<b>Kelley and Tedder (1993), USA</b>	-	VI	Psychiatric disabilities		Narrative review	Professionals in mental health care and care for VI work separately and are not informed about each other's expertise. Therefore, clients experience stigma and problems in adjusting to society. Collaboration, multidisciplinary training and a team approach is important for people with a combination of these problems.	Challenges for collaboration are, among others: interdisciplinary approaches instead of multidisciplinary approaches; lack of knowledge about the comorbid impairment; guarding of territories; lack of attention to the psychiatric problems in programmes for visual rehabilitation and lack of research providing evidence for the mental burden that people with a visual impairment experience.

**Table 7.7**

*Overview and summary of a study that focuses on an intervention or implications for practice in treatment for adults with VI and personality disorder.*

<b>Study</b>	<b>Target group</b>		<b>Comorbid condition</b>	<b>Setting</b>	<b>Design</b>	<b>Results</b>	<b>Implications</b>
	<b>N, age</b>	<b>VI</b>					
<b>Adams (1980), USA</b>	Adult, (n=1), 34	Blind (bilateral eye prostheses)	Depressive neurosis with underlying personality disorder of a passive-aggressive type	Out-patient	Case report	Patient-therapist interactions are crucial. It might take longer to establish a good therapeutic relationship. Psychotherapists can play a crucial role in facilitating clients' participation in social and vocational rehabilitation.	Therapist needs to be conscious of own attitudes towards blindness and willing to "take a more active role in the therapeutic process": announce his presence, touch the client and to be touched (during guidance to office), interpret client's non-verbal behaviour, learn to provide verbal clues instead of non-verbal reactions and explain the environment.

### 7.4 Discussion

In this section the main findings of the study are presented by answering the research questions formulated in section 7.1. The strengths and limitations of the study are discussed, and conclusions are drawn.

#### 7.4.1 Main findings

A scoping review was conducted to gain more insights into the published evidence available relevant to the care and treatment for adults with VI and SMI. The results show that a limited number of studies were found addressing interventions or implications for practice for different comorbid mental disorders in adults with VI. However, the studies that have been conducted reveal that having a combination of VI and a mental disorder can have an impact on the (daily) care and treatment. Studies show that people with VI have a higher risk of developing comorbid mental disorders, such as depression and anxiety. Studies referring to interventions to prevent or treat depressive and anxious symptoms in (elder) persons with VI show that interventions using CBT or PST that are adjusted for the VI in terms of addressing specific VI-related themes, and adopting a suitable presentation mode and examples/materials seem to be effective. The articles that describe studies into interventions for other mental disorders in persons with VI also indicate that effective treatment of comorbid mental disorders is possible when the intervention is adjusted for the VI. Adjustments are made, for example, in communication, number of treatment sessions, and the place of treatment. Furthermore, the importance of building a trusting relationship, of not being judgemental and of following an intermittent process are mentioned. This calls for specific skills in a professional, such as being more active and engaging in specific VI-related behaviours. However, due to the required adjustments in interventions and specific skills in professionals needed, it is difficult for persons with VI to be included in general treatment programmes for mental disorders. Also, the importance of multidisciplinary collaboration between different health care sectors is mentioned. Across sectors, specific knowledge is lacking about the care and treatment for adults with VI and comorbid mental disorders. Sectors need to cooperate to gain knowledge and provide suitable and effective care and treatment.

The outcomes of the different studies show a pattern consistent with the characteristics of adults with VI and SMI described in chapters 4 and 5, such as the complexity of the problems of these persons and how this influences the way care and treatment is provided. Furthermore, different studies emphasize the importance of gaining trust. The higher risk of developing comorbid mental disorders is addressed in different studies investigating a comorbid mild depressive and/or anxiety

disorder. Note that the studies in the Netherlands mentioned in the introduction of chapter 6, addressing PTSD in adults with VI and a mentalisation-based treatment for adults with VI and psychological or psychiatric problems, were not included in the review. These studies were started in 2018 and therefore no outcomes and/or publications were available for these studies at the time the search was conducted.

### 7.4.2 Strengths and limitations

A concise search and a selection procedure were used to search for and analyse articles describing interventions and/or implications for practice in treatment for adults with VI and comorbid mental disorders. To our knowledge, no such specific review has been reported in the literature. In combination with the mapping review, this gives a broad overview of the current status of the research literature related to adults with VI and SMI, and provides an overview of the best research evidence available relevant to the current care and treatment for adults with VI and SMI. The review provides an overview of the most important outcomes based on the different studies described in the results section. However, no specific conclusions can be derived from these outcomes. For this, a systematic review would be needed that also assesses the quality of the different studies. Based on the studies found in this review, it was concluded that a systematic review would not be worthwhile at this time as only a few studies use a research design that determines the effectiveness of a specific intervention in accordance with one of the different types of evidence considered valid in healthcare contexts (Murad et al., 2016). Another limitation to this study could be that no specific search term(s) for serious mental illness was formulated, and this may have resulted in relevant articles being missed during the search. However, it seems reasonable to expect that other search terms that were used, such as “mental ill\*”, “mental disorder\*” and “mentally ill persons”, would have retrieved any articles referring to serious mental illness.

### 7.4.3 Conclusion

Based on the results, it can be concluded that there seems to be a gap in the scientific literature describing interventions and/or implications for practice relevant to the care and treatment for adults with VI and SMI. In recent years, much attention has been paid to depressive and anxious symptoms in adults with VI. Based on these studies it can be concluded that interventions can be effectively applied in adjusted form for persons with VI with a mild form of depression or anxiety disorder. The case reports and (narrative) reviews conducted for other comorbid mental disorders indicate that treatment of more severe mental health problems is also possible. These studies highlight different important aspects that need to be understood by professionals, such as an emphasis on building trust, not being judgemental, following an intermittent process, adopting



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specific VI-related behaviours, tailoring the programme to the needs of the person, and the importance of multidisciplinary collaboration between different healthcare sectors. These findings provide important indicators for the care and treatment for adults with VI and SMI. However, further exploration into the specific care and treatment offered is needed to be able to establish an explicit description of how these aspects are related to current practice.

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## CHAPTER 8: CURRENT CARE AND TREATMENT FOR ADULTS WITH VI AND SMI. KNOWLEDGE AND EXPERIENCES OF PROFESSIONALS.

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### 8.1 Introduction

As introduced in the first chapter, the aim of this study is to establish a logic model of current care and treatment for adults with VI and SMI, showing not only current care and treatment and its outcomes, but also the assumptions of professionals (underlying theories) and the elements in the context that influence the outcomes. Based on the activities described in chapter 4 and 5, an explicit description was developed of adults with VI and SMI and of the underlying theories of professionals of how problems have developed in these adults and should be taken into account when providing care and treatment. Furthermore, in the studies described in chapter 6 and 7 insights were gained into the nature and extent of the current available research evidence relevant to the care and treatment for adults with VI and SMI. These outcomes provide important input for the description of current care and treatment, but are not sufficient to describe all the elements of the logic model and to gain an understanding of the “what, why and how” of current practice.

In this chapter, clinical expertise, described as one of the important components in evidence-based practice (Sackett et al., 1996), is explored. A PAR approach was used to work with professionals and translate their tacit knowledge regarding the care and treatment for adults with VI and SMI into explicit knowledge. Based on this knowledge, an agreed logic model can be created, describing the key elements of the approach, the general aims professionals strive for, and the requirements that need to be met to optimally support the service users. Therefore, the following research question would be addressed: *What is the tacit knowledge of professionals regarding the care and treatment for adults with VI and SMI?*

This research question was decomposed into the following sub-questions:

- What can be identified as the tacit knowledge of professionals and how do they describe the current care and treatment they provide?
- Which assumptions do professionals make regarding the care and treatment for adults with VI and SMI?
- Which important contextual elements do professionals consider to influence the care and treatment and its outcomes?
- How can these insights be transformed into a logic model?

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- In how far do the key elements, aims and requirements described in the logic model correspond to the important elements described in the literature?

### 8.2 Method

In this section the design of the study is presented. Furthermore, a description is given of how the participants were to be recruited and how data collection and analysis was to be executed.

#### 8.2.1 Design

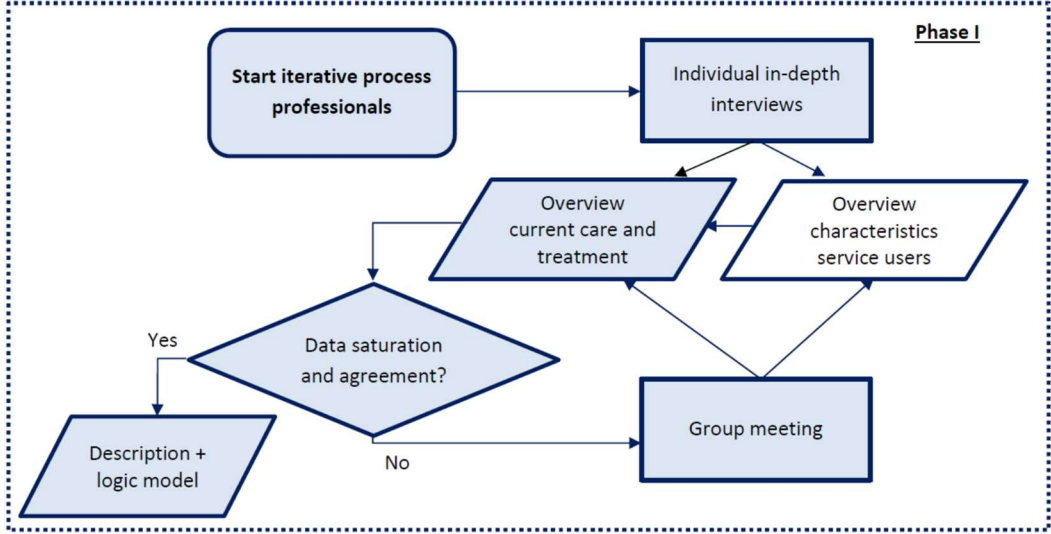
As described in section 4.2.3, the study would collect the data required for two descriptions: the problems and needs that characterise adults with VI and SMI and their current care and treatment. For the study described in this chapter the focus was on obtaining an explicit description of current care and treatment, based on which a logic model could then be developed. First, individual interviews with professionals were conducted, leading to a first overview of current care and treatment. This overview was shared in a group meeting, so forming the input and stimulus to a discussion among the professionals of the important elements in care and treatment. By doing so, professionals were facilitated to *share* their knowledge and *conceptualise* this in words and meaning. A total of three group meetings were conducted. Based on the discussions in each meeting the description of current care and treatment was adapted by the researcher and this formed the input for the next meeting. By discussing these overviews with each other, professionals were facilitated to become aware of their own activities and the theories underlying those activities. This iterative process of inquiry eventually resulted in an explicit description of current care and treatment and an agreed logic model. A flowchart of the procedure is displayed in figure 8.1 (p. 147).

#### 8.2.2 Participants

Participants were recruited as described in section 4.2.2. The individual in-depth interviews and first group meeting were used for both data collection of the characteristics of the service users and a description of the current care and treatment; as a consequence, the same professionals participated in both research activities.

**Figure 8.1**

*Flowchart of the steps and activities in the data collection process; shaded are the steps taken for the study described in this chapter*



Note. The overview of the characteristics of service users was considered in chapter 4

8.2.3 Instruments for data collection

Data was collected through in-depth one-to-one semi-structured interviews and three group meetings (see table 8.1).

**Table 8.1**

*Overview of the activities conducted for data collection.*

Activity	Input
Individual in-depth interview	Two cases (one successful and one ‘difficult’) would form the basis of the description of current practice.
Group meeting 1	The overview of emerging themes was used to discuss the care process.
Group meeting 2	A schematic overview and description of the care process was shared with participants and discussed. Based on this model the basic requirements (conditions, competencies, culture of organisation, etc.) were established.
Group meeting 3	A refined model of the care process and basic requirements was shared. Based on this model an in-depth discussion was conducted about the specific elements of the care process and specific elements of the basic requirements, and a final description was established.

Individual in-depth interviews with professionals

Professionals were asked to describe their current care and treatment in an in-depth one-to-one semi-structured interview (Polit & Beck, 2017) with an average duration of one hour, referred to hereafter as the *individual interview*. According to research in clinical reasoning for health professionals, *critical appreciation* can be used as a strategy of inquiry to generate knowledge within

professionals. This is defined as *'a process of examining and seeking to understand an activity or an object by as many means and from as many points of views possible'* (Higgs et al., 2008, p. 164). Critical appreciation also incorporates *'evaluating its achievements and failures'* (Higgs et al., 2008, p. 164). By encouraging professionals to critically appraise their own actions and thinking strategies, they are facilitated to become aware of their tacit knowledge (Higgs et al., 2008). This critical appraisal was facilitated by asking participants to select two cases, a case which they felt was successful or illustrated well their way of providing care and treatment, and a second case in which they felt that there were difficulties or with whose result or current situation they remain unhappy. By asking the participants questions about these specific cases, they invited to critically appraise their own actions and thinking strategies, and as a result an understanding of *why* participants act the way they do could be obtained (Higgs et al., 2008; Polit & Beck, 2017). The use of specific cases would give them the opportunity to describe their current care and treatment on a more concrete basis and thereby to reach the core of their practice. Furthermore, by choosing a successful and an unsuccessful case, not only the qualities of the professional and the care and treatment they provide were discussed, but also their struggles and limitations. This balanced view is important to account for possible biases. During the individual interview, professionals were asked to elaborate upon the strategies they actually use in their care and treatment for adults with VI and SMI. The professional was asked to describe the care process in these cases, guided by different questions concerning their actions, reasoning and methods used in each case. The interview guide is enclosed as appendix 4.

All interviews were recorded digitally and transcribed verbatim. The resulting documents were sent to the participants for a member check. The checked transcripts from the interviews formed the basis for data analysis.

### Group meeting 1

A mix of professionals who participated in the individual interviews and new professionals were invited to the first group meeting (see section 4.2.3 for an explanation). The themes emerging from the individual in-depth interviews were structured according to the steps generally accepted within a care process (see the section 8.2.4 for more information). This was presented in a PowerPoint presentation and sent to participants in advance. The participants of the group meeting were asked to study this before the start of the group meeting. In the group meeting a discussion took place, based on the elements presented for each step in the care process, guided by the following questions:

- Do the presented elements accurately represent current care and treatment?

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- Which elements and/or characteristics are important for, or specific to, the care and treatment of persons with VI and SMI?
- Which elements and/or characteristics are missing, according to your experience of providing care and treatment?

The group meeting was recorded digitally and based on this record a report was made. This report was sent to the participants for a member check. On the basis of this report, combined with the nature of the discussion during this first group meeting, a schematic overview of the specific care process was made.

### Group meetings 2 and 3

In each of a second and a third group meeting with professionals a similar cycle as described for the first group meeting was undertaken. For the second group meeting, the description and schematic overview was presented in a PowerPoint presentation with a spoken explanation of the overview using audio recordings for each slide. This presentation was sent to the participants in advance. During the second group meeting participants were asked if this overview was an accurate representation of their way of providing care and treatment, and if they had any comments or feedback on this overview. Furthermore, a discussion took place about important contextual elements that are required to be able to provide the care and treatment as described. The group meeting was recorded digitally, and a report of the meeting was made. The report was sent to the participants for a member check.

For the third group meeting, a refined description and schematic overview of the care process and an overview of the contextual themes that emerged from the second group meeting were sent in advance. In this meeting a discussion took place about which elements in this description and schematic overview could be designated as specific to the care and treatment for adults with VI and SMI. This meeting was recorded and transcribed verbatim.

In this manner, the model of the care process that was constructed or refined based on the contents of one meeting was checked by the same participants in the next meeting. In each meeting, the participants indicated that the model as a whole was considered to be in line with the content of the previous meeting, based on which corrections and/or refinements on the model were discussed.

### Validation

The description and schematic overview of current care and treatment were presented to the behavioural scientists of the RCF. They were asked if this overview accurately represented the care process and to provide any other feedback.

### Reflection

The advisory board of the study was regularly updated about the progress and outcomes of the different steps of data collection. During these meetings, the outcomes were presented and the board was asked to reflect on these outcomes, by discussing how these outcomes are related to the vision of the RCF, the protocols used for care and treatment, and the different care programmes of the RCF. Based on these reflective discussions, the outcomes were further refined. These meetings were recorded digitally and based on these records reports were made.

The input of the behavioural scientists and advisory board regarding the description and logic model were used to refine the models. This was then sent to the participants for a final validation.

#### 8.2.4 Data processing and analysis

##### Individual in-depth interviews

The interview transcripts were analysed by two researchers using a *qualitative content analysis* methodology (Mayring, 2014) consisting of deductive category assignment followed by inductive category formation. This method is described in detail in section 4.2.4. A deductive category assignment was conducted by structuring the care process into generic phases of care and treatment (Buntinx & Schallock, 2010; Kievit et al., 2008). After a first reading of the texts, the following phases were chosen as representative of the process in current care and treatment:

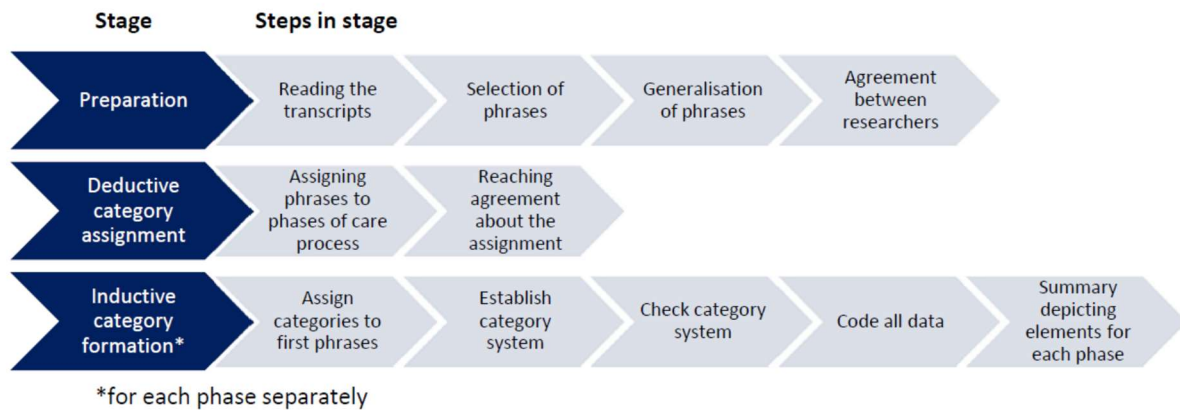
1. Intake;
2. Assessment of goals and care needs;
3. Planning;
4. Implementation;
5. Evaluation;
6. Ending care.

By structuring the analysis around these phases, the ability to interpret the different statements of the participants and to identify important elements was facilitated.

In figure 8.2 (page 151) a schematic overview of the stages and steps taken in the analysis procedure is displayed.

**Figure 8.2**

*Overview of stages and steps conducted for each phase in the qualitative content analysis.*



As a preparation, the transcripts were read line-by-line and phrases were selected and copied to a Microsoft Excel spreadsheet, each phrase representing one row in the spreadsheet. Then, each phrase was generalised to a more abstract level by each researcher separately. After checking the abstract phrases, agreement was reached between the two researchers. In the deductive category assignment process, the set of abstract phrases was divided between the researchers and the phrases were assigned to the representing phase. When the researchers had reached agreement on the assigning of all abstract phrases, the inductive category formation started. The different phases in the care process were divided between the researchers and within each phase the steps for inductive category formation were applied. The first phrase was assigned a category representing the content of the phrase. For the second phrase it was decided if the content was substantively equivalent to the first category or else if a new category should be made. This was continued for each phrase. Based on this process different categories were assigned in each phase in the care process. After a first coding procedure, the categories were checked by the other researcher and the definitive category system was the result of discussions between the two researchers. This definitive category system was then used to code all the data within each phase separately. Based on these categories, a summary was made for each phase depicting the important elements of the care process.

### Group meetings 1, 2 and 3

Based on the recording of each group meeting a detailed report was made. The content of this report was analysed using the qualitative content analysis procedure described above and based on this analysis a schematic overview of the care process (the output from the first group meeting) and a description of the important basic requirements (that resulted from the second group meeting) was made. In the third group meeting, the total group meeting was transcribed and analysed. Based on



this analysis, the description of current care and treatment was refined resulting in an overview of the most important themes and elements for each phase in the care process and the basic requirements needed to perform these steps.

### 8.3 Results

Following an overview of the characteristics of participants, in this section the results are presented in the form of an explicit description of current care and treatment, as expressed by professionals. Based on this description, a logic model was established. To substantiate these results, quotations are provided derived from the individual interviews and the group meetings. These meetings were held in Dutch and the quotations provided in this section are translated from Dutch into English by the researcher.

#### 8.3.1 Participants

In chapter 4 (section 4.3.1) an overview of the characteristics of the participants in general and for the individual interviews and first group meeting is given. In table 8.2 an overview of the number of participants and the descriptive statistics (mean and range) for age and years of experience (YoE) of participants in the second and third group meeting is given. To prevent the inadvertent identification of participants based on their characteristics, only overall statistics for age and years of experience are given.

**Table 8.2**

*Number of professionals, age and years of experience for second and third group meeting*

<b>Meeting (N)</b>	<b>Organisation (N)</b>	<b>Participant (no.)</b>	<b>Age</b>	<b>YoE</b>
Group meeting 2 (5)	RCF (4)	P3, P5, P10, P11	54 (42-61)*	14 (4-34)*
	Bartiméus (1)	P7		
Group meeting 3 (5)	RCF (3)	P3, P5, P10	53 (38-63)*	19 (4-34)*
	Royal Dutch Visio (2)	P1, P2		

\*mean (and range)

Professionals who were not able to attend a group meeting provided additional input in a separate individual interview (as was the case with P5 for the first group meeting, P1 and P12 for the second group meeting and P12 for the third group meeting).

During the interviews and group meetings a pleasant atmosphere was created; this was considered to facilitate the sessions.

### 8.3.2 Current practice

Based on the outcomes a logic model was built, indicating the theoretical assumptions of professionals underlying the intervention, the implementation outputs (activities) and the (intermediate and final) outcomes of the described activities in current care and treatment, and the contextual factors that influence the outcomes of the care process (see figure 8.3, page 154). In the following sections this logic model is further explained.

#### Theory behind the intervention

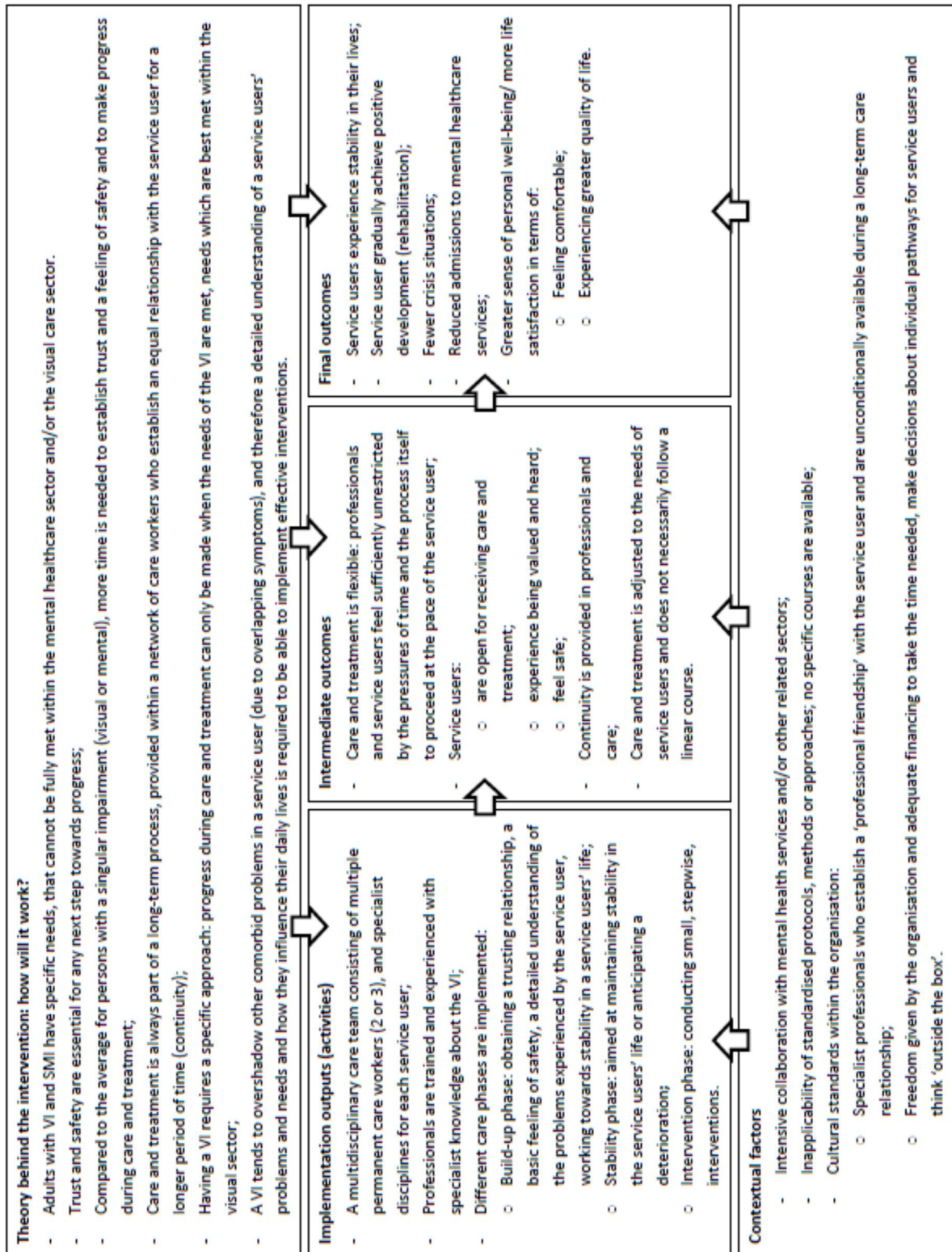
The individual interviews and discussions during the group meetings revealed the different theoretical assumptions made by professionals, and that guide their daily practice. Professionals emphasize that the problems and needs that characterise adults with VI and SMI, as described in chapter 4, have an impact on how they structure their care processes. Due to the fragile trust of service users both in themselves and in others, their lack of a feeling of basic safety, and the problems in attachment they experience, professionals indicate that their first aim is to ensure that a service user builds a trusting relationship with the care worker and obtains a basic feeling of safety.

*'Trust is what is very important for them, when you cannot see well, you cannot scan the environment, the VI specifically needs attention, because a lot of communication is non-verbal. Therefore, persons are used to not feeling connected to their care worker or they are neglected in the conversation. Time is also important, that things like this can be given the space and time needed. That is something very specific for our service users. You cannot use your facial expressions, everything must be done verbally. Our service users have acquired a lot of mistrust, specifically on these terrains, more than average compared to other persons, specifically because of this lack, and also because of the lack of positive non-verbal communication.'* (P3, RCF, group meeting 1).

However, developing this trusting relationship and feeling of basic safety is a challenge because of the impact of the VI, a challenge that the professionals discussed, along with the specific knowledge and skills needed to anticipate problems in this respect. The professionals experience that, due to the VI, service users and professionals lack reciprocity during contact, and therefore different limitations are encountered.

Figure 8.3

Logic model of current care and treatment for adults with VI and SMI based on the description of professionals



From a service user's perspective the professionals describe the following limitations:

- Not being able to form a first impression of a person based on sight ('Can this person be trusted?');
- Not being able to make eye contact;
- Not being able to see facial expressions and gestures;
- Not having an overview of the environment and the situation ('How am I positioned in the room?' 'Where are possible escape routes?');
- Being mainly dependent on verbal information.

From a professional's perspective, the limitations concern a reduced ability to read a service user's facial expressions and assess their reactions, as persons with VI show fewer facial expressions or else their expressions are obscured by the use of dark glasses. As was illustrated in the individual interview with P5:

*P5: '...so you have to be very alert to small other behaviours, that you can normally just see in a person's face, emotion. But yes, she is blind. She wears very dark glasses, so I can't see her eyes, so I really need to read other things. God, I realise now that I'm talking about it, that I do very different things. That's nice. Because I cannot do as I always did before. ...'*

*Researcher: 'What is different?'*

*P5: 'You pay more attention to facial expressions, but these facial expressions are much more ambiguous. I cannot see her eyes, but she cannot see how I react either. If someone told me something painful, I was touched by it and then the other person saw that and of course you do not have that reaction right now. Even if you are yawning, she does not see that. Although she would notice it, I am sure. But still.'*

*Researcher: 'That interaction is very different.'*

*P5: 'It's very different, so you have to pay attention to very different things. And I think it is just literally naming things. In the other case [in a setting with persons without VI] it was more: you do not have to name it, you can see it. Or if I have tears in my eyes, oh this does it to me. Now I really have to name it: "Gee I think this is quite a bit" or "I see in your facial expressions that it is...". Normally this is done with reciprocity. Really naming it.... And then I think that safety is even more important. It is quite a challenge to say something like that, that is quite difficult for you, and normally you can see if someone is listening or if the person is trustworthy, reliable. And all you have to work with now: you hear a voice and hope that it.... So, I can understand that it takes longer.'*

Professionals describe how they need specific knowledge and perform specific activities to compensate for the VI, such as:

- continuously telling service users who you are when greeting them;
- adequately explaining/telling a person what is happening or what you are doing ('providing subtitles');

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- making use of subtle non-visual gestures (humming, touching the hand or shoulder of a service user) to let them know you are still there or still listening;
- having knowledge about the impact of a VI and how different problems and needs of a service user can be interpreted.

Other specific conditions, related to the VI, that influence the care and treatment are the energy level of a person and their often relatively high verbal capacity. Due to the VI, performing daily tasks requires more effort, often resulting in low energy levels. Furthermore, because a person is dependent on verbal information many service users have developed a high verbal capacity that is not representative of their overall level of (cognitive) functioning. Therefore, the risk of overestimating a person's overall capabilities was mentioned.

Professionals emphasize the influence that the comorbid problems of service users, in combination with their fragile trust and problems of attachment, can have on their ability to build a trusting relationship and acquire a feeling of basic safety. This makes this process even more challenging compared to that for persons with a singular impairment (visual or mental). Due to this combination, professionals indicate that they need more time than average to establish these basic conditions and stress the importance of viewing care and treatment as a long-term process in which a service user feels no pressure while professionals connect to the needs of a service user, position themselves as equals in the process and proceed at the pace of the service user. As was illustrated in the individual interview with P5:

Researcher: *'Why do you have to put so much time and patience into it?'*

P5: *'That she has such a wall around her. So, it takes a very long time before she shows something and before you understand it. She actually shows almost nothing yet. You have to push and prick for a very long time. And that almost seems like a game because otherwise she doesn't show it. You have to do that all the time. It just takes a really long time.'*

As described in chapter 4, due to overlapping symptoms the VI tends to overshadow other problems and/or impairments in a person. Therefore, professionals emphasize the importance of obtaining a detailed understanding of a person. It is important to 'unravel the complexity' of a person and form a picture of the service user's problems, and to determine if these can be explained by their VI or mental disorder (or both). Only when this understanding is obtained can suitable interventions be implemented. As P8 explained in the first group meeting:

*'What you do see in this group with VI is the diagnostics component. A number of service users with complex disorders were sometimes admitted to a psychiatric hospital for years and*

*suddenly someone got the idea: could this person have an intellectual disability? It is not possible to make a proper diagnosis, because of the hectic nature of the process. I think this also plays a role in this target group. Is it someone who is dependent because of the VI, because of a personality disorder, or has he been raised this way and has he never learned? If that is the case, then there are learning opportunities. All three underlying problems lead to other interventions. It is important to unravel that. Or is he dependent because he is also autistic?'*

#### Implementation outputs (activities)

The discussions in the group meetings revealed that the phases in the care process as formulated in section 8.2.4 were present, but not so specifically applied in current care and treatment.

Professionals indicated that a clear transition between the different phases could not be identified, but rather that it was more fluid. In addition, professionals indicated that there was intermittent progression, going back and forth between the different phases. Based on the discussions in the group meetings, the following classification of phases in the current care process could be made:

- *Build-up phase:* During this phase the main focus is on reaching a stable balance for service users with regard to a number of different aspects, such as in their emotional functioning and functioning in other aspects of their lives, but also in the way care is provided for these service users. This state will hereafter be designated as a '*stable balance*'. Professionals emphasized the importance of developing a trusting relationship, creating a basic feeling of safety for the service user, and obtaining a detailed understanding of the problems and needs (assessment) to be able to achieve this stable balance. Professionals indicate that this can take several years (2-5) and experience it as an intermittent process. They are continuously going back and forward in the steps to build a trusting relationship, and to reach a basic feeling of safety and a stable balance;
- *Stability phase:* The build-up phase slowly transitions into the stability phase. This phase is mainly focused on maintaining the stable balance in the life of a service user that is built in the previous phase or on anticipating a deterioration. In this phase too, the progress is described as intermittent, as the level of functioning of a service user fluctuates around this stable balance;
- *Intervention phase:* The times when a service user experiences some state of stability during the stability phase can be used to conduct small, stepwise interventions aimed at increasing the independence of the service user or at enlarging their societal participation. Professionals emphasize the importance of tailoring interventions to the capacity (such as the energy level) of the service user and proceeding at the service user's pace. When too much pressure is exerted it is likely that the service user will fall back to an earlier stage of their fluctuating progress.

The natures of the build-up phase and stability phase are illustrated by the following citations:

*'In the beginning, when a new service user starts, you start working on different things, you are faced with gaps, you can build different things, search for clarity in the problems experienced by the service user, do a lot of different things. ... At a certain point you reach a stable base, where a person feels comfortable in the situation. Then all energy goes on maintaining this feeling of comfort.'* (P3, group meeting 3).

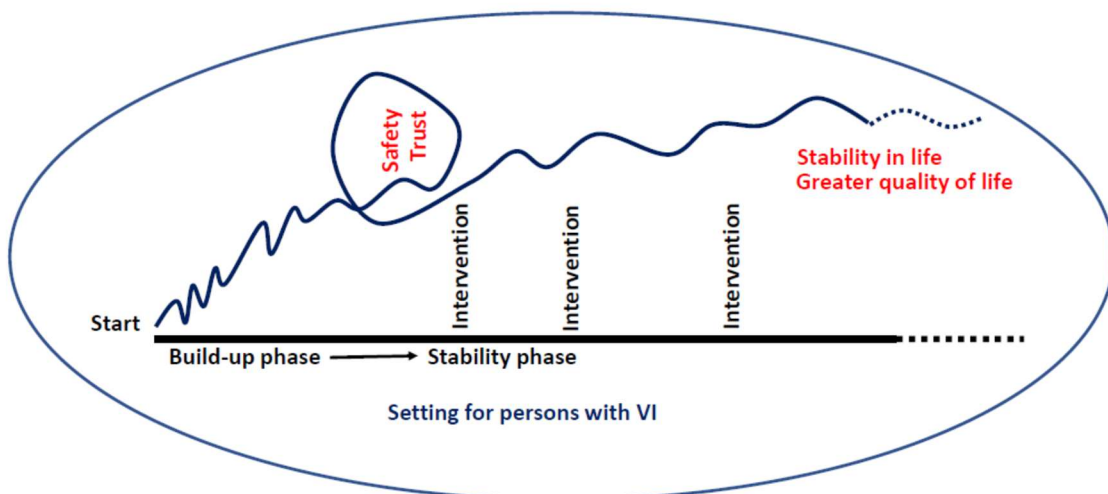
*'What I am proud of is that in the end we have succeeded, which has been a long process to build up a little trust with him. He really just did not want anything at all, in the first instance.'* (P4, individual interview).

A visual representation of the care process over these phases is presented in figure 8.4.

In these phases it is important to provide continuity in the care and treatment. This is guaranteed by building a care team around a service user, with 2 or 3 permanent care workers as key contact persons in combination with a multidisciplinary team (care worker, care coordinator, psychologist/behavioural scientist, (advising) psychiatrist and/or general practitioner) for monitoring and reflecting on the progress of the provided care and treatment. The members of the team are all trained and experienced in the care and treatment for persons with VI.

**Figure 8.4**

*Overview of the phases and process during care and treatment as was revealed during the group meetings*



Text in black: phases in care process Text in red: outcomes Blue line: process of care Dotted line: proceeding care

Intermediate and final outcomes

When the care is structured as described above, professionals indicate that they are able to provide tailored and flexible care and treatment, and can anticipate the non-linear course of the phases, going back and forward in the phases or implementing specific interventions based on the potential and capacity of the service user at a given moment. This was illustrated by the following dialogue between two participants in the third group meeting:

*P3: 'Especially going back and forth, and always avoiding putting pressure on the service user'*  
*P10: 'Pressure is killing.'*

Through the provision of this tailored and flexible care and treatment, service users experience being valued and heard, and feeling safe, and therefore professionals are not rejected and can prolong their care and treatment. Eventually this leads to service users experiencing more stability in their lives and they can gradually achieve positive developments that in turn give them a greater sense of personal well-being or more life satisfaction. By creating a stable balance, crisis situations for service users and admissions to mental health institutions can be reduced.

Contextual factors

Professionals identify different important contextual factors that influence the ability to provide care and treatment as described above. First of all, having strong collaborations with mental health and/or other care organisations (such as addiction care, hospitals and nursing care) is crucial to prevent or anticipate crisis situations, to conduct specific assessments, or to implement interventions. Also, professionals are not able to depend upon standardised interventions, protocols or test material. This makes it more difficult and calls for creativity to achieve a detailed understanding of a person and enact interventions. As was expressed by P1 and acknowledged by all participants in the third group meeting:

*P1: 'There are wonderful books with protocols, we all have them. But there is not one protocol that you can apply 'as-is' for a service user, none that takes into account their VI, their energy, their capacity. So, you always have to choose from different protocols and add this and that, and then see where we are at that moment.'*  
*All: '[Protocols have to be] Tailor-made.'*

Furthermore, professionals from the RCF indicate the importance of the freedom provided by the organisation to be able to use the necessary time and space to fulfil these requirements. They expressed the importance of being able to think 'outside the box', of being flexible, and of providing care from a demand-oriented perspective (in terms of care programmes and financing). RCF



professionals envisage their role as being part of the personal life of a service user, creating a 'professional friendship' and providing unconditional availability for a service user. In the other organisations the importance of being available and sincere was acknowledged; however, this occurs under more 'limited' conditions. This was illustrated in the following dialogue during the third group meeting:

*P3 (RCF): 'I really consider it as a professional friendship, making it hard to name the other a "service user". That relationship has in the first place no end, when I start it. At your organisation it is more clear, in our organisation it is just... someone enters and you know that there is a chance that that person will be under my wing for 25 to 30 years. And it is not possible to consider someone a "service user" of mine for such a long period. Because I also will develop a bond with that person.'*

*P1 (Royal Dutch Visio): 'I understand that, but there are also restrictions. It is about being available, approachable. But when a service user is going to say, I will come to have a cup of coffee with you on Saturday....'*

*P3 (RCF): 'That is possible sometimes.'*

*P10 (RCF): 'Yes.'*

This explicit description and logic model show that there is consensus about the 'framework' of the care and treatment and the conditions required in order to reach effective outcomes. However, it seems that there is no general approach to fulfilling the necessary conditions or to monitoring progress. Within the interviews and meetings, it was difficult to obtain a concrete description of the specific steps made in each phase and for each condition, revealing an inconsistency in the approach between professionals. Every professional seems to have their own approach to professional practice, based on (as specifically mentioned by several professionals) 'Fingerspitzengefühl' [tact and sensitivity], and a variety of methods/techniques was mentioned. Furthermore, there is no fixed procedure for measuring progress. Professionals expressed a need for more general and widely disseminated guidelines for their service users.

### 8.4 Discussion

In this section the main findings of the study are presented by answering the research questions formulated in section 8.1. Furthermore, the strength and limitations of the study are discussed, allowing some conclusions to be drawn.

#### 8.4.1 Main findings

A PAR approach was applied to translate the tacit knowledge of professionals into an explicit description of current care and treatment for adults with VI and SMI. The iterative process of inquiry

conducted together with professionals revealed that the general phases considered to exist in care and treatment were not specifically recognised by professionals in their current practice. Instead, current care and treatment could be divided in three different phases: a build-up phase, a stability phase and an intervention phase. The build-up phase plays a crucial role in delivering effective care and treatment. It is through the activities in this build-up phase that a service user feels valued and heard, and a trusting relationship and feeling of safety is established. Based on this trust and safety, a detailed understanding of the service user's problems and needs can be obtained, and a stable care balance reached. This forms the essential basis for the stability phase and the intervention phase, and upon which small, stepwise interventions can be delivered. Final outcomes are mostly concerned with reaching a greater sense of well-being or personal life satisfaction and with creating more stability in life.

Professionals emphasize that they give specific attention to the task of developing a trusting relationship and providing the service user with a feeling of basic safety. The VI has a high impact on the way this trusting relationship, basic safety and stable balance can be established in the build-up phase. Due to the service users' VIs, professionals must take a different approach, provide verbal explanation and make use of touch to establish a relationship with their service users. The SMI of the service users makes this even more difficult, as trust and safety are fragile within this population. Therefore, it takes a lot of time to establish these key elements, and professionals stress the importance of a prudent approach that places no pressure on a service user by connecting to the needs of a service user, positioning themselves as equals and proceeding at the pace of the service user. Furthermore, due to the imbalance in their stressing factors and the ability to cope with these factors, their care process is intermittent. As essential elements in the wider context, professionals identified the importance for achieving outcomes by collaboration with other health care sectors and an organisation where the approach as described above is facilitated. The use of standard protocols or interventions is limited: these have to be adjusted to the personal needs of a service user. At the moment, professionals do not adopt a uniform approach and concrete ways to establish the important elements are needed. Based on this explicit description, a logic model of current care and treatment was built as is displayed in figure 8.3 (page 154).

These results are consistent with the key elements indicated in the studies described in the scoping review in chapter 7. As is the case here, those studies indicated the importance of a trusting relationship, the intermittent nature of the care process, the time required, the necessity of not being judgemental, the need for a multidisciplinary approach, the adjustments required to general protocols and procedures, tailoring to the personal needs of a service user, and the role of specific

activities to compensate for the VI. In this study, a more specific description is given of the influence of a VI in combination with an SMI on the ability to form this trusting relationship and provide a feeling of safety for a service user. Professionals emphasize the importance of devoting time to this process and the need for a prudent approach. Based on the descriptions of professionals, different phases in the care process can be identified; these give a more detailed understanding of how the care process is structured and its nature as a process extending over the long term.

The care and treatment as described by the professionals can also be compared to the way care and treatment is provided to adults with SMI within the mental health care sector. In this sector, care and treatment is mainly focused on working towards recovery. This involves *'the development of new meaning and purposes in one's life as one grows beyond the catastrophic effects of mental illness.'* (Anthony, 1993, p. 20). Reaching a state of recovery does not mean that the mental illness is cured, but more subjective outcomes such as self-esteem, empowerment and self-determination are reached. The process for reaching these outcomes is described as unsystematic and unplanned, with the service user experiencing growth and setbacks. Care and treatment with this focus is mainly provided in a community-based manner. In the Netherlands, Flexible Assertive Community Treatment (F-ACT) is a form of treatment that is often provided to persons with SMI (Nugter et al., 2016; Van Veldhuizen, 2007). In this programme, a holistic and individualised approach is provided in a community setting by individual case management. The care workers who provide these services are part of a multidisciplinary team. In this way, care can be rapidly upgraded to a shared caseload and assertive outreach, in which the crisis plan of a service user is put into operation and all members of the team work together to prevent a relapse or readmission to a psychiatric hospital. A service user is for example given a daily visit by one of the team members and an appointment with the psychiatrist is made within two days. In the last years, a new programme, called the Active Recovery Triad (ART) (Van Mierlo et al., 2016), has been developed for persons with SMI that remain hospitalised and whose recovery process has stagnated. ART offers an integral framework, by focusing on personal growth, increased responsibility and autonomy, within an active triad (i.e., a service user, a significant other and professionals). In this approach, an emphasis is placed on the relationship between the professional and the service user. This is seen as an important aspect to provide service users with a new perspective and to create a willingness to reach a state of recovery.

When the outcomes of this study are compared to current practice in mental health care, some similarities can be found. Both within this study as in mental health care the importance of providing care and treatment in a multidisciplinary team is stressed, taking a holistic and individualised approach and building a relationship with the service users. Also, both sectors indicate the care

process as intermittent, going back and forth in little steps. However, differences can also be indicated, as care in mental health has a clear focus on reaching a state of recovery, by working towards dehospitalisation, empowerment of service users, autonomy and responsibility. It seems that within the care and treatment of adults with VI and SMI, professionals are more reserved in motivating service users to such outcomes, as professionals stress the importance of putting no pressure on the service user. Future research could provide more clarity to what extent a state of recovery can be reached by adults with VI and SMI and if more specific guidelines based on FACT and ART could facilitate professionals and service users to reach such outcomes.

### 8.4.2 Strengths and limitations

The description of current care and treatment, and the logic model are a direct result of the collaboration between the professionals and the researcher that lay at the core of the PAR approach. Professionals expressed that they felt directly involved and the iterative process of inquiry helped them to take a high-level view and reflect on their activities, and to reach the core elements of their specific approach. Professionals indicated that they really enjoyed the discussions, and that they felt an atmosphere of trust among the group and felt that they were understood. The researcher experienced that by discussing the key elements of current care and treatment in group meetings helped professionals to take a 'bird's-eye view' of the specific elements, as professionals could react on each other and therefore expressed gaining insights into their own practice. By conducting an iterative process, with groups of participants of a varying composition the credibility of the study was likely to be enhanced. The knowledge and experience of the researcher in providing care and treatment to service users with VI and SMI was also experienced as a facilitating factor. As a consequence, the participants expressed that they felt understood and were more comfortable expressing their own strengths and limitations. Also, the extensive data analysis by two researchers of the results of the individual interview round and the group meetings, and the subsequent presentation of this analysis helped professionals to discuss the core elements of their practice. Within this process, participants were extensively involved in the interpretation of the data. Participants were not only asked to confirm the analysis and/or interpretation of the data, but also give examples that disconfirm the analysis and/or interpretation. Also, participants were recruited from different organisations, providing different perspectives on the care and treatment of adults with VI and SMI. These factors can be indicated as facilitating the dependability and confirmability of the results. Furthermore, by providing a 'thick' description of the results, substantiated with quotations, the transferability of the results of the study is likely to be increased.

Different limitations can be identified in the study, such as the influence of the researcher's own knowledge and experience. Although this helped professionals to share their stories, it could also be identified as a limitation, since it might have hindered an openly inquisitive and 'blank slate' approach. The researcher understood the dilemmas or themes a professional was talking about and therefore was not always able to take a completely objective view. This was compensated by the participation of a second researcher during the group meetings, who had no experience of the care and treatment of persons with VI and SMI, and so was able to ask the more fundamental questions. Furthermore, a limitation arose from the fact that the iterative process of data collection was conducted over an extended period of a total of two years. The participants varied during the different meetings due to personal reasons (for example maternity leave or change of jobs). This influenced the iterative process. However, this also presented an opportunity to add new perspectives to the process and bring new enthusiasm to the discussions. Nevertheless, despite the time taken and the changes in participation, in total only twelve participants were involved during the process. During the process data saturation was reached, an indication that the most important factors had been addressed. However, the explicit description of care and treatment, and the logic model are currently based on the experiences of a select group of professionals, to ensure that this can be used as a representative description of current practice, these results need to be validated by presenting it to a larger group of participants; this will be the subject of chapter 10.

### 8.4.3 Conclusion

The results of the study and the logic model provide an explicit description of the impact that a combination of VI and SMI has on the way in which the care process is structured, and the prudent approach needed to provide this care and treatment. This model shows that the care process can be structured according to three different phases. Professionals proceed through these phases by following a fluid and intermittent approach, going back and forward through these phases. The study shows that these phases are different from the more generally accepted phases used in care (as outlined in section 8.2.4), which have a more structured and progressive approach. The use of the phases as described in the study can help professionals to gain greater insight into their own practice and how the care process is structured. Although there is consensus among the professionals about the framework of their approach and its important elements, the results also show that there is no consensus about how these elements are achieved, and it seems that no uniform approach is used to achieve them. In consequence, this raises the question of whether a more structured approach (such as that described by the generally accepted phases) could help professionals to achieve this uniformity or if these more structured phases are simply not applicable to the care and treatment of adults with VI and SMI. Furthermore, professionals indicate that their long-term and prudent

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approach can be a pitfall, as this can make it difficult to make the transition from the build-up and/or stability phase to the intervention phase. When such difficulties occur, service users may not make the progress they could have made, resulting in an increased risk of becoming hospitalised and other adverse outcomes. Insights from mental health care, where persons with SMI are facilitated in reaching a certain state of recovery, may provide a new perspective to help overcome this pitfall. More research is needed to gain insights into the suitability of this approach for adults with VI and SMI.

Furthermore, still lacking is the service user's perspective: this should help to validate the description provided by the professionals and may also give a more complete description of the process. This perspective will be studied in chapter 9.

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## CHAPTER 9: AN OVERVIEW OF SERVICE USERS' NEEDS AND THEIR EXPERIENCES AND EXPECTATIONS REGARDING CARE AND TREATMENT

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### 9.1 Introduction

As described in chapter 8, based on the knowledge and experience of professionals, an agreed logic model was established regarding the current care and treatment for adults with VI and SMI. The elements described in the logic model were compared to the current available research evidence, showing a consistency in the outcomes. By doing so, the best research evidence and clinical expertise were integrated. However, the service users' values are not yet addressed. This is described as the third important component for providing evidence-based practice by Sackett et al. (1996). To integrate this component, insights need to be obtained into the service users' experiences and expectations regarding their care and treatment.

In this chapter, the following research question is addressed: *What are the experiences and expectations of service users regarding their care and treatment?*

This question is further decomposed into the following sub-questions:

- What do service users identify as their problems and needs?
- How do service users experience their care and treatment and what do they indicate as important?
- What adjustments should be made to the logic model based on the experiences and expectations of service users?

### 9.2 Method

In this section the design of the study is presented. Furthermore, a description is given of how the participants were recruited and of how data collection and analysis were executed.

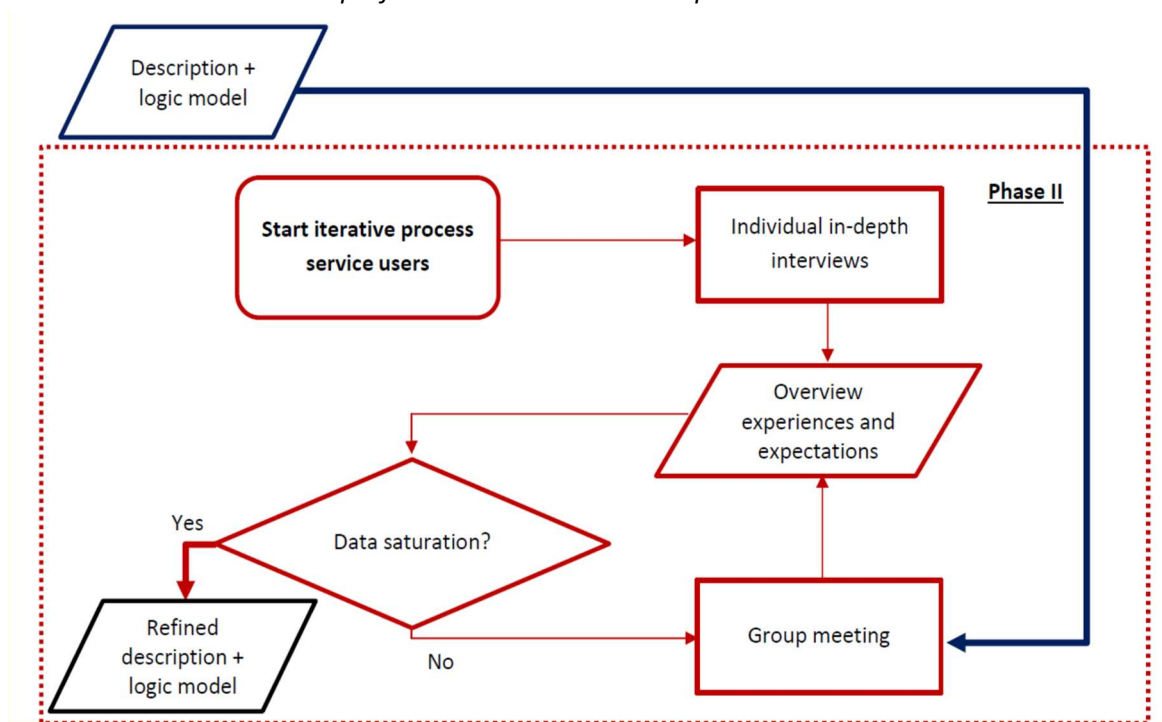
#### 9.2.1 Design

An iterative process of inquiry would be conducted, in line with the process conducted by professionals as described in chapters 4 and 8. Individual in-depth interviews with service users would be used to *enlarge* and *share* their knowledge. These interviews would be transcribed and analysed, resulting in a description of the characteristics of adults with VI and SMI and the current care and treatment they receive, as described by service users themselves. In a group meeting

service users would be asked to reflect on the phases in the care process and the key elements in current care and treatment that were depicted in the logic model derived from the iterative process with professionals described in chapter 8. Based on these activities, the logic model as constructed based on the experiences of professionals would be assessed in light of the outcomes of this iterative inquiry into the experiences of service users and refined accordingly. In figure 9.1 a flowchart of this process is presented.

**Figure 9.1**

*Flowchart of the steps taken for data collection with the service users and how this is combined with the data collection with the professionals described in chapter 7.*



### 9.2.2 Participants

Those who met all the following criteria would be eligible to participate:

- having a VI, operationally defined by Van Rens et al. (2011) as having a visual acuity of less than 0.3 or a restricted visual field of less than 30 degrees;
- having SMI, according to the definition of Delespaul and Consensusgroep EPA (2013);
- receiving care at a residential care facility of the RCF;
- willing and able to share his or her knowledge and experiences with the researcher and group members and to be able to reflect on that knowledge and experience.

A purposive sampling strategy was used to identify potential participants who varied in age, years in care at RCF and diagnoses of mental illness; such maximum variation sampling (Polit & Beck, 2017)



was thought to be of most benefit to the study. The behavioural scientists indicated which service users met the criteria and, based on this list, a selection of six possible participants was made by the researcher. These potential participants were approached using the same procedure as described in chapter 7 for the recruitment of professionals. The recruitment letter was provided in adjusted form for their VI (braille, enlarged or by email as an accessible Microsoft Word or Adobe PDF document).

Based on this selection procedure, a total of three of the six service users who were approached agreed to participate. The service users who did not agree to participate, expressed that they were very interested in the study subject and considered it relevant, but their current condition or the stress they were experiencing at that moment made them decide not to participate. Therefore, a second selection of three service users was made, based on the list provided by the behavioural scientists and approached as described above. Eventually, a total of five service users agreed to participate and provided information during an individual interviews. Of these five service users, two participated in a group meeting and one service user participated in a second individual interview in which the same questions were asked as in the group meeting. All service users provided informed consent at the start of data collection, acknowledging that they were fully informed and had had adequate opportunity to ask questions, that they participated voluntarily, that they would provide information and that this information could be used for the specific aims of the study, and that they would keep information that is shared during group meetings confidential. Furthermore, the researcher affirmed that all data would be handled according to the European Law on Data Protection and the Dutch Central Committee on Research Involving Human Subjects (CCMO), with all information collected and shared confidentially and anonymously.

### 9.2.3 Instruments for data collection

#### Individual in-depth interviews with service users

Service users were asked to reflect on the characteristic features of their life histories, previous care experiences, and current care and treatment in an in-depth one-to-one semi-structured interview (Polit & Beck, 2017), from now on referred to as the 'individual interview', with an average duration of one-and-a-half hours. These individual interviews took the form of a dialogue about the service user's experiences of their care and treatment, and what they felt was effective and/or not effective. Participants were asked to tell a personal story about:

- their life histories and experiences during previous care and treatment;
- their experiences of current care and treatment as provided by the RCF.

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The service user was asked to deliberate about these topics, guided by different questions concerning their experiences and reasoning. A translated version (from Dutch to English) of the interview guide is enclosed as appendix 8.

All interviews were recorded digitally and transcribed verbatim. The resulting documents were sent to the participants for a member check in adjusted form for their VI. The checked transcripts from the interviews formed the basis for data analysis.

### Group meeting

In the group meeting a funnel approach was conducted, starting with an open interview without addressing the elements indicated by professionals and ending with a discussion of these elements with the service users. To facilitate a structured way to discuss the service users experiences and expectations in a group meeting, the researcher provided a description of the general phases in a care process at the start of the meeting (as was described in section 8.2.4 and as was used for the data analysis of the individual in-depth interviews with professionals). Service users were asked to discuss to what extent they were aware of these phases and which specific actions were taken by professionals in these phases. After this discussion, the researcher presented the key elements indicated by professionals to the service users and they were asked if they acknowledged these elements as an accurate description of the key elements they experience in their care and treatment and to discuss their own experiences and views of these elements. A translated version of the interview protocol for the group meeting is enclosed in appendix 9.

The group meeting was recorded digitally and, based on this record, a detailed report was made including key quotations of the participants' contributions. This report was sent to the participants for a member check in adjusted form for their VI. Based on this report a description was made of the key elements of their care and treatment as experienced by the service users.

### 9.2.4 Data processing and analysis

The interview transcripts of the individual interviews were analysed by two researchers using a *qualitative content analysis* approach as described by Mayring (2014) consisting of a deductive category assignment followed by an inductive category formation (see section 4.2.4 for a detailed description of this approach).

After reading the transcripts line by line, phrases were selected and copied to a Microsoft Excel spreadsheet, each phrase representing one row in the spreadsheet. According to the deductive

category assignment process, each phrase was generalised to a more abstract level by each researcher separately. These more general phrases were then assigned to one of the following categories:

1. Descriptions of the characteristics of the service user;
2. Descriptions of current care and treatment.

### Descriptions of the characteristics of the service user

The phrases that were assigned to the first category were further categorised based on the ICF-framework as described in chapter 4 (see section 4.2.4). Each phrase was assigned to one of the following ICF categories (WHO, 2001a) by one of the researchers:

- Health condition (disorder or disease)
- Body functions & structures
- Activities & participation
- Environmental factors
- Personal factors

Based on this categorisation, a table was created. In this table, for each service user, the expressed problems and/or needs were structured according to the ICF-categories. This categorisation was checked by the second researcher.

### Descriptions of current care and treatment

The phrases assigned to the second category, were further categorised based on the generally accepted phases in a care process as described in chapter 8 (section 8.2.4). One of the researchers assigned each phrase to one of the following phases of a care process:

1. Intake;
2. Assessment of goals and care needs;
3. Planning;
4. Implementation;
5. Evaluation;
6. Ending care.

The categorisation was checked by the second researcher and agreement was reached, each phase was then appointed to one of the researchers and within each phase the steps for inductive category formation were applied (as described in section 8.2.4). After a first coding procedure, the categories resulting from the inductive category formation process were checked by the other researcher, and, once the categories had been approved, the definitive category system was discussed and agreed between the two researchers. This category system was then used to code all data. Based on these

categories, a summary was made for each theme depicting the important elements of the care process.

### Group meeting

Based on the contents of the report made after the group meeting, the experiences of the service users, according to the different phases in the care process, and the key elements of their care and treatment were categorised and compared to the logic model derived from the iterative process with professionals, as described in chapter 8.

## 9.3 Results

In this section, an overview is provided of the age, gender and years in care at RCF of the service users who participated, followed by a description of the problems and needs of the participants, as expressed by themselves and their experiences of current care and treatment. Finally, a description is given of the extent to which the service users' experiences confirmed the key elements as expressed by professionals to be an accurate representation of their current care and treatment. To substantiate these results, quotations are provided derived from the individual interviews and the group meeting. The interviews and meeting were held in Dutch and the quotations provided in this section are translated from Dutch into English by the researcher.

### 9.3.1 Participants

The recruitment of service users presented a challenge (see section 9.4.2, for a more detailed description). As described in section 9.2.2, eventually, a total of five service users agreed to participate in the study. Four participants had severe low vision and one participant was blind. Furthermore, the following classifications were mentioned in their records as being diagnosed by a mental health psychologist or psychiatrist based on the DSM-IV or V among the participants: psychosis (n=3), anxiety (n=2), schizophrenia (n=1), autism (n=1) and personality disorder (n=1). In table 9.1 an overview of the characteristics of the participants is given.

**Table 9.1**

*Characteristics of service users who participated in phase II of the study.*

No.	Age	Gender	Years in care at RCF	Participated in
S1	39	Male	4	Individual interview, second additional interview
S2	52	Female	6	Individual interview
S3	50	Male	2	Individual interview, Meeting
S4	52	Female	10	Individual interview, Meeting
S5	40	Male	7	Individual interview

As shown in table 9.1, only two of the participants participated in the group meeting. One service user (S2) had to end her participation at an early stage, because of a relapse of her mental health problems. S5 agreed to participate in only the individual interview; this was accepted, due to the difficulties experienced in recruiting participants. Finally, S1 cancelled his participation in the group meeting on the day of the meeting, due to feeling too much tension in anticipation of the meeting. This participant agreed to participate in a second individual interview after the group meeting.

### 9.3.2 Problems and needs of service users

Based on the service users' stories about their life histories and problems an overview could be made of the ICF characteristics for each participant, as was also done for the cases described in chapter 4.

In table 9.2 an overview is given of the health conditions mentioned by service users. The overview makes clear that all participants reported different diseases and disorders with respect to their VI and comorbid mental disorders or problems. Furthermore, three participants reported comorbid physical/somatic problems.

**Table 9.2**

*Health conditions (disorder or disease) mentioned by service users while describing their life histories*

<b>Category</b>	<b>Health condition</b>
Mental health problems	Psychosis (3 participants) Anxieties (3 participants) Autism Obsessive/compulsive behaviour Flashbacks of traumatic experiences Personality disorder Depressive complaints Suicidality
Somatic condition or symptom	Sensitivity to developing tumours Skin problems Juvenile arthritis Retinoblastoma Physical problems (intestines, removal of the uterus (fibroid))
Other	Charles Bonnet syndrome (visual hallucinations)

In table 9.3 (page 173) the affected body functions and structures as mentioned by service users are listed. Aside from their vision problems, service users mainly reported difficulties in social contact, low energy levels due to the VI and difficulties in controlling their emotions.

**Table 9.3***Affected body functions and structures mentioned by service users while describing their life histories*

<b>Category</b>	<b>Function</b>
Visual functions	Severe low vision (4 participants) Blind
Other	Experiencing a lack of reciprocity in social contacts Low level of energy due to visual hallucinations Difficulties of acknowledging own emotions. Low energy level due to low vision Not having control of own emotions

In table 9.4 the care needs in the domain of activities and participation as mentioned by service users are displayed. They reported problems in the areas of general tasks and demands, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life.

**Table 9.4***Problems in activities and participation mentioned by service users while describing their life histories*

<b>Category</b>	<b>Problems</b>
Activities	Being dependent on others due to the VI Difficulties with asking help of strangers Problems in performing domestic activities (2 participants)
Participation	No regular employment (3 participants) No normal existence (with the usual life phases) Limited possibility of being employed at a sheltered workplace Financial problems Difficulties maintaining social relationships Difficulties handling tension/conflicts in social situations Social withdrawal

In table 9.5 (p. 174) are listed several personal and environmental factors, that are experienced by the service user as positively or negatively influencing their capabilities in daily life. In terms of personal factors, service users reported the following: loneliness, low self-confidence, paranoia, tendency to cancel appointments, the desire to make full use of their residual vision and experiences of stress/tension when under pressure. In terms of environmental factors, experiences reported included: not feeling understood in their needs because of their VI during care or treatment in a mental health care setting, difficulties in their family life, not feeling understood by their family, not living at home as a child, limited social networks and maltreatment in youth. One participant stated that she experienced positive support from her family.

**Table 9.5***Environmental and personal factors mentioned by service users while describing their life histories*

<b>Category</b>	<b>Factor</b>
Environmental	Crisis admission in mental health care
	Parents divorced, not able to live at home with parents
	Mother maltreated by father
	Overprotective family
	Not feeling understood by family (2 participants)
	Limited social support network
	Receives mental health care for psychosis (medication)
	Crisis admission in mental health care (2 participants)
	Rehabilitation trajectory at Royal Dutch Visio
	Lives independently
	Living in a residential care facility (4 participants)
	Received mental health care for psychosis (medication)
	Lived at a boarding school (2 participants)
	Positive support from family
	Previously lived at a residential care facility of the RCF (2 participants)
	Received treatment within mental health care
	Attended different high schools, not graduated from high school
	Lived in a residential care facility for mental health care
	Parents divorced at young age
	Has received care from different stepfathers
Physical punishments	
Being employed at a sheltered workplace	
Personal	Experiences stress/tension when pressure is given
	Wants to make full use of residual vision
	Loneliness
	Low self-confidence
	Paranoia
	Tendency to cancel appointments

### 9.3.3 Experience and expectations of service users

The individual interviews and group meeting resulted in a description of the service users' experiences and expectations regarding their care and treatment. This is structured based on the components of the logic model as described in chapter 8, figure 8.3.

#### Theory behind the intervention

Based on the conversations with the service users the following theoretical assumptions could be identified:

- Having a special bond with a professional is an important condition for acquiring a feeling of safety;

- Building a relationship with a professional is facilitated by engaging in informal activities, by having a shared sense of humour, and by the impression that the professional is not simply doing their job but has a sincere interest in the service user as a person.
- Daily care can best be given from within the visual sector. However, professionals need to have a basic knowledge about mental health problems and how these problems can best be supported. Furthermore, intensive collaboration with mental health care is needed, to prevent or to react to any crisis situations encountered by a service user.
- When too much pressure is applied or when the goals set are perceived as too ambitious, a service user can become lost.
- Without having a stable and trusted support network, a service user may not be able to live outside a residential care facility.

*S2: '[name of care worker] not only helps me with training and stuff, I can tell her anything. When I am sad, she is also a support for me. ... We have such a trusting relationship. If she does something I do not like, I can tell her. And if I do something she does not like, she will say it. Just be open and honest with each other.'*

*'What I think is a dirty word is: "to report". I would rather not hear that. For example, I told my whole story to an intern and then she said, "I have to report it", like that. I did not want to hear that at all. ... Then I think, who am I talking to, a human being or a computer? Where does it all go to? A little bit of a personal involvement. You should not talk about reporting, at least it will come across as sincere. You only ask it as a formality, so you can write something down. ... A little humanity in care would be nice.'* (S1, individual interview).

*'I was able to rely on my family a lot in the past, because my family was quite large. However, they are slowly disappearing. If I would live on my own, I do not know how that would go. That is why I want to stay living in a residential care facility.'* (S4, individual interview).

#### Implementation outputs (activities)

The service users did not experience their care process as a transition through the general model of six sequential care phases as described in section 9.2.4. In the group meeting service users could recognise these phases and could indicate some care activities belonging to each phase. However, they did not recognise an explicit transition through these phases. Below are discussed some of the activities that service users indicated as important in their care and treatment.

At the start of the care process, service users emphasize the importance that professionals maintain an accessible and user-friendly approach, in which they take the needs of a service user as a guiding principle, not being too strict on the rules. In order to get to know each other, service users mention



the importance of undertaking informal activities with service users (as expressed in the quotation of S1 during the individual interview):

*'A bit of casual care and treatment, not being too strict on the rules. ... Elastic cannot break by bending, you know. ... [responding to the question: What do you need to find out if there is a connection with a professional?] You often notice that when talking during a trip to the supermarket, or walking around, outside. A trip to the dentist, so to speak, and then have a chat, you know'* (S1, individual interview).

Furthermore, paying sincere attention to and taking interest in the life story of a service user, and taking the time to get to know one another at a slow pace was mentioned as important factors for establishing a relationship.

Service users noted the importance of not feeling pressured by not directly establishing concrete, time-specific rehabilitation goals aimed at enlarging the independence of the service user. When asked for their concrete goals or achievements, service users could not provide specific answers. Through additional questions, service users mainly expressed having achieved more stability in their lives with clear and structured basic care and treatment, as was illustrated by S1 in the individual interview.

S1: *'I do actually like the structure. Just having day time activities.'*

Researcher: *'What else?'*

S1: *'I don't really have an answer to that. Just the structure, actually.'*

Researcher: *'Ensuring that you find your place here.'*

S1: *'But structure as well, that was a real drama with me. Nothing was right, and then I felt no need to go to the day care facility. I do have that now.'*

More stability included such things as having a clearly structured day, feeling safe in the facility, knowing how to get around in the immediate environment, receiving suitable care and treatment for daily life activities and domestic activities, living a healthy lifestyle, having meaningful daytime activities, being able to express feelings or uncertainties to a professional, and suitable management and use of medication. Furthermore, service users reported working on specific goals such as learning different skills, building a social network, training to achieve a higher level of independence, and searching for a suitable day-care facility. They experienced this as a trajectory with both ups and downs, and being able to work on these goals was dependent on the state in which a service user found themselves at that moment or their degree of motivation, as is illustrated by S4 in the group meeting:

*'I had cooking lessons for a while, to learn how to use the cooking plate. But then I chose writing, so cooking is on the back burner again. ... I want to devote as much time as possible to writing, because in four years' time I want to publish a book about my own life.'* (S4, group meeting)

Participants reported making small steps towards a certain goal, although sometimes a big leap is made.

All participants described receiving basic care for their mental disorder(s), mediated through a search for the right balance in the intensity of the care and treatment, and collaboration with the mental health care facility. Service users emphasized the importance, when experiencing mental health issues, of the availability of professionals, who are able to check on things the service user is not able to see, and of regulating feelings of anxiety, depression or suspicion.

Researcher: *'And what, above all, have they [care professionals of RCF and mental health care] been working on?'*

S2: *'Well, that of course I would ring the bell in time. ... At that time, I only had one care worker who visited me. She came twice a week and a nurse from mental health care came once a week. And they kept on stressing from time to time: if anything happens, ring the bell. So, I was watched so closely. That I could always fall back on them, if there was anything.'* (S2, individual interview).

In general, service users emphasized the importance of relying on a consistent team of professionals who provide care and having a permanent contact person who has overall responsibility for the care and treatment provided. This professional has an important role as a mediator between the different care professionals who are involved with the service user. This was expressed in a dialogue between S4 and S3 during the group meeting, responding to the importance of continuity over the long term during the care and treatment:

S4: *'I don't recognise this in myself, but I do recognise it in other service users. They really got affected by building up trust with a care worker and then that care worker leaves after 2 or 3 years. Then they have already told him everything and then he goes away again. And I also think that you should let those people keep the same person for a longer time. We have one person living with us who has had 7 care workers in 6 years.'*

S3: *'That's very bad, you have to tell the same story over and over again.'*

Service users stated the importance of living in a residential care facility. With regards to personal contact, service users emphasize the importance of a professional being humorous, open and honest.

### Intermediate and final outcomes

When asked about the outcomes of their care and treatment, participants had difficulty expressing concrete outcomes, as is evident in the following quotation from the individual interview with S5.

Researcher: *'What are things you have achieved?'*

S5: *'What have I achieved [laughs], well ... Actually, I don't know very clearly. I do hear a lot from the professionals: you have worked hard and you have grown a lot and so on. I would like to believe that, but over the years I have come to a point where I think: I will have to be satisfied with the place I am now, with the state I am in...'*

Despite the difficulty service users have of recognising them as such, a number of different outcomes could be identified from their stories. As intermediate outcomes service users reported the following:

- Knowing that they can always fall back on a professional;
- Experiencing more stability in their lives;
- Feeling at home in the residential care facility, and not experiencing this as an institution;
- Not explicitly working on goals or progression;
- Being able to share their stories and uncertainties with professionals.

In addition, several final outcomes could be identified:

- Maintaining their independence on certain levels;
- Personal growth (accepting themselves, being able to express their feelings);
- Stability in their mental health problems, reduction in the care and treatment from mental health care;
- Having structure in life (see the quotation below from the individual interview with S1).

*'I think structure is important. I had to learn to wash my clothes by myself. I could have given it to LIPS [laundry service]. But I am doing that myself ... Everything you see here in my room, is all mine. And when I came here, all I had was a sports bag. That is a difference. That you are slowly getting your finances sorted out. That you can just do your own thing, actually. That you can go for a walk and say, I am going to get some ice cream. Being financially independent, I have not been able to feel that for a long time. Everything is a little bit in order, actually.'* (S1, individual interview).

### Contextual factors

To identify important contextual factors, service users shared their experiences of receiving care and treatment within a mental health care facility. In this facility they experienced feelings of being lost due to their VI. Within mental health care, professionals lack the experience and knowledge of what

is needed for the care and treatment of a person with VI. Furthermore, the building itself is not equipped with the right aids for a person with a VI. This resulted in service users feeling unsafe, being dependent on others and not feeling understood, as was expressed in the quotations from the individual interviews with S1 and S2:

*'You do notice that when you go to [name of mental health care facility] and you have bad eyes, they have trouble with that. I stayed at the 'Time Out' [a crisis unit of the mental health care facility] for nine months, there were sixteen interns there, so there was always someone who went to the supermarket with me. But they do not know that they have to grab your arm, because otherwise somebody is falling on his bottom. Things like that, just the little things.'* (S1, individual interview)

*'Let's see... Yeah, of course they forgot to give me an arm if we had to walk somewhere, they were already ahead. Then I really had to shout, "I have to have an arm, because I cannot see it." Or taking a shower in the morning, they forgot about me, and I said, "I need help to take me to the shower." Or therapies, that happened with cards, I could not do that, of course. So that is what I said, "I cannot do that, because I cannot see that." They just did not have anything for people with VI.'* (S2, individual interview).

Although service users felt more at home within the visual sector, their experience is that professionals within this sector lack basic knowledge of how to provide care to someone with their mental health problems. They stress the importance of training professionals on this subject and collaboration with mental health care, as S2 indicated in the individual interview:

*'At first, [name of care worker] did not know anything about mental health problems. And then she wanted to get a little involved. And then I said, "You should not do anything you do not know anything about." But then she collaborated with the mental health services and the nurse and from there she learnt a lot. And now she knows what to look out for and now she can.'* (S2, individual interview).

#### 9.3.4 Key elements indicated by professionals

The different key elements that were indicated by the professionals were also acknowledged by the participants as being key elements in their care and treatment. Of these, offering appropriate time and space could be considered the most important, however, this was also seen as an ambiguous factor, as it was expressed as difficult to find the accurate extent of this freedom and space, as was indicated by S4 in the group meeting:

*'That you can keep doing your own things. ... I need structure and space to feel free, but too much space/freedom is not good either. Then you lose the structure again. ...then you lose yourself a little.'* (S4, group meeting).

Another important aspect was having specific knowledge about the VI, as expressed in the following comment made by S4 during the group meeting:

*'If they were general care workers, I would not feel comfortable with them. They need to know a little bit about how you might feel, know something about VI, then they can empathise more easily.'* (S4, group meeting).

Service users also acknowledge the importance of obtaining a detailed understanding of the problems and needs of a service user and indicate that every service user is different. Even when they are diagnosed with the same problems, they can have different needs. Furthermore, trust and feelings of safety are important and service users express the importance of the attitude of care workers to be able to achieve this trust and sense of safety. As is made clear in this quotation from the second individual interview with S1:

*'I do have trust here, I did not have that at all when I had the psychosis. ... if they help you with packing the suitcase, when you go on holiday, that gives you safety, they give you trust that you are able to do that.'* (S1, second individual interview).

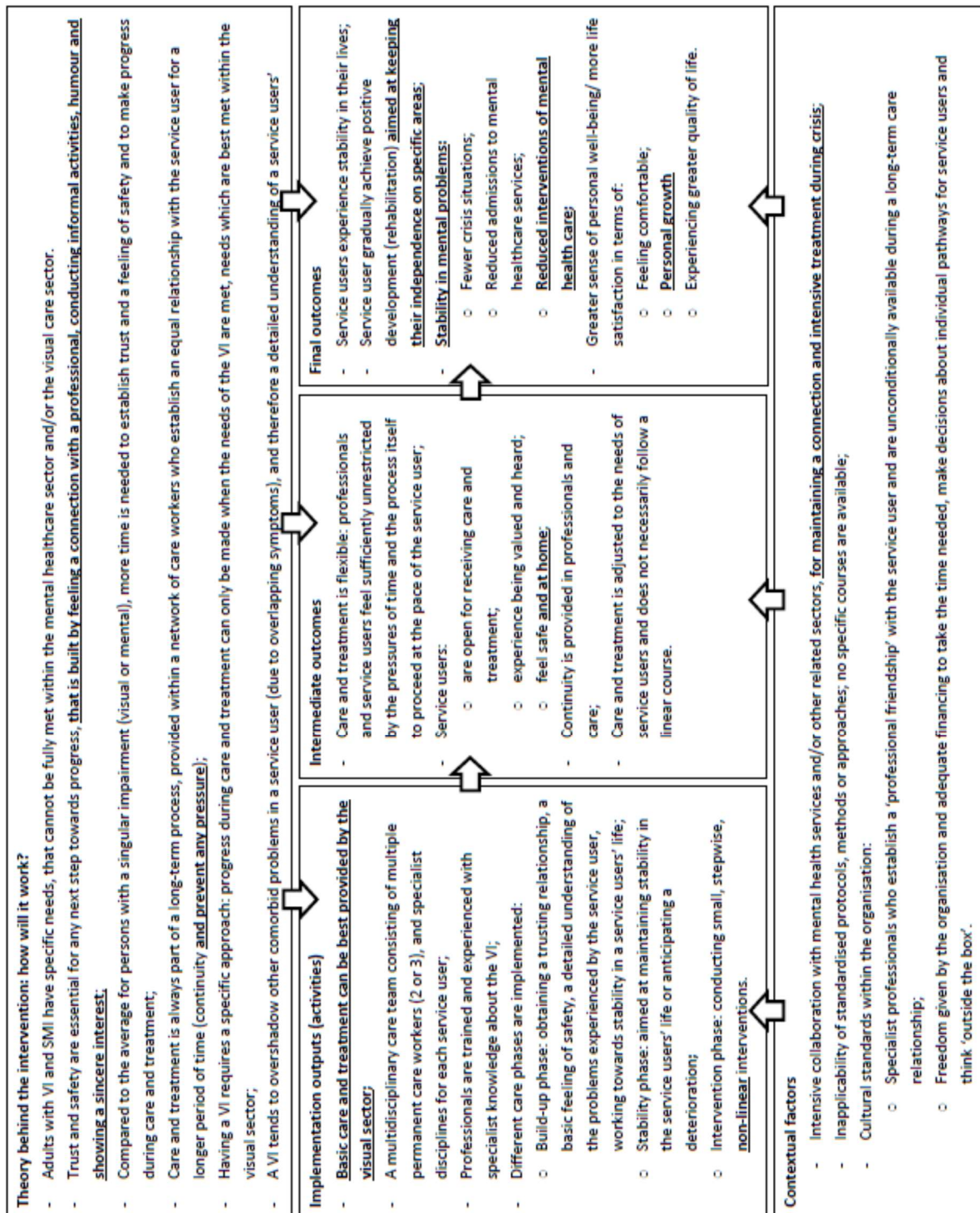
Finally, the participants acknowledged the importance of offering slow, long-term and stepwise care and treatment, as was indicated in the individual interview with S5:

*'Focusing it all on developing, or continuously aiming for a developing trajectory, that is how I should put it. ... It might also give a feeling of pressure, then maybe something is expected of me and then I am going to force myself more to do it. Then it will only get more exciting. That's counterproductive. Yeah, of course you need some pressure, but not too much.'* (S5, individual interview).

Based on the experiences expressed by the service users, no substantial changes were made to the logic model; only a few additions were made, providing more specificity. In figure 9.2 (page 181), these additions are shown using a bold and underlined font.

Figure 9.2

Refined logic model of current care and treatment based on the experiences and expectations of service users



### 9.4 Discussion

An iterative process of inquiry was conducted to gain insights into the problems and needs indicated by service users, into the current care and treatment they receive, and into what they consider important in their care and treatment. Based on these insights, certain adjustments could be made to the logic model that was built based on the experiences of professionals. In this section the main findings are presented and how these findings relate to the available evidence, followed by the strengths and limitations of the study and the main conclusions that can be drawn from the outcomes of this study.

#### 9.4.1 Main findings

The problems and needs expressed by service users are mainly experienced in terms of societal participation, emotion regulation, domestic care and care in social interactions. Furthermore, the overview of the service users' characteristics show that service users experience different comorbid mental disorders and sometimes additional physical or somatic problems. When looking across their life histories, service users indicated that they have encountered different problems in their care and treatment and with their families, problems that in turn have had an influence on their current daily functioning. Some participants mentioned personal factors that impede their daily functioning, such as high levels of stress and tension.

The participants consider the current care and treatment provided within their residential care facility to be suitable. The different factors important for that care and treatment that were mentioned mainly concern being able to develop at their own pace and just living their lives as they wanted. Other important conditions are that the care worker needs to have specialist knowledge about the VI and a sincere interest in the service user, and that the service user feels a connection with the care worker. Service users have difficulties recognising and sharing their achievements. However, when prompted by supplementary questions, they indicated that, by living in the residential care facility and obtaining care and treatment, they have gained more stability in their lives and have found a place they feel at home, valued and heard.

Finally, the key elements contained in the logic model derived from the iterative process with professionals are also acknowledged by service users as being important for their care and treatment, with a strong emphasis on the importance of offering time and space, and on the need for specific knowledge regarding the VI. This suggests that the experiences of service users of their care

and treatment are in line with the characteristics and elements of care and treatment identified by professionals.

### 9.4.2 Strengths and limitations

The iterative process facilitated the involvement of service users in the collection and interpretation of the data. Participants reported that the individual interviews and group meeting were positive experiences for them. They expressed the fact that they felt comfortable during the interviews, which helped them to gain new insights into their care and treatment and into what they experience as important, and to see what they have achieved. This suggests that a trusting and safe environment, in which the service users were able to become aware of their experiences and to be open and honest in sharing these with the researcher was created. Also, it was experienced that this environment was also facilitated by the researcher being someone from within the RCF with whom the participants were already acquainted, but who was, at that moment, not involved in their daily care and treatment. A funnel approach was used in the interviews with the service users, starting with an open interview without addressing the elements indicated by professionals and ending with a discussion of these elements with the service users. By adopting this approach, service users were first facilitated to become aware of their own experiences about the care and treatment, allowing an independent impression to be gained of these experiences. Later, by presenting the key elements expressed by professionals to them, service users were better able to form and share an objective assessment of these elements. This feedback allowed validation of the key elements within the description and logic model as derived from the experiences of professionals.

A limitation of the study concerned the recruitment of participants, which took longer than expected as described in section 9.2.2. Although only five service users participated, data saturation was achieved in the group meeting and second individual interview with one of the participants of the process, suggesting that the outcomes form a complete representation of the experiences of the participants. However, stronger evidence for these outcomes would be provided by consulting a larger group of service users to confirm if the findings represent the experiences of service users in general. This will be described in chapter 10.

### 9.4.3 Conclusion

By conducting an iterative process of inquiry, in which service users were asked to share their experiences in individual interviews and a group meeting, service users were able to become aware of their current care and treatment and develop an objective view of it. Based on their stories and feedback on the outcomes of the iterative process with the professionals, it can be concluded that



## CHAPTER 9

service users' experiences of their care and treatment are in line with the experiences of professionals. In the course of this, the logic model as established in the first phase of the study could be confirmed with some additions. In chapter 10, this logic model will be presented to a larger number of professionals and service users to assess the extent to which this logic model is acknowledged to be an accurate representation of current care and treatment. Service users' combination of VI and SMI restricted their ability to participate in the study, which made it a challenge to obtain a strong representation of their point of view. However, the service users who did participate expressed the opinion that it was a valuable process, providing them with more insights into their care process. As such it might be recommended that such sessions could be regularly held with the purpose of improving the quality of care delivery. However, in order to do this in an inclusive manner, ways of overcoming the barriers to service users' participation in such sessions would be needed.

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## CHAPTER 10: A VALIDATION OF THE DESCRIPTION AND LOGIC MODEL OF CURRENT CARE AND TREATMENT FOR ADULTS WITH VI AND SMI

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### 10.1 Introduction

By conducting an iterative process of inquiry together with professionals and service users, an explicit description of the characteristics of adults with VI and SMI and an agreed logic model of their current care and treatment was established. However, in line with the nature of qualitative research, the description and the logic model were based on the input of a small group of professionals and service users. Based on only their views, it cannot be determined in how far the results form an accurate representation of wider current practice. In order to validate them, a larger number of professionals and service users would need to be consulted.

Therefore, the following research question was addressed: *In how far can the description and logic model of current care and treatment be validated as an accurate representation of current practice?*

This research question was further divided into the following sub-questions:

- What elements do professionals and service users acknowledge as being the most important?
- What elements are not accepted by professionals and service users?
- What elements do professionals and service users identify as missing from the current representation?

### 10.2 Method

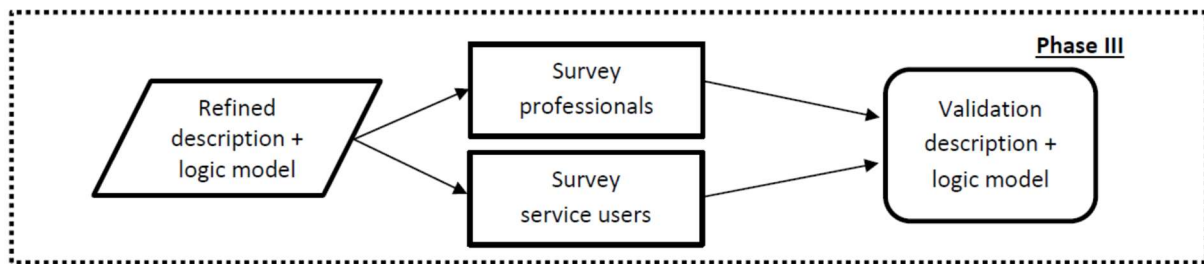
In this section the design of the study is presented. Furthermore, a description is given of how the participants were recruited and of how data collection and analysis were executed.

#### 10.2.1 Design

As described in the general design in chapter 3, validation of the description and logic model was part of the last phase of the study. In figure 10.1 (page 186) the flowchart of this last phase is presented.

**Figure 10.1**

*Flowchart of the stages and steps in data collection and processing for phase III*



A survey was to be conducted among a larger number of professionals and service users. Professionals would be approached by email and asked to review the descriptions of the characteristics of adults with VI and SMI and of the current practice of care provision, and the resulting logic model. After going through the descriptions and logic model, the professionals would be asked to complete a short questionnaire in which they would be asked if they acknowledged the descriptions and logic model to be an accurate representation of current practice. Service users would be approached by email or telephone and asked to review the description of the characteristics and current practice. The logic model was not presented, due to the difficulties of making tables and figures readable for persons with VI. After going through the description, service users would be asked to complete a short questionnaire in which they would be asked if they acknowledged the descriptions to be an accurate representation of current practice.

### 10.2.2 Participants

As described above, two groups of participants would be asked to participate in this study:

1. Professionals who provide care and treatment to adults with VI and SMI;
2. Service users living in a residential care facility of the RCF.

To reach the professionals, recruitment was conducted in April 2020 in two ways:

- An email was sent to all professionals of the RCF who were active in daily practice in the residential care facilities, outreach care, day-time activities or who were a member of the strategic team. In the email a short description of the overall study and the aim of this specific phase were given, and the professionals were asked to participate by clicking on the link in the email before May 1<sup>st</sup>, 2020.
- An extra edition of the regular email newsletter was sent to the Dutch members of the online community of practice Psyvisnet (see section 3.2.3 for a description). In this newsletter the

same content as described for the professionals of the RCF was shared. Members of Psyvisnet were also asked to participate by clicking on the link in the email before May 1<sup>st</sup>, 2020.

Many professionals of the RCF are also members of Psyvisnet. To prevent duplication of responses, the members of Psyvisnet were informed that it was possible that they received this invitation twice and that they should only participate once. Based on the patterns of answers of the participants, there is no evidence that any professional participated more than once; however, this possibility cannot be fully discounted.

To reach the service users, the care coordinators of the different residential care facilities of the RCF were sent an email (June 2020) in which they were asked to provide the names of suitable service users who could be approached for the last phase of the study. The criteria for inclusion in the previous, iterative, in-depth study with service users, as described in section 9.2.2, were shared with the care coordinators, with the last criterion being changed into: *able to read basic information and respond to a short questionnaire*.

If a care coordinator did not respond to the email they were contacted by telephone. After the selection of suitable service users, the care coordinators were asked to share an information letter with the service users, in which the latter were informed about the overall study and the aim of this phase of the study in particular, and were asked if they would like to participate. If a service user agreed, they were sent the information to participate by their own email or by post or by the email of the care coordinator and they arranged that a care worker went through the information with the service users and helped them with completing the questionnaire.

### 10.2.3 Instruments for data collection

The process of data collection differed for the professionals and service users. The two processes are described below.

#### Professionals

For the RCF professionals and members of Psyvisnet, the study materials were shared using the e-learning online course-creation web app *Rise 360* of Articulate Global, Inc.. By using this program, information can be divided into different 'lessons' and shared. In each lesson, text can be presented, through different 'assets', such as lists, processes or flashcards. In addition, images and videos can be added. These assets can be used to present the information in a clear way. This program is regularly used within the RCF to share information or educate employees in different aspects. For this study,

the results of the studies described in chapter 4, 8 and 9 and the logic model were presented using the e-learning program (see appendix 10 for an example). For this purpose, this information was presented in Dutch. After a short introduction, participants were asked to read the information presented in the following six lessons:

1. *Characteristics of adults with VI and SMI*: presenting the information as described in chapter 4, followed by the schematic overview of the characteristics.
2. *Description of current care process*: presenting the information described in the section *implementation outputs (activities)* as described in chapter 8, supplemented with information derived from the study presented in chapter 9.
3. *Underlying theories*: presenting the information described in the section *theories behind the intervention* in chapter 8, supplemented with information derived from the study presented in chapter 9.
4. *Outcomes*: presenting the information described in the section *intermediate and final outcomes* in chapter 8, supplemented with information derived from the study presented in chapter 9.
5. *Contextual factors*: presenting the information described in the section *contextual factors* in chapter 8, supplemented with information derived from the study presented in chapter 9.
6. *Logic model*: presenting the logic model as given in chapter 9.

After finishing these lessons, participants were asked to click on a link that guided them to a questionnaire built using the Google Forms web-based survey administration app. In this questionnaire participants were first asked to answer two closed questions concerning their position (the organisation to which they belong and the kind of care they provide, such as residential, outreach or day care). This was followed by another closed question which asked if they acknowledge the validity of description of current care and treatment (yes or no). Their answer to this question was explored in the next three questions, each allowing a free-text response followed in which respondents could explain their answer and provide information about aspects they did not acknowledge or which they thought were missing from the description. In appendix 11, the complete questionnaire (translated from Dutch to English by the researcher) is presented.

### Service users

For the service users, in order to enhance accessibility, a Microsoft Word version of the e-learning course and the questionnaire was sent by email or post. The content of the e-learning course was reduced and expressed in short sentences and simple words to help service users read and understand the text (see appendix 12 for the introduction letter enclosed with the description,

translated to English by the researcher). This version was sent to the participants in their preferred reading mode (email, braille, daisy player, normal font or enlarged and/or bold font). After reading the information, the service users were asked to respond to a questionnaire, that was enclosed as a separate Word document. Service users could choose to respond to the questionnaire by typing their answers in the Word version and returning this by email or else by providing their answers in a telephone conversation with a research assistant. One participant asked to provide the answers in an individual meeting with the researcher. In the questionnaire, service users were asked to answer 'yes' or 'no' to the question of whether they acknowledged the description as an accurate representation of their current care and treatment. Then, three free-text response questions followed, in which they were asked to provide information about the elements they do acknowledge, those that they do *not* acknowledge and what they think is missing from the description. In appendix 13, the complete version of the questionnaire (translated from Dutch to English by the researcher) is given.

### 10.2.4 Data processing and analysis

The professionals' answers to the questionnaire were transformed automatically by Google Forms into a Microsoft Excel spreadsheet. The answers of the service users were collected and manually inserted in an Excel spreadsheet by a research assistant. Descriptive statistics were extracted in terms of the number of professionals and service users that responded in total. Furthermore, bar graphs were made displaying the number of professionals employed in a residential, outreach or 'other' setting for each different organisation separately, and showing the number of service users who responded by email, telephone conversation or in an individual meeting.

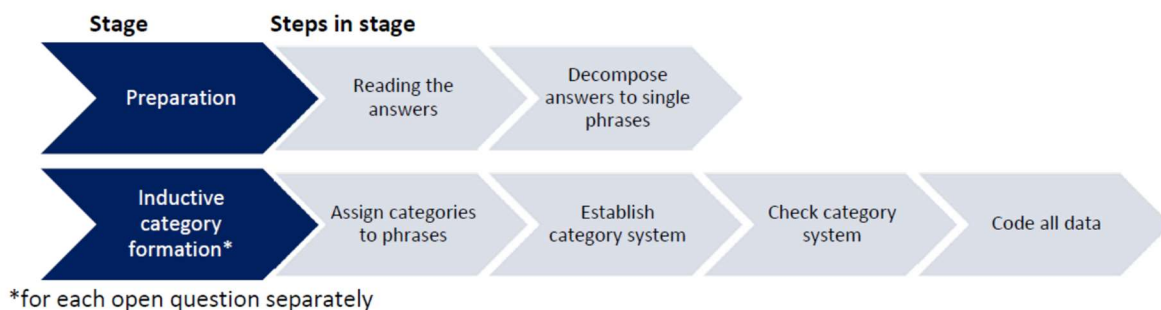
The answers to the free-text response questions were analysed by applying a qualitative content analysis methodology, specifically by following an inductive category formation process for each question (Mayring, 2014) (see section 4.2.4 for a detailed description of this process). With regard to professionals, the answers of those employed at the RCF and those employed at another organisation inside the visual sector were analysed separately, to gain insights into the similarities and differences between the care provision for adults with VI and SMI at the RCF and the other organisations.

In figure 10.2 (p. 190) an overview of the stages and steps in each stage of the qualitative content analysis is provided. For each question with a free-text response, the answers of each respondent were reduced to single phrases for each element that was addressed by the respondent. Then the inductive category formation procedure (Mayring, 2014) was started. The first phrase was read and

assigned a category representing the content of the phrase. For the second phrase it was decided if the content was substantively equivalent to the first category or a new category should be made. This was continued for each subsequent phrase. Based on this process different categories were assigned for each question with a free-text response. After a first coding procedure, the categories were checked by the other researcher and the definitive category system was the result of discussion between the two researchers. This definitive category system was then used to code all the data for that particular question. The process was repeated for the other two free-text-response questions.

**Figure 10.2**

*Overview of stages and steps in each stage of the qualitative content analysis of the responses to each open question*



### 10.3 Results

In this section the results are provided divided into an overview of the participants and the results of the survey. To substantiate these results, phrases are provided derived from the answers of participants to the questions with free-text responses. The original responses were in Dutch and have been translated to English by the researcher.

#### 10.3.1 Participants

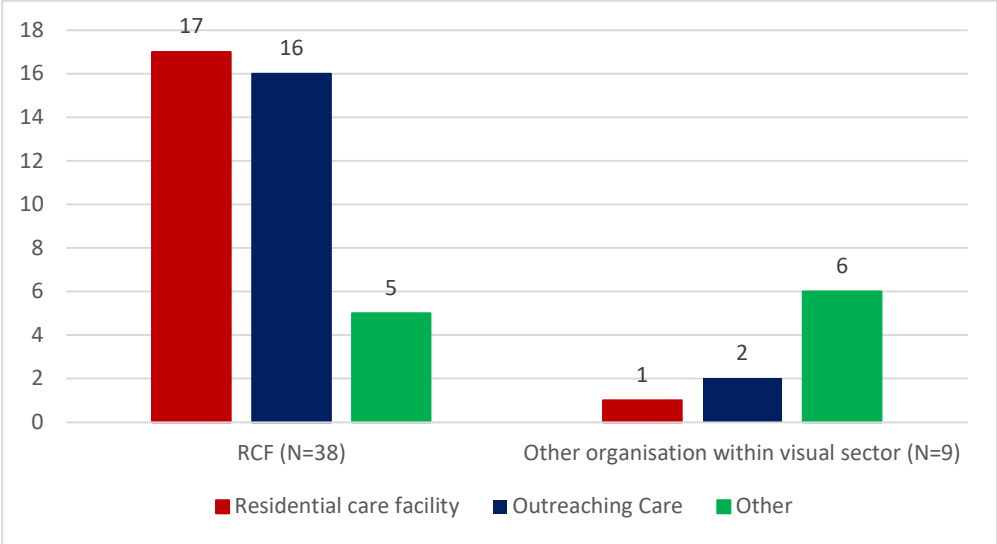
The following two sections present the overview of respondents and their backgrounds.

##### Professionals

A total of 47 professionals responded by completing the questionnaire. Most of these professionals were employed at the RCF with the remainder being employed at one of the other organisations within the visual sector. None of the professionals were employed at an organisation outside the visual sector. For the RCF, there was an equal distribution of professionals working in residential care and outreach care. A minority of the professionals provided day-care activities for service users. For the other organisations within the visual sector, most professionals provided day-care activities, two professionals worked in outreach care and just one worked in a residential care facility.

Figure 10.3 shows the number of professionals per setting for the RCF and for another organisation within the visual sector.

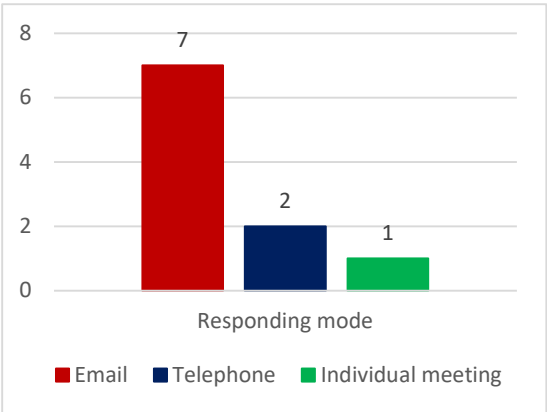
**Figure 10.3**  
*Number of professionals per operational setting for the RCF and for other organisations within visual sector*



Service users

A total of ten service users responded by completing the questionnaire. Nine of the respondents were living in one of the residential care facilities of the RCF and one was living independently and receiving outreach care. Figure 10.4 shows the number of service users who utilised each mode of response. Most (n=7) service users responded by completing the questionnaire with the help of a care worker, with the care worker then returning the answers by email; two service users indicated that they wanted to give their answers in a telephone call with a research assistant; and one service user requested an individual meeting with the researcher to provide the answers.

**Figure 10.4**  
*Number of service users per responding mode*





### 10.3.2 Survey

In this section the results of the analysis of the free-text responses are presented for:

- professionals of the RCF;
- professionals employed at another organisation within the visual sector;
- service users.

The description is further substantiated by different examples of the answers provided by professionals or service users. These answers are translated from Dutch to English by the researcher.

#### Professionals of the RCF

All professionals being employed at the RCF acknowledged that the descriptions of the problems and needs that characterise adults with VI and SMI, of their current practice, and the logic model were, on the whole, accurate representations of their own practice and experiences.

#### *Elements indicated as most important*

With respect to the problems and needs that characterise adults with VI and SMI, the complexity of their problems, their difficult life histories and the importance of obtaining a detailed understanding of their problems and needs were all acknowledged.

With respect to the description of current care and treatment and the logic model, professionals of the RCF mentioned that they acknowledged the importance of having a trusting relationship and providing a feeling of safety, and indicated that this takes time and that specialist knowledge is needed to establish this relationship, as is illustrated by the following answer given by one participant:

*'In particular, building the relationship is of great importance and is an ongoing investment. It takes a lot of time before the foundation is established. Even after years, trust remains fragile due to mental illness or a traumatic past.'*

Professionals of the RCF indicated that the different phases in the care process are accurate, and stressed the intermittent nature of this process, going back and forward between the phases and taking just small steps. Another important aspect the professionals acknowledged was the attitude on the part of the professional by indicating the following activities: putting no pressure on the service user; going at the pace of the service user; using humour while providing care and treatment; being flexible; and being truthful and authentic. The latter was indicated by the following response:

*'Truthfulness is indeed also important, if I show my true self, my service users also show their true self more quickly. I notice that I also tell personal things here more often than I did to other target groups, because that strengthens the relationship between me and the service user.'*

Furthermore, the importance of a consistent team (see quotation below) and good collaboration with mental health in providing this care were acknowledged by professionals.

*'Within the stability phase, I recognise that many service users have had the same care workers for many years, this makes them feel safe and secure. From this basis, you can quickly recognise and intervene when problems arise.'*

#### *Elements that are not accepted in the descriptions and logic model*

A total of 20 professionals of the RCF indicated that there were no aspects in the description that they did not accept. Professionals who did see aspects they did not accept indicated that they could not see themselves in the unconditional relationship with a service user as described in the e-learning or that they felt the term "professional friendship" was problematic. They also indicated that many service users did not make progress or that this progress is very small. Professionals characterised this as preventing deterioration or mainly trying to decrease the vulnerability of service users (as is illustrated in the answer below).

*'Progress is not always possible, as seems to be the case in the intervention phase. Sometimes maintaining mental health and skills is the highest achievable [aim] and [the service user] would deteriorate if there is no suitable care and treatment.'*

Furthermore, professionals indicated, as described above, that they acknowledged the importance of good collaboration with mental health organisations, but expressed that this collaboration is sometimes lacking for service users.

#### *Elements indicated as missing*

A total of 18 professionals of the RCF indicated that nothing was missing in the description. Professionals who did detect missing elements in the description mentioned more specific elements, such as the use of motivating conversation techniques in care and treatment, the influence on care and treatment of grief due to the VI, and searching for previous achievements in a service user's life or those aspects that are going well.

*'In the build-up phase, I think care workers often look for what is already going well in a service user's life. What has facilitated the service user to persevere in this way so far? What strengths does the service user have, what positive qualities does someone have? How can this be used in daily life?'*

Also, professionals mentioned the struggle experienced by service users to keep control over and responsibility for their own lives and to maintain their independence of others. Another aspect mentioned as missing by professionals of the RCF is the importance of having a multidisciplinary team.

#### Professionals of another organisation within the visual sector

With one exception, all professionals of other organisations within the visual sector acknowledged that the descriptions of the problems and needs that characterise adults with VI and SMI, of their current practice, and the logic model were, on the whole, accurate representations of their own practice and experiences. The one professional who did not accept the description was employed in a setting offering short-term care and treatment.

#### *Elements indicated as most important*

With respect to the problems and needs that characterise adults with VI and SMI, these professionals also acknowledged the complexity of the problems of service users. With respect to the description of current care and treatment and the logic model, the importance of establishing a trusting relationship and safety (see the answer given by one of the participants below) and the importance of working in a multidisciplinary team was mostly mentioned by these professionals as something they recognise as most important.

*'That a trusting relationship is very important. And safety.'*

#### *Elements that are not accepted in the descriptions and logic model*

A total of 2 professionals employed at another organisation indicated that there were no aspects in the description that they did not accept. The other professionals indicated that they did not acknowledge the long-term relationship or 'endlessness' in this relationship and mentioned the possible difference in needs of service users in different organisations.

*'[I do not recognise] the endlessness of it. In our setting, we work towards sufficient self-reliance or referral within a year or so (difference in setting/target group).'*

*Elements indicated as missing*

One professional employed at another organisation indicated that nothing was missing in the description. The following elements were indicated as omitting by the remaining professionals in the description of current care and treatment and logic model: the influence of the VI on the possibility of using standard criteria for a proper diagnosis of a specific mental disorder; the influence of the VI on the service user's ability to concentrate; the influence of the onset of a VI on the developmental process of a service user and the effect of this on the way a service user needs to be approached; and the restrictions on the funds available to provide suitable care to service users, as illustrated in the following response:

*'The limitation of financing for the intervention. In both outreach residential care and rehabilitation, the importance of the deadline for achieving goals determines the definition of the intervention to a greater or lesser extent. People with multiple comorbid problems actually need permanent care and treatment. This should be described in guidelines.'*

Service users

All service users replied with yes to the question of whether they acknowledge to be accurate the descriptions of the problems and needs that characterise adults with VI and SMI, and of their current care and treatment. One service user added a remark that this is how it should be, but in reality this is not always the case.

*Elements indicated as most important*

With regards to the description of the problems and needs that characterise adults with VI and SMI, service users agreed with this description, stressing the complexity of their problems, their difficult life histories and the late recognition of their mental health problems. This last point is illustrated by one service user's response:

*'Late discovery of mental health problems. Difficult for parents to take good care of service user. Negative [events in their] past.'*

With regards to the description of current care and treatment, service users stress the importance of the attitude of the professional in building a relationship, demonstrated by showing interest in the service user, being authentic and placing themselves as an equal, by providing time and exerting no pressure, and by searching for possibilities. This is illustrated by the following answer that was written by a care worker on behalf of the service user:

*'... she recognises her own ideas in the description of the basic attitude needed for professionals in the care and treatment. Remarkably, she names each point that is described, actually the service user can confirm the whole description from her own experience.'*

The following answer of a service user also illustrates the importance of providing time and exerting no pressure:

*'Especially slowly getting used to the house and the care and treatment, and no pressure to do things. Just being able to live my own life.'*

Other important aspects indicated by service users are continuity in care workers, collaboration with other organisations, engaging in informal activities and the professional's possession of specialist knowledge, as is illustrated in the following answer:

*'Care workers of the RCF understand more about us, than the mental health services do, about VI.'*

#### *Elements that are not accepted in the descriptions*

A total of three service users indicated that they agreed with all elements in the description. One service user did not accept that they lacked an overview of the situation and did not experience the lack of eye contact as an impediment.

*'No overview of the surroundings. Not being able to make eye contact, I don't miss that [lack].'*

Furthermore, service users stressed that building a relationship is different with each care worker. They are not able to share their life story with every care worker, since there is not always the necessary personal connection. Also, one service user indicated that it is difficult for him to achieve goals.

*'When working on goals, it sometimes feels as if it is not feasible. The service user then has the idea that he is not moving forward at all, but is standing still.'*

#### *Elements indicated as missing*

A total of six service users did not identify any elements missing from the description of the problems and needs that characterise adults with VI and SMI and the current care and treatment. Those who did indicate missing aspects mentioned the importance of empathy in a professional, the importance of setting limits or having clarity (points which were not further clarified by the participant), and the

influence of living in a residential care facility and not being able to choose their own social environment.

*'The influence of living in a residential care facility, in a non-self-chosen social environment. You do not choose your co-residents and care and treatment. Group dynamics can also be demanding and influential.'*

#### 10.4 Discussion

In this section the main findings are presented, followed by a discussion of the strengths and limitations of the study and the main conclusions that can be drawn from the results of the survey.

##### 10.4.1 Main findings

All but one professionals acknowledged the explicit description of the problems and needs that characterise adults with VI and SMI and their current care and treatment as an accurate representation of current practice. Professionals mostly mentioned in their free-text responses the importance of building a trusting relationship and a sense of safety, and acknowledged the time this requires and the special knowledge needed about the VI to build this relationship. They indicated that the different phases (build-up, stability and intervention) form a good representation of current practice and emphasized the intermittent nature of the process, going backwards and forwards between these phases. Furthermore, professionals acknowledged the importance of the attitude of the professional, of being authentic and putting no pressure on a service user, and of collaboration with mental health care services. A minority of professionals indicated elements they did not accept: they emphasized the difficulty faced by service users in making progress; that sometimes a good collaboration with mental health care services is lacking; and some professionals had a problem with the term “unconditional” used to describe their relationship with the service user. Professionals indicated minor elements were missing in the description.

When comparing the answers of professionals of the RCF and those employed in another organisation, differences were found in the extent to which the care was experienced as being ‘endless’, that is, the undetermined duration, of the care they provide. Also, a difference could be indicated in the financing available to provide suitable care and treatment, professionals employed in another organisation than RCF mentioned that they felt restrictions in the availability of sufficient financing.

All service users acknowledged the description of the problems and needs that characterise adults with VI and SMI and of current care and treatment as an accurate representation of their experiences

with this care and treatment. Service users also stressed the importance of the relationship with the professionals, and the authentic and informal attitude of professionals required to create this relationship. They also acknowledged the importance of continuity in care and treatment and the need for specialist knowledge about the VI on the part of the professional. Aspects service users did not accept were the assumption that it is always possible to create a suitable relationship with a care worker, the assumption that achieving goals is always possible and the assumption that a VI necessarily places a restriction on social contact. Furthermore, service users noted the absence in the description of the importance of empathetic professionals, the influence of living in a residential care facility with non-chosen co-residents, the need to set limits in the care and treatment and the need to be clear in communication.

The responses of the professionals and service users are in line with the outcomes of the in-depth studies with professionals (chapter 4 and 8) and service users (chapter 9), showing that these outcomes seem to be an accurate representation of current practice. The elements indicated as not representative or as missing from the description and logic model mainly emphasize the elements described in the model that need further elaboration or are not accepted by all professionals working with adults with VI and SMI. These include factors such as when collaboration with mental health care services is lacking or having different views regarding the unconditionality of the professional relationship with a service user. These factors show the complexity of providing suitable care and treatment for adults with VI and SMI. The responses of professionals employed at another organisation within the visual sector show that there is a difference in the culture or context (such as the length of the care and treatment and its unconditionality, or the financing available) that may impede the ability to provide suitable care and treatment. It seems that, within the context of the RCF professionals experience the freedom and flexibility to follow the pace of a service user, whereas within other organisations more restrictions are experienced. However, professionals from these other organisations indicate that the care and treatment of adults with VI and SMI does not have to be endless, and that ending care and treatment can be contemplated. This endlessness of the care and treatment should be further explored to determine in how far this is a consequence of the needs of a service user due to their VI and SMI, and whether other, more structured, approaches could allow service users to achieve greater independence. Furthermore, professionals emphasize the challenge of making progress with certain service users, stressing that they are often trying to prevent deterioration or trying to keep a service user stable (which in itself is already a significant challenge with some service users).

### 10.4.2 Strengths and limitations

By using the e-learning online course-creation web app *Rise 360*, an accessible and clearly arranged way was chosen to present the outcomes of the study and the logic model to professionals. This can be seen as an innovative way to present outcomes and collect data in a study. By using this program, the outcomes of the study and logic model could be presented to a large number of professionals, and as a consequence it allowed a high number of responses to the survey to be obtained. Furthermore, this e-learning course provides a basis on which professionals could be educated regarding the care and treatment for adults with VI and SMI. By doing so, the study was able to conclude that the description of current practice and the logic model can be validated as an accurate representation of current practice. For the service users, some limitations were experienced in the data collection. It was time consuming to communicate directly with service users, and so the information was provided and the questionnaires were completed with the help of a care worker. This could have influenced the responses to the questionnaire. Also, the recruitment of service users took longer than expected, as many service users declined due to not having the space, time or ability to respond. This also shows the complexity of the service users' problems and needs, and their dependence on the professionals.

### 10.4.3 Conclusion

Based on the responses of 47 professionals and 10 service users the description and logic model of current care and treatment of adults with VI and SMI could be validated as an accurate representation of current practice and no changes or additions had to be made. Furthermore, the responses provide more clarity about those parts of the logic model that are very accurate, such as the importance of a trusting relationship, the need for specialist knowledge about VI and for an environment suited to VI, and the different phases identified in current practice. However, other parts of the description and logic model seem to be weaker. Professionals indicate that, although they acknowledge the importance of collaboration with mental health care, an effective collaboration with mental health services is lacking. Clear agreements between the sectors and guidelines on how effective collaboration can be established may facilitate an effective collaboration. Also, more specific knowledge is needed about the outcomes that can be reached in adults with VI and SMI with the provided care and treatment. Both professionals and service users recognise that no clear goals are formulated during the care and treatment process, which makes it difficult to assess the progress a service user is making. There seems to be a contradiction here: on the one hand, professionals acknowledge that setting goals is a sensitive issue for their service users, while on the other the lack of goals can also hinder their progress and make any progress difficult to assess.



## CHAPTER 10

These are elements in current practice that need more discussion in order to clarify what is suitable for adults with VI and SMI, and how they can be best provided with care and treatment.

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## CHAPTER 11: GENERAL DISCUSSION

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### 11.1 Introduction

In this chapter the outcomes of the overall study are discussed by summarising the main findings of the study for each research question. Also, the usefulness of the theoretical framework on which the design and procedure of the study was based (theoretical considerations) and the strength and limitations of the study are discussed (methodological considerations), resulting in the main conclusions of the study. Finally, the pathways to impact are elaborated, divided into the implications for further research, societal value and impact, and activities for further dissemination.

### 11.2 Main findings

In section 1.3, the aim of this study and main research questions were formulated. By adopting a PAR approach and an iterative process of inquiry, the tacit knowledge of professionals could be transferred to explicit knowledge. This has led to the following insights into the problems and needs that characterise adults with VI and SMI and their current care and treatment.

#### 11.2.1 Problems and needs that characterise adults with VI and SMI

In this study, the definition of SMI as defined by Delespaul and Consensusgroep EPA (2013) was taken as a reference for the mental illness the service users experience. This definition was described in section 1.1.1 as follows:

*'... a person has a mental disorder in need of care or treatment; involving serious impairments in social and/or societal functioning; this is structural and over a longer period of time. The impairment is caused by and a consequence of the mental disorder and coordinated care from professionals in care networks is needed to realise a treatment plan.'* (p. 429-430, translation by author).

The iterative process of inquiry with professionals, in combination with the analysis of the service users' records, revealed that this definition is appropriate for identifying the mental health problems experienced in adults with VI and SMI. Although this is the case, among service users there is a wide variety in the diseases or disorders that constitute their VI and SMI, and a cumulative impact of the combination of the two disorders is experienced. Furthermore, other comorbid cognitive and/or somatic disorders can be present. The multimorbidity and overlapping symptoms of the different disorders make it a challenge to establish an official diagnosis of a mental disorder based on the classification of the DSM-V (American Psychiatric Association, 2013), as the problems identified within service users do not fit neatly into diagnostic categories or there are overlapping symptoms

that could belong to different classifications. Therefore, professionals experience difficulties in arriving at a full and nuanced understanding of the problems and needs of a service user. For these service users, a recovery perspective in which the focus lies not primarily on curing the illness, but on reaching a full state of recovery seems to be more suitable. Furthermore, the VI of a person seems to overshadow the presence of a mental disorder. This process of '*diagnostic overshadowing*' is also a well-known phenomenon in other care sectors. For example, mental illness is also known to be missed in persons with an intellectual disability (Jopp & Keys, 2001). Also, in mental health care this phenomenon is known. In this sector physical and/or somatic conditions can be missed in service users with a mental illness (Bueter, 2021; Jones et al., 2008). It seems that the first diagnosis in a person can overshadow other comorbid problems, as behavioural aspects that might indicate another diagnosis are easily linked to this first one.

Despite the wide variety in disorders and/or diseases among the service users, the study revealed that different problems and needs could be identified that characterise adults with VI and SMI. Professionals describe how their service users experience a cumulative impact of their multimorbidity on their daily functioning, are dealing with (negative) experiences in their life history, have developmental problems (mainly on a socio-emotional level), use dysfunctional coping strategies and lack a social network. As a result, they experience an imbalance between the stressing factors they are faced with and their resilience to cope with these stressing factors. According to professionals, service users are vulnerable and they experience complex problems. They have only a fragile trust in themselves and others, and lack a feeling of basic safety, which may be explained by underlying problems in attachment. Professionals emphasize these as important characteristics of adults with VI and SMI, characteristics which shape their care and treatment.

These findings show that, although adults with VI and SMI appear to be a diverse group with a relatively small prevalence, different characteristic problems and needs that influence their care and treatment can be identified.

### 11.2.2 Research evidence relevant to the care and treatment for adults with VI and SMI

The mapping and scoping review described in chapters 6 and 7 revealed that limited research evidence is available relevant to the care and treatment for adults with VI and SMI. The mapping review showed that there are some specific groups that receive attention in the literature, such as persons with deaf-blindness and persons with VI and comorbid intellectual disability. With respect to a comorbid mental disorder, there has been a relatively high amount of attention paid to depressive

and anxious symptoms in adults with VI. However, research specifically focusing on adults with VI and SMI seems to be a subject that is not yet addressed in the scientific literature.

The scoping review revealed that some studies describe interventions or implications for practice for adults with VI and a comorbid mental disorder. Comorbid mental disorders addressed in these studies were: depression/anxiety; eating disorders; problematic alcohol and/or drug use; dementia; PTSD; personality disorders; and unspecified psychiatric/psychosocial disorders. None of the studies specifically focused on SMI. Only in studies addressing comorbid depression or anxiety disorders had the effectiveness of a specific intervention been evaluated, with the majority of the studies being non-randomised controlled trials or observational, leading to weaker levels of evidence (Murad et al., 2016). Only three studies were found to have used a design resulting in a higher level of evidence, being either a RCT or a systematic review with a meta-analysis. This shows that more studies providing more robust evidence are needed to indicate the effectiveness of these interventions. Although these studies provide some indications of evidence, they are mainly focused on the treatment or prevention of depressive or anxiety symptoms within elder persons with VI and are therefore considering a population different from the group of adults with VI and SMI. Most studies addressing other comorbid mental disorders were descriptive, using designs that result in lower levels of evidence for an intervention, such as narrative reviews, case reports or qualitative studies. One study addressed the effectiveness of a specific intervention using a pretest-posttest design (Needham et al., 1992) and one study conducted a systematic review in which the literature on post-traumatic stress reactions among adults with VI was described (Brunes et al., 2019). Although, limited research evidence is available for the care and treatment of adults with VI and SMI, the studies that were found reveal that a combination of a VI and comorbid mental disorder in a person requires a specialised approach in the care and treatment, for example through the adjustment of standard interventions to the VI (O'Donnell, 2005; Stewart et al., 1998; Van der Aa, van Rens, et al., 2015; Whitson et al., 2011); putting an emphasis on building trust (Chapman et al., 1998; Greenleaf, 1971; Leddy, 1974); not being judgemental and following an intermittent process (Greenleaf, 1971; Leddy, 1974); adopting specific VI-related behaviours (Adams, 1980); tailoring the programme to the needs of the person (Chapman et al., 1998; Fernandez-Aranda et al., 2006; Thomas et al., 2012); and multidisciplinary collaboration between different health care sectors (Koch et al., 2002; Koch et al., 2005).

### 11.2.3 The tacit knowledge of professionals regarding the care and treatment for adults with VI and SMI

By conducting a PAR-approach with an iterative process of inquiry, the tacit knowledge of professionals could be revealed and based on this knowledge an agreed logic model of current care and treatment could be developed. This model contained the theoretical assumptions of professionals about how effective care and treatment can be provided, revealing a high consensus between professionals about the important elements in their approach. They stressed the importance of building a trusting relationship, the impact of the VI on the process of establishing this relationship and the specific VI-related behaviours that as a result are needed to build this relationship. Furthermore, in order to reach a stable balance, professionals stress the importance of time and a prudent approach. The activities of professionals (implementation outputs) could be described by structuring the care process in three phases: the build-up phase, the stability phase and the intervention phase. By performing different activities during these phases, intermediate and final outcomes can be reached. Professionals indicated that through the activities in the build-up phase service users become more open to receiving care and treatment, and experience being valued and heard. Professionals identify the following final outcomes: service users experiencing more stability in their lives, reducing the amount of crisis situations; and service users having a greater sense of personal well-being. Also, different elements in the context can be considered to be important facilitators for the provision of specialised care and treatment. The cultural standards within the RCF regarding the relationship with a service user and the freedom given to professionals to provide the care and treatment that is needed, can be indicated as important facilitating factors and ones which are specific for the organisation. Also important for achieving outcomes is a strong collaboration with other (mental health) care sectors. Another contextual element which has an influence on care and treatment is the inapplicability of standardised protocols and interventions.

The description and logic model also brought to light certain ambiguities and imprecisions in current care and treatment. Although the iterative process of inquiry led to insights into the basic structure of the care process and the basic professional attitude needed, there seems to be no uniform approach within this basic structure and attitude. Professionals expressed a need for more uniformity and standardisation within this basic structure and attitude. Furthermore, due to experienced difficulties in motivating service users to set and achieve higher goals, target outcomes are mainly focused on providing more stability in a service user's life or achieving a sense of well-being. However, no concrete picture could be made about what this stability and well-being specifically entails. These outcomes seem to differ from the societal perspective, in which

independence and striving for full participation in society is the general norm for persons with a disability. This is illustrated by the more general aims formulated within the care and mental health care sector. For example, the Dutch Ministry of health welfare and sport (2020) also placed a focus on the well-being for persons receiving long-term care, but this is considered to be derived from a decrease in the degree of dependence on care. Also, the Dutch association for disability care (2020) stresses the importance of well-being for persons with a disability and formulates this as being able to be part of society and live a meaningful life. In the mental health care sector, reaching a state of recovery and equal citizenship are formulated as the most important outcomes for persons with SMI (Dutch Association of Mental Health and Addiction Care, 2009). In the vision of the RCF, a focus is placed on humanity, looking at possibilities and independence (RCF, 2019). It seems that the prudent and long-term approach can represent an obstacle to formulating more specific outcomes that are related to the aims as formulated by the different health care sectors, and which in turn can lead to de-hospitalisation or downscaling the intensity of the care and treatment. At the moment, it is not clear whether such aims can be achieved by the service users or that there are factors that influence the ability to reach these outcomes. Therefore, the study could not provide clarity about the ability to set and work to specific goals with service users. Improvements in current care and treatment may overcome these pitfalls and facilitate the ability to provide goal-related care.

#### 11.2.4 Experiences and expectations of service users

Based on the iterative process conducted with service users with VI and SMI within the residential care facilities of the RCF, it can be concluded that their experiences and expectations of current care and treatment are in line with the important elements and factors identified by professionals. Based on the service users' input the logic model was refined, mainly emphasizing the importance of the different phases in the basic structure. Service users also indicated the importance of VI-related behaviours on the part of professionals, of living in a VI-friendly environment to compensate for their VI, and of feeling understood by professionals with regards to the impact of their VI on their daily lives. Furthermore, the service users emphasized the importance of an equal relationship with professionals without a feeling that pressure is applied to them. However, without applying pressure it can be difficult to set and work on clear goals and hence to achieve higher outcomes, a difficulty that is encountered by professionals. Moreover, this in turn seems to inhibit the service users' ability to gain insights in the progress they have made, as they had difficulties identifying specific goals in their care and treatment, or were unable to provide a clear picture of their achievements.

### 11.2.5 Validation of the description and logic model of current practice

In the last phase of the study, the description of current care and treatment and the logic model could be validated. Both professionals and service users acknowledged as accurate the explicit descriptions of the problems and needs that characterise adults with VI and SMI and of current care and treatment. In addition, the logic model was confirmed by professionals as accurate. Their answers also revealed that currently a basic structure and attitude is present, but there is a need for a more structured approach and to work towards clear outcomes. Also, the important contextual factors could be further specified as the survey revealed a specific difference between the RCF and other organisations within the visual sector concerning the nature of the relationship between a professional and service user, which is described by professionals of the RCF as a 'professional friendship', a description other professionals reject. Further differences were experienced in the 'endlessness' of the care and treatment and in the way the care provision is facilitated by the organisation. This shows that there are factors that are specific for the RCF and its culture, providing long term, continuous care without clear independence goals. This is not in line with the general perspective in society, as outlined in section 11.2.3. Future research and a societal debate about these differences should provide more clarity on what can be expected from this group of service users.

### 11.3 Theoretical considerations

In chapter 2 the theoretical framework for the study was presented. The organisational knowledge creation process of Nonaka (1994) was used as a concrete framework for the transfer of tacit to explicit knowledge, and the processes of enlarging, sharing and conceptualisation were facilitated by choosing a PAR approach as strategy of inquiry. It was expected that this strategy would lead to an explicit description of current care and treatment and the creation of an agreed logic model. By doing so, the level of evidence of current care and treatment was transformed from being *intuition-based* to the stage of *explicit* and *promising*, as described in the methodological framework of Van Yperen et al. (2017). Based on these activities, it was expected that the conditional elements of current care and treatment could be clarified and that this may provide important indicators for future research in which focused improvements can be developed and a specific intervention can be implemented and its effectiveness evaluated, as is described in the framework for the evaluation of complex interventions (Moore et al., 2015). In this section the strengths and limitations of the theoretical framework will be discussed.

### 11.3.1 The model of Nonaka and the PAR approach

Within this study, the organisational knowledge creation process developed by Nonaka (1994) was used as a framework on which the design of the study and activities for data collection and interpretation were built. Although, this process was found to be very useful in this study, different authors have criticised the model, as summarised by Sarayreh et al. (2012), who note that within the academic field the model was considered to be too simplistic. Different authors have criticised the condition that all knowledge first needs to be codified before it can be transferred to explicit knowledge, since it is thought that not all (tacit) knowledge can be codified. Another point of criticism has come from practitioners, who have indicated that the model is too abstract for implementation in organisations. Gourlay (2003) suggests that Nonaka's model is mainly based on some vague ideas of knowledge and is not substantiated with empirical data. Furthermore, the model has been developed for knowledge transfer in more conventional, industrial organisations and was not intended to be used for knowledge transfer in a care organisation. This could be a limitation, as within a care organisation different factors can play a role in knowledge creation, such as the interaction between professionals and service users.

For the current study, the model formed the basis for the design of an iterative process of inquiry. By conducting individual interviews and several group meetings, professionals were facilitated in *enlarging* and *sharing* their tacit knowledge and reaching *conceptualisation* and *crystallisation* as described in the model. Furthermore, Nonaka (1994) has described different enabling conditions to go through the steps of the knowledge creation process. One of the most important is individual commitment, that can be facilitated by creating an environment in which each person's *autonomy* and *intention* is respected. By choosing a PAR approach as strategy of inquiry, this individual commitment was encouraged. The professionals participated in the data analysis and interpretation by discussing the different steps and outputs of the previous meeting with the researcher and each other. Furthermore, an atmosphere of mutual respect was created in the group meetings. By doing so, the autonomy and individual intention of each professional was considered to be respected. This was further facilitated by the researcher's own experience, as the researcher was seen as 'one of their own' and someone who could understand the professionals. This was considered as an important aspect to facilitate the transfer from tacit to explicit knowledge. Furthermore, by sharing each other's experiences and ideas, *fluctuation*, the interaction with the knowledge of others, was induced. Also, the composition of the professionals in the group, from a variety of organisations, and a range of roles and years of experience, led to the required variety needed to discuss and identify knowledge. This was experienced as very helpful, as different ideas and experiences facilitated the



discussion between professionals, but also brought professionals to a higher level of understanding of their own knowledge and practice. Also, *chaos*, the productive state of highlighting discontinuities or discrepancies in knowledge, was created by interviewing professionals on the basis of two cases, one successful and one in which they had experienced difficulties. By discussing the professionals' knowledge based on these two cases, it was considered that their critical appraisal of their own actions and decisions was facilitated (Higgs et al., 2008). It enabled the professionals to describe their own practice in a concrete manner and to take a bird's-eye view of their current practice and reconsider their own knowledge. By doing so, the professionals were encouraged to become aware of their own actions and the assumptions guiding these actions (what they do and why they do it). These points show that the organisational knowledge creation process could be effectively used in this study to build an iterative process of inquiry and create an atmosphere among professionals in which they were facilitated to become aware of their tacit knowledge and to be able to share this with each other. Based on this process an explicit description of current practice could be made. Although the Nonaka model can be considered to be too abstract, vague and not empirically substantiated in the academic and practitioner field, here it was considered to be a useful tool for facilitating the transfer of tacit to explicit knowledge.

The study was designed and conducted with close involvement of the advisory board of the study. Different stakeholders were represented on this board, including members of the strategic team of RCF, professionals from RCF (including the researcher) and the mental health care sector, and members of the research team. For this study, a researcher was appointed with several years of experience in practice. This researcher developed the design of the study with the close involvement of the advisory board. During the study, members of the advisory board were involved in the roles of advisor and partner in planning the next steps and selecting the instruments for data collection and analysis. Also, the interpretations of the outcomes were presented to the advisory board and they were asked to reflect on these results. This close involvement with the advisory board was considered to be the core of the PAR approach and was experienced as essential for reaching the core of practice. Furthermore, by conducting an iterative process of inquiry the participating professionals and service users were closely involved as partners in the analysis and interpretation of the data.

Although the involvement of service users was very valuable, the process of recruiting service users presented a challenge. Service users confirmed the importance of and the need for the study, but were reluctant to participate. Their vulnerability, current challenges in their daily life and the requirement to participate in a group meeting made several service users decide to decline the

invitation. This shows the complexity of and challenges faced by this group of persons, and the difficulty of involving them in important aspects of their care and treatment.

### 11.3.2 Building a logic model

Based on the iterative process of inquiry in which professionals and service users were closely involved and asked to share their tacit knowledge, a programme theory about the current care and treatment could be developed by building a logic model (Kellogg Foundation, 2004; Moore et al., 2015). This process provided insights into the specific elements which constitute current care and treatment. Furthermore, some of these elements were expressed in all research phases and designated as important by different stakeholders, showing that these elements are established and stable components. Other elements were mentioned by different participants, but there remain uncertainties about these elements making their reliability less sure. These elements need further exploration before they can be implemented and evaluated. By describing the underlying theoretical assumptions and structuring current practice into phases, professionals recognised that they gained more insights into their own practice, making it easier to explain their actions and decisions to other important stakeholders. Furthermore, by involving professionals from different organisations, similarities and differences between organisations became clear; this provided important input to identify those influential contextual elements that are specific to the RCF.

During the study, it became clear that the tacit knowledge of professionals revealed mainly basic elements within current practice and that no specific intervention that is generally used and accepted within current practice was present. Therefore, the focus of the study was shifted to identifying the aspects within current practice that can be described as the common ground, mainly revealing the basic structure of and attitudes adopted for the care and treatment of adults with VI and SMI. Because no specific intervention could be identified, building an explicit logic model was a challenge. It was difficult to identify concrete descriptions for each category in the model, as concrete steps were not present within current practice. In consequence, more attention was given to determining the format and content of the logic model that best represented the current state of practice. By choosing the format in accordance with the MRC framework as described in section 2.2.2 (Moore et al., 2015), a clear and representative model of current practice could be made.

### 11.3.3 Methodological framework to determine the level of evidence of an intervention

As described in section 2.2.4, the methodological framework of Van Yperen et al. (2017) can be used as a reference to identify the current state of the description and logic model of current practice. The results of this study provide important input for the first two stages of the methodological

framework (*explicit* and *promising*). To reach the first stage in the framework, an explicit description of the approach of an intervention and its implementation needs to be present, in addition to the other criteria described by Van Yperen et al. (2017), such as a description of the target group, the name and origin of the intervention, its goal, the executive organisations, the similarities with other interventions and its scientific sources. In this study, an explicit description of the approach of current care and treatment and its implementation was established. Also, an explicit description of the problems and needs that characterise adults with VI and SMI was established. Furthermore, insights were gained into the aspects in the context that seem to be conditions for reaching effective outcomes. The study revealed that a basic structure of and attitude adopted for current care and treatment could be made explicit based on the tacit knowledge of professionals. This description of the basic structure and attitude can form the basis for developing more specific guidelines and a uniform approach.

In the second stage of the framework, a potential theory as to why and how an intervention should work can be developed. Therefore, different mechanisms and factors of influence on a characteristic or problem of a specific target group need to be described and a theory of how these mechanisms and factors can be used to reach a specific end goal can be established (Van Yperen et al., 2017). The outcomes of the current study provide insights into different mechanisms that exist in the service user, the professional and the context that influence the way care and treatment is provided to reach specific outcomes.

The methodological framework of Van Yperen et al. (2017) could be used as a reference to gain insights into the current state of the description of current care and treatment. Based on the criteria formulated for stage 1 and 2 in the framework, those aspects that are already well described and those that need further exploration and/or development can be identified. This provides an important starting point from which the logic model can be further specified and an intervention with clear guidelines can be developed. These guidelines could then be implemented and the intervention's effectiveness evaluated.

### 11.4 Methodological considerations

In this section some methodological considerations regarding the study will be discussed, structured by the quality criteria as formulated in qualitative research to indicate the credibility (trustworthiness and believability), transferability, dependability (consistency) and confirmability (personal biases) of the study (Frambach et al., 2013).

### 11.4.1 Credibility

Different activities were conducted to enhance the trustworthiness and believability of the study (Frambach et al., 2013). Below the strengths and limitations with respect to this criterion are discussed.

#### Strengths

This study was characterised by the close involvement of professionals through participation in the data collection and interpretation phase of the study, facilitating a bottom-up approach and a faithful representation of the experiences and actual knowledge of professionals. This close involvement was established by conducting an iterative process of inquiry, in which professionals were provided time between meetings to reflect on the discussions and how these reflect their daily practice, thereby reaching a higher level of understanding. Also, professionals were thoroughly informed in a timely fashion about the data analysis and interpretation of the content of the previous meeting, which facilitated the reflection and the discussions in subsequent meetings. By doing so, a process of continuous member checking was established, asking participants to provide feedback on the data interpretation of the previous meeting and using this feedback to refine the outcomes. Another important aspect that enhanced the credibility of the study was the researcher's own experience as a behavioural scientist at the RCF. Participants considered the researcher to be 'one of their own', facilitating the process of sharing and reflecting as they could be confident they would be understood by the researcher.

Conducting a PAR approach with professionals was the main strategy of inquiry in this study. This was complemented with the use of a variety of participating groups and methods to further refine and/or validate the outcomes. The outcomes were refined based on the experiences of service users. Furthermore, the online community of practice Psyvisnet was used to recruit a larger group of participants for the last phase of the study. Alongside the PAR approach, an analysis of service users' records was conducted to refine the description of adults with VI and SMI, and a mapping and scoping review were conducted to gain insights into the current available research relevant to the care and treatment of adults with VI and SMI and to refine and validate the outcomes of the iterative process with professionals and service users. In the validation phase a (qualitative) survey was conducted among a larger group of professionals and service users.

Another strength was the close involvement in the study of a second researcher who had no experience in the care and treatment for adults with VI and SMI and therefore was able to take a more objective view. Debriefing was regularly conducted with the advisory board, in which the

progress and outcomes of the study were presented and reflected on, and based on the input of the advisory board the next steps in the study were determined.

### Limitations

Although the time provided between the meetings was indicated as a strength of the study, this was also experienced as a limitation. Due to the long period between the individual interviews and the group meetings, not all participants were able to continue their participation and new participants had to be recruited. This may have influenced the reflective process, as new participants were not involved in previous steps and did not have the opportunity to enlarge their tacit knowledge.

However, by adding new participants to the group meetings, these participants were able to ask questions about the information from a more objective perspective, which facilitated the discussion and thereby the access to the tacit knowledge of all participants.

#### 11.4.2 Transferability

Here the strengths and limitations of the study in terms of the extent to which the outcomes can be transferred and applied to other settings (Frambach et al., 2013) are discussed.

### Strengths

The transferability of the study was enhanced by providing ‘thick’ descriptions of the process, methods and material used in the study. Also, the results were intensively described and further substantiated with the use of quotations. Another strength could be identified by the thorough sampling strategy of the study, in which a deliberate selection of participants was made taking into account different perspectives from different organisations.

### Limitations

A Dutch context was studied within the framework of a UK-related research setting and perspective. Although this conjunction was experienced as refreshing, bringing new perspective and theoretical background to the study, at times it also had its limitations. For example, the data collection and analysis activities were conducted in Dutch and had to be translated to the English language. This may have limited the possibility to provide a ‘thick’ description, as changes to the meaning of the original data can occur. Also, activities and/or elements that are commonplace or widely understood in a Dutch context can be difficult to translate or explain in an British context (such as the way Dutch healthcare is financed).

#### 11.4.3 Dependability

In this section the strengths and limitations regarding the consistency of the findings in relation to the context in which they were generated (Frambach et al., 2013) are discussed.

### Strengths

The dependability of a study can be enhanced through the use of a flexible and emergent research design, and iterative data collection and analysis (Frambach et al., 2013). This can be indicated as one of the strengths of this study. By conducting an iterative process of inquiry, each next step in the study was dependent on the outcomes of the previous meeting. Based on the discussion in the group meetings, the outcomes were adjusted and feedback was given by different groups (participants, behavioural scientists of the RCF and the advisory board). During the last meeting with the participants, no new information emerged, indicating that data saturation had been reached. In the next phases of the study (the iterative process of inquiry with service users and the survey of professionals and service users) new information did occur, but this information did not substantially affect the earlier research. As a final point, the dependability of the study was enhanced by conducting a thorough and systematic data analysis of the individual interviews, by using the strategy of qualitative content analysis as described by Mayring (2014). In this analysis, deductive category formation was done by structuring the participants' phrases according to the different phases in a care process. This proved helpful in gaining an overview of the large amount of text to be analysed and lead to a clear and structured approach that could be replicated.

### Limitations

This study was conducted within the context of the RCF, in which organisational developments and expectations would, at times, put pressure on the progress and course of the study. This could have impeded the adoption of a truly flexible and emergent design. To overcome this limitation, the direct control of the study was placed with the supervisors at the University of Sheffield, who could operate independently of the RCF. Furthermore, the progress and steps in the study were discussed with the advisory board, who were able to provide feedback and input, but the final decisions were made by the researcher and the supervisors. All steps and decisions taken in the study were documented.

Other limitations that were experienced and which may have limited the dependability of the study were related to the recruitment of participants. At the start of the study a thorough sampling strategy was conducted; however, due to changes in participants and the limited time available, the recruitment of new participants in a later stage of the study was more dependent on the availability of professionals. Furthermore, challenges were experienced in the recruitment of service users. Almost half of the service users that were asked to participate in the study were interested, but chose not to participate because of their current situations.

### 11.4.4 Confirmability

The strengths and limitations regarding the extent to which the findings are a consistent representation of the input from the participants and the extent to which the researchers' biases have influenced the outcomes (Frambach et al., 2013) are discussed in this section.

#### Strengths

During the study, care was taken to search for evidence that disconfirmed the findings, and not only that which confirmed the findings or experiences of the researcher. This was done to minimize the effect of any possible biases that may influence the outcomes. This was facilitated by asking the participants to select an 'unsuccessful' case in the individual interview, giving the interviewee and researcher the opportunity to search for aspects in the care and treatment that do not work well or that need to be improved. Also, during the group meetings, attention was paid to the elements in the outcomes that were not acknowledged by the participants or were still missing from the description. Finally, other groups were consulted to give their feedback on the outcomes.

#### Limitations

While the researcher's own experience can be seen as a strength of the study in terms of enhancing its credibility, this experience could also be considered a limitation with respect to the study's confirmability. The researcher's own experience could have limited the objectivity of the researcher and may have introduced bias. This possibility was mitigated by the close involvement during data collection and analysis of a second researcher who did not have experience in the care and treatment within the RCF. Furthermore, the discussions with the supervisors about the interpretation of the data could be seen as a way of avoiding any possible bias. Finally, it was difficult to compare the outcomes of the study to existing evidence, because of the lack of evidence available for this specific topic. Therefore, only partial comparisons with existing literature could be made.

### 11.5 Conclusion

Based on the tacit knowledge of professionals an agreed logic model of current practice has been developed. This model provides an explicit description of current practice including an overview of its underlying assumptions and the important elements in the context that influence the outcomes of current care and treatment. An important outcome of the study is the description of the problems and needs that characterise adults with VI and SMI, providing important indicators that shape their care and treatment. Furthermore, the study revealed that there is a firm consensus among professionals regarding the theoretical assumptions underlying their current practice as described in section 8.3.2 and important aspects in terms of their attitude and activities based on these theoretical assumptions. The representative structure of current practice can now be described in

terms of three different phases: build-up, stability and intervention. Also, the study showed that a specialised setting is a precondition for effective care and treatment. Service users benefit from an environment that compensates for the VI (in terms of both the design of the environment and the behaviours of professionals) and from professionals who have specific knowledge about the impact of a VI on the service users' comorbid problems and daily life. Important contextual factors were established by comparing the organisational philosophy and context of the RCF with those of other organisations. This revealed differences in the nature of the relationship between professional and service user (indicated as 'professional friendship' by one of the RCF professionals), the ability to take time during care and treatment and to follow an intermittent process, and the freedom given to professionals to provide the care and treatment that is needed.

Although different specific elements could be established and described, limitations in current care and treatment were also identified. Neither professionals nor service users could provide firm ideas about the outcomes that were derived from care and treatment. Focus is placed on establishing a trusting relationship and reaching stability in a service user's life, but no clear vision was formulated as to how this stability is used to reach other, so-called 'higher', outcomes. The iterative process revealed general outcomes, such as achieving a greater personal well-being/life satisfaction, but no insights were obtained into the concrete elements that need to be achieved to arrive at these outcomes.

Furthermore, the study revealed that the development of specific guidelines and a uniform approach is needed if care and treatment is to be shared and implemented more systematically, and its effectiveness evaluated. This need for a more uniform approach and the use of specific guidelines is also expressed by professionals.

### 11.6 Pathways to impact

In the following sections, the impact of the outcomes of this study for scientific research and society are described. Furthermore, activities for further dissemination of the outcomes of the study will be listed.

#### 11.6.1 Implications for future research

Based on the outcomes of the study, implications for future research can be formulated with respect to three domains:

1. The acquisition of insights into the attachment patterns of adults with VI and SMI and how this affects care and treatment;



2. The formulation of specific outcomes that can be reached for adults with VI and SMI through the provision of care and treatment;
3. Based on the outcomes of 1 and 2, the development of a uniform approach with specific guidelines for the care and treatment of adults with VI and SMI.

In the following sections these implications will be further elaborated.

#### Attachment patterns of adults with VI and SMI

One of the key findings of the study is that professionals report a fragile sense of trust and the feeling of a lack of basic safety within adults with VI and SMI. It seems that these problems can be linked to underlying problems in attachment. As described in section 4.4.1, different risk factors can be indicated for children with VI which can lead to the development of an unsafe attachment pattern (Dekker-van der Sande & Janssen, 2009; Fraiberg, 1977; Sterkenburg, 2019) and this may also be a cause of mental health problems (Dekker-van der Sande & Janssen, 2009; Pearse et al., 2020). Based on these findings it can be hypothesised that attachment problems play a central role in the problems and needs of adults with VI and SMI. However, the analysis of records of service users revealed that no structured and clear assessments are available for the service users of the RCF. By developing a more structured and clear assessment procedure within the RCF, more insights can be gained into the extent to which service users can be diagnosed with a specific SMI and the extent to which other related problems are present. Within this procedure, attention should be placed on the assessment of the attachment patterns of adults with VI and SMI. This could provide a better understanding of how these aspects are interrelated and how these influence daily functioning in adults with VI and SMI. This may provide important indicators for the way in which these mechanisms can be influenced through care and treatment. A clear and concise assessment procedure also facilitates shared decision making. As more clarity in all steps of the care and treatment process provides the service user with the opportunity to gain insights into the decisions that should be taken and why this is important. Based on this assessment, clear goals can be formulated that are widely accepted by both the service user and professionals and offers an important foundation for the evaluation of the provided care. By doing so, service users are provided with the ability to have a strong voice in their own care and treatment process.

#### Outcomes of care and treatment

The study revealed that no clarity could be provided regarding the outcomes that are derived from current care and treatment. Professionals expressed that a principal focus in current care and treatment is placed on building a trusting relationship, on providing safety and on gaining a stable balance both in the way care and treatment is provided and in a service user's life. It is important to

gain more insights into the perspectives of professionals and service users about desired and possible outcomes of the care and treatment for adults with VI and SMI. These insights can be used to develop an explicit vision of the specific outcomes that are possible through the provision of care and treatment and how these relate to the outcomes formulated by the Dutch government and associations for disability care and mental health care (as described in section 11.2.3). Furthermore, when outcomes are specified, recommendations can then be formulated on specific (evidence-based) interventions that can be implemented to reach these outcomes, thereby improving current care and treatment.

### Uniform approach and specific guidelines

Another aspect that needs more clarity is the use of a uniform approach within the basic structure and attitude as described in this study. By gaining more insights into the specific problems of the service user and their attachment patterns and by specifying the envisaged outcomes of care and treatment, an important framework is provided within which a systematic approach incorporating this basic structure and attitude can be developed. This systematic approach should also include clear guidelines and agreements on the collaboration with the mental health care sector. In this study, three phases were formulated that describe current care and treatment: the build-up, stability and intervention phases. In the build-up phase an emphasis is placed on establishing a trusting relationship and feeling of safety with the service user and on bringing stability to their lives. Currently, the RCF is exploring the applicability of the *presence approach*, developed by Baart (2004) in its practice. This approach sees *relational adjustment* between service user and professionals as the base for care and treatment, with as main components *connecting to the other* and *adjusting to* what that person needs. Furthermore, within the consortium 'Visual' a study is currently being conducted with the aim of developing guidelines and a training program for providing mentalisation-based support for adults with VI and mental health problems, with a specific focus on persons with attachment problems (Sterkenburg, 2017). By following these guidelines, professionals should gain insights into their own thoughts and feelings about the behaviour of a service user and, even more importantly, insights into the service user's own thoughts, feelings and intentions. By doing so, a better understanding can be gained about certain 'unpleasant' behaviours of a service user, leading to a different attitude on the part of a professional and creating a willingness on the part of a service user to be open to care and treatment (Dekker-van der Sande & Sterkenburg, 2015). These components may provide a concrete framework on which to establish specific guidelines about the professional attitude needed in the build-up phase. Within mental health care, the presence approach is also incorporated within a new programme called *Active Recovery Triad* (ART) (Van Mierlo et al., 2016). As explained in section 8.4.1, this programme is developed for persons with SMI

who remain hospitalised and offers a new perspective on the creation of willingness for reaching a state of recovery. Insights from this programme may be used to develop a more specified framework and the formulation of clear guidelines for the three different phases that facilitate the achievement of the envisaged outcomes. The formulation of specific outcomes and guidelines for care and treatment are preconditions for the implementation of a specific intervention that can be evaluated in terms of its effectiveness.

### Transferability to other contexts

The results of this study could be of benefit for other settings within the visual sector as for other care sectors where persons with multiple disabilities are part of the client group. For example, the results of the study show the impact of the VI on the ability to build a trusting relationship and the time needed for reaching certain goals. This is a factor that is also important for professionals providing care to persons with VI in others settings, for example ophthalmologists in a hospital.

Also, the research method used in this study can be seen as an innovative approach leading to clarity within an organisation about the methods used and activities in a complex care setting. Other settings, in which care is provided to persons with multiple disabilities could also benefit from this specific research approach.

### 11.6.2 Societal value and impact

The societal value and impact of the study will be discussed by describing the relevance of the outcomes for stakeholders and the novelty of the study.

### Relevance for stakeholders

An important stakeholder in the care and treatment for adults with VI and SMI is the consortium 'Visual'. As described in section 1.1.3, this consortium is a cooperation between the three organisations for persons with VI in the Netherlands together with the Eye Association and Macula Association. The consortium aims to continuously develop, implement and share expertise for persons with VI. In their work plan for 2020-2022 the consortium has formulated the aim to ensure that their knowledge is easily accessible for persons with VI and their personal and professional network (Consortium Visual, 2019). The outcomes of this study provide an important step towards the aim of easily accessible knowledge for adults with VI and SMI, and fit into two of the five programme lines formulated by the consortium: 'I feel good about myself' and 'I receive the best professional care' (see appendix 1 for the content of these programme lines).

The study also provides important evidence for the RCF as an organisation and their aim to be an advocate for adults with VI and SMI and to provide them with the best possible care and treatment. By describing the current care and treatment within the RCF, an initial evidence base is created that addresses their aim of creating an environment in which innovation, and creating, sharing and applying knowledge for adults with VI and SMI is facilitated (RCF, 2015). Based on this initial evidence base, the RCF should be able to gain insights into and share its specific expertise and to implement focused improvements.

The outcomes of the study are important for professionals at the RCF and professionals providing care and treatment for adults with VI and SMI in other care organisations. Professionals within the RCF have acknowledged the value of the schematic overview of the problems and needs that characterise adults with VI and SMI, which provides them with a tool that helps to substantiate to other stakeholders the complexity of their service users and the importance of their receiving specialised care. Through the outcomes of the study, the different phases of current care and treatment and the importance of receiving care from a specialised setting has been acknowledged. By doing so, professionals feel that their thoughts and experiences have been recognised and their practice appreciated. The PAR approach used in this study was experienced as very helpful and a suitable strategy to reach the core of practice. This approach is recommended in further activities for the development and implementation of a uniform approach and specific guidelines. The outcomes and insights derived from this study can be used to facilitate the dialogue among professionals about the strengths and limitations of current practice.

Most importantly, the outcomes of the study are relevant for service users, as the description of current care and treatment and the logic model provide more clarity about the theoretical assumptions and activities of professionals, providing service users with more insights into their care process. This gives them the opportunity to express their own values and how they want care and treatment to be provided, and to be advocates for their own care process.

### Novelty

To our knowledge, this study is the first attempt to gain insights into the problems and needs that characterise adults with VI and SMI. In addition, no previous attempt has been made to gain an overview of the current available research evidence relevant to the care and treatment of adults with VI and SMI. This study has led to an initial evidence base for care and treatment on which further improvements can be made. By doing so, the study has raised the level of attention paid to adults with VI and SMI, providing insights into their problems and needs.

In this study an innovative approach was adopted, which consisted of transferring the tacit knowledge of professionals into explicit knowledge by means of an iterative process of inquiry within a PAR approach. Through this approach it was possible to gain a systematic overview of the care and treatment of a complex group with a large diversity in terms of problems and needs, without losing sight of the flexibility and tailor-made aspects of that care and treatment. This may also inspire researchers to conduct comparable studies with complex groups and/or situations in other care settings.

In the last phase of the study, an e-learning program was used to share the results to a larger group of professionals. By using this program, the outcomes could be structured in the form of different lessons and different presentation modes could be used to present the outcomes. This was experienced as an approachable, very useful and clearly arranged manner to present the outcomes of the study and acquire input from a larger group of professionals.

### 11.6.3 Activities for further dissemination

During the final phase of the study, different dissemination activities have already been carried out. The description of the problems and needs that characterise adults with VI and SMI and of their current care and treatment were integrated into the basic curriculum for new employees starting at the RCF. Also, the findings were used to create a description of a specific care programme within the RCF, called the 'intermittent care programme', that will be included in the intervention database of the Visual consortium (part of the project Dare2Share), as described in section 1.1.3 (VIVIS, 2020).

In the last phase of the study, an e-learning program was used to create an overview of the outcomes. This e-learning course provides an easily accessible means of presenting the results to a larger group of professionals and service users. An updated version of the e-learning course will be used to communicate the findings to relevant stakeholders.

The outcomes of the study have already been presented at different conferences, which were principally concerned with sharing knowledge and expertise about the care and treatment of persons with VI (see appendix 14 for a list of the conferences). The findings will be presented at the VISION 2022 conference in Dublin, Ireland, and a minimum of two articles will be written based on this dissertation and submitted for publication in peer-reviewed journals.

## CHAPTER 11

The study provided a basic framework on which the care and treatment of adults with VI and SMI can be further specified and improved. This framework will be the starting point for the design of a follow-up study in which the applicability of (evidence-based) interventions will be explored and used to develop a uniform approach and to formulate specific guidelines for care and treatment of adults with VI and SMI.

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**ABBREVIATIONS AND/OR GLOSSARY**


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ACT	Assertive community treatment
Actiz	Dutch Association of Nursing Homes (in its Dutch abbreviation)
ART	Active recovery triad
CBT	Cognitive behavioural therapy
CCMO	Dutch Central Committee on Research Involving Human Subjects (in Dutch)
CRPD	Convention for the rights of persons with disabilities
CIZ	Care Assessment Centre (in Dutch)
CMOc	Context Mechanism Outcome configurations
DSM	Diagnostic and Statistical Manual of Mental Disorders
EPA	Ernstige psychiatrische aandoening (serious mental illness in Dutch)
F-ACT	Flexible Assertive Community Treatment
GAF	Global Assessment of Functioning
GGZ NL	Dutch Association of Mental Health and Addiction Care (in Dutch)
ICD	International Classification of Disorders
ICF	International Classification of Functioning, Disability and Health
INFORMS	The Institute for Operations Research and the Management Sciences
METC	Medical Ethical Review Committee (in Dutch)
MRC	Medical Research Council (UK)
NIMH	National Institute of Mental Health (USA)
PAR	Participatory Action Research
PCC	Population, concept and context
PICO	Population, Intervention, Comparison and Outcome
PIMD	Profound intellectual and multiple disabilities
PST	Problem-solving treatment
PTSD	Post traumatic stress disorder
RCF	Robert Coppes Foundation
RCTs	Randomised controlled trials
RVS	Council of Public Health & Society (NL, in Dutch)
SAMHSA	Substance Abuse and Mental Health Services Administration (USA)
SchARR	School of Health and Related Research
SMI	Serious mental illness
VA	Visual acuity

VGN	Dutch Association for Disability Care (in Dutch)
VI	Visual impairment
VIVIS	Institutions for persons with VI
WBP	Personal data protection act (NL, in Dutch)
WHO	World Health Organisation
WMO	Dutch Medical Research Involving Human Subjects Act (in Dutch)
YoE	Years of experience
ZonMw	Netherlands Organisation for Health Research and Development (in Dutch)



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## **APPENDIX 1: OVERVIEW OF THE PROGRAM LINES DESCRIBED IN THE WORK PLAN 2020-2022 OF THE VISUAL CONSORTIUM**

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### Programme line 1: I feel good about myself

Feeling good about yourself means that you are doing well physically, mentally, psychologically and socially. By balancing the amount of stressing factors and the resilience of a person, people with VI can give their own interpretation to life. In this programme line, it is, for example, about personal control, social relationships and concepts like 'positive health'.

### Programme line 2: The world is accessible to me

The second programme line is about removing the barriers to full and equal participation in society. Knowledge development concerns the promotion of inclusion across a broad spectrum: from education, study and work, traffic and public transport to accessibility to the physical and digital (technological) environment. This programme line stimulates a change towards 'inclusive' thinking and acting by companies, organisations, governments and society.

### Programme line 3: My abilities and limitations are well understood

When a VI is diagnosed, people have many questions. Can I still drive a car? How can I continue to do my work? Can my child go to a regular school? How can my father continue to exercise his hobby? The third programme line focuses on the diagnostic process, with tailor-made solutions, a client-oriented approach, state-of-the-art instruments and a diagnostic standard as important core concepts. The aim is to arrive at efficient diagnostics that place as little burden on people as possible.

### Programme line 4: I receive the best professional care

All persons with VI deserve adequate education, care, treatment, rehabilitation and consultation. The fourth programme line develops specialised knowledge and expertise for professionals and initiates research into the effectiveness of what they do. This is not because everything professionals do has to be scientific, but to continually strengthen the effectiveness of their actions.

### Programme line 5: Technology offers opportunities

Technology and digital developments could be given a place in each of the programme lines. Technology is also a means, not an end in itself. Nevertheless, it has been given a separate programme line, aimed at making technology applicable according to the design for all-principle. We

pay specific attention to maintaining professional knowledge and expertise in order to utilise (new) technological possibilities.

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## APPENDIX 2: OVERVIEW OF MULTIDISCIPLINARY EVIDENCE-BASED GUIDELINES FOR THE INDICATION AND TREATMENT OF MENTAL DISORDERS

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In table A.1 an overview is provided of the mental disorders on which a multidisciplinary evidence-based guideline is developed by the Trimbos Institute (Trimbos Institute, n.d.)

**Table A.1**

*Overview of the multidisciplinary evidence-based guidelines as provided by the Trimbos Institute*

<b>Name of the multidisciplinary guideline</b>
Adjustment disorder in patients with cancer
ADHD
Alcohol
Anxiety disorders
Autism spectrum disorder in adults
Bipolar disorders
Depression
Double diagnosis
Eating disorders
Family and domestic violence
Lifestyle in patients with a serious mental illness
Opiate addiction
Personality disorders
Psychotic disorders
Somatic screening in patients with a serious mental illness
Suicidal behaviour
Unexplained somatic symptoms and somatoform disorders
Work and serious mental illness

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## APPENDIX 3: OVERVIEW OF THE ETHICAL REVIEW PROCEDURE

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### 3.A Ethical submission to METC Zuyderland – Zuyd, The Netherlands

The following documents were enclosed for MEC-approval at METC Zuyderland – Zuyd:

1. Submission letter to METC Zuyderland – Zuyd (in Dutch)
2. Research protocol (In English)
3. Participant information (including informed consent form) for professionals (in Dutch)
4. Participant information (including informed consent form) for service users (in Dutch)
5. Curriculum Vitae coordinating researcher (translated to English)
6. Curriculum Vitae person of trust (English translation of relevant parts by using comments)

These documents are available on request. Documents 3 and 4 are added in Dutch as figure A.1 (page 228-236) and figure A.2 (page 237-246) .

The letters for participant information were composed in Dutch. These letters were written in concordance with the format of the Central Committee on Research Involving Human Subjects (CCMO). This format can be found using this link:

<https://english.ccmo.nl/investigators/publications/forms/2018/05/01/standard-research-file-e1-template-subject-information-english>

More information about the Dutch procedure for ethics approval in English can also be found on this webpage. This is the procedure the committee of Zuyderland-Zuyd follows in order to review applications: <https://english.ccmo.nl/>

Approval was given by METC Zuyderland – Zuyd on 21 February 2017 as confirmed in the approval letter (as enclosed as figure A.3, page 247). This letter is in Dutch.

### 3.B Ethical submission to the SchARR Research Ethics Committee of the University of Sheffield

The information and documents as described under 3.A were send by e-mail to the SchARR Ethics Committee of the University of Sheffield on 31 January 2019. Based on this information the METC Zuyderland – Zuyd was added to the list of organisations who's ethics process is compatible with the UoS ethics process and therefore the ethics approval was acknowledged by the SchARR Research Ethics Committee (see figure A.4, page 249).

**Figure A.1**

Participant information as was send to professionals who were asked to participate in the study with the consent form added as 'bijlage C'.

## **Deelnemersinformatie voor deelname aan wetenschappelijk onderzoek**

### **Verborgen schatten onthult**

Verborgen schatten onthult: bouwen van een kennis basis en ontwikkelen van een methodologische en systematische werk- en benaderingswijze voor en met personen met een visuele beperking en bijkomende psychiatrische beperkingen.

### **Inleiding**

Geachte heer/mevrouw,

Wij vragen u om mee te doen aan een wetenschappelijk onderzoek.

Meedoen is vrijwillig. Om mee te doen is wel uw schriftelijke toestemming nodig.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt.

Lees deze informatie rustig door en vraag de onderzoeker uitleg als u vragen heeft. U kunt ook de onafhankelijk deskundige, die aan het eind van deze brief genoemd wordt, om aanvullende informatie vragen. En u kunt er ook over praten met uw partner, vrienden of familie.

### **1. Algemene informatie**

Dit onderzoek wordt gedaan door de Robert Coppes Stichting in samenwerking met Zuyd Hogeschool. De Programmaraad Visuele Sector vergoedt mogelijk een deel van de kosten van dit onderzoek.

Voor dit onderzoek zijn in totaal 16-20 deelnemers nodig, 8-12 cliënten van de Robert Coppes Stichting, Koninklijke Visio en Bartiméus (of hun vertegenwoordigers) en 8 professionals, 3 van de Robert Coppes Stichting, 2 van Bartiméus, 2 van Koninklijke Visio en 1 van Reinier van Arkel. De medisch ethische toetsingscommissie Zuyderland heeft dit onderzoek goedgekeurd.

### **2. Doel van het onderzoek**

Het doel van dit onderzoek is het bouwen van een stevig fundament voor de begeleiding en behandeling van volwassenen met een visuele beperking en bijkomende psychiatrische en overige problematiek. Met behulp van het onderzoek willen wij:

1. Inzicht krijgen in de kennis die (niet uitdrukkelijk verwoord) aanwezig is bij de professionals die met cliënten met een visuele beperking en bijkomende psychiatrische problematiek werken.
2. Een overzicht maken van bestaande interventies, methoden en benaderingswijzen die door professionals die met deze doelgroep of met cliënten met een visuele beperking of een psychiatrische problematiek werken, gebruikt (kunnen) worden.

3. Een gefundeerde methodische en systematische benaderingswijze voor de doelgroep ontwikkelen, op basis van bestaande kennis, literatuur en methodieken en behandelingen of interventies die in een andere context al wetenschappelijk bewezen zijn.

### **3. Achtergrond van het onderzoek**

De doelgroep van mensen met een visuele beperking en bijkomende psychiatrische en overige problematiek vraagt om een specifieke benadering, behandeling en begeleiding. De Robert Coppes Stichting biedt gespecialiseerde zorgverlening voor deze doelgroep, maar de kennis die hiervoor nodig is, zit vooral in de hoofden en handen van professionals. Gestandaardiseerde en wetenschappelijk bewezen interventies zijn beschikbaar voor volwassenen met een visuele beperking en voor volwassenen met psychiatrische problematiek of overige beperkingen. Door de combinatie van problematiek kunnen deze echter niet zomaar toegepast worden bij de doelgroep. Kennis die er al is, wordt duidelijk omschreven en voor betrokken professionals toegankelijk gemaakt. Kennislacunes worden opgespoord en ontbrekende kennis wordt verzameld en geïmplementeerd. Het resultaat is een duidelijk omschreven systematische werkwijze die leidt tot meer transparantie, op wetenschappelijk bewijs gebaseerde dienstverlening en tot een kwaliteitsverbetering van de geboden zorg.

### **4. Wat meedoen inhoudt**

Als u meedoet, duurt dat in totaal ongeveer 20 uur, verspreid over 20 maanden.

#### **Bijeenkomsten en metingen**

U neemt maximaal 10 keer deel aan een bijeenkomst die gehouden wordt bij de RCS in Vught of op een door u gekozen locatie (dit laatste geldt alleen voor de een-op-een diepte interviews). Een interview duurt ongeveer 1 uur, een PAR groepsbijeenkomst duurt ongeveer 2 tot 3 uur.

Er zal dan het volgende gebeuren:

- u neemt deel aan een een-op-een diepte interview - maximaal 5 keer
- u neemt deel aan een groepsdiscussie (PAR groep) - 2 keer in de fase van inventarisatie, 3 keer in de fase van ontwikkeling

### **5. Wat wordt er van u verwacht**

Om het onderzoek goed te doen verlopen, is het belangrijk dat u zich aan de volgende afspraken houdt.

De afspraken zijn dat u:

- regelmatig deelneemt aan de ruim van tevoren geplande bijeenkomsten.
- een vertegenwoordiger naar de bijeenkomsten stuurt, indien u zelf niet kunt of wilt deelnemen.
- alles wat tijdens de PAR groepsbijeenkomsten besproken wordt vertrouwelijk te behandelen.

Het is belangrijk dat u contact opneemt met de onderzoeker:

- als u niet meer wilt meedoen aan het onderzoek.
- als uw contactgegevens wijzigen.

## 6. Mogelijke ongemakken

Deelname aan dit onderzoek kan mogelijk emotioneel en cognitief belastend zijn. Mocht u na deelname aan een van de een-op-een diepte interviews of aan de PAR groepsbijeenkomsten behoefte hebben om met een onafhankelijke persoon te praten, dan kunt u ten allen tijde contact opnemen met Hans van den Heuvel (gedragswetenschapper Robert Coppes Stichting) of met de dienstdoende achterwacht. De contactgegevens worden in de bijlage vermeld.

## 7. Mogelijke voor- en nadelen

Het is belangrijk dat u de mogelijke voor- en nadelen goed afweegt voordat u besluit mee te doen.

U heeft zelf geen voordeel van meedoen aan dit onderzoek. Uw deelname kan wel bijdragen aan meer kennis over de behandeling en begeleiding van volwassenen met een visuele beperking en bijkomende psychiatrische of overige problematiek.

Voor cliënten die meedoen aan dit onderzoek betekent het niet dat de visuele beperking en bijkomende psychiatrische of overige problematiek ervan overgaat of minder last krijgen van de problematiek. Maar deelname draagt wel bij aan de verbetering van de kwaliteit van de geboden zorg voor volwassenen met visuele beperkingen en bijkomende psychiatrische of overige problematiek.

Nadelen van meedoen aan het onderzoek kunnen zijn:

- mogelijke confronterende vragen en onderwerpen die tijdens de interviews of gedurende de PAR groepsbijeenkomsten aan bod kunnen komen.

Met alle deelnemers worden de thema's die uit het vooronderzoek "Verborgene schatten" naar voren zijn gekomen, verder verdiept. Cliënten en professionals noemden aandachtspunten die zij belangrijk vinden in de begeleiding, zoals multi-methodisch handelen, continuïteit, samenwerking en eigen regie van de cliënt, kennislacunes en bestaande kaders.

Als cliënt wordt u in de eerste fase gevraagd om uw verhaal te vertellen over de zorg, begeleiding en behandeling die u bij de Robert Coppes Stichting ontvangen heeft, hoe u dit ervaren heeft en hoe u daarover denkt.

Bij professionals wordt achterhaald welke strategieën zij normaal gesproken gebruiken en de kennis die bij hen (mogelijk niet eerder uitdrukkelijk verwoord) aanwezig is. Daarnaast kunnen zij aangeven tegen welke problemen zij in de behandeling en begeleiding van de doelgroep aanlopen (mogelijk aan de hand van een specifieke casus) en welke kennis zij nog missen om de behandeling en begeleiding zo goed mogelijk te laten verlopen.

Deelname aan het onderzoek betekent ook:

- dat u extra tijd kwijt bent;
- dat u afspraken heeft waaraan u zich moet houden.

## **8. Als u niet wilt meedoen of wilt stoppen met het onderzoek**

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig.

Als u niet wilt meedoen, wordt u op de gebruikelijke manier behandeld en begeleid binnen de Robert Coppes Stichting. Ook voor professionals heeft het geen enkele consequentie of zij wel of niet meedoen aan het onderzoek.

Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. Als cliënt wordt u dan verder op de gebruikelijke manier behandeld en begeleid binnen de Robert Coppes Stichting. Als professional heeft dit verder ook geen enkele consequentie. U hoeft niet te zeggen waarom u stopt. Wel moet u dit direct melden aan de onderzoeker.

De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek.

Als u wilt, kunnen reeds verzamelde gegevens worden vernietigd.

Als er nieuwe informatie over het onderzoek is die belangrijk voor u is, laat de onderzoeker dit aan u weten. U wordt dan gevraagd of u blijft meedoen.

## **9. Einde van het onderzoek**

Uw deelname aan het onderzoek stopt als

- alle bijeenkomsten zoals beschreven onder punt 4 voorbij zijn
- u zelf kiest om te stoppen
- het einde van het hele onderzoek is bereikt
- de onderzoeker het beter voor u vindt om te stoppen
- de Robert Coppes Stichting, de overheid of de beoordelende medisch ethische toetsingscommissie, besluit om het onderzoek te stoppen.

Het hele onderzoek is afgelopen als alle deelnemers klaar zijn.

Na het verwerken van alle gegevens informeert de onderzoeker u over de belangrijkste uitkomsten van het onderzoek. Dit gebeurt ongeveer 3 maanden na uw deelname.

## **10. Gebruik en bewaren van uw gegevens**

Voor dit onderzoek is het nodig dat uw persoonsgegevens worden verzameld en gebruikt. Elke deelnemer krijgt een code die op de gegevens komt te staan. Uw naam en andere persoonsgegevens worden weggelaten.

### **Uw gegevens**

Al uw gegevens blijven vertrouwelijk. Alleen de onderzoekers weten welke code u heeft. Wij geven uw gegevens door aan de opdrachtgever van het onderzoek, maar alleen met die code, nooit met uw



naam. De sleutel voor de code blijft bij de onderzoeker. Ook in rapporten over het onderzoek wordt alleen die code gebruikt.

Sommige mensen mogen uw (persoons)gegevens inzien. Dit is om te controleren of het onderzoek goed en betrouwbaar uitgevoerd is.

Mensen die uw gegevens kunnen inzien zijn: het onderzoeksteam en de Inspectie voor de Gezondheidszorg. Zij houden uw gegevens geheim. Als u de toestemmingsverklaring ondertekent, geeft u toestemming voor het verzamelen, bewaren en inzien van uw (persoons)gegevens.

De onderzoeker bewaart uw gegevens 15 jaar.

## **11. Verzekering voor deelnemers**

Als u deelneemt aan het onderzoek, loopt u geen extra risico's. De Robert Coppes Stichting hoeft daarom van de METC Zuyderland geen extra verzekering af te sluiten.

## **12. Vergoeding voor meedoen**

Cliënten die meedoen aan dit onderzoek krijgen een onkostenvergoeding (exclusief reiskosten) van € 20,- per bijeenkomst. Voor professionals die meedoen aan dit onderzoek vallen de bijeenkomsten onder werktijd, daarnaast ontvangen zij een reiskostenvergoeding. Als u stopt voordat het onderzoek is afgelopen, krijgt u voor de bijeenkomsten waar u niet meer aan deelneemt geen vergoeding uitbetaald.

## **13. Heeft u vragen?**

Bij vragen kunt u contact opnemen met Marit van Buijsen (Robert Coppes Stichting) of met Uta Roentgen (Zuyd Hogeschool). Voor onafhankelijk advies over meedoen aan dit onderzoek kunt u terecht bij de onafhankelijke deskundige: Hans van den Heuvel (Robert Coppes Stichting). Hij weet veel over het onderzoek, maar heeft niets te maken met dit onderzoek.

Bij klachten kunt u het beste terecht bij de vertrouwenspersoon/klachtencommissie van de Robert Coppes Stichting. Alle gegevens vindt u in **bijlage A**: Contactgegevens.

## **14. Ondertekening toestemmingsformulier**

Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen. Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek.

Het handtekeningblad wordt door de hoofdonderzoeker bewaard. U krijgt een kopie of een tweede exemplaar van deze toestemmingsverklaring.

Dank voor uw aandacht.

## **16. Bijlagen bij deze informatie**

- A. Contactgegevens
- B. Schema onderzoekshandelingen / omschrijving onderzoekshandelingen
- C. Toestemmingsformulier

## Bijlage A: Contactgegevens voor Robert Coppes Stichting

Hoofdonderzoeker van de Robert Coppes Stichting: Marit van Buijsen, e-mail: [mvbuijsen@robertcoppes.nl](mailto:mvbuijsen@robertcoppes.nl); telefoonnummer: 073-6579157

Bereikbaar: maandag, dinsdag, woensdag (oneven week) of donderdag (even week) van 8.30 tot 16.00 uur

Hoofdonderzoeker van Zuyd Hogeschool: Uta Roentgen, e-mail: [uta.roentgen@zuyd.nl](mailto:uta.roentgen@zuyd.nl); telefoonnummer: 088 0272120.

Onafhankelijk deskundige: Hans van den Heuvel, Gedragswetenschapper Robert Coppes Stichting, e-mail: [hvdheuvel@robertcoppes.nl](mailto:hvdheuvel@robertcoppes.nl), telefoonnummer: 073-6579157

Bereikbaar: maandag t/m donderdag van 9.00 tot 17.00 uur.

Klachten:

- Cliënten:

Jozien Verkuijlen, werkzaam bij Stichting Vugterstede (locatie Huize Elisabeth)

Telefonisch te bereiken via 073-6583399, per mail via [j.verkuilen@vugterstede.nl](mailto:j.verkuilen@vugterstede.nl)

- Professionals:

P/a Stichting Vugterstede

T.a.v. Mevrouw H. Martens, secretaresse RvB

Molenrijnselaan 48

5262 TN Vught

Onder vermelding van vertrouwelijk

Indien u na deelname aan een interview en/of een PAR groep behoefte hebt om met iemand te praten, dan kunt u terecht bij de dienstdoende achterwacht via het algemene telefoonnummer van de Robert Coppes Stichting 073-6579157 (24 uur, 7 dagen per week bereikbaar). Degene die u aan de lijn krijgt kan u doorverbinden met de achterwacht.

## Bijlage B – Overzicht metingen

Tussen 04/17 en 08/17:	maximaal 5 individuele diepte interviews
Tussen 10/17 en 01/18:	2 PAR groepsbijeenkomsten (inventarisatie)
Tussen 06/18 en 08/18:	2 PAR groepsbijeenkomsten (ontwikkeling)
Tussen 10/18 en 11/18:	laatste PAR groepsbijeenkomst (ontwikkeling / feedback)

Deelnemers aan het cliëntenpanel worden in de eerste fase (inventarisatie) ook geïnterviewd (zie boven). In de tweede fase (ontwikkeling) geven zij in eerste instantie feedback.

## Bijlage C: Toestemmingsformulier deelnemer

### Verborgene schatten onthuld

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik weet dat sommige mensen mijn gegevens kunnen inzien. Die mensen staan vermeld in deze informatiebrief.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens op de manier en voor de doelen die in de informatiebrief staan.
- Ik geef toestemming om mijn gegevens op de onderzoekslocatie nog 15 jaar na dit onderzoek te bewaren.
- Ik geef  **wel**  **geen** toestemming om mij na dit onderzoek opnieuw te benaderen voor een vervolgonderzoek.
- Ik wil meedoen aan dit onderzoek.

Naam deelnemer:

Handtekening:

Datum : \_\_ / \_\_ / \_\_

-----  
Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Aanvullende informatie is gegeven door:

Naam:

Functie:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
\* Doorhalen wat niet van toepassing is.

*De deelnemer krijgt een volledige informatiebrief mee, samen met een kopie van het getekende toestemmingsformulier.*

## Bijlage D: Toestemmingsformulier vertegenwoordiger cliënt

### Verborgene Schatten onthult

Ik ben gevraagd om toestemming te geven voor deelname (in plaats) van de volgende persoon aan dit onderzoek:

Naam deelnemer:

Geboortedatum: \_\_ / \_\_ / \_\_

- Ik heb de informatiebrief voor de deelnemer gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of deze persoon meedoet. Als de deelnemer dit wenst, neem ik in plaats van hem / haar aan het onderzoek deel.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen dat deze persoon toch niet meedoet of dat ik niet langer deelneem als zijn / haar vertegenwoordiger. Daarvoor hoef ik geen reden te geven.
- Ik weet dat sommige mensen de gegevens van deze persoon kunnen inzien. Die mensen staan vermeld in deze informatiebrief.
- Ik geef toestemming voor het gebruik van de gegevens op de manier en voor de doelen die in de informatiebrief staan.
- Ik geef toestemming om de gegevens op de onderzoekslocatie nog 15 jaar na dit onderzoek te bewaren.
- Ik ga ermee akkoord dat deze persoon of ik als zijn / haar vertegenwoordiger meedoe(t) aan dit onderzoek.

Naam wettelijk vertegenwoordiger:

Relatie tot de deelnemer:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Ik verklaar hierbij dat ik deze persoon/personen volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de wettelijk vertegenwoordiger zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Aanvullende informatie is gegeven door (indien van toepassing):

Naam:

Functie:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----

**Figure A.2**

Participant information as was send to service users who were asked to participate in the study with the consent form added as 'bijlage C'

## **Deelnemersinformatie voor deelname aan wetenschappelijk onderzoek**

### **Verborgten schatten onthult**

Verborgten schatten onthult: bouwen van een kennis basis en ontwikkelen van een methodologische en systematische werk- en benaderingswijze voor en met personen met een visuele beperking en bijkomende psychiatrische beperkingen.

### **Inleiding**

Geachte heer/mevrouw,

Wij vragen u om mee te doen aan een wetenschappelijk onderzoek.

Meedoen is vrijwillig. Om mee te doen is wel uw schriftelijke toestemming nodig.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt.

Lees deze informatie rustig door en vraag de onderzoeker uitleg als u vragen heeft. U kunt ook de onafhankelijk deskundige, die aan het eind van deze brief genoemd wordt, om aanvullende informatie vragen. En u kunt er ook over praten met uw partner, vrienden of familie.

### **15. Algemene informatie**

Dit onderzoek wordt gedaan door de Robert Coppes Stichting in samenwerking met Zuyd Hogeschool. De Programmaraad Visuele Sector vergoedt mogelijk een deel van de kosten van dit onderzoek.

Voor dit onderzoek zijn in totaal 21-25 deelnemers nodig, 8-12 cliënten van de Robert Coppes Stichting, Koninklijke Visio en Bartiméus (of hun vertegenwoordigers) en 13 professionals, 6 van de Robert Coppes Stichting, 3 van Bartiméus, 3 van Koninklijke Visio en 1 van Reinier van Arkel. De medisch ethische toetsingscommissie Zuyderland heeft dit onderzoek goedgekeurd.

### **16. Doel van het onderzoek**

Het doel van dit onderzoek is het bouwen van een stevig fundament voor de begeleiding en behandeling van volwassenen met een visuele beperking en bijkomende psychiatrische en overige problematiek. Met behulp van het onderzoek willen wij:

1. Inzicht krijgen in de kennis die (niet uitdrukkelijk verwoord) aanwezig is bij de professionals die met cliënten met een visuele beperking en bijkomende psychiatrische problematiek werken.
2. Een overzicht maken van bestaande interventies, methoden en benaderingswijzen die door professionals die met deze doelgroep of met cliënten met een visuele beperking of een psychiatrische problematiek werken, gebruikt (kunnen) worden.

3. Een gefundeerde methodische en systematische benaderingswijze voor de doelgroep ontwikkelen, op basis van bestaande kennis, literatuur en methodieken en behandelingen of interventies die in een andere context al wetenschappelijk bewezen zijn.

## 17. Achtergrond van het onderzoek

De doelgroep van mensen met een visuele beperking en bijkomende psychiatrische en overige problematiek vraagt om een specifieke benadering, behandeling en begeleiding. De Robert Coppes Stichting biedt gespecialiseerde zorgverlening voor deze doelgroep, maar de kennis die hiervoor nodig is, zit vooral in de hoofden en handen van professionals. Gestandaardiseerde en wetenschappelijk bewezen interventies zijn beschikbaar voor volwassenen met een visuele beperking en voor volwassenen met psychiatrische problematiek of overige beperkingen. Door de combinatie van problematiek kunnen deze echter niet zomaar toegepast worden bij de doelgroep. Kennis die er al is, wordt duidelijk omschreven en voor betrokken professionals toegankelijk gemaakt. Kennislacunes worden opgespoord en ontbrekende kennis wordt verzameld en geïmplementeerd. Het resultaat is een duidelijk omschreven systematische werkwijze die leidt tot meer transparantie, op wetenschappelijk bewijs gebaseerde dienstverlening en tot een kwaliteitsverbetering van de geboden zorg.

## 18. Wat meedoet inhoudt

Als u meedoet, duurt dat in totaal ongeveer 11 uur, verspreidt over 20 maanden.

### Bijeenkomsten en metingen

U neemt maximaal 8 keer deel aan een bijeenkomst die gehouden wordt bij de RCS in Vught of op een door u gekozen locatie (dit laatste geldt alleen voor de een-op-een diepte interviews). Een interview en/of groepsbijeenkomst duurt ongeveer 1 uur.

Er zal dan het volgende gebeuren:

- u neemt deel aan een een-op-een diepte interview
- u neemt deel aan een groepsbijeenkomst - 2 keer in de fase van inventarisatie, 3 keer in de fase van ontwikkeling

## 19. Wat wordt er van u verwacht

Om het onderzoek goed te doen verlopen, is het belangrijk dat u zich aan de volgende afspraken houdt.

De afspraken zijn dat u:

- regelmatig deelneemt aan de ruim van tevoren geplande bijeenkomsten.
- een vertegenwoordiger naar de bijeenkomsten stuurt, indien u zelf niet kunt of wilt deelnemen.
- alles wat tijdens de groepsbijeenkomsten besproken wordt vertrouwelijk te behandelen.

Het is belangrijk dat u contact opneemt met de onderzoeker:

- als u niet meer wilt meedoen aan het onderzoek.
- als uw contactgegevens wijzigen.

## 20. Mogelijke ongemakken

Deelname aan dit onderzoek kan mogelijk emotioneel en cognitief belastend zijn. Mocht u na deelname aan een van de een-op-een diepte interviews of aan de groepsbijeenkomsten behoefte hebben om met een onafhankelijke persoon te praten, dan kunt u ten allen tijde contact opnemen met Hans van den Heuvel (gedragswetenschapper Robert Coppes Stichting) of met de dienstdoende achterwacht. De contactgegevens worden in de bijlage vermeld.

## 21. Mogelijke voor- en nadelen

Het is belangrijk dat u de mogelijke voor- en nadelen goed afweegt voordat u besluit mee te doen.

U heeft zelf geen voordeel van meedoen aan dit onderzoek. Uw deelname kan wel bijdragen aan meer kennis over de behandeling en begeleiding van volwassenen met een visuele beperking en bijkomende psychiatrische of overige problematiek.

Als u meedoet aan dit onderzoek betekent het niet dat uw visuele beperking en bijkomende psychiatrische of overige problematiek ervan overgaat of u minder last krijgt van uw problematiek. Maar u draagt wel bij aan de verbetering van de kwaliteit van de geboden zorg voor volwassenen met visuele beperkingen en bijkomende psychiatrische of overige problematiek.

Nadelen van meedoen aan het onderzoek kunnen zijn:

- mogelijke confronterende vragen en onderwerpen die tijdens de interviews of gedurende de groepsbijeenkomsten aan bod kunnen komen.

Met alle deelnemers worden de thema's die uit het vooronderzoek "Verborgene schatten" naar voren zijn gekomen, verder verdiept. Cliënten en professionals noemden aandachtspunten die zij belangrijk vinden in de begeleiding, zoals multi-methodisch handelen, continuïteit, samenwerking en eigen regie van de cliënt, kennislacunes en bestaande kaders.

Als cliënt wordt u in de eerste fase gevraagd om uw verhaal te vertellen over de zorg, begeleiding en behandeling die u bij de Robert Coppes Stichting ontvangen heeft, hoe u dit ervaren heeft en hoe u daarover denkt.

Bij professionals wordt achterhaald welke strategieën zij normaal gesproken gebruiken en de kennis die bij hen (mogelijk niet eerder uitdrukkelijk verwoord) aanwezig is. Daarnaast kunnen zij aangeven tegen welke problemen zij in de behandeling en begeleiding van de doelgroep aanlopen (mogelijk aan de hand van een specifieke casus) en welke kennis zij nog missen om de behandeling en begeleiding zo goed mogelijk te laten verlopen.



Deelname aan het onderzoek betekent ook:

- dat u extra tijd kwijt bent;
- dat u afspraken heeft waaraan u zich moet houden.

## **22. Als u niet wilt meedoen of wilt stoppen met het onderzoek**

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig.

Als u niet wilt meedoen, wordt u op de gebruikelijke manier behandeld en begeleid binnen de Robert Coppes Stichting.

Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U wordt dan verder op de gebruikelijke manier behandeld en begeleid binnen de Robert Coppes Stichting. U hoeft niet te zeggen waarom u stopt. Wel moet u dit direct melden aan de onderzoeker.

De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek.

Als u wilt, kunnen reeds verzamelde gegevens worden vernietigd.

Als er nieuwe informatie over het onderzoek is die belangrijk voor u is, laat de onderzoeker dit aan u weten. U wordt dan gevraagd of u blijft meedoen.

## **23. Einde van het onderzoek**

Uw deelname aan het onderzoek stopt als

- alle bijeenkomsten zoals beschreven onder punt 4 voorbij zijn
- u zelf kiest om te stoppen
- het einde van het hele onderzoek is bereikt
- de onderzoeker het beter voor u vindt om te stoppen
- de Robert Coppes Stichting, de overheid of de beoordelende medisch ethische toetsingscommissie, besluit om het onderzoek te stoppen.

Het hele onderzoek is afgelopen als alle deelnemers klaar zijn.

Na het verwerken van alle gegevens informeert de onderzoeker u over de belangrijkste uitkomsten van het onderzoek. Dit gebeurt ongeveer 3 maanden na uw deelname.

## 24. Gebruik en bewaren van uw gegevens

Voor dit onderzoek is het nodig dat uw persoonsgegevens worden verzameld en gebruikt. Elke deelnemer krijgt een code die op de gegevens komt te staan. Uw naam en andere persoonsgegevens worden weggelaten.

### Uw gegevens

Al uw gegevens blijven vertrouwelijk. Alleen de onderzoekers weten welke code u heeft. Wij geven uw gegevens door aan de opdrachtgever van het onderzoek, maar alleen met die code, nooit met uw naam. De sleutel voor de code blijft bij de onderzoeker. Ook in rapporten over het onderzoek wordt alleen die code gebruikt.

Sommige mensen mogen uw (persoons)gegevens inzien. Dit is om te controleren of het onderzoek goed en betrouwbaar uitgevoerd is.

Mensen die uw gegevens kunnen inzien zijn: het onderzoeksteam en de Inspectie voor de Gezondheidszorg. Zij houden uw gegevens geheim. Als u de toestemmingsverklaring ondertekent, geeft u toestemming voor het verzamelen, bewaren en inzien van uw (persoons)gegevens.

De onderzoeker bewaart uw gegevens 15 jaar.

## 25. Verzekering voor deelnemers

Als u deelneemt aan het onderzoek, loopt u geen extra risico's. De Robert Coppes Stichting hoeft daarom van de METC Zuyderland geen extra verzekering af te sluiten.

## 26. Vergoeding voor meedoen

Voor het meedoen aan dit onderzoek krijgt u een onkostenvergoeding (exclusief reiskosten) van € 20,- per bijeenkomst. Als u stopt voordat het onderzoek is afgelopen, krijgt u voor de bijeenkomsten waar u niet meer aan deelneemt geen vergoeding uitbetaald.

## 27. Heeft u vragen?

Bij vragen kunt u contact opnemen met Marit van Buijsen (Robert Coppes Stichting) of met Uta Roentgen (Zuyd Hogeschool). Voor onafhankelijk advies over meedoen aan dit onderzoek kunt u terecht bij de onafhankelijke deskundige: Hans van den Heuvel (Robert Coppes Stichting). Hij weet veel over het onderzoek, maar heeft niets te maken met dit onderzoek.

Bij klachten kunt u het beste terecht bij de vertrouwenspersoon van de Robert Coppes Stichting. Alle gegevens vindt u in **bijlage A**: Contactgegevens.

**28. Ondertekening toestemmingsformulier**

Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen. Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek.

Het handtekeningblad wordt door de hoofdonderzoeker bewaard. U krijgt een kopie of een tweede exemplaar van deze toestemmingsverklaring.

Dank voor uw aandacht.

## **17. Bijlagen bij deze informatie**

- A. Contactgegevens
- B. Schema onderzoekshandelingen / omschrijving onderzoekshandelingen
- C. Toestemmingsformulier

## Bijlage A: Contactgegevens voor Robert Coppes Stichting

Hoofdonderzoeker van de Robert Coppes Stichting: Marit van Buijsen, e-mail: [mvbuijsen@robertcoppes.nl](mailto:mvbuijsen@robertcoppes.nl); telefoonnummer: 073-6579157

Bereikbaar: maandag, dinsdag, woensdag (oneven week) of donderdag (even week) van 8.30 tot 16.00 uur

Hoofdonderzoeker van Zuyd Hogeschool: Uta Roentgen, e-mail: [uta.roentgen@zuyd.nl](mailto:uta.roentgen@zuyd.nl); telefoonnummer: 088 0272120.

Onafhankelijk deskundige: Hans van den Heuvel, Gedragswetenschapper Robert Coppes Stichting, e-mail: [hvdheuvel@robertcoppes.nl](mailto:hvdheuvel@robertcoppes.nl), telefoonnummer: 073-6579157  
Bereikbaar: maandag t/m donderdag van 9.00 tot 17.00 uur.

Klachten: Vertrouwenspersoon Jozien Verkuijlen, werkzaam bij Stichting Vughterstede (locatie Huize Elisabeth)

Telefonisch te bereiken via 073-6583399, per mail via [j.verkuilen@vughterstede.nl](mailto:j.verkuilen@vughterstede.nl)

Indien u na deelname aan een interview en/of een PAR groep behoefte hebt om met iemand te praten, dan kunt u terecht bij de dienstdoende achterwacht via het algemene telefoonnummer van de Robert Coppes Stichting 073-6579157 (24 uur, 7 dagen per week bereikbaar). Degene die u aan de lijn krijgt kan u doorverbinden met de achterwacht.

## Bijlage B – Overzicht metingen

Tussen 04/17 en 08/17:	één individueel diepte interview
Tussen 10/17 en 01/18:	2 groepsbijeenkomsten (inventarisatie)
Tussen 06/18 en 08/18:	2 groepsbijeenkomsten (ontwikkeling)
Tussen 10/18 en 11/18:	laatste groepsbijeenkomst (ontwikkeling / feedback)

Deelnemers aan het cliëntenpanel worden in de eerste fase (inventarisatie) geïnterviewd (zie boven). In de tweede fase (ontwikkeling) geven zij in eerste instantie feedback.

## Bijlage C: Toestemmingsformulier deelnemer

Verborgen schatten onthuld

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik weet dat sommige mensen mijn gegevens kunnen inzien. Die mensen staan vermeld in deze informatiebrief.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens op de manier en voor de doelen die in de informatiebrief staan.
- Ik geef toestemming om mijn gegevens op de onderzoekslocatie nog 15 jaar na dit onderzoek te bewaren.
- Ik geef  **wel**  
 **geen** toestemming om mij na dit onderzoek opnieuw te benaderen voor een vervolgonderzoek.
- Ik wil meedoen aan dit onderzoek.

Naam deelnemer:

Handtekening:

Datum : \_\_ / \_\_ / \_\_

-----  
Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Aanvullende informatie is gegeven door:

Naam:

Functie:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
\* Doorhalen wat niet van toepassing is.

*De deelnemer krijgt een volledige informatiebrief mee, samen met een kopie van het getekende toestemmingsformulier.*

**Bijlage D: Toestemmingsformulier vertegenwoordiger cliënt**

Verborgen Schatten onthult

Ik ben gevraagd om toestemming te geven voor deelname (in plaats) van de volgende persoon aan dit onderzoek:

Naam deelnemer:

Geboortedatum: \_\_ / \_\_ / \_\_

- Ik heb de informatiebrief voor de deelnemer gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of deze persoon meedoet. Als de deelnemer dit wenst, neem ik in plaats van hem / haar aan het onderzoek deel.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen dat deze persoon toch niet meedoet of dat ik niet langer deelneem als zijn / haar vertegenwoordiger. Daarvoor hoef ik geen reden te geven.
- Ik weet dat sommige mensen de gegevens van deze persoon kunnen inzien. Die mensen staan vermeld in deze informatiebrief.
- Ik geef toestemming voor het gebruik van de gegevens op de manier en voor de doelen die in de informatiebrief staan.
- Ik geef toestemming om de gegevens op de onderzoekslocatie nog 15 jaar na dit onderzoek te bewaren.
- Ik ga ermee akkoord dat deze persoon of ik als zijn / haar vertegenwoordiger meedoe(t) aan dit onderzoek.

Naam wettelijk vertegenwoordiger:

Relatie tot de deelnemer:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----

Ik verklaar hierbij dat ik deze persoon/personen volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de wettelijk vertegenwoordiger zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----

Aanvullende informatie is gegeven door (indien van toepassing):

Naam:

Functie:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----

\* Doorhalen wat niet van toepassing is.

Figure A.3

Approval letter received by the METC Zuyderland – Zuyd (in Dutch).



Zuyd Hogeschool  
Mw. dr. U. Roentgen  
Uta.roentgen@zuyd.nl

<b>Datum</b>	<b>Titel</b>
21 februari 2017	Hidden treasures revealed: building a knowledge base and a methodological and systematic approach for and with visually impaired adults with a psychiatric impairment
<b>Onderzoeker</b>	<b>Nummer</b>
Dr. U. Roentgen	17-N-42

Geachte onderzoekers,

Op uw verzoek van 20 februari 2017 heeft de Medisch Ethisch Toetsingscommissie in het overleg van voorzitter en secretaris kennis genomen van bovengenoemd onderzoeksprotocol. De Commissie heeft de volgende documenten beoordeeld:

- Uw aanbiedingsbrief van 20 februari 2017
- Onderzoeksprotocol versie 1.0, d.d. 20 februari 2017
- Proefpersoneninformatie en toestemmingsverklaring versie 1 d.d. 20 februari 2017
- CV onafhankelijke deskundige H. van den Heuvel, versie 1 d.d. 20 februari 2017
- CV hoofdonderzoeker M. van Buijssen, versie 1 d.d. 20 februari 2017
- Deelnemersinformatie cliëntenpanel
- Deelnemersinformatie expert groep

Inzake bovengenoemde studie delen wij u mede dat de Commissie van mening is dat de studie niet WMO-plichtig is, aangezien er geen sprake is van het onderwerpen van personen aan handelingen of het opleggen aan personen van een bepaalde gedragswijze.

Mits u de code Goed Gedrag alsmede de WBP in acht neemt hebben wij geen bezwaar tegen uitvoeren van het onderzoek.

Verder wil de Commissie u erop attenderen dat het onderzoek VOOR de start, bij een openbaar trialregister aangemeld dient te worden. U kunt dit doen bij: <http://www.trialregister.nl> of bij [ClinicalTrials.gov](http://ClinicalTrials.gov). Zonder aanmelding kunt u in bepaalde journals niet publiceren.

METC Z is de Medisch Ethische Toetsingscommissie van Zuyderland en Zuyd Hogeschool. METC Z toetst -in het kader van de WMO- medisch-wetenschappelijk onderzoek, waaronder ook onderzoek in de eerste lijn, de care- en revalidatiesector. METC Z toetst conform de Wet medisch-wetenschappelijk onderzoek met mensen (WMO), de Richtlijn Externe Toetsing (RET 12), ICH-GCP en andere (EU) wet- en regelgeving. METC Z is erkend door de CCMO.

Correspondentieadres  
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Secretariaat, T3 Heerlen  
Postbus 5500  
6130 MB Sittard

metc@zuyderland.nl

Bezoekadres  
K&E  
Hoofdgebouw etage 3  
H. Dunantstraat 5  
Heerlen  
T 045 – 5767 194

[www.zuyderland.nl/METC](http://www.zuyderland.nl/METC)

METC Z leden:  
dr. J.W. Greve (voorzitter)  
dr. J. Kragten (vicevoorzitter)  
mw. drs. L. Diele  
mw. mr. C. Essed  
mw. mr. dr. R. ten Hoopen  
dr. R. Jankegt  
dr. M. de Kruijff  
dr. H. van der Kuy  
mw. dr. A. Moser  
mw. dr. B. Panis  
dr. M. Reinders  
drs. B. Simons  
drs. J. van der Snoek  
dr. A. Voogd  
mw. dr. I. Widdershoven  
dr. B. Winkens

vaste adviseurs:  
dr. W. van Asten  
mw. dr. A. van den Hout

METC Z secretariaat:  
mw. mr. H. van den Besselaar  
mw. J. Jennekens





Voor de goede orde zij hierbij nog geattendeerd op het feit dat het de onderzoeker(s) slechts met schriftelijke toestemming van de Raad van Bestuur is toegestaan te starten met het onderzoek, daartoe ontvangt de Raad van Bestuur van Robert Coppes Stichting een kopie van deze brief.

U dient de Commissie op de hoogte te stellen van de startdatum van het onderzoek ([metc@zuyderland.nl](mailto:metc@zuyderland.nl)). Tevens dient u alle wijzigingen die u aanbrengt in het onderzoek voor te leggen aan de Commissie.

Bij beëindiging van de studie ontvangt de Commissie het eindverslag.

Met vriendelijke groet,  
METC Z  
dr. J.W. Greve, voorzitter  
namens deze,

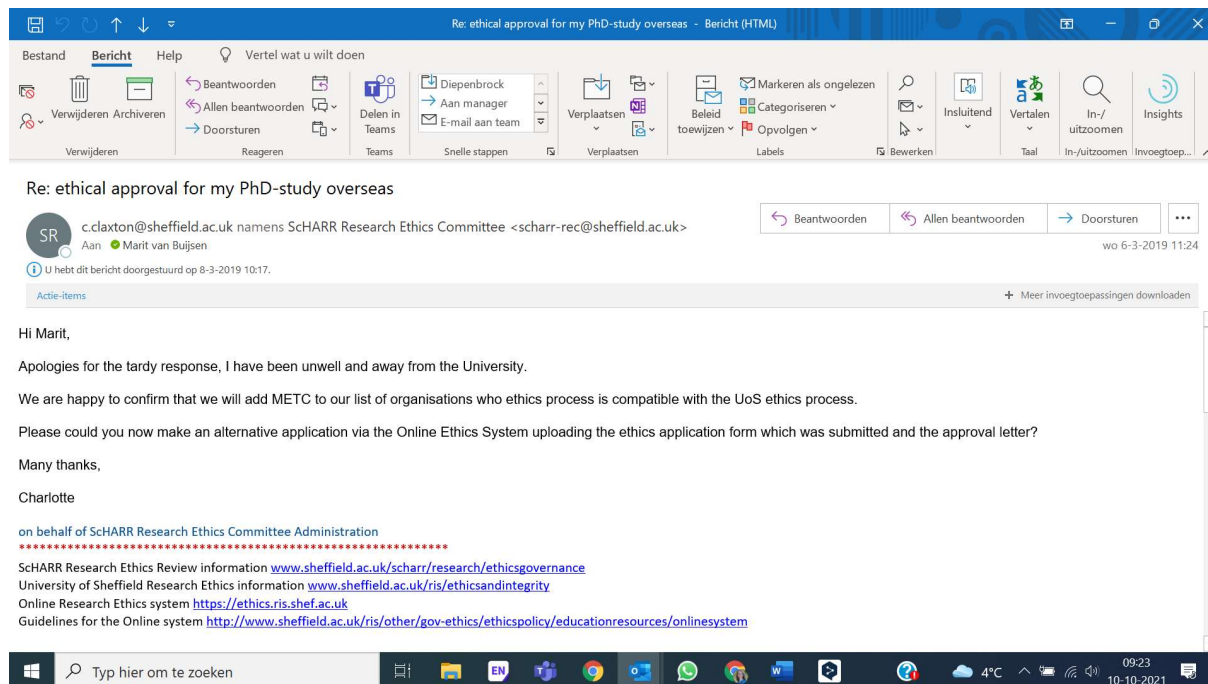
A handwritten signature in blue ink, appearing to read 'Hélène', written over a horizontal line.

mr. Van den Besselaar (Hélène)  
secretaris METC Z

i. a. a. Raad van Bestuur Robert Coppes Stichting, [mbeukers@robertcoppes.nl](mailto:mbeukers@robertcoppes.nl)  
M. van Buijsen, hoofdonderzoeker, [mvbuijsen@robertcoppes.nl](mailto:mvbuijsen@robertcoppes.nl)

**Figure A.4**

Email with approval of the METC Zuyderland – Zuyd procedure by the SchARR research ethics committee



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## APPENDIX 4: INTERVIEW PROTOCOL USED FOR THE IN DEPTH ONE-TO-ONE SEMI-STRUCTURED INTERVIEWS WITH PROFESSIONALS

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In the in depth one-to-one interviews the professionals were asked to select two cases:

1. a case which they felt was successful or illustrated their way of providing care and treatment;
2. a case in which they felt that there were difficulties or with whose result or current situation they remain unhappy.

For the successful case the professional was asked to deliberate about the following questions:

- Give a short description of the case
- Why did you choose this case, what do you think that this case makes clear?
- What has mostly contributed to the success?
- Which steps did you take in this case?
- Which considerations have you made in this case? Why did you choose for these?
- Could you also have made other decisions? Why didn't you choose for these?
- Did you use specific methods or approaches for this case? Did you had to make changes to this method or approach specific for this target group?
- What is the source of the knowledge you have used in this case?
- Is there something else you would like to tell about this case?

For the difficult case the following questions were asked:

- Give a short description of the case
- Why did you choose this case, what do you think that this case makes clear?
- What is, according to you, the most important reason that there where difficulties in this case?
- What where the difficulties in this case?
- To what content was the usual approach you used not applicable for this case? Was there missing knowledge? When yes, what knowledge was missing?
- Which knowledge would you have needed in this case?
- What do you need to make this case a success?
- Is there something else you would like to tell about this case?

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## APPENDIX 5: OVERVIEW OF THE SERVICE USERS' CHARACTERISTICS, STRUCTURED BY THE ICF CATEGORIES, SELECTED AS A CASE BY THE PROFESSIONALS IN THE INDIVIDUAL INTERVIEWS

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In tables A.2 to A.5 an overview is provided on the service users' characteristics, structured by the ICF categories, that were indicated by professionals in their case descriptions.

**Table A.2**

*Health conditions (disorder or disease) mentioned by professionals while describing the cases chosen for the interview*

<b>Category</b>	<b>Health condition</b>
Mental health problems	(Probably) personality disorder Borderline personality disorder Presumption of mood, adaptation and anxiety disorder Post-traumatic stress disorder (PTSD) Reasonably extensive psychiatric history Personality problems (never confirmed) Depression Generalised anxiety disorder Mental problems A lot of classifications within mental health care A very confused picture Anxiety Adherence problems Borderline has also been mentioned Autism in combination with personality disorder Stressed out Depressive (already at young age) Stress complaints Anxieties getting bigger and bigger Panic attacks Possible borderline problems Suspicion of Asperger Psychosis, psychotic symptoms Suspicion on borderline Conversion, no explanation for major vision loss Suspicion on autism
Somatic condition or symptom	Progressive muscular disease Disease cerebellum A number of physical diseases

---

Category	Health condition
Other	Charles Bonnet Syndrome
	Born with a hydrocephalus
	Atone bladder by operation
	Diabetes (from early age)
	Heart problems
	Mild intellectual disability
	optic atrophy, onset 1,5 year before admission cortical dystrophy

**Table A.3**

*Affected body functions and structures mentioned by professionals while describing the cases chosen for the interview*

Category	Body functions and structures
Visual functions	VI due to disease
	VI in a short period of time (VA 0.08)
	VI from adolescence, deterioration
	VI, blind in one eye
	VI from birth, blind since adolescence
	VI since young adulthood, deterioration
Other	Low vision
	physical abilities vary each day
	Does not function as well physically
	Low level of functioning versus high level of verbal ability Language impairment

**Table A.4**

*Problems or possibilities on activities and participation mentioned by professionals while describing the cases chosen for the interview*

Category	Problem or possibility
Activities	Used to being cared for
	Difficulties talking and moving
	Could not be touched, said almost nothing
	Difficult to approach
	In the beginning, was not able to walk (only 40 metres)
	Has to catheterize daily
	Sleeps very badly, eats badly
	Could sleep very badly, sat under the bed every night
	Self-harm
	Working on rehabilitation goals not possible
	Can do housekeeping, but not able to go outside independently

Category	Problem or possibility
Participation	<p>'Enormous experience of unsuccessful daytime activities'</p> <p>No daytime activities, only a trip to the market</p> <p>Has daytime activities, voluntary work</p> <p>Used to work at a residential facility as formal carer</p> <p>Was no longer able to perform the tasks at work</p> <p>Had no daytime activities, was lying in bed all day</p> <p>Had no daytime activities, little leisure activities</p> <p>Was mainly inside, just had little to do</p> <p>Just had no desire at all to want anything</p> <p>Has finished a study at University, now falls into a hole</p> <p>Sits inside a lot, cannot take a step anymore</p> <p>Studied / graduated</p> <p>Did a vocational training, now day time activities</p> <p>Wants to do a training course (excessive demand)</p> <p>Goal: to discover what was possible in terms of work</p>

**Table A.5**

*Environmental and personal factors mentioned by professionals while describing the cases chosen for the interview*

Category	Factor
Environmental factors	<p>Lived with family until late adult hood</p> <p>Contact between service user and carers was difficult</p> <p>Married for the 2nd time</p> <p>Partner is diagnosed with personality disorder</p> <p>Low / small social network</p> <p>Much more social interaction, because of hearing aid</p> <p>Single</p> <p>Problems with friends and family</p> <p>Very limited social network</p> <p>Long trajectory of mental health care; now small-scale housing</p> <p>Over-medication (many psychiatrists involved)</p> <p>lived from an early age in various institutions rehabilitation</p> <p>Conflicts with carers</p> <p>Showed manipulative behaviour in the group</p> <p>Quickly overestimated, due to high verbal ability</p> <p>Has lost many relatives, experienced a lot of negative events</p> <p>Got stuck in own situation</p> <p>Is married, has stepchild, who does not live at home</p> <p>Deterioration of VI had a major impact on social contacts</p> <p>Struggled a lot in regular school, finally went to special education</p> <p>Things are not going well in the social domain</p>

Category	Factor
Personal factors	Nobody is doing well (It is all pretty tiring to offer support)
	Lives in an independent-living training centre
	Lives in the institution for years
	Moved back home to family
	Admitted with psychotic symptoms
	Seriously ill mother
	Referred for rehabilitation from locked psychiatric ward
	Admission to crisis service mental health care
	Every time up and down to crisis service
	Avoiding/dependent personality, learned helplessness
	'Struggling with shocking change in life'
	Enormous resistance to support and nannying
	Not accepting VI
	Has applied for rehabilitation, because was not able to manage
	Somatisation
	The feeling of: nobody hears me, I am not allowed to be there
	Difficult to assess behaviour, difficult to get a grip
	'A bottomless pit, there is no foundation from which to build'
	Avoiding behaviour
	Not accepting the VI, wants to function as someone who can see
	Says: "I have been hurt very often"
	No emotions, only tension, thinking as a strategy for avoiding
	Did not manage diabetes properly (which caused the VI)
	Attributes everything on VI, but other things did not run well either
	No insight into demanding nature and how this affects social contacts
	Very clever, IQ of 140
	A hoarder, piles everywhere
	Very vulnerable
	Fluctuates in thinking about abilities (over- versus underestimating)
	Is searching enormously how to organise life
Homosexual, 'but does not dare to take the steps'	
After 2-3 weeks of rehabilitation, expressed suicidal statements	
The problem related to the acceptance of the handicap	
Not motivated, 'nothing is good enough'	
Not having a clear goal in life	
Very vulnerable in social contacts, can be damaged in this	

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## APPENDIX 6: SCORING CATEGORIES USED FOR MAPPING REVIEW

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### Titles

#### Criteria:

1. English or Dutch.
2. Title refers to adults with a VI (=3).
  - a. When the title refers to 'students' or 'youth': doubt is given (=2) if inclusion criterium 3 can be applied, when this is not the case than a non-relevant score is given (=1).
3. Title indicates that the article focuses on adults who are having at least 1 comorbid disorder or disability, other than the VI (=3).
  - a. Doubt is given (=2) when the title refers to 'multiple disabilities', but the VI is not mentioned explicitly.
4. Titles referring to children under the age of 18 are excluded.

#### Scoring system:

1. Not relevant (in order to answer the research questions)
2. Doubt about relevance
3. Relevant article

All sum scores of the three researchers higher than 6 were included (minimum = 3; maximum = 9).

### Abstracts

#### Criteria:

1. English or Dutch publication.
2. Publication focuses on adults with VI.
3. Besides criteria 2, at least one other impairment is mentioned.
4. Publication focuses on adults older than 18.

#### Scoring system, categories:

- |   |  |
|---|--|
| 0 | Not relevant; publication does not refer to adults with VI and comorbid problems or does not meet the established criteria.                              |
| 2 | Relevant target group; publication refers to the target group, meets the formulated criteria but focuses on a subject other than formulated in score 10. |



- 10 Extremely relevant; publication refers to the target group, meets the formulated criteria and focuses on a method, approach, intervention or tool.

Publications scored in category 0 where excluded. Publications that were scored belonging to category 2 or higher by all three researchers where included. These publications were not fully read, but a classification was made on the following subjects: incidence/prevalence, association, etiology, diagnostics/assessment, case report and other. When a difference in scores was found between the three researchers a definite score based on agreement between the three researchers was given.

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## APPENDIX 7: SCORING CATEGORIES FOR SCOPING REVIEW

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### Titles

#### Criteria:

1. English or Dutch.
2. Title refers to adults with VI (=3).
  - a. When the title refers to 'students' or 'youth': doubt is given (=2) if inclusion criterium 3 can be applied, when this is not the case than a non-relevant score is given (=1).
3. Title indicates that the article focuses on adults who are having at least comorbid mental disorder or disability (=3).
  - a. Doubt is given (=2) when the title refers to 'multiple disabilities', but the VI or mental disorder is not mentioned explicitly.
4. Titles referring to children under the age of 18 are excluded.

#### Scoring system:

1. Not relevant (in order to answer the research questions)
2. Doubt about relevance
3. Relevant article

All sum scores of the two researchers higher than 3 were included (minimum = 2; maximum = 6).

### Abstracts

#### Criteria:

1. English or Dutch publication.
2. Publication focuses on adults with VI.
3. Besides criteria 2, at least 1 comorbid mental disorder is mentioned.
4. Publication focuses on adults older than 18.

#### Scoring system, categories:

- |   |  |
|---|--|
| 0 | Not relevant; publication does not refer to adults with VI and comorbid mental disorder or does not meet the established criteria;                       |
| 1 | Dubious;   |
| 2 | Relevant target group; publication refers to the target group, meets the formulated criteria but focuses on a subject other than formulated in score 10; |

- 5 Highly relevant; publication is about the target group, satisfies all the criteria as described above AND is about a methodology, course of action, intervention and/or tool; the abstract is not scored with a 10, because it concerns persons who are deaf-blind, under 18 years of age, with a comorbid severe intellectual disability and/or if it only concerns medical or surgical treatment;
- 10 Extremely relevant; publication refers to the target group, satisfies all the criteria as described above and focuses on a methodology, course of action, intervention and/or tool.

Publications scored in category 0 or 2 were excluded. Publications that were scored belonging to category 5 or 10 by the two researchers were included and fully read by two researchers. For publications scored in category 1 and when a difference in scores was found between the two researchers a definite score based on agreement between the two researchers was given.

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## APPENDIX 8: INTERVIEW GUIDE USED FOR INDIVIDUAL IN DEPTH INTERVIEWS WITH SERVICE USERS

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The goal of the interview guide is to give service users the opportunity to share their stories.

Therefore, the interviewer will start with the open question 'Can you tell me about...' and will ask about different aspects. During the conversation, the interviewer will ask probe questions, to obtain a detailed understanding of the service user's stories, such as:

- How did you feel at that moment?
- Why do you think that this happened?
- Why was that important for you?

It is important that during the interview, the interviewer uses a curious approach and continues to ask open questions, until the service user does not give a new answer anymore (Socratic dialogue). After a short introduction between the interviewer and the service user and an explanation of the research and purpose of the interview, the conversation with the service user is started guided by the following questions:

### Past / background service user

Can you tell me about...:

- The reason you receive care and treatment at the Robert Coppes Foundation? Focus on: Impairments, functions, external and personal factors and the influence on the functioning of the service user.
- Your experiences with care and treatment elsewhere before or during the care and treatment provided by the RCF?
- Important events in your past that you think have affected your current functioning?

### Care process

Can you tell me about...:

- Your experience with the care and treatment you receive from the RCF?
- Your experience with the care and treatment you receive from the RCF compared to previously received care and treatment at other institutions?
- The things/milestones you have achieved thanks to the care and treatment you receive from the RCF?

- What were the most important elements/characteristics in the care and treatment from the RCS that enabled you to achieve this?
- Which aspects (in knowledge, skills, attitude, vision, organisation) of your care worker(s) have contributed to this in your opinion?
- Your goals in the future, that you want to achieve with the care and treatment from the RCF?
- How does the care and treatment from the RCF facilitate in this?
- What do you think is lacking in the care and treatment of the RCF to achieve this?

#### Additional questions

- Can you give an example of a situation in which you had a good experience about the care and treatment of the RCF?
  - In this example, what, in particular, has contributed to this good experience?
- Can you give an example of a situation in which you were dissatisfied with how you were provided care and treatment by the RCF?
  - In this example, what in particular contributed to the dissatisfaction?
- Suppose you get a new employee as a care worker, what important tips would you give this care worker from your experience so that they can support you as well as possible?
- Are there any things lacking or you want differently in your current care and treatment?

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## APPENDIX 9: INTERVIEW GUIDE USED IN THE GROUP MEETING WITH SERVICE USERS

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General introduction about the care process by explaining the general phases in the care process (application/intake, assessment, executing plan, evaluation).

### Questions:

1. To what extent does this match what you need? Can you explain why this is a match or does not match?
2. How do you experience the care and treatment at the RCF? What is similar? Where is the difference?
  - How do you experience this?
  - Why is this so important?
3. What is the purpose of the care for you in particular?
  - Why is this so important to you?

Explaining the key elements indicated by professionals in the care and treatment for adults with VI and SMI:

- Safety and trust
- Obtain a detailed understanding of the problems and needs
- Offer time and space
- Slow, long-term and stepwise
- Specific knowledge needed on the VI

### Questions:

1. Which of the elements do you think are really indispensable in the care and treatment?
  - Why is this so important?
  - When did you achieve this?
  - What do you need in this?
2. Are there also elements that you do not acknowledge as important in the care and treatment?
  - Why do you not acknowledge this?
3. What do professionals need (in terms of knowledge / preconditions) to be able to offer this?
  - Is this present now?

## APPENDIX 10: EXAMPLE OF LESSON IN THE E-LEARNING COURSE

Figure A.5

Example of a lesson in the E-learning course

The screenshot displays an e-learning interface. On the left, a sidebar contains a navigation menu with the following items: 'Kenmerken van cliënten met VB en EPA', 'Beschrijving van het hulpverleningsproces', 'Onderliggende theorieën', 'Uitkomsten', 'Contextuele factoren' (highlighted in red), 'Logisch model', and 'Vragen'. The main content area is titled 'met een visuele beperking en ernstige psychiatrische aandoening' and 'OK COMPLEET'. Below the title, a sub-header reads 'Er zijn verschillende contextuele factoren die van invloed zijn op de aanpak en uitkomsten'. A horizontal menu below this sub-header includes 'SAMENWERKING GGZ', 'TOEPASSEN PROTOCOLLEN', 'CULTUUR ORGANISATIE', and 'HOUDING PROFESSIONAL'. The main text discusses the challenges of providing care for individuals with visual impairments and serious mental health conditions, noting a lack of experience in the sector and the need for a supportive environment. It includes a quote from a person with a visual impairment: 'Ja, dat ze vergaten natuurlijk om mij een arm te geven als we ergens naar toe moesten lopen, liepen ze al vooruit; dan moest ik echt roepen, ik moet een arm hebben, want ik kan het niet zien, of je 's ochtends douchen, dat ze me vergaten, en dat ik zei van ik moet hulp hebben om naar de douche gebracht te worden; of therapieën, dat gebeurde dan met kaarten, dat kon ik dan niet natuurlijk; dus dat zei ik ook, ik kan daar niet om meedoen, want ik kan dat niet zien; ze hadden gewoon helemaal niks voor visueel beperkten, en continu eigenlijk vergeten, van oja wat heeft iemand nodig, en met het eten, bij de [naam woonvorm] werd het voor je opgeschept en klinkgewijs vertelt waar het lag en het vlees gesneden, en daar was het, hier is je bord en zoek het maar uit; met brood, moest ik vragen, kun je even voor me smeren; ja, het was heel vermoedend.' (C2). The text concludes with 'Binnen de visuele sector is er basiskennis over psychiatrische problemen aanwezig, maar is er weer te weinig ervaring als het gaat om'.

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## APPENDIX 11: QUESTIONNAIRE USED IN PHASE III FOR PROFESSIONALS

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1. At which organisation are you employed? (Respondents could choose one of the following answers by ticking the box:)

- RCF;
- other organisation within the visual sector;
- other organisation outside the visual sector.

2. What is the setting you are working in? (Respondents could choose one of the following answers by ticking the box:)

- residential care;
- outreach care;
- other.

3. Do you acknowledge the description of current practice as accurate? (Respondents could choose ticking the box for either:)

- Yes;
- No.

4. Explain your answer (respondents could supply a free-text response);

5. Which elements in the description do you not accept as accurate? (Respondents could supply a free-text response.)

6. What is missing in the description? (Respondents could supply a free-text response.)



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## **APPENDIX 12: ACCOMPANYING LETTER TO THE DESCRIPTION OF CURRENT CARE AND TREATMENT SENT TO THE SERVICE USERS**

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**What is important when providing care and treatment to service users who have a VI and mental health problems?**

Hi [name of service user],

In a study by the Robert Coppes Foundation we try to describe the care and treatment to our service users who also experience mental health problems. We have done this by asking professionals and service users what is important in the care and treatment. Through these conversations we were able to make a description of the current care and treatment.

We would now like to check whether this description is really in line with how the service users experience this. Would you therefore like to read through the accompanying text and answer the four questions in the other document?

You can reply, by sending your answers to the following e-mail address: [email research assistant]. If this is difficult for you, we can also call you and then you can pass on your answers.

Enjoy reading this description and we are looking forward to your response.

Thank you very much,

Marit van Buijsen.

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**APPENDIX 13: QUESTIONNAIRE USED IN PHASE III FOR THE SERVICE USERS**

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1. Do you acknowledge this description as accurate? (Respondents could choose either:)

- Yes;
- No.

1. What aspects do you find particularly accurate? (Respondents could supply a free-text response.)

2. What aspects do you not acknowledge? (Respondents could supply a free-text response.)

3. What is missing in the description? (Respondents could supply a free-text response.)

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## APPENDIX 14: LIST OF CONFERENCES ON WHICH THE OUTCOMES OF THE STUDY WERE PRESENTED

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- Buijsen, M. van (2018). *Ondersteunen van volwassenen met een visuele beperking en psychiatrische problematiek. Wat is de huidige werkwijze en waarom? [Providing care and treatment for adults with VI and SMI. What can be indicated as current practice and why?]* Presentation on Focus on research 2018, Ede, the Netherlands, June.
- Buijsen, M. van., Zutphen, S. van, Roosmalen, N. van, Laak, T. van de (2018). *Specialistische begeleiding aan blinde of slechtziende volwassenen met psychiatrische problemen. Delen van kennis en ervaringen uit de dagelijkse praktijk. [Specialist care and treatment to adults with VI and mental health problems. Sharing knowledge and experiences of daily practice]* Presentation on the National knowledge day of the visual consortium, Zeist, The Netherlands, June.
- Buijsen, M. van, Munster, E. van, Teunissen, L. (2019). *De visuele beperking als loden mantel. Combinatie van een visuele beperking en een ernstige psychische aandoening: signalering, impact en hulpverlening. [The visual impairment as a lead cover. Combination of a VI and SMI: detection, impact and care provision].* Workshop on Meeting day of ZonMW programme InSight, Amersfoort, March.
- Buijsen, M. van, Roentgen, U., Verstraten, P., Hove, G. van, Weich, S., & Witte, L. de (2019). *Current practice in the support of visually impaired adults with a serious mental illness: knowledge and experiences of professionals.* PGR Conference, SchARR, University of Sheffield, Sheffield, UK, 6 juni & ESLRR conference, Manchester, UK, September 10-12.
- Buijsen, M. van & Vlodrop, V. van (2019). *Onderzoek, leren en ontwikkelen. Psychiatrie in combinatie met een visuele beperking. [Research, learning and development. Mental health problems in combination with a VI].* Presentation on the annual knowledge day of the RCF, Vught, September.

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