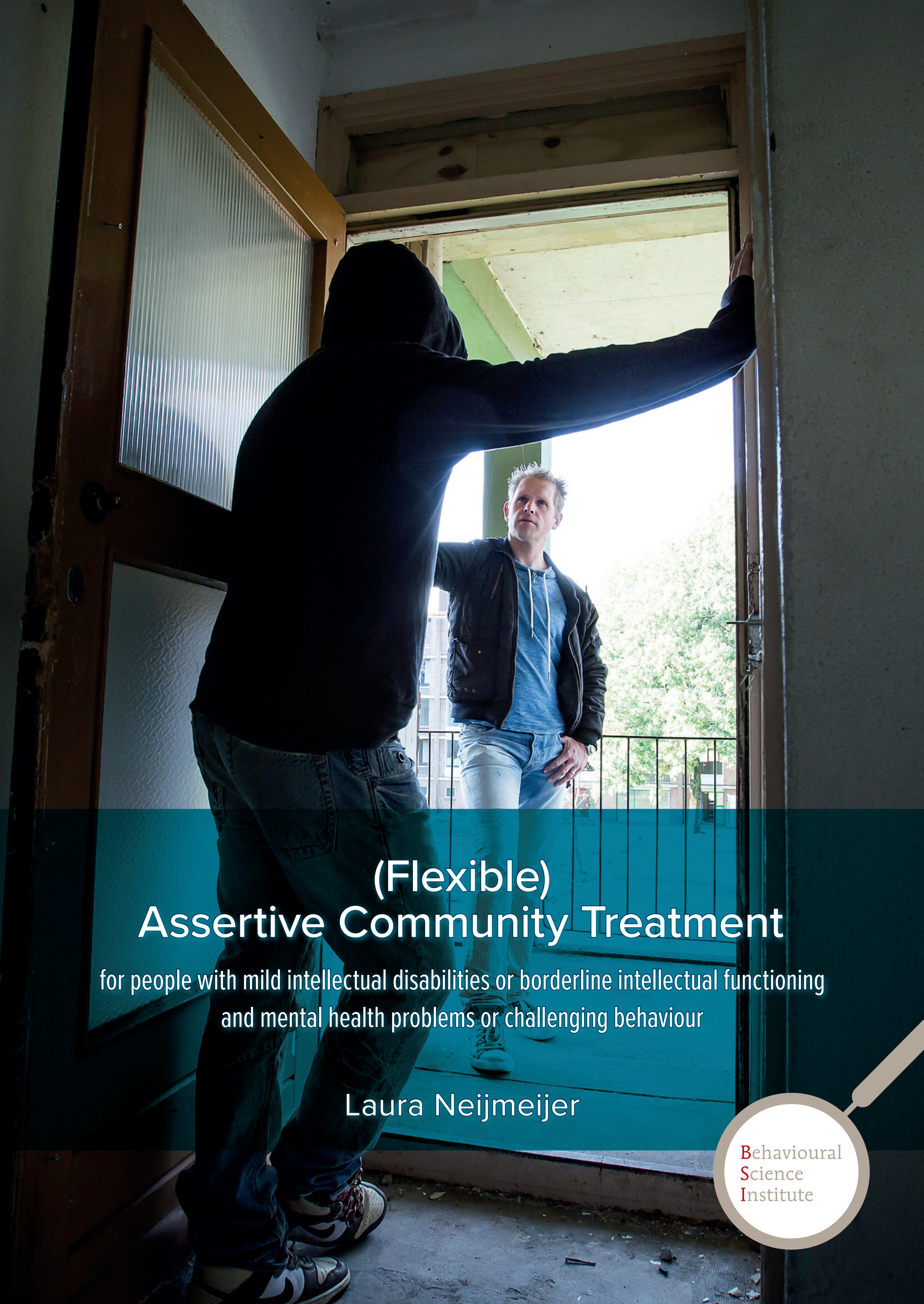

(Flexible) Assertive Community Treatment

for people with mild intellectual disabilities or borderline intellectual functioning and mental health problems or challenging behaviour

Laura Neijmeijer

Behavioural
Science
Institute

(Flexible)
Assertive Community Treatment

for people with mild intellectual disabilities or borderline intellectual functioning and mental health problems or challenging behaviour

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Behavioural Science Institute
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Table of contents

1

General introduction

1.1 Joey

Joey is 31 years old when he becomes a client of the Flexible Assertive Community Treatment (FACT) team of Trajectum, an organisation that is specialised in the treatment of individuals with mild intellectual disabilities (MID) or borderline intellectual functioning (BIF) and mental health problems or severe challenging behaviour. Joey was referred by the probation officer connected to the Salvation Army, where Joey ended up in a shelter after his last detention period of two months. In the past, Joey was convicted several times, usually because of driving under the influence of alcohol and unpaid fines. As far as known, Joey does not have a history in youth care or (mental) health care. There are suspicions that Joey has a mild intellectual disability. The suspicion is strengthened after Joey completes the SCIL, a screening instrument for mild intellectual disabilities. Because of the persistency of his alcohol use and criminal behaviour, Joey is legally obliged to undergo FACT treatment.

The first period in FACT, one or two case managers visit Joey several times a week at the shelter. Initially, Joey shies away for the involvement of the FACT team; as a 'self-made man' he wants to live his life in his own way. But when the team members continue to visit him and even arrange a benefit and an identity document for him, he changes his attitude and finally accepts the professional help.

Over time, it becomes clear that Joey has many problems in daily life. Joey has no daytime activities and spends his days with hanging around, drinking and smoking. He does not have a house of his own and has large debts. He is not able to take care of his administration, and contacts with local authorities and instances usually end up in hassle and quarrels. Joey's social network consists mainly of tipplers who regularly cause social disturbance and who are known by the police. Long-term use of alcohol has affected his physical condition. An intelligence test shows a total IQ-score of 63.

In close contact with Joey, the FACT team formulates a treatment plan. First priority is to find independent housing since living in a shelter with other people gives Joey a lot of stress. Over time, when housing is realised and Joey has found more rest and stability in his life, the team members notice that the possibilities to discuss Joey's lifestyle gradually increase. In conversations with the psychologist of the team, Joey decides that he wants to regulate his alcohol use by creating more structure in daily life and by avoiding his 'friends'. Through an intervention of the team, Joey starts helping in a work shop for bicycles, where he also stays over for lunch. To support Joey with respect to finances and administration, the team establishes contact with an administrator. To monitor his physical situation, Joey receives an invitation for a physical examination every six months. When visiting physicians, hospitals and local authorities, Joey is assisted by one of the case managers.

1.2 Background

Assertive community treatment (ACT) and flexible assertive community treatment (FACT) are relatively new forms of care for people with (mild) intellectual disabilities or borderline intellectual functioning and mental health problems or challenging behaviour. The case of Joey already reflects some key features of the working method of (F)ACT teams, and is illustrative for its clients as well. In this chapter these features are considered in more detail. Also, the underlying principles and objective of (F)ACT are explained.

ACT and Flexible ACT

Originally, ACT was developed for individuals with severe mental illness. ACT teams in mental health care offer ambulant, intensive and long-term treatment and support to people who suffer from, for example, recurrent psychotic disorders or severe mood disorders. Individuals who receive treatment from ACT teams usually have a long history in mental health care and have been (involuntarily) admitted several times. The severity of the symptoms and the long-term course of the illness have far-reaching adverse consequences for the daily life, the social and psychological functioning and the wellbeing of the persons concerned and their families. Because of their illness, but also because of their negative experiences with mental health care in the past, they are often not open for professional help and involvement from mental health care. Some of them are avoidant or downright dismissive.

ACT was developed in the seventies of the last century in the United States as a response to the so-called ‘revolving door’ phenomenon: the phenomenon in which clients with severe psychiatric (often psychotic) symptoms had to be admitted repeatedly because of a relapse in symptoms (Kroon, 2015). In that time, there was a big gap between inpatient and outpatient care; individuals who were admitted to the hospital were backed by multidisciplinary, intensive treatment and medication management, while outside the hospital, the contact with mental health care was reduced to a visit to a counsellor of the outpatient department every two weeks. For many clients the organisation of mental health care was not in line with their needs, and reformers in mental health care advocated for a new organisation principle based on the needs of the clients instead of the services offered by health care organisations. This implied that the partitions between inpatient and outpatient care should disappear and that outpatient care should be as intensively and comprehensively as inpatient care. Additionally, the outpatient care should not only be aimed at reducing the symptoms of the disease, but also at resuming personal and social life and participation in society, i.e. ‘training in community living’ (Stein & Test, 1985).

ACT teams consist at least of a psychiatrist, behavioural specialists, social workers and (specialist) psychiatric nurses and provide intensive and long-term treatment and care in the client's home or elsewhere in the community (e.g. in a shelter, at work, on the street). A team of around 10 professionals has joint responsibility (shared caseload) for providing a wide range of treatment and supportive interventions, including medication, support regarding living, work and finances, psychological treatment (e.g. cognitive behavioural therapy, emotion regulation, trauma treatment), addiction care and somatic care for approximately 100 clients. In the case of admission to a psychiatric hospital, the ACT team remains involved in the client's treatment and maintains contact with the client and clinical staff. ACT has been described and standardised, and widely implemented inside and outside the US. ACT is the most extensively studied care delivery model for people with severe mental illness and is recognized as an evidence-based practice in the US (Kroon, 2015).

In the Netherlands, an adaptation of the original ACT model has been developed: Flexible ACT (FACT). FACT teams combine highly intensive multidisciplinary treatment (ACT) for unstable clients at risk of relapse with moderate intensive care for the more stabilised ones. In FACT teams the intensity of treatment and care can be scaled up easily and flexibly (from, for instance, once or twice a week to once a day) if necessary (Van Veldhuizen, 2007; Van Veldhuizen, Polhuis, Bähler, Mulder & Kroon, 2015). FACT teams work according to the same principles as ACT teams, but usually serve more clients (around 150).[1] With circa 400 FACT teams, FACT has become the standard for organising care for individuals with severe mental illness in the Netherlands and has found favour in other European countries, such as Belgium, Norway, Denmark, Sweden and the UK (Firn & Brenton, 2015).

(F)ACT MID/BIF

In several countries, attempts have been made to extend ACT principles to other groups of people with special needs such as individuals with forensic histories, children and adolescents in multi-problem situations, and individuals with (mild) intellectual disabilities and comorbid problems. These groups have in common that they are difficult to reach by regular facilities of (mental) health care - on the one hand because of the complexity and multiplicity of the problems of these clients, on the other hand because of factors related to the organisation of health care, such as insufficient collaboration between sectors and facilities, lack of expertise, different funding structures and rigid formulation of inclusion and exclusion criteria.

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[1] For an overview of the similarities and differences between ACT and FACT, see Table 1 on page 25.

In the nineties of the last century, the first publications appeared on ACT for people with intellectual disabilities. One of the first studies was a Dutch study in which ‘outreach treatment’ was compared with inpatient treatment (Van Minnen, Hoogduin & Broekman, 1997) among individuals with mild intellectual disabilities (MID; IQ between 50 and 70) or borderline intellectual functioning (BIF; IQ between 70 and 85). Outreach treatment for individuals with MID/BIF and severe mental disorders turned out equally effective in reducing psychiatric symptoms when compared with inpatient treatment, against lower costs. Also, the results showed that in 84% of the cases admission to a mental health hospital could be prevented. The interest in assertive outreach for individuals with lower intellectual functioning was amplified by the UK-700 trial (Hassiotis et al., 2001) which showed that individuals with BIF and psychotic disorders were admitted less frequently to hospitals than individuals with an average or higher intelligence when they received ‘intensive case management’ instead of ‘standard case management’.

In spite of these promising results, ACT or comparable forms of assertive outreach have been implemented in no country on a large scale in the ID-field. As a consequence, the research base of ACT for people with ID is relatively small. Moreover, the few studies that have been publicised on this subject differ in design, study population[2] and studied intervention, with the consequence that it is hard to draw firm conclusions about the effectiveness of (F)ACT for people with ID in general and people with MID/BIF in particular.

In the Netherlands, four organisations (cooperating in expertise centre “De Borg”) have been appointed by the government to provide highly specialised treatment for people with MID/BIF and mental health problems or severe challenging behaviour. Between 2011 and 2017 these organisations participated in a nation-wide research and development project. The goal of the project was two-fold: to gain experience with (F)ACT for clients with MID/BIF and to study the outcomes of this new form of specialized treatment in the ID-field. As a first step, the original (F)ACT model was adapted and described for use with people with MID/BIF, using both outcomes of empirical studies and expert opinions. With this, we met the needs stated by researchers to describe and standardize (F)ACT for people with intellectual disabilities to facilitate the comparison between studies. In 2011, a first guide was developed for the purpose of supporting starting (F)ACT MID/BIF teams in the delineation of their target group and determining their team structure and team processes (Rijkaart & Neijmeijer, 2011). In the subsequent years, the model was tested and implemented in practice, leading to a revised version of the (F)ACT MID/BIF model description (Neijmeijer, 2015). Also, to assess

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[2] While some studies focussed on people with MID and/or BIF, others included clients with moderate ID (IQ between 35 and 50) as well or did not specify levels of IQ or ID.

the degree of implementation of the model a fidelity scale was developed, based on the (Dutch translation of the) original Dartmouth Assertive Community Treatment Scale (DACTS) (Van Dijk, Mulder & Roosenschoon, 2004) and the Flexible Assertive Community Scale (FACTS) (Van Vugt et al., 2011) by which the degree of implementation of the model can be measured (see Table 1).

In the (F)ACT MID/BIF model the leading principles of the original (F)ACT model have been maintained. Similar to the (F)ACT-teams in mental health care, (F)ACT MID/BIF teams provide ambulant, multidisciplinary, intensive, continuous, long-term and outreach treatment and support on all areas of life. Also, (F)ACT MID/BIF teams work with a shared caseload. The target group of (F)ACT MID/BIF is described as follows: “People with MID/BIF who have (severe) mental health problems or challenging behaviour, in combination with varying problems in different fields of life. It concerns people who, for a variety of reasons, lost their grip on life, who can not take care of themselves, who do not ask for help actively, who are difficult to stabilise and frequently end up in crisis situations. Several of them are dependent of alcohol and/or drugs and exhibit aggressive or criminal behaviour. Some people live independently, others live in shelters or in residential facilities” (p. 13, Neijmeijer, 2015).

The most important additions to the original (F)ACT model concern the relational aspects: team members should adjust their attitude, communication and treatment to the emotional, cognitive and adaptive level of functioning of their clients. For instance, caregivers should find a balance between a structuring approach on the one hand, and a coaching approach on the other. Also, it is important not to overcharge, neither to undercharge clients, and to focus on competences and successful experiences instead of their limitations and their experiences of failing. In addition, the special characteristics and needs of the caseload put demands on the staffing of the (F)ACT teams and the services they provide. For instance, a smaller caseload per staff member (than in ‘regular’ teams) seems indicated since clients with MID/BIF need intensive support on different areas of life. Also, the composition of (F)ACT MID/BIF teams is somewhat different; it is recommended, for example, that besides a psychiatrist, an intellectual disability physician participates in the team. Further, educational/behavioural expertise and systemic expertise should be present in the team and all team members should be educated and skilled in the treatment of people with MID/BIF. Since clients may have a criminal history, it is also important to equip the team with expertise in risk assessment and risk management, and to develop a policy regarding safety. Through the deficiencies in learning capacities and coping skills of people with MID/BF, systemic and environmental interventions are at least as important as client based interventions. Table 1 shows an overview of all (59) items of the (F)ACT MID/BIF model, ordered by subscale.

Table 1 FACT MID/BIF fidelity scale

	Subscale	Items
I	Team structure	11 items: small caseload, staff capacity, scope of employment, psychiatrist / intellectual disability physician, behavioural specialist, social workers and nurses, system specialist, addiction specialist, supported employment specialist, peer specialist, case managers staff
II	Team process	12 items: shared caseload during less intensive care, shared caseload during ACT, frequency of briefings, multidisciplinarity of briefings, multidisciplinarity of treatment plan meetings, client and family involvement in treatment plan, team leader criteria, FACT board placement criteria, FACT board placement procedure, FACT board removal procedure, contact frequency during ACT, contact frequency during less intensive care
III	Diagnostics and treatment	14 items: multidisciplinarity of diagnostic procedure, risk assessment, shared caseload during introductory phase, multidisciplinarity of practical support, treatment plan, crisis intervention plan, medication plan, psychoeducation, specialised behavioural treatment, family interventions, integrated addiction treatment, medical care, education and daytime activities, consultation to other facilities
IV	Organization of services	10 items: admission procedure, waiting list, 24-hours accessibility and crisis support, safety policy, responsibility for hospital admission, emergency admission, services during hospitalisation, responsibility for discharge planning, transfer of care at program discharge, dropout prevention
V	Community care	4 items: outreach, coordination and cooperation, assertive engagement, cooperation with informal support system
VI	Monitoring	4 items: periodic client assessment, routine outcome monitoring, feedback clients and family, quality improvement cycle
VII	Professionalism	3 items: reflective feedback, training, team spirit

1.3 The present thesis

This thesis focuses on the treatment outcomes of (F)ACT in individuals with MID/BIF and mental health problems or challenging behaviour. The main research question addressed in this thesis was: *What are the treatment outcomes of (F)ACT for individuals with MID/BIF and mental health problems or challenging behaviour?* Since (F)ACT can be characterized as a 'complex intervention containing several interacting components' (Craig et al., 2008), different research sources and designs were used to answer the following questions:

1. What is known about the effectiveness of (F)ACT for individuals with intellectual disabilities, and how has (F)ACT MID/BIF been developed in the Netherlands? (chapter 2)
2. What are the characteristics of the clients who receive treatment in FACT MID/BIF teams, and what are the outcomes of FACT MID/BIF over time, in terms of social and psychological functioning, admissions in (mental) health care, (risk of) challenging and criminal behaviour, and social participation? (chapter 3)
3. Is there an association between client variables and treatment outcome of (F)ACT MID/BIF, in terms of social and psychological functioning? (chapter 4)
4. How do clients with MID/BIF value the treatment and the results of (F)ACT, in terms of daily functioning and well-being, and which factors are perceived as supportive? (chapter 5)

For an overview of the international state of the art regarding (F)ACT for people with MID/BIF, we performed a literature review. The results of this critical review address the first research question and are described in chapter 2. For answering the second research question we used a data set derived from a six-year longitudinal study in which eight FACT teams participated. Data comprised assessments of 604 clients of whom 278 had at least two measurement moments over time. Outcome measures concerned hospital admissions and incarcerations, social and psychological functioning, (risk of) challenging and criminal behaviour, and social participation. The results are described in chapter 3 and 4. In addition, a qualitative study was performed to explore the perspectives of clients who receive treatment of (F)ACT. Fifteen clients from two FACT MID/BIF teams were interviewed on their experiences with FACT. The results provide an answer to question 4 and are described in chapter 5. The final chapter (chapter 6) provides a summary of the main findings of this thesis and presents its general conclusions.

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2

Assertive Community Treatment for people with mild intellectual disability or borderline intellectual functioning and mental health problems or challenging behaviour: State of the art and implementation in the Netherlands

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Abstract

Individuals with mild intellectual disabilities (MID) or borderline intellectual functioning (BIF) and mental health problems or challenging behaviour are difficult to reach by mainstream health care facilities and support organisations and frequently avoid the care they need. To improve the care for this client group in the Netherlands, the (Flexible) Assertive Community Treatment (ACT) model - originally developed for people with severe mental illness - was adapted and implemented by five organisations specialised in the care for people with MID/BIF and mental health problems or challenging behaviour. After an introduction of the original ACT model and a description of the international state of the art of ACT for people with (M)ID/BIF, this paper describes the (Flexible) ACT-MID/BIF model as developed and implemented in the Netherlands. Professionals' and clients' experiences with this new type of care are reported as well. Implications for clinical practice, policy and research are discussed.

Introduction

In many countries, there is a growing awareness that individuals with mild intellectual disabilities or borderline intellectual functioning (MID/BIF) form a vulnerable group in society. On average, they live more often in adverse social and economical conditions, are more often unemployed and are more likely to report being in poor health and receiving insufficient emotional support (e.g., Emerson, Hatton, Robertson & Baines, 2014; Havercamp & Scott, 2015; Kavanagh, Krnjacki, Beer, Lamontagne & Bentley, 2013; Mithen, Aitken, Ziersch & Kavanagh, 2015). Further, people with MID/BIF are at increased risk for developing substance use disorders and for the harmful consequences of substance use (e.g., Slayter, 2008; Van Duijvenbode et al., 2015), and have a higher risk for chronic stress and mental health disorders such as anxiety, post traumatic stress disorder (PTSD), affective disorders and (anti-social) personality disorders (e.g., Chen, Lawlor, Duggan, Hardy & Eaton, 2006; Gigi, et al., 2014; Hassiotis et al., 2008; Zammit et al., 2004). They also seem to be overrepresented in shelters for homeless people (Lougheed & Farrell, 2013; Van Straaten et al., 2014) and in prisons (Hellenbach, Karatzias & Brown, 2015; Kaal, Nijman & Moonen, 2015). Finally, the number of individuals with MID/BIF who receive care and treatment in ID facilities has also increased, both absolutely and in respect to the proportion of individuals with severe or moderate ID. On the basis of a series of interviews with experts and policy makers in the ID field, the Netherlands Institute for Social Research (Woittiez, Putman, Eggink & Ras, 2014) concludes that this increase is not so much a consequence of demographic changes (i.e., increase of number of people who develop MID/BIF), but a result of developments in society. In short, experts agree that as a consequence of the increasing complexity of the society, individuals with MID/BIF find it harder to function in daily life and to participate in society. Work demands have increased, education has become large-scaled and less structured, and daily activities, such as traveling by public transport and arranging financial matters, require relatively high levels of intellectual and adaptive skills which people with MID/BIF often lack. At the same time, there is a growing awareness that people with an ID should participate in society as much possible. However, many people with an ID do not succeed in this without professional support (Woittiez et al., 2014).

Organizing good health care for people with ID and mental health problems or challenging behaviour has been a concern for many countries for a long time. Research to existing models of services for adults with ID and mental illness shows that the evidence for which is the best approach (services integrated in mainstream health care or separately organized), is limited (Balogh et al., 2016). Whereas in some countries, such as the UK, policy dictates that people with ID who have additional mental health problems should access mainstream psychiatric services whenever possible, other countries rely on a categorical approach with specialized facilities for this client group. In the Netherlands, both models are applied, which implies that the care for individuals with MID/BIF and mental health problems or challenging behaviour has allocated to both mainstream facilities and to some specialized organisations. However, both research and practice learn that general health care facilities often are not able to fit the needs of individuals with MID/BIF and mental health problems or challenging behaviour. For example, most staff members in mental health care facilities are not equipped to identify clients with MID/BIF and to interact and communicate with them, resulting in false diagnoses, inadequate treatment, more lengthy hospital stays, more use of coercive measures and poor treatment outcome (e.g., Chaplin, 2009; Hurley, 2006; Nieuwenhuis, Noorthoorn, Nijman, Naarding & Mulder, 2017). Conversely, the same holds true for staff members in the ID field: because of their lack of knowledge with regard to mental health issues, mental disorders are missed and treatment facilities adapted to these individuals are insufficient (e.g., Hassiotis, Tyrer & Oliver, 2003).

In the Netherlands, four facilities (cooperating in expertise centre ‘De Borg’) have been appointed by the government to provide highly specialized treatment for people with MID/BIF and mental health problems and challenging behaviour. Since the Ministry of Security and Justice is an important referrer and financer of these facilities and many clients have a criminal sanction, the attention of policy and management has been focused mainly on (highly secured) inpatient care, which made the ‘De Borg’ strongly inpatient-oriented for a long time. As a consequence, a gap has arisen between the (extensive, highly specialized, intensive and regionally oriented) inpatient ID care and the (lower intensive, lower specialized and locally oriented) outpatient care for this client group, leading to discontinuity after discharge and readmissions. Moreover, there was a growing awareness that individuals with MID/BIF and mental health problems or offending behaviour *without* a judicial or legal measure (yet) and who were not motivated for help, were often not reached by health services, neither from the specialized ‘Borg’ facilities, nor from the mainstream facilities.

Since several years, the Dutch Ministry of Security and Justice and health insurers have placed ambulant programs for people with challenging and offending behaviour, including individuals with MID/BIF, on their internal policy agenda more firmly, with the aims of diminishing the pressure on inpatient care, enhancing integration of individuals in society, reducing nuisance in the neighbourhood and beyond, and in the end, reducing costs. With this, the Netherlands takes the same route as other countries like the UK and Canada did before (see e.g., Guinn, Jaydeokar, McCarthy, Roy & Hassiotis, 2016; King et al., 2009). Consequently, intensive and specialized community mental health services for individuals with MID/BIF have become increasingly important.

Assertive Community Treatment in mental health care

Assertive Community Treatment (ACT) is a model for the organization of treatment, support and recovery for people with severe mental illness combined with problems in important domains of life (e.g., housing, finances, work, social functioning). ACT teams focus on individuals who can not (sufficiently) be reached by and treated in regular inpatient or outpatient mental health care facilities (i.e., hospitals, outpatient centres and supportive housing). Most clients in ACT-teams suffer from schizophrenia or other psychotic disorders, often combined with drug or alcohol abuse and addiction (see e.g., Van Vugt et al., 2011). Because of negative experiences with professional help in the past, many clients are not motivated or even refuse to accept help. Hence, assertive engagement can be considered as one of the primary active ingredients of ACT (McGrew, Pescosolido & Wright, 2003).

ACT has been developed in the 1970's in the US (Stein & Test, 1980) as an alternative for the strongly medically oriented, inpatient treatment at that time. To bridge the gap between the extensive, highly specialized, intensive and multidisciplinary inpatient treatment on the one hand and the small-scaled, low-intensive and monodisciplinary outpatient treatment on the other, Stein & Test introduced a 'training in community living program' which was as intensive as inpatient treatment programs. By delivering intensive and comprehensive treatment, training and support at the clients' home from a multidisciplinary team, the developers aspired to prevent admissions in mental hospitals, to improve clients' quality of life and to contribute to the recovery of people with mental health problems.

ACT, the re-naming of the training in community living program, has been described and standardized, and empirical studies have yielded positive results in (mainly) the US, for example with respect to number and duration of admissions, homelessness, living conditions, employability and client satisfaction (Marshall & Lockwood, 1998). These positive results cleared the road for dissemination of the ACT model in countries all over the world, including Canada, Australia, Japan and several countries in North-western Europe. However, the faith in ACT as a evidence -based model of care was challenged when research from the UK suggested that 'assertive outreach' was not more effective than standard care provided by community mental health teams (Killaspy et al., 2006) - probably because of the relatively high standard of care as usual provided by community mental health teams, as well as the reluctance to embrace strict interpretations of model fidelity (Firn & Brenton, 2015). While in some countries these controversies led to a stagnation in the implementation of ACT, in other countries the developments continued.

In the Netherlands, an adaptation of the original ACT was developed: Flexible ACT (FACT). FACT combines highly intensive multidisciplinary treatment (ACT) for unstable clients at risk of relapse, neglect and readmission with moderate intensive case management for the more stabilized clients (Van Veldhuizen, 2007).

Clients of the latter category receive individual, outreach and recovery-oriented treatment from the same treatment team. In this less intensive phase, clients are visited on average once a week. When symptoms of aggravate or life events occur and more care is needed, the treatment is ‘scaled-up’ to the ACT-level. ACT-clients within FACT are visited on average four times a week. By combining two treatment modes in one team, the continuity of care is guaranteed and the intensity of treatment can be adjusted to the needs of the client at that moment.

With more than 400 FACT-teams, Flexible ACT has become the standard for organizing care for individuals with severe mental disorders in the Netherlands and has found appeal among other European countries such as Belgium, Norway, Sweden and also the UK (Firn & Brenton, 2015). The Certification Centre for ACT and FACT (CCAF) was set up by Dutch mental health care professionals and researchers to maintain model fidelity and to assure organizations, family representatives and mental health care purchasers of the quality provided by these teams. Table 1 represents the essentials of both models, as well as the most important distinguishing elements between the ACT and the FACT-model, as applied in the Netherlands.

ACT for individuals with (M)ID/BIF: the state of the art

In several countries attempts have been made to extend ACT principles to groups of individuals with special needs, including individuals with addiction, individuals with forensic histories, children and adolescents and individuals with (M)ID/BIF. Table 2 presents the results of a selective and critical review of studies on ‘assertive outreach’ for individuals with (M)ID/BIF and mental health problems or challenging behaviour. In all studies displayed in the table, the investigated ‘intervention’ consists at least of outreach and multidisciplinary treatment.

One of the first studies on individuals with MID/BIF is a Dutch study in which ‘outreach treatment’ was compared with inpatient treatment (Van Minnen, Hoogduin & Broekman, 1997). Outreach treatment for individuals with MID/BIF and severe mental disorders turned out equally effective in reducing psychiatric symptoms when compared with inpatient treatment, against lower costs. Also, the results showed that in 84% of the cases admission to a mental health hospital could be prevented. The interest in assertive outreach for individuals with lower intellectual functioning was amplified by the UK-700 trial (Hassiotis et al., 2001) which showed that individuals with BIF and psychotic disorders were admitted less frequently to hospitals than individuals with an average or higher intelligence when they received ‘intensive case management’ instead of ‘standard case management’.

In spite of these promising results, ACT or comparable forms of assertive outreach have not been implemented on a large scale in the ID-field. As a consequence, the research base of ACT for people with ID is small. Two studies

Table 1 Essentials and criteria of ACT and FACT

Essentials of both models:

a) a multidisciplinary team including community mental health nurses, social workers, a psychiatrist, a psychologist, a client/family expert and an addiction expert, provides integrated care and treatment;
b) the team is responsible for the care of the whole caseload (shared caseload) and organizes daily briefings;
c) care and treatment are delivered for the main part in the community (at clients' home, at a centre for homeless people, at work) and continue if a client is hospitalized or incarcerated (continuity);
d) assertive strategies are used for getting in contact with clients who avoid care;
e) treatment and care are delivered as long as needed (long-term) and as intensive as needed.

Key criteria	ACT	FACT
Team caseload	100	200
Intensity of care	High intensive care (on average 3-5 face-to-face contacts per week)	Two levels of care: - high intensive care for the most instable clients - moderate care for the more stabilized clients (on average 1 face-to-face contact per week)
Staff/client ratio	1:10	1:15
Shared caseload	≥ 80% of the clients is seen by at least 4 disciplines each month	≥ 80% of the clients is seen by at least 4 disciplines each year
Daily coordination meeting	For all clients in caseload	For clients who are marked as 'ACT' client i.e. in need of high intensive care

(i.e., Martin et al., 2005; Oliver et al., 2005) compared ACT for individuals with mild ID (IQ 50-70) or moderate ID (IQ 35-50) and mental disorders with standard community treatment in a randomized controlled trial. Both studies could not find significant differences between the two conditions in terms of quality of life, level of unmet needs, individual functioning and carer burden. However, both groups of authors cautioned that their results did not indicate that ACT in people with intellectual disabilities is ineffective. Instead, the studies highlighted the difficulties in both the research methodology and in the implementation of ACT in ID services (also see Hemmings, 2008). Problems in developing and evaluating ACT-type

Table 2 Evaluation studies on assertive outreach for individuals with (M)ID/BIF.

Study	Participants	Investigated model / intervention	Results	Methodological and substantive comments
Coelho et al. (1993) Design: RCT Follow up period: 3 years (3 measurements) Location: Michigan, USA *n*=46	Clients with mild to moderate intellectual disability and mental illness or behavioural complications concerning mental illness	Experimental condition: Active community treatment model - Team composition: 'the team consisted of three mental health staff members and was able to appeal to the mental health services of the community mental health agency' - Staff/client ratio: 1 : 7-10 - Contact frequency: twice a week in client's natural environment - Treatment interventions: care coordination, training and support, behavioural programming, medication, brief individual psychotherapy and access to 24-hour crisis intervention and support Control condition: Traditional case management model - Team composition: services were coordinated and planned using an interdisciplinary team approach - Staff/client ratio: 1 : 35 - Contact frequency: 1 à 2 contacts per month (information on the place of the contacts not available) - Treatment interventions: the case manager coordinated the development of treatment plans, programs, and provided consultation and assistance to service providers and staff	Active community treatment was more effective than standard case management, i.e. resulted in: - Increased functional behaviours (AAMD) - Decreased maladaptive behaviours (MMBC) - Less intensive use of housing facilities (questionnaire) Persons in the active treatment model used more respite / crisis interventions than persons in the case management model	Coelho et al.: - Small sample size - Limited generalizability to other persons than persons at risk for institutionalization Authors of this present article: - Provision of services was brokered out to other services as well, rather than provided by one team as in ACT

Van Minnen et al. (1997) Design: RCT Follow-up period: 28 weeks (2 measurements) Location: The Netherlands *n*= 50	Clients with mild to borderline ID and psychiatric disorders	Experimental condition: Specialist outreach treatment - Team composition: psychiatrist, educationalist, social worker, community psychiatric nurses, co-ordinator - Staff/client ratio: information not available. - Contact frequency: on average, a total of 28.1 hours was allocated to each patient during the 28-week research period (7.2 with the patient in patient's natural environment, 13.0 with patient's direct carers and 7.9 with third parties). - Treatment interventions: as hospital treatment (see below), combined with psycho-education, support and therapy of client's social network Control condition: Standard specialized hospital treatment - Team composition: information not available - Staff/client ratio: information not available - Contact frequency: 24/7 staff availability - Treatment interventions: psychopharmacological medication, behavioural therapy, social skills training, education , and structured daily activities	Outreach treatment resulted in the same reduction in psychiatric symptoms (measured with the PIMRA, Reiss Screen and GSI) as inpatient treatment, against lower costs and no increase in family burden (measured with the NSCQ). Admissions to the special hospital could be prevented for 84% of the outreach-treated patients	Van Minnen et al.: - A relatively small and heterogeneous group was examined - Research period was relatively short Authors of this present article: - The experimental condition consisted of treatment interventions only (no supportive interventions), meaning that the criteria for ACT were not fully met - Contact frequency of the experimental condition was relatively low (once a week) - No information on staff / client ratio in both conditions

Table 2 Continued.

Study	Participants	Investigated model / intervention	Results	Methodological and substantive comments
Meisler et al. (2000) Design: Preliminary evaluation / observational study Follow-up period: 1 year Location: North Carolina, USA *n*=10	Clients with a moderate or mild ID and severe mental illness and conduct disorders, who had participated in the ACT program for 1 year and who spent a year or more in intensively supervised community residential arrangements prior to referral to ACT	Specialist ACT team for clients with both ID and mental illness - Team composition: The ACT team included a psychiatrist, a psychologist, nurses, a social worker and a vocational rehabilitation specialist. ACT team members shared responsibility for all clients. The program was centred on a cluster of apartments within a large complex. - Staff/client ratio: information not available - Contact frequency: information not available - Treatment interventions: Programming centred on achieving an individualized daily structure consisting of a balance of homemaking, socialization, recreation and employment. Members of the ACT team provided direct services to the clients and supervised the habilitation specialists.	The ACT approach resulted in a considerable decrease of days in hospital, less costs and more participation in (working) activities.	Meisler et al.: - Small sample size - Absence of a representative comparison group Authors of this present article: - No information on staff/client ratio and contact frequency
Hassiotis et al. (2001) Design: Post-hoc analysis on the basis of RCT-data ('UK 700 trial')	Clients with psychotic disorders and borderline intelligence resp. normal intelligence	Experimental condition: Intensive case management - Team composition: Multidisciplinary; several members of the team work with the same client - Staff/client ratio: 1:10-15	ICM appeared significantly more beneficial for borderline-IQ patients than those of normal IQ in terms of reductions in days spent in hospital, hospital admissions, total costs and needs and increased satisfaction	Hassiotis et al.: - Only one key variable (caseload size) distinguished the experimental and control condition

Follow-up period RCT: 2 years after randomisation Location: Manchester and London, UK *n*=586 (from 708)		- Contact frequency: on average, 3.35 face to face contacts per client per month (Burns et al., 2000) - Treatment interventions: ‘The ACT team provides rather than arranges interventions, practices assertive outreach, emphasises medication compliance and offers emergency cover’. Control condition: Standard case management - Team composition: care delivery from one case manager - Staff/client ratio: 1:30-35 - Contact frequency: on average, 1.46 face to face contacts per client per month (Burns et al., 2000) - Treatment interventions: ‘A case manager is expected to assess the person’s needs, develop a care plan, arrange for suitable care, monitor the quality of care provided and maintain contact with the client’. In the post-hoc analysis, outcomes were compared between borderline- and normal-IQ patients	ICM did not appear to increase social functioning or improve the clinical symptoms of patients with borderline IQ, compared with those of normal IQ	- Local service arrangements and perception of ID could limit the generalisation of the findings - The sample size was not calculated specifically to detect differences within subgroups Authors of this present article: - In ICM provision of services is brokered out to other agencies rather than provided by one team (as in ACT) - The intervention was not adjusted for people with BIF

Table 2 Continued.

Study	Participants	Investigated model / intervention	Results	Methodological and substantive comments
Martin et al. (2005) Design: Exploratory RCT with stratified randomisation Follow-up period: 6 months (2 measurements) Location: South-East London, UK *n*= 20	Clients with mild to moderate ID and schizophrenia or mood disorders	Experimental condition: specialist ACT team for people with mild or moderate ID and psychiatric disorders: - Team composition: community psychiatric nurses, a clinical psychologist or an occupational therapist - Staff/client ratio: information not available - Contact frequency: 'as many as contacts required per week' (not specified) - Treatment interventions: information not available Control condition: Standard community treatment (STC-ID): - Service delivery by one member of the service, usually a CPN - Staff/client ratio: information not available - Contact frequency: maximum once per week - Treatment interventions: assessment and monitoring	Both groups showed decreased levels of unmet needs and carer burden, and increased functioning. The standard care-group also showed a small increase of quality of life.	Martin et al.: - The results must be viewed with caution because of the small sample size - Possibility of selective sampling because clients with challenging behaviour and no demonstrable psychiatric disorder were excluded. However, psychiatric diagnosis in people with ID is often missed. - The main criterion for identifying ACT in this study was frequency of contact. This use of narrow criteria to define ACT could have resulted in blurring of the distinction between both treatment arms. - It is possible that the two treatment arms were too similar

				- The formation of the ACT team was problematic and limited by service constraints. This may have resulted in people receiving a diluted form of ACT. - It is possible that the chosen research design should not have been employed, because ACT is a complex intervention. Authors of this present article: - Client/staff ratio and treatment interventions in both arms were not specified - No psychiatrist in the team - Relatively short follow-up period (6 months)

Table 2 Continued.

Study	Participants	Investigated model / intervention	Results	Methodological and substantive comments
Oliver et al. (2005) Design: RCT ('TACTILD trial') Follow-up period: 12 weeks (2 measurements) Location: London / North Leicestershire *n*=30	Clients with mild or moderate ID suffering from severe mental illness and/ or challenging behaviour	Experimental condition: Specialist assertive outreach team for adults with mild or moderate ID and psychiatric disorder or challenging behaviour - Team composition: 'Multi-disciplinary and good accessibility to professionals'. 'Delivery of care by one or more professionals' (not specified) - Staff/client ratio: information not available - Contact frequency: on average, 16.8 contacts in 12 weeks (=1,4 per week) - Treatment interventions: 'following evidence based practice methods' (not specified) Control condition: Standard community care - Team composition: 'Multi-disciplinary and good accessibility to professionals'. 'Delivery of care by one professional' (not specified) - Staff/client ratio: information not available - Contact frequency: on average, 9.87 contacts in 12 weeks (=0.8 per week) - Treatment interventions: 'following evidence based practice methods' (not specified)	No significant differences were found between the primary (functioning) and secondary (burden on carers and quality of life) outcomes in the two groups	Oliver et al.: - The lack of difference in outcome could be explained by the overlap between the two interventions in practice (blurring) - Possible limitations in the choice of the primary outcome measures (GAF) and absence of other measures (e.g. adherence to medication) - Small sample size Authors of this present article: - Assertiveness was measured in terms of frequency and duration of contacts only. Team composition and treatment interventions were disregarded. - Short follow-up period (12 weeks)

Prakash et al. (2007) Design: Case note audit (retrospective study) Study period: 2 years (retrospective) Location: Oxfordshire, UK *n*=11	Adults with a MID and evidence of a severe and mental disorder, challenging behaviour, a history of non-engagement with health services and frequent admissions, who received standard community care from a learning disability team in the 2-year period before entering the assertive outreach team	Learning disability assertive outreach team: - Team composition: nurse, occupational therapist, social worker, behavioural support worker, consultant psychiatrist - Staff/client ratio: 1:20 - Contact frequency: on average 2 à 3 times per week - Treatment interventions: support in daily living, monitoring of client's mental health status, practical support, maintaining working relationships with community teams, risk assessment	The level of engagement with services improved for all participants. None of the participants had deteriorated in any area. This has not been translated into a short-term reduction in bed-occupancy.	Prakash et al.: - Small sample size - The questionnaire used was subjective and asked clinicians about a previous period, and was therefore prone to subjective bias Authors of this present article: - Standard community care was not defined by the authors - Consultant psychiatrist instead of a psychiatrist in the team
King et al. (2009) Design: Naturalistic, retrospective chart review Study period: 8 years (retrospective) Location: Ontario, Canada *n*=43	Clients with ID and mental health concerns or challenging behaviour	Specialist ACT team for individuals with intellectual disabilities and mental health concerns - Team composition: psychiatrist, nurses, social workers, vocational specialist, team leader, family physician, behavioural technicians - Staff/client ratio: information not available - Contact frequency: information not available - Treatment interventions: information not available	The number of hospitalizations (episodes and days) pre and post ACT-DD support showed a considerable decline. Due to reduced numbers of admissions, financial savings were realized.	King et al.: - Contrary to core ACT principles, the ACT-DD team continued the relationships with community-based agencies Authors of this present article: - Staff/client ratio, contact frequency and treatment interventions were not specified

Table 2 Continued.

Study	Participants	Investigated model / intervention	Results	Methodological and substantive comments
Douglas & Hurtado (2013) Design: Evaluation study (2 measurements) Follow-up period: 6 to 9 months Location: Buckimhamshire, UK *n*= 13	Clients with an ID, mental health problems and challenging behaviour, who did not effectively engage with healthcare services	Specialist assertive outreach team (AOT) for adults with ID and enduring mental health needs - Team composition: The AOT comprised a senior nurse / team leader, a staff nurse and two support workers and had access to multidisciplinary input of the community learning disability team (CLDT) - Staff/client ratio: information not available - Contact frequency: information not available - Treatment interventions: The AOT team made assessments of needs, strengths and risks and offered individualised treatment to improve health and quality of life	Clients showed significantly better functioning (measured by the HoNOS-LD) and less risk of harm (Risk Five-by-Five matrix) to self or to others, as well as a reduction in hospital admissions.	Douglas & Hurtado: - No reliable results for the MANS-LD and the satisfaction questionnaire because of low response - Findings of the studies are specific for the AOT in the study (no generalisability) Authors of this present article: - Staff/client ratio and contact frequency were not reported - Small research group

models for people with ID included the fidelity of the models to the original ACT model, a lack of distinction between the experimental and the control condition in practice, and other methodological issues such as a small sample size and a short time of follow-up measurements. Overall, more research was recommended (Balogh, Ouellette-Kuntz, Bourne, Lunsky, & Colantonio, 2008; Balogh et al., 2016), leading to publications of other (predominantly observational) studies on the effectiveness of assertive outreach for people with ID. For instance, King et al. (2009) conducted a naturalistic retrospective chart review among 43 clients of an ACT-DD (dual diagnosis, i.e. intellectual disabilities and mental health problems) team in Ontario, Canada. Most of the clients (*n*=31) had a mild ID, but the study included clients with moderate and severe ID and borderline intellectual functioning as well. The authors concluded that the reduced number of days of hospitalization, which were retrospectively measured pre and post engagement with the team, clearly demonstrated the value of the ACT approach in supporting individuals with an ID and severe mental health problems or challenging behaviour. More recently, Douglas and Hurtado (2013) investigated the outcomes of an assertive outreach team in the UK in 13 clients with ID and longstanding mental disorders. After 6 to 9 months of ACT, clients showed significant better functioning and less risk of harm to self or others. Also, the number of admissions decreased. However, the (positive) results of this study should be interpreted in the light of the small number of participants involved, the limited generalisability and the lack of a control group.

Several studies have been published on the structure, that is the distinguishing elements or the specific requirements, regarding ACT for people with (M)ID and mental illness. Prakash, Andrews and Porter (2007) described the experiences with an assertive outreach team for adults with mild ID and mental illness or challenging behaviour in Oxfordshire, UK, and concluded that “although superficially the assertive outreach team might appear little different from the standard community team, apart from having smaller caseloads, there are significant differences” (p. 141). As most important distinguishing features the authors mentioned the provision of services at weekends and the need for “working qualitatively in a different way” (p. 141), that is providing practical support to enable patients to access a range of community resources and establishing close relationships with the community teams and local services and constabularies. On the basis of the above mentioned Canadian study among clients of a ACT-DD team, King et al. (2009) formulated five necessary adaptations to the regular ACT model. These are: flexibility to admission criteria, to address misdiagnosis and the under-diagnosis of serious, persistent mental health illness in individuals with ID; the need to be flexible with respect to the maintenance of a ‘can-do-all approach’ given the reality that funding is provided by different government ministries; the need to encourage sub-specialty areas of expertise among team members, such as trauma psychotherapists and skilled systemic advocates to address the unique needs of the population served by the team; the need to educate hospital-based support teams regarding the needs of individuals with dual diagnosis and assisting in their support through extending the continuum of team support to individuals while hospitalized; and the availability of resources to address the needs of clients who are traumatised and/or suffer from PTSD.

It may be concluded that there are some indications that ACT is effective for individuals with (M)ID/BIF and mental illness or challenging behaviour, but more research is needed. In order to conduct scientific research of good quality and to increase the comparability of research outcomes, it is important to describe the target group, the applied model or interventions and the outcome measures as clearly as possible and to achieve consensus on these subjects under professionals and researchers (Hemmings, 2008). In the next paragraph we will describe the process of model development in the Netherlands, the choices we made within the model as well as the experiences of professionals and clients with the (F)ACT MID/BIF model.

(F)ACT MID/BIF in the Netherlands

Between 2011 and 2017 the four above mentioned specialized facilities[3] in collaboration with one regular health care organisation for people with ID[4] have participated in a comprehensive research and development project. The goal of the project was two-fold: to gain experience with (F)ACT for clients with MID/BIF and mental health problems or challenging behaviour and to study the outcomes of this new form of specialized treatment in the ID-field.

Model description

As a first step, the (F)ACT model was adapted and described for use with people with MID/BIF, using both outcomes of empirical studies (see previous section) and expert opinions. In 2011 a first guide was developed for the purpose of supporting starting (F)ACT MID/BIF teams in the delineation of their target group and determining their team structure and team processes (Rijkaart & Neijmeijer, 2011). In the subsequent years, the model was tested and implemented in practice, leading to a revised version of the (F)ACT MID/BIF model description (Neijmeijer, 2015) as well as a fidelity scale.[5]

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[3] De Borg is an alliance consisting of Trajectum, Aventurijn (Fivoor), Stevig (Dichterbij) and Middenweg (Ipse de Bruggen). These four facilities offer specialized treatment and care for individuals with MID/BIF and mental health problems and severe challenging behaviour nationwide.

[4] Idris, part of Amarant Groep.

[5] This fidelity scale is called the Flexible Assertive Outreach MID/BIF Scale (FACT-MID/BIF) and is used by the Dutch Centre of Certification of ACT and Flexible ACT teams (CCAF).

In the (F)ACT MID/BIF model the leading principles of the original (F)ACT model have been maintained (see table 1). Similar to the (F)ACT-teams in (regular) mental health care, (F)ACT MID/BIF teams provide ambulant, multidisciplinary, intensive, continuous, long-term and outreach treatment and support on all areas of life. Also, (F)ACT MID/BIF teams work with a shared caseload. The most important adaptations of and additions to the original (F)ACT model are in line with the recommendations of King et al. (2009) and Prakash et al. (2007). These are:

- In addition to the 'core disciplines' (i.e., community mental health nurse, social worker, psychiatrist, psychologist, client/family expert, addiction expert) (F)ACT MID/BIF teams consist of educational/behavioural and systemic expertise. All team members have been educated and skilled in the treatment of individuals with MID/BIF and are able to adapt their style of support and communication to the emotional, cognitive and adaptive level of functioning of their clients.
- Because clients with MID/BIF and mental health problems or challenging behaviour usually need intensive support on different areas of life and professionals have to spend a lot of time on arranging basic conditions (housing, financing) and contacts with community services and general health care facilities in the area of service, (F)ACT MID/BIF teams have smaller staff/caseload ratio's, i.e., 1:8 in ACT to 1:13 in FACT. The norm for the average number of face to face contacts with clients and/or their family members varies from 1.5 a week in FACT to 3 a week in ACT.
- With respect to treatment interventions: appropriate to the specific features of the clients in the caseload, (F)ACT MID/BIF teams focus on training in social and adaptive skills, emotion and aggression regulation, risk management, trauma treatment and addiction treatment. Through the limited learning capacities and coping skills of individuals with MIB/BIF and their dependency on others for support, systemic interventions (i.e., family support, training and coaching of formal care givers and employers) are at least as important as client based interventions.
- Although delimited to individuals with MID/BIF, the (F)ACT teams apply broad admission criteria. Whereas the regular (F)ACT teams in mental health care focus mainly on individuals with psychotic symptoms, the target group of (F)ACT MID/BIF will be more mingled, also because of the atypical presentation of mental disorders by individuals with intellectual disabilities (e.g., Deb, Thomas & Bright, 2001).

Implementation support

To support the teams in implementing the (F)ACT MID/BIF model, we developed a practical guideline for the team start-up, and organised training sessions and visits to experienced teams in regular mental health care for both team members and managers. During the implementation process, supervised briefings and staff meetings took place regularly, both individually on the spot as with all participating teams. To give the teams feedback on their functioning, all teams were audited on program fidelity after 6 to 12 months from their start-up, using the fidelity scale we developed. The audits were performed by the first author and a staff member of another team and consisted of interviews with team members, managers and clients, examination of client files and observations of a briefing and a home visit. The audits resulted in a ‘state of the practice’ report for each participating team with recommendations for further improvement and program fidelity.

Table 3 Routine information abstracted from CCAF audits in eight FACT MID/BIF teams

Number of clients in caseload	78
Team size in fte	11,7
Staff to client ratio	1 : 6,7
Number of visits a week ACT	1.75
Number of visits a week FACT	1.4
% of ACT clients seeing 4 disciplines a year	70
% of FACT clients seeing 4 disciplines a week	66
% Outreach	87

During the project, ten FACT MID/BIF teams and one ACT MID/BIF team were established by the five participating facilities. So far, eight of these teams (all FACT) have been audited and certified by the CCAF. Some data, collected routinely as a part of these audits, is represented in table 3. The table shows that the average caseload of the FACT MID/BIF teams largely meets the standards as described, as does the staff to client ratio. However, the contact frequency is relatively low; clients (and/or their family members) who are in need of intensive care (the ACT-clients) are seen on average 1.75 times a week, whereas the FACT-clients (and/or their family members) are seen on average 1.4 times a week. Around two third of the clients is visited by at least four disciplines a year, among whom a psychiatrist and a behavioural specialist.

Research

To study the outcomes of (F)ACT MID/BIF we established a structure for routine outcome monitoring (ROM) at the start of the project. We instructed the teams to collect data on client characteristics and a variety of outcome measures at time of enrolment and subsequently each year, at deregistration or at the end of the data collection period (May 2017). Outcome measures concerned number and duration of admissions and incarcerations; social and psychological functioning; delinquency and delinquency risk; social participation; and client satisfaction. Data are given consideration at present.

In addition to the longitudinal ROM-study, we set up a process evaluation to examine the experiences with (F)ACT for individuals with MID/BIF and to test the feasibility of the model in practice. The process evaluation consisted of 20 semi-structured (group) interviews with professionals, managers, referrers and clients of the participating teams. Professionals, managers and referrers were interviewed about the appropriateness of the model for individuals with MID/BIF, the applicability of the model, facilitating and complicating factors in the implementation process and the effectivity of treatment and support offered by (F)ACT MID/BIF. In the interviews with clients, the emphasis was put on their experiences with FACT, as well as their appreciation of the way of working (seeing different team members, being visited at home) and the treatment of the team. All interviews were transcribed, submitted to the respondents, analysed and processed by the first author. Concept versions of the report were discussed with the participating teams and managers, resulting in a final report (see Neijmeijer, Van Vugt, Place & Kroon, 2017).

Outcomes of the interviews showed that the respondents, both professionals and clients, have positive experiences with (F)ACT MID/BIF. Team members and referrers report that in general, clients benefit from (F)ACT. Although it requires patience and perseverance, many clients achieve more stability in life and cause less problems and nuisance in the community. Especially the investments in the relationship with the client, the supportive activities of the team, the outreach approach, the shared caseload and the continuity of care were indicated as the ‘active ingredients’ of the (F)ACT MID/BIF model. Clients especially value the practical assistance concerning housing, financing and work, which gives them more overview and structure and less stress. Further, they report that the FACT team members are really interested and involved. Sometimes these experiences are in sharp contrast to their previous experiences with health services: “In the addiction care they did not listen to me and they did not have time for me. Here they really want to help you”.

A second important finding is that although the participating teams find the FACT MID/BIF model appropriate for their client group, it is challenging to implement the model in its full extent. For instance, not all teams have a sufficient number of mental health professionals (i.e., psychiatrists and community mental health nurses), which makes it difficult to respond effectively to the needs of for example clients with psychotic symptoms. Further, nearly all teams indicate that the client turn-over is considerable because of the way of funding and that much time and effort goes into administration, coordination and consultation – which could be an explanation for the relative low contact frequency. In combination with a client group that is very receptive to psychiatric and psychosocial crises, the focus of FACT MID/BIF teams is on crisis intervention and activities aimed at stabilizing clients and their situation. As a result, it is difficult to pay enough attention to individual psychological and training interventions for clients who can benefit hereof.

Discussion

The first experiences with recently established (F)ACT MID/BIF teams in the Netherlands are encouraging. Clients especially value the practical assistance and the involvement and attitude of the FACT team members, which reduces their daily stress and feeds their confidence. Professionals and referrers experience the (F)ACT MID/BIF model as adequate and suitable and indicate that (F)ACT MID/BIF has an added value compared to mainstream facilities in mental health care or care for people with an ID. (F)ACT MID/BIF teams are able to 'find and bind' a vulnerable and complex group of people in the community who often would remain out of scope otherwise, or would emerge in emergency wards of mental health facilities, facilities for homeless people or prisons. Professionals, referrers and financers expect that this new type of care may result in substantially higher quality of life and better functioning for the clients with MID/BIF and their families, more safety for the society and – in time – less costs. (F)ACT MID/BIF teams distinguish themselves by their structural features (or the 'hardware elements') on the one hand: they provide outreach, intensive treatment and support on important areas of life from a highly qualified multidisciplinary team which stays involved with their clients and their formal and informal networks as long as needed – irrespective of possible interruptions as admission or incarceration. On the other hand, and at least as important according to professionals and referrers, are the 'software elements' within (F)ACT MID/BIF which make the difference. Since many clients have negative experiences in youth care, mental health care or care for ID, it is crucial to build up a good relationship and build on trust. Clients have to feel understood and in order to reach that it is important that the professional has knowledge on MID/BIF and is able to align with the client with MID/BIF, both intellectually and emotionally (see e.g., Irvine & Beail, 2016).

Despite the broad support for the (F)ACT MID/BIF model and the experienced added value, the pilot in the Netherlands shows that the implementation is a major challenge which may partly be attributed to the complexity and the level of unmet needs of this target group (see also Durbin, Sirotich, Lunsky & Durbin, 2017), but for a large part to the rigidity of the funding structure and the health care system. The teams observe that the current organization and financing of health care for people with MID/BIF and mental health problems or challenging behaviour conflict with the leading principles of the (F)ACT model. (F)ACT aims to deliver client-oriented care and to think and act from the client's perspective. However, because of the funding system, the legislation and the barriers between the different health sectors and settings, it is hard to deliver continuity of care. For example, in some cases facilities feel obliged to unsubscribe their clients prematurely from (F)ACT because of the expiry of the judicial measure and consequently the funding - despite the risks for both the client and society. Further, as mentioned by King et al. (2009), several of the participating FACT teams have considerable difficulties with the maintenance of the 'can-do-all approach' what assertive outreach stands for – for instance because the funder only compensates 'treatment interventions' and not 'supportive interventions'. In this sense, implementing (F)ACT in the ID-field takes tough demands on the commitment, flexibility, risk taking and entrepreneurship of organisations – which is difficult in times of savings, restructuring and transitions. It should be clear that tailored-made care needs tailored-made financing, and that innovations in care need investments and support from policy and funders instead of a policy that is mainly focussed on control and regulation.

An issue that often arises in the literature is whether the care for people with MID/BIF and mental health problems should be organized categorially (i.e., in specialized services) or be integrated in mainstream mental health care. While policy makers in the UK and the US head for the integrated variant, the categorical variant is adhered to in other countries, like Canada and – to some extent – in the Netherlands. Specifically with respect to the organisation of (F)ACT for people with both MID/BIF and mental health problems or challenging behaviour, the same issue is at hand. In the Netherlands the pilots with specialized (F)ACT MID/BIF teams have been evaluated positively. At the same time, the coverage of (F)ACT MID/BIF is still relatively small at the moment. To reach more people with MID/BIF in the future, it would be advantageous and efficient to make (also) use of the (F)ACT structure that has been set up in Dutch mental health care in the past decades, and to add expertise of MID/BIF to the regular (F)ACT teams.

With respect to research: the research area on (F)ACT MID/BIF is still small yet and research results are hardly comparable across studies because of differences in research populations, designs and outcome measures. With our model, we hope to contribute to the development of international criteria for the (F)ACT MID/BIF model. Standardization of interventions is an important step in developing evidence based practices. Since (F)ACT can be characterized as a 'complex intervention' containing several interacting components (Craig et al., 2008), it is important to investigate *whether* it works, but also *what* works, and for which subgroups of clients. Among researchers the idea is wide spread that complex interventions can only be investigated properly by using different research sources (Craig et al., 2008) and by combining quantitative and qualitative research methods (e.g., Burns & Catty, 2002; Campbell et al., 2000). While quantitative research gives insight in the outcomes of (F)ACT MID/BIF, qualitative research explores the active ingredients in the model, the relationship between professional and client and the required treatment of individuals with a (mild) ID (Chaplin, 2006; Hemmings, 2008; Priebe, Watts, Chase & Matanov, 2005). Especially with regard to the evidential value of treatments for individuals with MID/BIF and mental health problems or challenging behaviour, it is obvious that many research activities have to be done yet. To encourage the (inter)national policy to invest in the development of evidence based practices for this client group, efforts should be combined as much as possible.

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3

Flexible Assertive Community Treatment for individuals with a mild intellectual disability or borderline intellectual functioning: results of a longitudinal study in the Netherlands

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Abstract

Background - (Flexible) Assertive Community Treatment ((F)ACT) is an organisational model for intensive assertive outreach that was originally developed for individuals with severe mental illness. It is increasingly applied to people with (mild) intellectual disability ((M)ID) or borderline intellectual functioning (BIF) and challenging behaviour or mental illness. Research on this type of care for this population is limited. To gain experience in (F)ACT MID/BIF in the Netherlands and to obtain insight in its outcomes, four organisations specialised in the treatment of individuals with MID/BIF and challenging behaviour participated in a six-year implementation and research project.

Method – A longitudinal study was set up to investigate outcomes over time. Outcome measures concerned admissions to (mental) health care, social and psychological functioning, (risk of) challenging and criminal behaviour, social participation and client satisfaction. Data were analysed using descriptive statistics and linear mixed models (LMMs).

Results - Over time, clients showed improvement in their social and psychiatric functioning and living circumstances. The number of admissions to (mental) health care diminished as well as the number of contacts with police and justice, the level of social disturbance and the risk factors for challenging and criminal behaviour. Problems related to finances, work and substance abuse remained unchanged.

Conclusions - The results are encouraging and give rise to continued development of and broader research on (F)ACT MID/BIF.

Background

Individuals with mild intellectual disabilities (MID; IQ 50-70) or borderline intellectual functioning (BIF; IQ 70-85) and mental health problems or challenging behaviour are difficult to reach with mainstream healthcare facilities and frequently do not receive the care they need. To improve care for this client group, several countries have gained experience in Assertive Community Treatment (ACT) (Hassiotis *et al.* 2003). ACT has its origin in mental health care and was developed for people with severe mental illness who were not (adequately) treated in regular facilities, leading to relatively high percentages of drop-out from treatment programmes and to crisis admissions in psychiatric hospitals. By providing 'assertive outreach' to (unmotivated) individuals with complex needs, ACT tries to re-engage these people. The ultimate goal of ACT is to improve the functioning and participation of clients in society and to prevent (crisis) admissions to hospitals.

An ACT team consists of a psychiatrist, behavioural specialists, social workers and (specialist) psychiatric nurses and provides intensive and long-term treatment and care in the client's home or elsewhere in the community (e.g. in a shelter, at work, on the street). A team of around 10 professionals has joint responsibility (shared caseload) for providing a wide range of treatment and supportive interventions, including medication, support regarding living, work and finances, psychological treatment (e.g. cognitive behavioural therapy, emotion regulation, trauma treatment), addiction care and somatic care for approximately 100 clients. In the case of admission to a psychiatric hospital, the ACT team remains involved in the client's treatment and maintains contact with the client and clinical staff. ACT has been described and standardised, and scientific research has shown positive results, albeit mainly in the US (Kroon 2015).

In the Netherlands, an adaptation of the original ACT model has been developed: Flexible ACT (FACT). FACT teams combine highly intensive multidisciplinary treatment (ACT) for unstable clients at risk of relapse with moderate intensive care for the more stabilised ones. In FACT teams the intensity of treatment and care can be scaled up easily and flexibly (from, for instance, once or twice a week to once a day) if necessary (Van Veldhuizen 2007). FACT teams work according to the same principles as ACT teams, but usually serve more clients (around 150). With more than 400 FACT teams, FACT has become the standard for organising care for individuals with severe mental illness in the Netherlands and has found favour in other European countries (Firn & Brenton 2015).

The research base of (F)ACT for people with intellectual disabilities (ID) is limited. Recently, we conducted a critical review on assertive outreach for people with (M)ID/BIF and mental health problems or challenging behaviour (Neijmeijer et al. 2018). We concluded that there are some indications that (F)ACT is effective for this client group, but that more research is needed. To contribute to the development of international criteria for this form of care, we introduced the (F)ACT MID/BIF model as applied in the Netherlands and briefly described the implementation and research project we set up. In the present paper we report on the outcomes of this study.

Methods

Participating organisations and teams

A six-year implementation and research project (October 2011- October 2017) was set up in collaboration with four organisations specialised in the treatment of people with MID/BIF and mental health problems or challenging behaviour. Each facility serves a part of the Netherlands and provides inpatient as well as outpatient treatment and care. Clients are referred mainly by judicial organisations and regular facilities in the ID field or mental health care.

During the project seven new FACT MID/BIF teams have been established within these organisations while one team was already in operation. The caseload of the teams was built up gradually using the admission criteria as described in the (F)ACT MID/BIF model: 18 years or older; with a determined or at least a serious clinical suspicion of MID/BIF in combination with mental health problems, addiction and/or challenging or criminal behaviour; ineligible or unmotivated for regular forms of care.

Simultaneously with the increased caseload, the staffing of the teams was also expanded, so that over time all teams had a psychiatrist, one or more behavioural therapists, social workers and (psychiatric) nurses. Team members were trained in the (F)ACT model and given coaching on the job by the first author / project leader. In addition, they participated in exchange meetings and visited other teams. Six teams were certified officially by the Dutch Certification Centre for ACT and FACT teams (CCAF) during or shortly after the project, indicating that the (F)ACT model was implemented adequately according to objective standards.

Study set-up and instruments

Data on client characteristics and outcomes were collected yearly between September 2012 and May 2017 by the eight participating teams. Since the teams were established at different moments in time and client enrolment and discharge took place during the whole study period, the number of measurement moments differed per team and per client.

Client characteristics included socio-demographics as well as data on referrer, criminal or civil measure, diagnosis and IQ. For psychiatric diagnosis the fourth version of the Diagnostic and Statistic Manual of Mental Disorders (DSM-IV) was used. The Global Assessment of Functioning (GAF) forms part of the DSM-IV and results in a score between 0 (no functioning) and 100 (optimal functioning). IQ was measured in most of the cases using the Wechsler Adult Intelligence Scale (WAIS).

Outcome measures concerned number and duration of admissions and incarcerations, social and psychological functioning, social participation and client satisfaction (see Table 3). Information on outcome measures was obtained from a questionnaire, containing three standardised instruments: the Health of the Nation Outcome Scales-Learning Disabilities (HoNOS-LD; Roy *et al.* 2002), the short version of the Dynamic Risk Outcome Scales (DROS-SV; Drieschner 2012) and the historical items of the Historical Clinical Future 30 (HKT-30; Werkgroep Risicotaxatie Forensische Psychiatrie 2002). The content of the questionnaire (including the standardized instruments) was determined in consultation with the participating teams, taking into account the psychometric properties of the instruments as well as the feasibility and relevance in clinical practice.

The HoNOS-LD is derived from the HoNOS, a widely used instrument to measure social and psychological functioning. The HoNOS has moderate psychometrical properties, takes a short time to fill in and is rated as useful by professionals (Mulder *et al.* 2004). The LD version consists of 18 items (regarding e.g. behavioural problems, cognitive functioning, communication, problems in relation with others) concerning functioning in the last four weeks. Each item can be scored from 0 (not problematical at all) to 4 (highly problematical). Compared to the HoNOS, the LD version has somewhat better psychometrical properties when applied to individuals with MID/BIF and complex problems and is preferred by professionals (see Tenneij *et al.* 2009). In our study, Cronbach's alpha was 0.83.

We used the short version of the DROS that measures dynamic risk factors for externalising behaviour in individuals with MID/BIF. The DROS-SV consists of 26 items (such as problem awareness, taking responsibility, attitude towards professional help, coping skills) that can be scored from 1 (present to the highest extent) to 5 (not present at all). Reliability and validity of the full DROS are good (Delforterie *et al.* 2018). In our study, Cronbach's alpha was 0.92.

Since the DROS only measures dynamic risk factors, we also used the 11 historical indicators of the HKT-30. The HKT-30 is a validated Dutch instrument for the risk assessment of violent behaviour in the future. All risk factors (such as judicial history, victimisation in youth, substance abuse) are scored from 0 (not present at all) to 4 (present to the highest extent). The interrater reliability and the predictive validity of the HKT-30 are good (0.77 and 0.72, respectively) (Hildebrand *et al.* 2005). Based on the outcomes of the DROS-SV and the H-items of the HKT-30, the team members were asked to make a final risk judgment, expressed as a score between 1 (low risk) and 5 (high risk).

Procedure

We trained the teams to routinely collect data on client characteristics and above-mentioned outcome measures at time of enrolment and subsequently each year and at deregistration. Data were provided by the team members who were most closely involved with the client. Client satisfaction was reported by the clients themselves, using a brief questionnaire. Clients were asked to give an overall score on a 10-point Likert scale illustrated with smileys.

On admission, clients were informed about the research project, both in writing and orally. Clients who did not gave consent were excluded from the research. Ethical approval was given by the Committee of Ethics of the Social Faculty of the Radboud University (ECSW2016-2811-451).

Data set

Our data set consisted of 604 unique clients. A second measurement was performed in 280 cases (46.4%), a third measurement in 79 (13.1%) cases and a fourth measurement in only seven cases. The second measurement was performed on average 13.9 months (*SD* = 7.1) after the first, the third after on average 24.6 months (*SD* = 7.8). The decline in response can be attributed partially to the time factor: teams started at different times and data collection ended in May 2017. The ending of the criminal measure of clients was also found to be responsible for the decline, since in many cases this implied the ending of financing of the treatment. In the third place, the response was negatively influenced by staff-related (illness, discharge, staff shortage) and organisational circumstances in the teams and organisations.

Missing value analyses on the outcome variables showed that our data set was not complete. All cases had missing values on one or more of the outcome variables. Especially the questionnaire on client satisfaction had a high non-response (81.5%). Regarding client characteristics it is noteworthy that in 34.1% of the cases recent IQ test scores were not available, unknown or missing. This is indicative of the nature of the client group; since many clients have a fragmented history in health care, shelters and/or judicial institutions, client records are often incomplete. Since financers of (F)ACT place high demands on evidence for the presence of MID/BIF (if IQ scores are not available, professionals are obliged to report school history or screening results), it is unlikely that our data set contained clients with no MID/BIF.

Statistical analyses

Statistical analyses were performed using SPSS 25. To measure changes over time we used linear mixed models (LMMs). In contrast with generalised linear models, LMMs take account of hierarchical clustering of data and correct for dependency of observations. In addition, LMMs correct for missing values and allow for an unequal number of repetitions, which are common in real-world longitudinal studies (Shek & Ma 2011; West 2009).

Based on the strategy suggested by Singer and Willet (2003), we took the following steps. To examine any mean differences in the outcome variables across individuals without regard for time, we tested an unconditional mean model. We calculated intraclass correlation coefficients (ICCs) to describe the amount of variance in the outcome that is attributed to differences between individuals and teams, respectively. For the outcome variables with an ICC > .25 we explored whether the growth curves were linear or curvilinear and whether the rate of change accelerated or decelerated across time by testing an unconditional growth model and higher-order polynomial models, respectively. To select the best model, we used a likelihood ratio test / deviance test, Akaike Information Criterion (AIC) and Bayesian Information Criteria (BIC). For model estimation, we used the Maximum Likelihood (ML) method. Since addition of ‘team’ as a level 2 variable resulted in ICCs < .10 (meaning that the amount of variance in the outcome variables was not affected by team differences substantially), it was not necessary to include this variable in the model. We employed a .05 alpha level / 95% confidence interval in statistical testing.

Results

Client characteristics

Client characteristics are presented in Table 1. The clients were mainly men and the average age was 33.5 years (*SD* = 11.5). Two thirds of the clients were born in the Netherlands. The majority were single or divorced, nearly a third had a relationship or were married. Most clients lived on their own – with (9.4%) or without (38.4%) professional help - or with family, friends or acquaintances (26.3%), while a smaller group lived in a supportive housing project. The majority (87.8%) did not have a paid job and were dependent on social welfare. Two thirds (69.2%) of the clients had financial problems or debts, 39% were placed under guardianship. About half of the caseload (46.9%) had a criminal or civil measure on admission. Most referrals came from the probation service (35.4%), followed by facilities for people with ID (19.3%) and mental health care (17.9%).

The total IQ was on average 69.4 (*SD* = 8.1). DSM diagnoses diverged. The majority of clients (79.1%) had a diagnosis at both Axis I and Axis II. Somatic disorders were diagnosed in about a third (32.4%) of the cases. Dependency or abuse of alcohol or cannabis was reported in 35.7% and 41.1% of the cases, respectively. In 18.4% of the cases dependency or abuse of hard drugs was reported. The average

GAF-score was 44.9 (*SD* = 8.7), which implies that there were severe symptoms or severe limitations in social functioning.

Table 1 Client characteristics (results based on first measurement)

	n	%
Sex		
- Male	504	83.3
- Female	100	16.6
Age in years		
- < 20	22	3.6
- 20 – 30	264	43.7
- 30 – 40	163	27.0
- 40 – 50	86	14.2
- >50	69	11.4
Marital status		
- married	49	8.1
- living together	68	11.3
- living alone, in a relationship	65	10.8
- living alone, single	350	57.9
- divorced	51	8.4
- other / unknown / missing	21	3.5
Country of birth		
- client and parents born in the Netherlands	315	52.2
- client and parents born outside the Netherlands	94	15.6
- client born in the Netherlands, (one or both) parents born elsewhere	82	13.6
- unknown/missing	113	18.7
Total IQ score		
- 50 - 60	38	6.3
- 60 – 70	115	19.0
- 70 – 85	171	28.3
- Unknown / not diagnosed (yet) / missing	206	34.1

Table 2 shows the five highest scored problem areas and the dynamic and historical risk factors. Team members assessed the risk of violent behaviour without (F)ACT on average as moderate/high, and with FACT as moderate.

Table 2 Highest scores on problem areas and risk factors

Instrument	Items	*n*	Mean item score	SD
HoNOS-LD 0 = no problems 4 = severe problems	Problems with work and daily activities	547	2.65	1.51
	Problems with social interactions and relationships	541	2.29	1.18
	Problems with focus and concentration	491	1.73	1.29
	Problems with mood and mood changes	532	1.48	1.16
	Problems with sleeping	453	1.37	1.32
DROS-SV 1 = high risk 5 = low risk	Coping with conflictual interactions	514	2.14	0.87
	Coping with other stressors	515	2.16	0.85
	Awareness of risk factors and danger signals	533	2.26	0.98
	Careless and short-term actions	514	2.29	1.08
	Coping with harmful impulses	498	2.32	1.00
Historical risk factors (HKT-30) 0 = low risk 4 = high risk	Labour history	508	2.87	1.29
	Drug/alcohol use	507	2.59	1.55
	History in (mental) health care	511	2.42	1.31
	Victimised by violence during youth	352	2.27	1.55
	Challenging behaviour before age of twelve	409	2.19	1.41
Final risk judgment 1 = low risk 5 = high risk	With FACT	511	2.89	1.20
	Without FACT	510	3.87	1.25

Results of longitudinal analyses

Table 3 shows the results of the analyses. For reasons of clarity we focus on the fixed effects. Information on the random effects is available on request. The 'linear time' column shows the change in time per month. The number of admissions to health care (regardless of the sector) declined significantly. The total score on the HoNOS-LD also declined significantly, indicating that clients showed improvement in their social and psychological functioning over time. Better functioning was not translated in a higher GAF-score, however, and neither alcohol and drugs use did change. Regarding challenging and criminal behaviour, clients showed improvement over time. The number of contacts with police and justice diminished and team members reported significantly less dynamic risk factors than at the start of the treatment, resulting in a lower final risk judgment. Financial problems and problems related to work and daily activities did not change statistically. Housing problems declined significantly (homelessness excluded) and clients caused less social disturbance. Client satisfaction remained unchanged.

Table 3 Results of longitudinal analyses on (F)ACT MID/BIF

Outcome variable	Intercept (SE)	95% confidence interval intercept	Linear time (SE)***	95% confidence interval linear time
Use of (mental) health care				
- Admitted to (mental) health care (1 = no, 2 = yes)	1.26 (.03)**	1.21, 1.31	-.01 (.00)**	-.01, -.00
Functioning				
- Social and psychological functioning (total score HoNOS-LD)	16.36 (.51)**	15.36, 17.37	-.11 (.03)**	-.17, -.06
- Global Assessment of Functioning (GAF) score	45.65 (.56)**	44.55, 46.75	.02 (.03)	-.04, .08
- Dependency / misuse of alcohol or drugs (sum score)	3.80 (.14)**	3.51, 4.08	.00 (.01)	-.02, .02
(Risk of) delinquency and challenging behaviour				
- Contact with police /justice (1 = no, 2 = yes)	1.58 (.03)**	1.52, 1.64	-.01 (.00)**	-.01, .00
- Risk factors for delinquent / challenging behaviour (total score DROS-SV)	77.27 (1.1)**	75.16, 79.38	.24 (.06)**	.13, .36
- Final clinical risk judgement without (F)ACT (1 = low risk, 5 = high risk)	4.00 (.07)**	3.86, 4.15	-.03 (.00)**	-.04, -.02
- Final clinical risk judgement with (F)ACT (1 = low risk, 5 = high risk)	2.96 (.07)**	2.82, 3.09	-.03 (.00)**	-.03, -.02
Social participation				
- Employment / daily activities (1 = no, 2 = yes)	1.42 (.03)**	1.37, 1.48	.00 (.00)	.00, .00
- Paid work (1 = no, 2 = yes)	1.09 (.02)**	1.06, 1.13	.00 (.00)	.00, .00
- Homelessness (1 = no, 2 = yes)	1.12 (.02)**	1.09, 1.16	.00 (.00)	.00, .00
- Financial problems (1 = no, 2 = yes)	1.70 (.03)**	1.64, 1.75	.00 (.00)	.00, .00
- Housing problems (1 = acceptable, 5 = unacceptable)	2.06 (.08)**	1.90, 2.22	-.02 (.01)**	-.03, -.01
- Social disturbance (1= no social disturb., 5 = severe disturb.)	1.88 (.07)**	1.75, 2.01	-.02 (.00)**	-.02, -.01
Overall client satisfaction (1=very bad, 10=very good)	7.94 (.17)**	7.60, 8.28	-.01 (.01)	-.03, .01

* $p < .05$
** $p < .01$
*** time-unit = 1 month

Higher-order change trajectories (i.e. quadratic and cubic models) were tested for outcome measures that showed significant values in slope parameters. The higher-order change trajectories did not contribute significantly to the model in any of the outcome variables. This indicates that the change was linear in all cases in which the analyses showed a significant change over time.

Discussion

In this paper we presented the results of a longitudinal study on outcomes of clients of eight Dutch (F)ACT MID/BIF teams that collected data between September 2012 and May 2017. The results show that the number of admissions to (mental) health care declines significantly and that clients of (F)ACT MID/BIF teams show improved social and psychological functioning. The number of contacts with police and justice diminishes significantly, as well as the level of social disturbance, the risk factors for externalising behaviour and clinical risk judgement.

While housing problems diminished significantly, clients continued to have problems with finances and employment. The fact that clients often have large debts and repayment takes a long time seems a plausible explanation for this finding. A recent study of the Netherlands Scientific Council for Government Policy shows that problematic debts, as a source for poverty and stress, lead to poor self-control and tunnel vision, which induces people to incur even more debts. This vicious circle is hard to break (Tiemeijer, 2016). Also with regard to substance abuse – a factor that probably interferes with problems with finances and work – (F)ACT did not result in changes over time. It is common experience that substance abuse is persistent in this group (Van Duijvenbode *et al.* 2015) and that collaboration with the addiction care is often hampered because of separated organisational and financial systems. As a result, these clients possibly remain longer in the care of (F)ACT teams and obtain less treatment results. This hypothesis should be studied in future research.

It is important to make some methodological remarks on our research project. Since we opted for an observational study without a control group, the results cannot be attributed to the efforts of the (F)ACT teams. We did not investigate what would have happened if clients were being treated ‘as usual’ or had no treatment at all. Nor did we investigate whether clients would have benefited from other forms of (community) treatment and care. Theoretically, it is possible that the results of our study can be attributed to factors other than (F)ACT treatment, such as changes in health care policy or in living arrangements of clients. However, as far as we can assess, such changes did not occur.

Assuming that the positive results on several outcome measures could be (partly) attributed to the efforts of (F)ACT MID/BIF, a next question would be which ingredients of the (F)ACT model have contributed to the improvements. This question will be studied in the near future. Qualitative research among clients and professionals can generate useful information on how they perceive and experience the treatment from the (F)ACT team, and which factors do and do not contribute to recovery.

In this study we also did not analyse the influence of certain client factors on the treatment results. It is plausible that some subgroups of clients benefit more or less from (F)ACT MID/BIF. In addition to the subgroup of long-term and heavy users of alcohol and drugs, we know from clinical practice that clients who are referred by probation and do not seem to suffer from a severe mental illness (a group which is indicated as 'just MID/BIF and antisocial') often turn their back on professional care after the expiration of the criminal measure, before real treatment effects could have been obtained. It may be assumed that the client's level of intellectual and/or adaptive functioning and the severity of challenging behaviour influences the treatment results as well; this hypothesis should also be studied.

Inherent in the set-up of our research project, the data collection was relatively difficult to regulate. Several (staff-related and organisational-related) obstacles were met in daily practice that influenced the response. Although LMMs deal with missing values and include all available data in the analyses to study trends in time, a bias caused by selective non-response cannot be ruled out. It is possible that individuals who are difficult to treat were overrepresented in the non-response group. Because of the lack of information, we failed to perform a non-response analysis.

Taking into account the strong points of our study (large *n,* variation of outcome measures, long follow-up period, consistency in results), the results of our study may be seen as encouraging and give rise to continued development of and broader research in (F)ACT MID/BIF. Since (F)ACT MID/BIF teams seem to succeed in engaging individuals who are difficult to reach by regular health care facilities, optimal facilitation through appropriate and cross-sectoral funding and well-equipped staff are prerequisites.

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4

(Flexible) Assertive Community Treatment for individuals with mild intellectual disability or borderline intellectual functioning: an exploration of client variables associated with treatment outcomes

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Abstract

Purpose – Recent research on Flexible Assertive Community Treatment (FACT) for individuals with mild intellectual disabilities (MID) or borderline intellectual functioning (BIF) has shown positive results. This paper aims to identify which client variables are associated with treatment outcome of FACT.

Design / methodology / approach - Analyses were performed on assessments made during a six-year longitudinal study in the Netherlands. Data comprised assessments of 281 clients with at least two measurements. Treatment outcome was measured by the Learning Disability version of the Health of the Nation Outcomes Scales (HoNOS-LD). Demographic variables and dynamic risk variables of the short version of the Dynamic Risk Outcome Scales (DROS-SV) were selected as potential predictor variables of outcome. Data were analysed using linear mixed models (LMMs).

Findings – Limited awareness of the need for treatment, limited treatment motivation and cooperation, limited social skills, impulsivity and substance abuse were significantly associated with worse treatment outcome. None of the demographic variables influenced treatment outcome significantly, and neither did IQ or having a judicial or civil measure.

Research limitations / implications – Because of the observational design, no causal inferences can be drawn.

Practical implications - This study produces guidelines regarding nature and scope of the treatment supply and the competences of professionals working in FACT MID/BIF teams.

Originality / value – This paper encourages other countries to make assertive outreach available for people with MID/BIF on a larger scale, taking into account the acquired insights.

Background

Assertive community treatment (ACT) is a model for the organisation of treatment and care that has been developed originally for people with severe mental illness. ACT teams focus on individuals who cannot sufficiently be reached by and treated in regular inpatient or outpatient mental healthcare facilities, because of the complexity and plurality of their problems and/or their lack of motivation for professional help. ACT was developed to engage these people again by assertive outreach and by supporting them in their direct needs and in their own environment. By doing so, ACT teams aim to improve clients' functioning and participation in society and to prevent or shorten hospital admissions (see, e.g., Bond et al., 2001; Stein and Santos, 1998; Van Vugt et al., 2011).

ACT teams consist at least of a psychiatrist, a psychologist, social workers and community mental health nurses and provide intensive and long-term treatment and care in the client's home or elsewhere in the community (e.g., in a shelter, at work, on the street). A team of around 10 professionals has joint responsibility (shared caseload) for providing a wide range of (evidence based) treatment and supportive interventions for approximately 100 clients. These interventions include medication, support regarding living, work and finances, psychological treatment (e.g., cognitive behavioural therapy, emotion regulation, trauma treatment, motivational interviewing), addiction care and somatic care. In the case of admission to a psychiatric hospital, the ACT team remains involved in the client's treatment and maintains contact with the client and the clinical staff. ACT has been described and standardised, and widely implemented in the United States and Europe. ACT is the most extensively studied care delivery model for people with severe mental illness and is recognized as an evidence-based practice in the US (Kroon, 2015).

In the Netherlands, an adaptation of the original ACT model has been developed: Flexible ACT (FACT). FACT teams combine highly intensive multidisciplinary treatment (ACT) for unstable clients at risk of relapse with moderate intensive care for the more stabilised ones. In FACT teams the intensity of treatment and care can be scaled up easily and flexibly (for instance, from once or twice a week to once a day) if necessary (Van Veldhuizen, 2007; Van Veldhuizen et al., 2015). FACT teams work according to the same principles as ACT teams, but usually serve more clients (around 150).

Internationally, ACT and FACT - referred to hereinafter as (F)ACT - is increasingly applied in other areas of health care, including the care for people with intellectual disabilities (ID). In the Netherlands, around fifteen specialised (F)ACT teams have been established since 2010 that provide intensive, pro-active care and treatment to individuals with mild intellectual disabilities (MID) or borderline intellectual functioning (BIF) and mental health problems, addiction and/or challenging behaviour. Similar to clients with SMI, these individuals are often at risk of social exclusion because of the complexity of their problems and their reluctance or aversion regarding professional care. This avoidant behaviour might be the result of bad experiences with professional help in the past, but could have to do with their need for autonomy and/or their limited problem awareness and awareness of the need for treatment as well (see Neijmeijer et al., in press).

(F)ACT MID/BIF teams work according to the same principles as (F)ACT teams for people with SMI (multidisciplinary approach, assertive outreach, shared caseload, integral treatment and care, long-term involvement), which distinguishes them from generic community services for people with ID. Also, while generic community services focus, generally speaking, on relatively stable functioning clients without additional mental health or (severe) psychosocial problems, (F)ACT MID/BIF teams focus on people with (severe) mental health problems or challenging behaviour in combination with varying problems in different fields of life. Regarding the target group of (F)ACT MID/BIF, the team composition, the team processes and the treatment interventions of (F)ACT MID/BIF teams, a model description has been developed (Neijmeijer, 2015 en Neijmeijer et al., 2018). In addition to the above mentioned core disciplines (F)ACT MID/BIF teams consist ideally of educational/ behavioural and systemic expertise as well. All team members have been educated and skilled in the treatment of individuals with MID/BIF and are able to adapt their style of support and communication to the emotional, cognitive, and adaptive level of functioning of their clients. Further, compared with (F)ACT teams in mental health care, (F)ACT MID/BIF teams have a smaller staff/caseload ratio, have a more systemic approach and offer treatment interventions that are appropriate to the specific features of the clients in the caseload.

Despite the small research base of the effects of assertive outreach for people with ID, there are indications that (F)ACT is of value. Recently, we reported on the results of a longitudinal study based on routinely collected data by four Dutch facilities specialised in the treatment of individuals with MID/BIF and mental health problems or challenging behaviour (Neijmeijer et al., 2019). Over time, clients showed improvement in their social and psychiatric functioning and their living circumstances. The number of admissions in (forensic) mental health care diminished, as well as the number of contacts with police and justice, the level of social disturbance and the risk factors for offending behaviour and delinquency. No improvements, however, were found with respect to financial problems, work and substance abuse.

As a next step it is important to know whether there are differences in receptiveness to (F)ACT between subgroups of clients with MID/BIF. Insight in the efficacy of (F)ACT in subgroups of clients with MID/BIF may be helpful to improve the treatment of specific client groups who seem to profit less from FACT than others (e.g., by adding certain treatment interventions) or to determine which subgroups are possibly more eligible for (F)ACT than others (Hemmings, 2008; Huguelet et al., 2012; Lunsky et al., 2011). Studies on the efficacy of ACT for clients with SMI have shown that several factors are associated with poor outcome. For instance, Kortrijk et al. (2009) investigated the associations between ACT treatment outcomes and demographic and clinical factors and found that substance abuse, higher age, problems with motivation and lower educational level were predictors for worse social and psychological functioning. Further, Beach et al. (2013) also found that problematic substance abuse as well as homelessness at enrolment were significant risk factors for arrest or incarceration and for homelessness at three-year follow-up. Also, clients with forensic histories in particular appeared to be vulnerable for an array of adverse outcomes, particularly during their first year of ACT.

The present paper explores which demographic and clinical characteristics of clients at baseline may predict outcomes of FACT, defined in terms of severity of symptoms with respect to social and psychological functioning, over time.

Methods

Setting and participants

Between 2011 and 2017, four Dutch facilities specialised in the treatment of individuals with MID/BIF and mental health problems or challenging behaviour participated in a nationwide implementation and research project. Each facility served a part of the Netherlands and provided inpatient as well as outpatient treatment and care. Clients were referred mainly by judicial organisations and regular facilities in the ID field or mental health care. During the project, seven new FACT MID/BIF teams were established within these organisations while one team was already in operation. The caseload of the teams was built up gradually using the admission criteria as described in the (F)ACT MID/BIF model (Neijmeijer, 2015). The (F)ACT MID/BIF model applies the following admission criteria for clients: being 18 years or older; a determined or at least a serious clinical suspicion of MID/BIF in combination with mental health problems, having an addiction and/or a history of challenging or criminal behaviour; and being judged by the intake committee of (F)ACT as ineligible for regular forms of care. To meet this inclusion criterion, clients should have severe problems on different areas of life and/or a lack of motivation for professional help.

Simultaneously with the increased caseload, the staffing of the teams was expanded so that over time all teams had at least a psychiatrist, one or more behavioural therapists, social workers and psychiatric nurses. Team members were trained in the FACT model and participated in exchange meetings with the other teams. Six teams were certified by the Dutch Certification Centre for ACT and FACT teams (CCAF) during or shortly after the project, meaning that these teams adequately implemented the FACT MID/BIF model.

All teams were trained to routinely collect data on client characteristics and outcome measures (see below) at time of enrolment and subsequently each year and at deregistration. Data were collected between September 2012 and May 2017 and resulted in a data set consisting of assessments of 604 unique clients, of whom 281 clients had at least two repeated measurements.

On admission, clients were informed about the research project, both in writing and orally. Clients who did not give consent were excluded from the research but not from treatment. All data were analysed anonymously. Ethical approval was given by the Committee of Ethics of the Faculty of Social Sciences Radboud University (ECSW2016-2811-451). For more details on the data collection and procedures, see Neijmeijer et al., 2019.

Outcome measure and predictor variables

In the present study, we measured treatment outcome by means of the sum score on the Learning Disability version of the Health of the Nation Outcomes Scales (HoNOS-LD), a standardised instrument that measures social and psychological functioning in individuals with learning disabilities. The original HoNOS is a widely used instrument in mental health care, as well as in studies on the effectiveness of mental health interventions, including regular (i.e., non-ID) ACT (e.g., Kortrijk et al., 2009; Van Vugt et al., 2011). The HoNOS has acceptable psychometrical properties, takes a short time to fill in and is rated as useful by professionals (Mulder et al., 2004). The LD version consists of 18 items concerning functioning in the last four weeks that can be scored from 0 (no problem) to 4 (very severe). The HoNOS-LD covers the following domains: 1. Aggressive, disruptive or agitated behaviour, 2. Non-accidental self-harm, 3. Other behavioural problems, such as obsessive or compulsive behaviour and inappropriate sexual behaviour, 4. Problems with focus and concentration (possibly as a result of drug-taking), 5. Problems with memory and orientation, 6. Problems with understanding of information, 7. Problems with expressing oneself, 8. Hallucinations and delusions, 9. Depressed mood, 10. Sleeping problems, 11. Problems with eating or drinking, 12. Physical illness and disability, 13. Epileptic seizure, 14. Problems with activities of daily living (indoor), 15. Problems with activities of daily living (outdoor), 16. Level of self-sufficiency, 17. Problems with social relations, and 18. Problems with occupation and activities. Compared with the regular HoNOS, the LD version has somewhat better psychometric properties when applied to individuals with MID/BIF and severe problems and is preferred by professionals (Tenneij et al., 2009).

The choice for predictor variables was based on both previous research and experiences from practice. Incorporating socio demographic variables, such as gender, age, country of birth and living situation is common in studies on the outcomes of treatment interventions, including assertive outreach (see for example, Beach et al., 2013; Kortrijk et al., 2009; Priebe et al., 2004). We supplemented these variables with IQ-scores based on diagnostic testing results and having a judicial or civil measure or not, since there are indications from professional practice that a lower IQ and undergoing involuntary treatment has a negative influence on treatment results. Further, since several studies incorporated “clinical” variables, such as motivation for treatment and substance abuse, we included the 14 subscales of the short version of the DROS as well (Drieschner, 2012). As opposed to the aforementioned static variables, the variables derived from the short version of the Dynamic Risk Outcome Scales (DROS-SV) are dynamic, i.e. sensitive for change – for example through treatment in FACT. The DROS-SV measures the risk of externalising behaviour in individuals with MID/BIF. The DROS-SV consists of 26 items and can be scored on a 5-point Likert scale from not present at all to present in the highest extent. Reliability and validity of both the full DROS and its short version are good (Delforterie et al., in press; Delforterie et al., in preparation). For an overview of the DROS-SV subscales, see Tables 2 and 3.

Statistical analyses

Statistical analyses were performed using SPSS (Version 25). To measure changes over time, we used linear mixed models (LMMs). In contrast with generalised linear models, LMMs take account of hierarchical clustering of data and correct for dependency of observations. In addition, LMMs correct for missing values and allow for an unequal number of repetitions, which are common in real-world longitudinal studies (Shek and Ma, 2011; West, 2009).

Following the strategy suggested by Singer and Willet (2003), several models were tested. Earlier we tested an unconditional model, an unconditional growth model and two higher-order polynomial models successively and found several significant trends in time, which were all linear (Neijmeijer et al., 2019). In the present study, we tested a conditional model to examine whether the growth parameters (i.e., initial status and linear growth) were related to client factors (predictors). For model estimation we used the maximum likelihood (ML) method as we focused on both fixed and random effects. Following Shek and Ma (2011, p. 58), we used an unstructured covariance structure as this commonly provides the best fit for longitudinal data, requires no assumptions regarding the error terms, and is the most parsimonious. Because “team” as a level 2 variable resulted in ICCs < 0.10 (meaning that the amount of variance in the outcome variables was not affected by team differences substantially), this variable was not included in the model. We employed a 0.05 α level / 95% confidence interval in statistical testing.

Results

Client characteristics

Table 1 contains an overview of the characteristics of the clients with repeated measurements. The clients were mainly men and their average age was 33.6 years (*SD* = 12.1). The majority of the clients were born in the Netherlands. Most clients lived on their own, usually without professional help, or with family, friends or acquaintances. About half of the caseload had a criminal or civil measure on admission. The total IQ, usually determined with the Wechsler Adult Intelligence Scale (WAIS), was on average 69.4 (*SD* = 8.1). It is striking that in 40% of the cases the IQ score was unknown or missing. Since many clients have a fragmented history in (mental) health care or remained under the radar of health care facilities in the past, precise information on IQ test results and other aspects often was lacking. There were a range of psychiatric diagnoses based on the criteria of the fourth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). The majority of the clients had a diagnosis on both axis I and axis II. Dependency of abuse of alcohol, cannabis or hard drugs was reported frequently.

The scores on the subscales of the DROS-SV (Table 3) show that coping problems were considered as the most striking risk factors of the clients, followed by impulsivity, lack of presence of prosocial structures, problem awareness, and hostility.

Results of longitudinal analyses

The average time between the first and the second measurement for the 281 included clients was 13.9 months (*SD* = 7.1), the third measurement was performed on average at 24.6 months (*SD* = 7.8) after the first. The sum score on the HoNOS-LD declined significantly (with .11 per month), indicating that clients as a group showed improvement in their social and psychological functioning over time (see Table 3).

Demographic variables, IQ and judicial title

No significant associations were found between socio demographic variables (i.e., gender, age, country of birth) and (changes in) social and psychological functioning, neither between IQ level and (changes in) social and psychological functioning.

Table 1 Client characteristics (results based on first measurement; n = 281)

	n	%
Sex		
- Male	239	85.1
- Female	42	14.9
Age in years		
- < 25	90	32.0
- 25 – 35	88	31.3
- 35 – 45	51	18.1
- 45 – 55	35	12.5
- >55	17	6.0
Country of birth		
- client and parents born in the Netherlands	155	55.2
- client and parents born outside the Netherlands	41	14.6
- client born in the Netherlands, (one or both) parents born elsewhere	43	15.3
- unknown/missing	42	14.9
Living situation		
- homeless or shelter	15	5.3
- independent	112	39.9
- with family or friends	77	27.4
- independent with professional support	24	8.5
- in residential facility	33	11.7
- unknown/missing	20	7.1
IQ class		
- mild intellectual disability (50-70)	80	28.5
- borderline intellectual disfunctioning (70-85)	87	31.0
- unknown	114	40.6
Legal measure at start treatment		
- no	129	45.9
- yes	145	51.6
- unknown	7	2.5
Diagnosis (DSM-IV)		
- axis I	35	12.5
- axis II	20	7.1
- axis I and II	220	78.3
- axis III	85	30.2
- axis IV	269	95.7
Substance abuse		
- alcohol	104	37.5
- cannabis	57	20.3
- speed, XTC, cocaine	34	12.1

Table 2 Mean scores on DROS-SV subscale items (1=not problematic, 5=very problematic)

Subscale item	mean	SD
I. Problem awareness	3.61	0.95
II. Awareness of the need for treatment	2.91	1.21
III. Realism of the situation after treatment	3.18	0.96
IV. Treatment cooperation	3.14	0.94
V. Antisocial attitudes	3.04	1.06
VI. Coping skills	3.84	0.74
VII. Hostility	3.26	1.20
VIII. Problematic sexual cognitions and behaviour	1.51	1.03
IX. Impulsivity	3.74	1.04
X. Presence of prosocial structures (daytime activities)	3.69	1.42
XI. Self-sufficiency	2.29	1.10
XII. Social skills	3.10	1.11
XIII. Substance abuse	2.77	1.32
XIV. Psychotic symptoms	1.60	1.07

Having a judicial or civil measure at the start of FACT treatment was significantly associated with social and psychological functioning at baseline, but not with changes in time. In other words: although clients with a judicial or civil measure had a higher (i.e., worse) mean sum score on the HoNOS-LD at baseline (*M* =17.6; *SD* =7.9) than voluntary clients (*M* = 15.0; *SD* = 8.2), both groups seem to benefit equally from FACT. The same holds true for living situation: on average, clients who lived independently had a significant higher (i.e., worse) score on the HoNOS-LD at baseline (*M* = 17.0; *SD* = 7.5) than those in a residential setting (*M* = 12.0; *SD* = 7.2), but benefitted equally from treatment over time.

Dynamic variables

The analyses showed that all dynamic risk variables, except problematic sexual cognitions and behaviour, were significantly associated with social and psychological functioning at baseline, in the sense that a more "problematic" score on each of the dynamic variables was associated with a higher (i.e., worse) sum score on the HoNOS-LD at the start of the treatment (Table 4). Five of these dynamic variables were associated with the changes over time as well. These are social skills (explained 12.1% of the overall variability in treatment outcome), impulsivity (10.2%),

Table 3 Prediction of HoNOS-LD total scores by static client variables

Client characteristics	Response categories	Estimate intercept	SE intercept (95% conf. interval)	p intercept	Estimate slope	SE slope (95% conf. interval)	p slope
Intercept	Sum score HoNOS-LD	16.44	.051 (15.44; 17.45)	.00**	-.11	.03 (-.17;-.06)	.00**
Gender	1 = Male 2 = Female	1.49	1.47 (-1.40; 4.38)	.31	-.06	.09 (-.23;.12)	.53
Age class	1 =<25 2 = 25-25 3 = 35-45 4 = 45-55 5 = >55	-.37	.41 (-1.19; .44)	.37	-.01	.02 (-0,5; .04)	.75
Country of birth	1= client and parents born in NL 2 = client born in NL, one or both parents born abroad 3 = client and parents born abroad	-.39	.51 (-1.40; -.63)	.45	.00	.07 (-.15; .16)	.98
IQ	1 = 50-70 (MID) 2 = 70-85 (BIF)	.20	1.15 (-2.07; 2.48)	.86	-.05	.09 (-25; .14)	.58
Judicial or civil measure	1 = no measure; voluntary 2 = judicial or civil measure	2.70	1.04 (.66; 4.75)	.01**	-.15	.12 (-.41; -11)	.24
Living situation	1 = independent 2 = in residential care	-2.97	1.46 (-5.86; -1.00)	.04*	-.09	.11 (-.31; .14)	.45

* $p < .05$
** $p < .01$

Table 4 Prediction of HoNOS LD total scores by dynamic client variables (DROS-SV)

DROS subscale	Response categories	Estimate intercept
I. Problem awareness	1 = not problematic 2 = a bit problematic 3 = rather problematic 4 = considerable problematic 5 = very problematic	2.97
II. Awareness of the need for treatment	Idem	1.22
III. Realism of the situation after treatment	Idem	3.00
IV. Treatment cooperation	Idem	2,40
V. Antisocial attitudes	Idem	1.83
VI. Coping skills	Idem	4.21
VII. Hostility	Idem	1.94
VIII. Problematic sexual cognitions and behaviour	Idem	.40
IX. Impulsivity	Idem	2.09
X. Presence of prosocial structures	Idem	2.05
XI. Self-sufficiency	Idem	4.04
XII. Social skills	Idem	2.28
XIII. Substance abuse	Idem	1.45
XIV. Psychotic symptoms	Idem	3.14

* $p < .05$
** $p < .01$

SE intercept (95% conf. interval)	p intercept	Estimate slope	SE slope (95% conf. interval)	p slope
.44 (2.11-3.84)	.00**	.06	.03 (-.00; .12)	.06
.35 (.52; 1,92)	.00**	.05	.02 (.00; .10)	.05*
.45 (2.12; 3.87)	.00**	.02	.03 (-.03; - .07)	.43
.45 (1.51; 3.29)	.00**	.06	.03 (.00;.12)	.04*
.44 (.96; 2.71)	.00**	.01	.03 (-.05; .08)	.67
.57 (3.09; 5.34)	.00**	.05	.04 (-.02; .13)	.19
.38 (1.19; 2.69)	.00**	.04	.03 (-.01; .09)	.12
.55 (-.69; 1.49)	.47	.01	.04 (-.06; .09)	.75
.42 (1.25; 2.92)	.00**	.09	.03 (03; .14)	.00**
.30 (1.46; 2.64)	.00**	.03	.02 (-.01; .07)	.15
.41 (3.24; 4.85)	.00**	.03	.03 (-.03; .08)	.31
.40 (1.50-3.06)	.00**	.07	.03 (.02; .13)	.01**
.37 (.71; 2.19)	.00**	.06	.02 (.02; .11)	.01**
.49 (2.18; 4.10)	.00**	.01	.03 (-.05; .07)	.75

treatment motivation and cooperation (8.6%), substance abuse (4.8%), and awareness of the need for treatment (2.4%). Thus, problematic functioning (higher scores on DROS-SV subscales) in these areas was associated with worse outcome (higher sum scores on the HoNOS-LD) of FACT.

Discussion

Previous research has suggested that FACT may be effective with respect to several outcome measures in individuals with MID/BIF (authors, 2019). The present study has investigated which specific client variables are associated with treatment outcome, in terms of social and psychological functioning.

Our analyses indicated that clients as a group, regardless of their gender, age, ethnicity, living situation, IQ and judicial or civil measure showed progression during their treatment in FACT. Compared with research in individuals with severe mental illness receiving ACT, our findings deviate with respect to age. Kortrijk et al. (2009) found that higher age was associated with worse outcomes on the HoNOS. As an explanation, the authors argued that a higher age is frequently associated with a longer duration of mental illness or with a longer period of untreated psychosis – factors that are proven to be associated with worse prognosis (Singh, 2007). However, since mental illness and psychotic symptoms might more often be the *results* of living under chronic stress and pressure in individuals with MID/BIF than the primary diagnosis (Došen, 2007), these symptoms are possibly less persistent, and thus more reversible, within this group. It is conceivable that an appropriate approach, in which client's limited cognitive and adaptive skills are taken into account, in combination with a "hands-on" strategy (taking away the sources of stress, e.g., by arranging financial administration or supporting the client in contacts with authorities) can have a direct relieving effect on client's wellbeing and daily functioning.

It may be seen as remarkable that neither the level of IQ, nor the judicial or civil measure of clients was associated with the outcomes of FACT. Kortrijk et al. (2009) found a significant relation between lower educational level and worse outcome, while as a contrast, Hassiotis et al. (2001) found that "intensive case management" was significantly more beneficial for borderline IQ clients than those with average IQ[6]. Our study indicated that within the group of people with a lower IQ (which is highly correlated with lower educational level) individuals with

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[6] Hassiotis et al. (2001) utilised data from the UK700 multi-centre randomised controlled trial which compared 'intensive case management' with 'standard case management' in patients with severe psychosis. On the basis of the National Adult Reading Test (NART) 104 patients (17.7%) were classified as having borderline IQ. This group was compared with a group of 482 normal-IQ patients.

MID and individuals with BIF benefited equally from treatment in FACT. The same applies for clients who are voluntary in treatment versus clients who have a judicial or civil measure, a finding that corresponds with the results of a qualitative study we performed recently on the experiences of clients with MID/BIF with FACT (authors, in press). In that study we found that receiving compulsory treatment was not related directly to the appreciation of FACT. Indeed, several clients indicated that FACT helped them to break the vicious circle of negative functioning, conflicts with local authorities and criminality and admitted that they needed FACT as a precaution and to stay on track. Apparently, FACT is able to build up a trusting bond with individuals with complex and multiple problems, regardless of their IQ level or their possible criminal background, who have found traditional services unable to meet their needs.

With respect to the dynamic risk variables, we found that five DROS-SV subscales had a significant association with changes in time: social skills, impulsivity, treatment cooperation and motivation, substance abuse and awareness of the need for treatment. In previous studies among clients with severe mental illness (e.g., Kortrijk et al., 2009), low motivation for treatment and substance abuse were also found to be associated with worse treatment outcome. It is plausible that treatment cooperation and motivation is related with awareness of the need for treatment, and that substance abuse, which is a quite common phenomena among clients of FACT MID/BIF, may often be linked with impulsivity.

Since they work with clients with severe problems and low motivation, our results emphasize how important it is for FACT MID/BIF teams to invest in building up a good relationship with clients based on trust. As with regular (F)ACT clients, building up a trusting bond takes time, but without a trusting bond there will be no motivation to accept help. Further, to address problems of motivation for treatment, we recommend implementation of motivational interviewing (Miller and Rollnick, 2012). The central purpose of motivational interviewing is to examine and resolve ambivalence in treatment goals. In our opinion, motivational interview techniques should form part of the competences and skills of professionals working in FACT MID/BIF teams. A second recommendation based on our results concerns the type and range of treatment programs within FACT MID/BIF. Since clients with better social skills achieve better treatment results, social skills training should form a structural part of the treatment supply of the teams. Also, the particular case of clients with substance abuse and addiction warrants attention. These are clients who often show avoidant behaviour although they need the most help with preventing challenging behaviour, both in terms of treatment and measures and restrictions. In our previous study (Neijmeijer et al., 2019), FACT did not appear to offer substantial help with regard to substance abuse, while in the present study, substance abuse at baseline is found to be a significant predictor of a worse outcome. Although exact information regarding nature and scale of the treatment program in the participating teams was not available, it is known from regular (F) ACT teams that implementing substance-abuse treatment is not an easy task (Kortrijk et al., 2009; Van Vugt et al., 2013). We recommend therefore to invest systematically in improving and incorporating substance abuse programs for individuals receiving treatment from FACT MID/BIF (see e.g., Van Duijvenbode et al., 2015).

It is important to make some methodological remarks on this study, which are mainly related to the design of our research project. Since this was an observational follow-up study without a control group, we cannot draw any causal inferences, although Shrier et al. (2007) suggests that, like randomized controlled trials, an observational study design can also contribute to evidence-based research. For example, whether clients with MID/BIF would benefit equally from other forms of (outpatient) care has not been investigated. Neither has been investigated whether and to what extent other factors, such as factors in clients' environment of the client (living problems, financial problems, relational problems) or team- or treatment-bound factors influenced the outcomes of treatment in FACT. For instance, it is possible that certain teams achieve better results than others, because they provide more intensive care, have a wider range of therapeutic interventions or have another mix of disciplines than other teams. Since we had no information on these team- or treatment bound factors at client level, we cannot draw any conclusions on this, and is therefore subject for future research. What we *do* know is that six of the eight participating teams were certificated by the CCAF, which means that the FACT model was implemented sufficiently or good by these teams. Research has shown that high ACT model fidelity is associated with better outcomes on the HoNOS (Van Vugt et al., 2011).

Also inherent in the design of our research project is that the data collection was relatively difficult to regulate. Several staff-related and organisational-related obstacles, such as illness, discharge and staff shortage, were met in daily practice that may have influenced the response. Although the statistical technique of LMMs deals with missing values and includes all available data in the analyses to study trends in time, a bias caused by selective non-response or selective drop-out during the study period cannot be ruled out. It might be possible that individuals who are difficult to treat were overrepresented in the non-response or drop-out group. Because of a lack of information, we could not perform a non-response analysis, and neither did we gather information on the reasons for (premature) termination of individual treatment courses.

The fact that for 40% of participants IQ scores were missing means that we cannot be certain that these 40% of participants meet the internationally agreed definitions of MID/BIF. Hence, it is possible that there were people in the sample who would fall outside of this group but were still in receipts of FACT teams for people with MID/BIF. However, since funders set high demands on providers of services for people with ID with regard to the underpinning of the presence of a MID/BIF, we have no reason to believe that the study results were distorted substantially by participants who did not fall under the target group.

It may be seen as an omission that in this study only clinician-rated measures were used. In a previous article (Neijmeijer et al., 2018) we reported on client satisfaction – expressed in a score between 1 and 10 by clients themselves – as well. For future research it would be commendable to include client rated measures as outcome variables. These can include self-report questionnaires, such as the Brief Symptom Inventory (Wieland et al., 2012).

In the Netherlands, the experience with (F)ACT has been limited to people with MID or BIF so far, while it might be argued that people with moderate intellectual disabilities and mental health problems or challenging behaviour could benefit of an assertive outreach approach as well. The main reason for this is that (F)ACT has originally been developed for people who live more or less independently in the community, are vulnerable to social exclusion and can not be sufficiently reached by regular health care (the so called 'drop outs' or 'care avoiders'). This is more often the case in people with MID/BIF than in people with moderate or severe intellectual disabilities, since the last group of people usually live in residential facilities where professional care is adequately available or with caring parents/family.

Overall, we can conclude that FACT may be of value for a heterogeneous group of people with MID/BIF. In addition, this study has produced some guidelines regarding nature and scope of the treatment supply and the competences of professionals working in FACT MID/BIF teams. We hope that this study encourages other countries to make assertive outreach available for people with MID/BIF on a larger scale, taking into account the acquired insights.

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5

Experiences of service users with a mild intellectual disability or borderline intellectual functioning with Flexible Assertive Community Treatment: a qualitative study

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Abstract

Background: In the Netherlands, Flexible Assertive Community Treatment (FACT) teams have been established for people with mild intellectual disability (MID) or borderline intellectual functioning (BIF) and mental health problems or challenging behaviour. Little is known yet about service users' experiences with FACT.
Method: An inductive grounded theory approach was used to explore how service users valued the treatment and their own functioning, and which factors were perceived as supportive. Semi-structured interviews were held with 15 service users.
Results: Most service users highly appreciated the contact with the staff and the practical and emotional support. Persistent involvement, availability and humanity, and respect for autonomy were distinguished as core values in the relationship with the staff. Most service users experienced improvement in time, and attributed this to intrapersonal changes and/or less stress in life.
Conclusions: From the perspective of service users with MID/BIF, FACT appears to have an added value.

Introduction

Assertive Community Treatment (ACT) is a relatively new type of care for people with mild intellectual disability (MID) or borderline intellectual functioning (BIF) and additional problems, such as mental health problems, addiction or challenging behaviour. ACT has its origin in mental health care and was developed in the 1970s in the United States for people with severe mental illness, combined with problems in important domains in life (e.g., housing, finances, work, social functioning) (Stein & Test, 1980). In short, ACT teams focus on individuals who cannot sufficiently be reached by and treated in regular inpatient or outpatient mental healthcare facilities, because of the complexity and plurality of their problems and/or their lack of motivation for professional help. ACT was developed to 'bind' these people again by assertive outreach and by supporting them in their direct needs and in their own environment. ACT teams provide ambulant, intensive, comprehensive, multidisciplinary and long-term treatment and care to improve clients' functioning and participation in society and to prevent or shorten hospital admissions (see, e.g., Bond, Drake & Mueser, 2001; Stein & Santos, 1998; Van Vugt et al., 2011).

In the Netherlands, an adaptation of the original ACT model was developed: Flexible ACT (FACT). FACT combines highly intensive multidisciplinary treatment (ACT) for unstable clients at risk of relapse with moderate intensive care for the more stabilized ones (Van Veldhuizen, 2007). In less intensive phases, clients are visited on average once a week. When symptoms aggravate or life events occur the treatment is 'scaled-up' to the ACT-level. With more than 400 FACT-teams, FACT has become the standard for organizing care for people with severe mental illness in the Netherlands. A second important development was the extension of the principles of the (F)ACT[7] model to other groups of people with special needs, including individuals with MID/BIF and mental health problems or challenging behaviour (Neijmeijer et al., 2018). As in mental health care, (F)ACT MID/BIF teams comprise several disciplines (psychiatrist, behavioural therapist, social workers, psychiatric nurses, addiction specialists) and provide a wide range of treatment and supporting interventions with respect to daily activities, housing, finances and administration, work and day structure. The teams offer long-term care and stay in touch in case of admission in a psychiatric hospital or detention.

Although the research base of (F)ACT for people with intellectual disabilities (ID) is small and the comparability of studies on this subject is limited, there are some indications that this type of care may be of value for this target group. Several authors reported positive outcomes, in terms of a reduction in behavioural problems and/or a decrease in admissions (Coelho et al, 1993; Douglass & Hurtado,

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[7] In this paper we use the term '(F)ACT' as a collective name for both ACT and FACT.

2013; Hassiotis et al., 2001; King et al., 2009; Meisler et al., 2000; Van Minnen et al., 1997).[8] Recently we performed a longitudinal study and found that in general, clients of FACT MID/BIF teams showed improvement on several outcome measures, including social and psychological functioning, admissions in psychiatric hospitals and the level of social disturbance (Neijmeijer et al., 2019). Assuming that these results could be (partly) attributed to the efforts of (F)ACT, an important question is which ingredients of the (F)ACT model have contributed to the improvements. Since (F)ACT can be characterized as a 'complex intervention' containing several interacting components (Craig et al., 2008), this is hard to investigate. Among researchers the idea is wide spread that complex interventions can only be investigated properly by using different research sources (Craig et al., 2008) and by combining quantitative and qualitative research methods (e.g. Chaplin, 2009; Oliver et al., 2005). Qualitative research can give insight into the active ingredients of the intervention, the relationship between professional and client and the required treatment of individuals with MID/BIF (e.g., Hemmings, 2008).

From research among service users with severe mental illness and, in general, average intelligence, it is known that they appear to benefit the most from non-specific elements of ACT, i.e., the relationship with the staff (Krupa et al., 2005; Mc Grew, Wilson & Bond, 1996). Also, research suggest that the relationship is facilitated by structural aspects of the ACT model, such as continuity, long-term involvement, flexibility and accessibility (Krupa et al., 2005). However, we cannot assume that the results of these studies can be applied automatically to service users with MID/BIF as well. Research on personal experiences of service users with an ID is scarce anyhow. Beail & Williams (2014) found that qualitative studies, published in three major intellectual disability journals over a decade, in which the participants were people with ID, represented only a minority of all published papers. Griffith, Hutchinson & Hastings (2013) came to a similar conclusion. Remarkably, the themes that emerged from their research had mainly to do with 'imbalance of power', i.e. the application of restrictive interventions and the impersonal and authoritarian attitude of the staff, and the effect on challenging behaviour. Further, the vast majority of participants in these studies (97%) were residing in a secure or supported residential placement and only one of the studies focussed on people with 'mild learning disabilities'.

The current qualitative study focusses on the experiences of service users with MID/BIF and mental health problems or challenging behaviour with FACT. The aim of the study is to explore how they value the treatment, how they value their (changes in) functioning and well-being, and which factors are perceived as supportive.

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[8] For a more detailed overview of the international state of the art of (F)ACT for people with (M)ID/BIF, see Neijmeijer et al. (2018) (chapter 2 of this thesis).

Method

Study design

Since little is known about the experiences of service users with MID/BIF with (F) ACT, this study has an explorative character. An inductive grounded theory approach (Glaser & Strauss, 1967) is most common for studies with an explorative character. To interpret and discuss the results of our study, we compare them with findings from literature and theories (triangulation or thick analysis) – which is considered a realistic and useful strategy to increase the methodological quality of qualitative research (Van Staa & Evers, 2010). Ethical permission was given by the Ethics Committee of the Radboud University (ECSW2016-2811-451).

Data collection

The current study used semi-structured interviews with service users of two FACT MID/BIF teams, located in the middle and the eastern part of the Netherlands. Both teams focussed on individuals with a high risk on offending behaviour. Both teams were certified by the Dutch Centre of Certification of ACT and FACT teams, meaning that they had implemented the FACT model adequately.

The teams were informed about the study and the procedure by the first author and were asked to deliver an overview list of service users who met the following inclusion criteria: meeting the general FACT criteria (long-term history in (mental) health care; severe and enduring mental health problems and / or challenging behaviour; severe problems on different areas of life); having a determined MID (IQ 50 – 70) or BIF (IQ 70 - 85); enrolled in FACT for at least 9 months. The last criterion was included so that participants could form a balanced opinion. Service users who were detained or admitted in a psychiatric hospital were excluded, as well as those who were mentally unstable.

From the service users who met the criteria, a purposive sampling strategy was applied to ensure variability in experiences amongst the participants (Patton, 1990). Purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon of interest. In our study, maximum variation sampling was used to reveal different perspectives and experiences. In this method, participants are chosen purposefully based on variation on dimensions of interest - in our case: gender, receiving voluntary / involuntary treatment, main diagnosis and IQ level. This is done to ensure the presence of maximum variability within the primary data, but simultaneously, to identify important common patterns that cut across variations. The selected service users were informed, both orally and by letter, by their case manager or therapist (psychologist or behavioural specialist) and were asked to participate in the interviews and to sign an informed consent form. Service users could indicate the location of the interview (at service users' home or residence, at the office of the FACT team or elsewhere) and whether they wanted to be accompanied by a family member, close friend or a FACT team member.

A topic guide was constructed for the semi-structured interviews. Questions that were asked to elicit experiences were, for example, "What has the FACT team done for you thus far?", "Do they listen to you?", "Has the FACT team ever done something or said something that you felt not happy or even angry about?", "How do professionals have to treat you? And how not?".[9] To help the participants comparing their actual functioning and well-being with their condition at the start of the FACT treatment, we asked them to rate their state on a scale from 1 (extremely bad) to 10 (extremely good).

The interviews were conducted in tranches between February 2019 and July 2019 by the first author, assisted by a trained master student educational science. Six service users declined to participate, one was not reachable for the team, one was assessed as mentally unstable and one had left the FACT team in the meantime. For them, other candidates were selected. To reduce the risk of bias by suggestive and leading questions, the first two interviews were, with permission of the participants, video-recorded and discussed afterwards with two experienced therapists. Also, the transcriptions of both interviews were discussed within an expert group, consisting of two psychologists with extensive experience in FACT and three researchers with expertise in qualitative research.

Interviews were conducted with 15 participants (see below), lasted 30 to 75 minutes, and were audio-recorded and transcribed verbatim for coding purposes. As a token of gratitude for their participation participants received a voucher. Afterwards, the audio recordings were deleted.

Data analysis

An iterative process of data collection and analysis was used to develop a conceptual understanding of participants' experiences. First, open coding was used on all transcripts, resulting in more than 350 codes. Next, clustering of the codes by axial coding resulted in 14 categories, mainly corresponding to the interview topics (Table 1).

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[9] For the complete list of questions, see attachment on page 111.

Table 1 Main categories derived from the interviews

1.	History client
2.	Personal characteristics / attitude client
3.	Previous experiences with professional help
4.	Relational aspects of FACT
5.	Practical support of FACT
6.	Emotional support / therapy of FACT
7.	Organisational aspects of FACT
8.	Functioning at the start of FACT
9.	Actual functioning and well-being: positive
10.	Actual functioning and well-being: difficulties
11.	Helping factors
12.	Hindering factors
13.	Negative experiences with FACT
14.	Compulsory treatment

Next, selective coding led to four overarching themes, each with a number of subthemes (Table 2).

Table 2 Themes and subthemes derived from interviews

Themes	Subthemes
FACT treats me well	They don't let me down They are there for me - as a human They respect my autonomy
FACT meets my needs	They support me practically They give me emotional support and treatment
Overall I'm doing better now	I have grown stronger I have more structure and less stress in life
Tension fields	They don't do anything for me They are too restrictive

Throughout the analysis, memos were created to record reflexive notes, impressions and thoughts, which were regularly discussed between both interviewers. An audit trail was performed by the second author, by reading and assessing a selection of the original transcripts. Also, all steps in the process of coding and analyses were shared with the expert group.

Atlas.ti was used to support the organisation and categorization of data. The COREQ criteria list for qualitative research (Tong, Sainsbury & Craig, 2007) was used to guide the analysis and report.

Participants

After 15 interviews had been reviewed, no new topics emerged from further coding and comparison and saturation was reached. Twelve participants were male and three were female, aged between 22 and 60 years. The duration in FACT varied between one and seven years. There was a wide variety of DSM diagnoses, including addiction, personality disorder, schizophrenia, autism and ADHD. Ten participants lived independently (two of them with support from a regular ID facility), while four lived in supported residential facilities and one lived in a shelter. Eight participants had an actual judicial order (e.g., conditional sentence, conditional release from prison), four had an expired judicial order and two had an actual civil measure (meaning that the service user had to undergo treatment within the framework of the Dutch mental health act). IQ scores ranged between 59 and 80; eight participants had a MID (IQ between 50 and 70), seven functioned at borderline level (IQ between 70 and 85).

Remarkably, in none of the cases a family member attended the interview. Instead, four service users chose to be accompanied by their case managers during the interview. Because of their limited communication skills or their mental health condition, some participants found it difficult to express themselves - resulting in less rich research material. Nevertheless we aimed to do justice as well as possible to the essence of the ideas and experiences of all participants (in the result section referred to with P1 to P15).

Results

Overall, all service users gave FACT favourable ratings. Expressed in a score between one and ten, three participants gave a seven, eight participants gave an eight or nine, while four valued FACT with even a ten.

Theme 1: FACT treats me well

Regardless their condition or situation, all participants expressed their appreciation for the way they felt treated by the members of the FACT team. The question “What do you appreciate in the contact with FACT?” resulted in a long list of relational aspects. Closer analyses showed that most of these aspects referred to three core values: persistent involvement, availability and humanity, and respect for autonomy.

Persistent involvement: They don’t let me down

Several participants reported that they found it difficult to trust people. As an explanation, they referred to their negative experiences with professionals and (local) authorities in the past, or to the long-term impact of life events, such as mental illness, drug abuse or (violent) death of parents during childhood, sexual abuse or victimhood of violence. Life events can have a deep influence on the sense of safety:

> For me it is very important that professionals take me seriously. I think it is because of my past of sexual abuse. It is very important that I can trust people. In the past I wasn’t taken seriously by people in my family (P6).

As an understandable reaction to adverse circumstances and life events, people might build a harness:

> In the beginning I didn’t want professionals around me. I acted like it was all fine with me, but I hided the things that happened in my past (P10).

> In the beginning I was a troublesome guy, I say this honestly. I was angry and aggressive. Trusting caregivers was very hard for me, because I have experienced certain things in residential youth care institutions that I never had wanted to experience (P15).

Eventually, it was especially the combination of an unconditional, non-judging attitude and the persistent involvement of FACT that broke the barriers. As the following quotations illustrate, FACT stayed involved regardless the circumstances and service users' behaviour and condition – even in case of admission in a (psychiatric) hospital or imprisonment:

> They supported me through thick and thin. I could become mad, I could react angry, you tell so, they have withstood everything with me (P6).
>
> I was admitted in a psychiatric hospital but no one looked after me or spoke with me. I just passed the time. Thankfully, FACT came to visit me. Actually, I had more contact with FACT than with the hospital staff (P2).
>
> I kept the door shut for them a couple of times. I just didn't want to see them because I wasn't in the mood or had a bad night or something. But they simply came back again. I didn't get rid of them that easy (P13).

All participants had been in treatment of FACT for quite a long time, a few even up to six or seven years. Because of FACT's unconditional support and their broad and open view with focus on the competences and qualities of service users instead of their disabilities, they got the opportunity to change and prove themselves:

> My family guardian has a certain picture of me. She thinks I'm angry and aggressive and I can't take care for myself and for my children (…) But she refers to an assessment of nine or ten years ago (…) A. (systemic therapist) stands up for me at least. She says: that boy does well and when will you give him a chance? (P15).

Availability and humanity: They are there for me, as a human

Another highly appreciated element – associated with unconditionality – is the accessibility, the availability and the flexibility of FACT. Participants indicated that they can always rely on FACT:

> When I call them and they don't have time for me at that moment, they always call me back. Or when I want to change an appointment, I send a text message and it's fixed (P2).
>
> I can call or mail them every day (P10).

The interviews revealed that availability goes beyond professional availability, and that availability as a human being is equally important. Generally, participants did not like it when professionals behave like professionals, i.e. hide behind their role as therapists and adopt an attitude of professional distance. Instead, sincere involvement requires authenticity, daring to show oneself as a human being, showing compassion and emotions:

> They are really involved with me. K. and M. (case managers) were present at the moment my children were taken away. I saw them crying (…) I had never seen that before, they were the first professionals who showed their emotions (P15).

> When I was sick, I had an infection, I showed it to W. (case manager) and he was in shock. I was really sick. I had to go to hospital. They were all worried about me. They were engaged with me, for 100% (P12).

> When I was in jail, they looked after my pets, they brought me clothes. They gave me the feeling that they really cared about me (P4).

Autonomy: They respect my personal space

Respect implies, among others, having sensitivity for someone's individuality and personal space. The interviews revealed that service users attach great importance to their autonomy and independence: they want to make their own choices and decisions.

> For me it is important that care givers just do what I need. Don't determine anything for me otherwise I will rock the boat (P1).

> They (care givers) must never say to me 'you have to'. Then I lose my head completely. The only thing I have to is to keep on breathing and to wipe my ass (P5).

Some participants referred to bad experiences in their past. The following statements were done by participants who stayed in (forensic) residential institutions previously.

> In the TBS (forensic psychiatric institution) the staff determined everything for me. I don't like that. I find it irritating when they push me and give me the feeling that I have to act in a certain way (P1).

> My heaviest period was when I stayed in residential youth care. I was an aggressive boy, I was put in isolation … they didn't know how to handle me, I was hold down and forced to the ground (P12).

Respecting someone's boundaries also implies taking into account service user's emotional condition, psychological capacities and coping style. Several participants indicated that keeping some control over the intensity of the treatment process was very important for them:

> Meanwhile I know when treatment suits me or not. FACT feels good. One moment, I talk with W. (case manager) about things that happened in the past. Another, I talk about football (...) Things must not go too fast for me. Otherwise it turns out bad (P12).

Generally, participants believed that FACT meet their needs regarding autonomy and self-determination sufficiently – even if there are disagreements at times:

> First they said to me I had to take medication. But when I told them I didn't want to, they didn't push me, they didn't force me to take it. However, they did inform me about the risks (P10).

> In the beginning, there were many things of which I thought 'mind your own business'. But now, I take things differently and at least I think about the things they say. And sometimes I say yes and sometimes I say no. From time to time they try to push through but when I refuse, they withdraw (P2).

Theme 2: FACT meets my needs

Besides the contact with the staff, participants appreciated the (daily) support they received from FACT. In reply to the question "What does FACT actually do for you?", most of the participants emphasized the practical support.

Practical support

As the following quotations illustrate, participants received assistance with all kinds of activities, such as mail, administration and finances, contacts with (local) authorities (such as Tax Authorities and Employees Insurance [...] Administration), day structure, work and housing – in general, much to their satisfaction.

> About six years ago, I was referred to FACT by the Salvation Army. I had lost everything, I lived on the street, slept in a squat. I was in a bad shape. And then they helped me to get everything on track again. I didn't have an identity document anymore. I also had lost my house, my stuff, everything (P14).

> Right now I have troubles with my disability benefits, because I am going to marry and my girl friend has moved in with me. They solve this for me, it's

> going to be all right. And I have problems with the internet and tv, although I pay for it. I've had a technician at home, but the problem is still there. And then I have to call 40 times and I'm being transferred all the time and eventually I break the line and then I have to start all over again. And they can arrange that for me, I think they have been trained or something (P14).

> Recently I had to go to the doctor because of sleeping problems. D. (case manager) went with me. She brought me with her car, so I didn't have to arrange my own transport (P13).

They give me emotional support and treatment

Besides the practical support, participants mentioned the emotional support of the FACT team, ranging from daily counselling and monitoring to anger management, trauma treatment and system therapy.

> For me it's difficult to deal with stress and emotional events. Last week I didn't feel well. When they came, I have discussed this with them. I have told them everything what bothered me and what's going on inside me (P15).

> I have had EMDR and that was very intense. All kind of things happened in my head, my past came up again and I saw images and flashes (…) EMDR is really an intense therapy, it tackles the problem in your brain (P6).

> A (systemic therapist) went to my parents when I was in jail for a long time. That was really nice, my mother told me how glad she was to talk with A. And A. gave relation therapy to my partner and me. Nowadays, the relationship is going just fine and we go along with each other well, so we don't need the therapy anymore (P9).

Some participants received pharmacotherapy from FACT as well:

> R. (psychiatrist) doesn't come often, but if he comes he talks with me. For example, when I had a relapse. And then he discusses with me why the relapse has happened. And he discusses the use of medication, recently we did (P4).

Theme 3: Overall, I'm doing better now

I have grown stronger

When asked "How are you doing now, compared to when you started FACT?", most participants perceived improvement over time. Several of them indicated that they are better able to cope with stress and stressful situations, to express and manage their emotions and that they are more in harmony with themselves and their environment. They have gained insight in their problems and disabilities, and have less problems with professionals and (local) authorities.

> I was referred by the probation. I drank a lot, I didn't give a shit about anything. I had problems with local authorities. But the last two years, I have made progress. I've learned to seek help. When I have troubles, I text K. (case manager) or S. (psychologist) and tell them that I need to talk for a moment (P8).

> I have learned to trust people. I can handle my emotions better now. I am less angry and aggressive. I can open up myself much better. The fact that I have lost a lot remains difficult for me. But it's a matter of learning to accept and to go on (P15).

> I'm doing better now. I don't relapse anymore, I don't become psychic anymore. In the past, when I was busy in my head, I ran away. Now I don't do that anymore (P11).

> In the past I leaped from one thing to another, and now I first think before I do something and that helps me (P2).

However, as the following quotations indicate, the way to recovery is hard and often not continuous:

> I still find it difficult to deal with stress and tensions. That can bring out certain behaviour in me, you know, old behaviour. And that's not social, it's asocial. When I think that people don't take me seriously or that I'm treated unfair .. I can't deal with that. I have learned things in my life in a hard way. I have to keep on doing my best since the consequences can be major (P15).

> I'm doing fine. I drink beer now but that's because I have a headache. I know why, yesterday I boozed, I drank beer and wine (…) Usually I have structure in drinking. I stand up and I drink coffee. The best is to stand up early and drink after 5 p.m. (P14).

> In the summer I am more stable, in the winter I am more depressed. That's because of my illness, sometimes I peak and then I go whoop (P2).

> I'm doing quite well. In fact I don't need support at all. Except when it's going bad, when I have voices in my head. Then I neglect myself and my environment, I look tv and I don't want to talk with anyone (P1).

When asked, in case of amelioration, "How could these changes happen?" several participants referred to intrapersonal changes and better coping skills – largely as a result of their treatment in FACT. For some participants, understanding of 'what's wrong with them' helped them to accept their intellectual and/or mental health limitations. Although several service users had been treated in (mental) health care before, a clear diagnosis was not always made, and therefore, adequate treatment has been left out for a long time:

> In the past I didn't know what was wrong with me. In residential care I was very aggressive, they couldn't handle me at all. Five years ago, I was tested in FACT. I have a learning disorder and a bipolar disorder. Maybe I have had it always, but I didn't know it (P2).

Some participants attributed the results not so much on what they had learned in FACT, but rather on an autonomous process, a kind of mind shift – motivated by intrinsic / pull factors (life goals) or extrinsic / push factors (not wanting to go in jail anymore).

> I took the decision that I didn't want to go to jail anymore. I turned the switch. I don't go to the city anymore to steal, I have really forsworn stealing. You're becoming older and then you just don't want that anymore. I don't want to look behind all the time and to steal for drugs (P13).

> When you are young, you are doing silly things, like jumping from a bridge, fighting and driving when drunk. But when my little daughter was born, my brother told me: Stop with doing that, you want to see grow up your daughter don't you? Now I live more careful (P14).

I have more structure and less stress in life

Besides personal growth, several participants mentioned that they experience more rest and less stress in life because of changes and improvements in their environment, particularly with respect to housing, finances and administration. Also, having a day structure and having distraction by daily activities was mentioned several times as an important source of support.

> I have chosen to stay under guardianship because when I have to do everything by myself, things turn wrong. It costs something, but everything is arranged and I don't come in problems anymore (P8).

> Work is an important distraction for me, otherwise I sit still the whole day, and I can't handle that. I have to stay active, go outside, into the nature. I walk a lot. In the past I went to the city. But now I know that's not good for me, so I avoid the city (P13).

> In the past I have been in jail many times. I had a lot of outstanding fines because I was driving under influence and so on. And I had many debts. But now I have a bike instead of car and my administrator handles my mail. And now I am penalty-free (P14).

Theme 4: Tension fields

Although the majority of the participants valued FACT positively, there were some critical remarks as well.

They don't do anything for me

Two service users (P1, P5) were considerable disappointed about the practical help from FACT. Both men were frustrated since FACT had not succeeded in what they needed the most: another home. One of them said:

> They don't do anything for me. Yes, they come along for a talk. But what can they do? They can't do anything. I am lost already. Nothing happens, they don't change my situation. They are just like the probation: they talk to me and then they go again (P5).

However, despite their dissatisfaction about what FACT has actually done for them, both participants were rather positive about the relational aspects of FACT:

> I've known them for quite a while now and they haven't done anything for me, but I don't dislike them (P5).

> They still haven't arranged my housing. And they keep moaning about my past. But the contact is reasonably well. At least, they don't control me 24 hours a day (P1).

They are too restrictive

While, as reported above, most participants believed that FACT respected their autonomy sufficiently, some of them reported restrictive practices as well. It should be noted that participants differed in their perception of restrictive or authoritarian. For instance, some participants indicated to benefit from a clear and directive approach, while others warned that they cannot stand it when caregivers are too compelling:

> When K. (case manager) sees that I'm not acting good, he calls me to account. That's okay. Sometimes I need someone to kick my ass. It doesn't help me when someone is just kind to me. Sometimes I need some pressure (P8).

> L. (case manager) is a woman that .. she isn't wrong or bad or something .. but she is more intrusive, in a kind of 'you must, I want to see this, I want to see that' and then I think: listen, if you tell me what to do, then I show you the door. I don't have to do anything (P15).

Sometimes, the feeling of restriction was related to their judicial status:

> It's not that I have the feeling that they oblige me or something. It's more that I think I have had probation supervision for so long now, why can't they stop it? My legal measure ends in 2021 and as long I'm under supervision, I receive treatment from FACT. And sometimes I'm just through with it (P9).

> FACT visits me twice a week. I believe that's too much actually. Sometimes I need more rest because I don't feel very well. But I can't cancel them too often, because I'm bound to receive treatment (P8).

Also, medication use can be experienced as a breach of someone's autonomy:

> I want to reduce my medication, but they say that's not good for me. Sometimes we have conflicts on this subject, while I always have done what they told me. Preferably I don't want medication at all (P3).

Discussion

Reflection on the results

In this paper we presented the results of a qualitative study on the experiences of service users with MID/BIF and mental health problems or challenging behaviour with FACT. The aim of the study was to explore how service users valued the treatment of FACT, how they valued the results of FACT, in terms of well-being and functioning, and which factors they perceived as supportive or helping. With respect to the overall valuation of FACT, the majority of participants were very satisfied. The positive valuation seemed to be connected with two factors: the relational aspects and the practical and emotional support they received. With respect to the relational aspects, service users appreciated especially the unconditional and long-term involvement of the team members (continuity of care), their availability, their sincere interest and humanity, and their respect for the autonomy and freedom of choice. For several participants, these positive experiences contrasted sharply with their previous experiences in mental health care, residential youth care and judicial institutions. With respect to the results of the treatment, most participants experienced improvement over time and indicated that they were better able to cope with stress and stressful situations and to express and manage their emotions. To what extent these improvements could be attributed to the interventions of the FACT team, was difficult to determine. While some participants made a clear link to what they learned in FACT, others spoke of an intrapersonal change that was motivated by intrinsic or extrinsic factors.

The finding that all participants had an overall positive valuation of FACT is remarkable. Even those who obviously struggled with complicated problems in life, mostly appreciated the involvement of FACT. Also, receiving compulsory treatment was not related directly to the valuation of FACT. Indeed, several service users indicated that FACT helped them to break the vicious circle of negative functioning, trouble with local authorities and criminality and admitted that they needed FACT as a precaution and to stay on track. Apparently, FACT is able to build up a trusting bond with individuals with complex and multiple problems, often with a burdened past and a criminal history, who have found traditional services unable to meet their needs. It is noteworthy that our findings contrast with the results of previous qualitative studies on the experiences of service users with ID – which were mostly performed in the context of residential settings (Griffith, Hutchinson & Hastings, 2013). Other than in many residential settings where individuals with ID experience accumulative stressors, causing continued challenging behaviour, FACT service users do not seem to be affected (that much) by the ‘iatrogenic harm’ of clinical institutions. Instead, they emphasize especially their positive experiences with FACT.

In this respect, a parallel may be drawn with the results of studies on experiences of service users suffering from severe mental illness with ACT. Overall, both groups of service users had positive experiences with ACT, and both groups referred to the relational as well as the content elements if asked for the supportive factors. The fact that care givers ‘just’ do what they need the most and ‘just’ treat them respectfully might be considered as obvious, but is often not in line with service users’ experiences with (mental) health care in the past. For example, Stuen, Rugkåsa, Landheim, & Wynn (2015) performed in depth interviews with 15 patients that received involuntary treatment by ACT and concluded that: “Although experiencing difficulties and tensions, many participants described the ACT team as a different mental health arena from what they had known before, with another frame of interaction. Despite being legally compelled to receive treatment, many participants talked about how the ACT teams focused on addressing unmet needs, the management of future crisis, and finding solutions to daily life problems” (p.11).

Although the majority of the participants valued FACT positively, it is important to reflect on the critical remarks as well. Some participants felt frustrated because FACT could not arrange adequate housing for them, while others struggled with, for example, medication use. Tensions and conflicting interests were found in studies among service users of regular ACT as well. For example, Mc. Grew, Wilson & Bond (2002) performed a study among clients on the negative aspects of ACT, and found that intrusiveness, the confining nature of ACT, overemphasis on the use of medication, low frequency of contacts and limited availability of staff were perceived as the most important drawbacks. The delicate balance between professional responsibility and clients’ self-responsibility, or between social control and building up a therapeutic relationship, is an ethical dilemma which is considered as inherent to ACT (Watts & Priebe, 2002). On the basis of a qualitative research on the experiences of clients with coercive techniques in ACT, Appelbaum & Le Melle (2008) recommend to keep on investing in the relationship with clients by caring, listening and encouraging, since this can be seen as the most important working ingredient of ACT.

Strengths and limitations

In qualitative research, the researcher is a central figure who influences, if not actively constructs, the collection, selection, and interpretation of data (Finlay, 2002). In the current study, the main researcher had extensive knowledge and experience in the area of (F)ACT MID/BIF, both as a researcher and as a trainer, coach and auditor. To reduce the risk of biased interpretations, we embedded a number of precautions in our study design, such as logbooks, frequent exchange of experiences and ideas between both interviewers, an audit trail performed by the second author, and critical conversations with an expert group containing both professional and methodological expertise. In our judgement, these measures have led to a balanced description of the results which reflect both the positive and the negative experiences of service users with FACT.

To what extent the findings are representative for the research population (i.e., service users of FACT MID/BIF teams) is hard to determine. The fact that most of the participants underwent the FACT treatment involuntary because of a judicial order, may limit the transferability of the results. Also, nine service users declined to participate to the interviews. Although avoidant and reluctant behaviour is common in this population and was found within the participant group as well, it is possible that the non-participants had less positive experiences compared with the participants. Moreover, most of the participants have been in treatment of FACT for quite a long time. It is possible that service users who were admitted more recently have different or less positive experiences, because they might experience more problems and suffering. However, our findings show that the valuation of FACT is not necessarily related to the current level of well-being of the service users. Further, our findings are congruent with the outcomes of earlier performed studies on the experiences of service users of regular ACT (Krupa et al., 2005; Mc Grew, Wilson & Bond, 1996), as well as with the recommendations of Griffith, Hutchinson & Warwick (2013) regarding the preferred attitude and treatment of people with ID and challenging behaviour.

Four service users chose to be accompanied by their case managers during the interviews. Since people with MID/BIF may be easily influenced, this could have distorted the findings. However, it is characteristic for the caseload of FACT MID/BIF teams as well that many of them live an isolated life and do not have caring relatives or close friends. For these people, their professional carers form their social network and are considered as relatives or friends – which was also reflected by the interviews. As far as we can assess, the presence of case managers at the interviews did not influence the participants in their answers. Indeed, the participants who were accompanied by there case manager did not mince words if they had critical remarks on FACT. Also, the presence of a case manager was a necessary support for several service users to participate. The possible influence of the case manager on the valuation of the participants was explicitly brought up in the interviews and all participants denied that this was the case.

This study was aimed at service users' experiences, not in finding the truth. During the evaluation of the pilot interviews it appeared that service users did not always give a correct representation of how things went in the past, and the support they received by FACT. Sometimes participants forgot things to tell or could not make clear in which sequence events had occurred, for what reasons they were referred to FACT or to argue their opinions. Also, some participants tended to overestimate themselves, at the expense of the efforts of FACT. It is known that interviewing persons with ID can pose problems in terms of reliability of data (see e.g., Finlay & Lyons, 2001). To optimize the quality of data collection, sentence structures were simplified, questions were adjusted, and answers were summarized and checked. However, what counts for people in general goes for people with MID/BIF as well; they reason, feel and interpret from their own perspectives. Personality, self-insight, level of understanding and experiences in the past colour their perceptions. For a more complete insight in the working ingredients of FACT MID/BIF, it might be useful to extend the research activities to FACT team members as well.

Conclusion

From service user's perspective, FACT appears to have an added value and seems to be able to build up a trusting bond with individuals with MID/BIF and complex and multiple problems, often with a burdened past and a criminal history. An important area of attention for FACT MID/BIF teams is to achieve an optimal balance between professional responsibility, control and structure on the one hand and client's autonomy, independence and freedom on the other.

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Attachment: List of questions used in semi-structured interviews

Introduction

- The goal of the interviews is to reveal how service users think about the care they receive from FACT. The interviews are done by my colleague and me.
- To prevent losing information, we make audio records. We will use the records to make a report and to write a paper. After the study we will delete the audio records.
- Everything that you tell me is confidential and does not have any consequences for your treatment. You don't have to tell things if you don't want to. We don't share any information with your care givers. In the report and paper we will not mention your name.
- The interview will last an hour approximately. When you want to pause, you can give me a sign.

Experiences with FACT

Appreciation of FACT

- Do you know when was your last contact with one of the care givers of the FACT-team? Who did you see?
- What has that person discussed with you, or what has he/she done for you the last time you saw him/her? Did you feel yourself helped/supported?
- Besides X, do you know other people from FACT? Who do you know? Do they do the same or do they have specialties?
- How do you feel about seeing different people from the team?
- Can you describe the relationship with the care givers of FACT? How do they treat you? Do they listen to you? Do they take you seriously? Can you trust them?
- Do the care givers of FACT have contacts with your family members or other people in your environment as well? And with other care givers, or your probation officer? How do you think about that?
- When you see a care giver of FACT, do you come to the office or do they visit you? How do you feel about that?
- How often do you see them? How do you feel about the frequency? Would you see them more often, or maybe less frequent?
- When you don't have an appointment with them but you need help or want to speak with them for a moment, can you reach them?
- What has the team done for you thus far? For example, have they helped you with your finances, household, contacts with local authorities, finding work? Do they join you when you have an appointment with your doctor, dentist,

probation officer or local authorities? How do you appreciate the things they did for you?
- Do you have contact with the psychologist or the psychiatrist of the team as well? What do you discuss with them? Do they give you medication?
- How do you think about the results of the treatment and support thus far? Do you feel helped/supported?
- Are there things that you don't like about FACT? Have they ever done something or said something that you were not happy about?
- If I ask you to rate the FACT team at a scale from 1 (extremely bad, couldn't be worse) to 10 (extremely good, couldn't be better), what rate would you give?

Comparison with other forms of professional care

- Do you know how long you have received care from FACT already? How did you get into contact with them?
- Did you receive professional care before FACT? Do you know yet how you felt about that care? How did they treat you? What did they do for you? What was good about that care? Were there things that you didn't feel good about as well?
- If I ask you to rate the treatment and support you got in the past at a scale from 1 (extremely bad, couldn't be worse) to 10 (extremely good, couldn't be better), what rate would you give?
- Can you explain why you rate that treatment with a X, and the treatment from FACT with a X?

Actual wellbeing and functioning

- How do you do recently? Can you rate yourself between 1 and 10? What goes well and what doesn't go well yet?
- Do you remember how you were doing when you came into contact with FACT for the first time? How did you do at that time on a scale from 1 to 10?
- Can you explain the differences between your actual functioning and your functioning back then?
- In case of amelioration: how comes that you feel better now than then? What has helped you the most? Were there also things that did not help you?
- In case of worsening: how comes that you feel worse now than then? What do you need to feel better?

Final questions

- Which things in professional care are the most important for you? What do you need the most to feel better? And are there things that they surely shouldn't do?

Conclusion

- How did you experience this interview?
- As told before, we will use the audio records to make a report of the interview. Would you like to receive that report?
- Handing the voucher.

6

General discussion

The overall discussion summarizes the main findings of the thesis and draws conclusions regarding the research questions. The main research question addressed in this thesis was: *What are the treatment outcomes of (F)ACT for individuals with MID/BIF and mental health problems or challenging behaviour?* In four chapters, we addressed the following sub questions:

1. What is known about the effectiveness of (F)ACT for individuals with intellectual disabilities, and how has (F)ACT MID/BIF been developed in the Netherlands? (chapter 2)
2. What are the characteristics of the clients who receive treatment in FACT MID/BIF teams, and what are the outcomes of FACT MID/BIF over time, in terms of social and psychological functioning, admissions in (mental) health care, (risk of) challenging and criminal behaviour, and social participation? (chapter 3)
3. Is there an association between client variables and treatment outcome of (F)ACT MID/BIF, in terms of social and psychological functioning? (chapter 4)
4. How do clients with MID/BIF value the treatment and the results of (F)ACT, in terms of daily functioning and well-being, and which factors are perceived as supportive? (chapter 5)

6.1 Main findings

Chapter 2 contains a paper in which we described the international state of the art of (F)ACT for people with MID/BIF. We conducted a critical review of studies on assertive outreach for individuals with (M)ID/BIF and mental health problems or challenging behaviour and found that in spite of the promising results of several studies on this subject, (F)ACT has not been implemented on a large scale in the ID-field. As a consequence, the research area of ACT for people with intellectual disabilities was small. To improve the care for people with MID/BIF and mental health problems or challenging behaviour in the Netherlands, the (F)ACT model – originally developed for people with severe mental illness – was adapted and implemented in practice by four organisations specialised in the care for people with MID/BIF and mental health problems or challenging behaviour[10]. In the (F)ACT MID/BIF model the leading principles of the original model were maintained: (F)ACT MID/BIF teams provide ambulant, multidisciplinary, intensive, continuous, long-term and outreach treatment on all areas of life. The most important adaptation to the original (F)ACT model concerned the required expertise in the team and the skills of team members to adapt to the emotional, cognitive and

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[10] These organisations cooperate in expertise centre De Borg and have been appointed by the government to provide highly specialised treatment for people with MID/BIF and mental health problems or challenging behaviour.

adaptive level of functioning of their clients. Also, since people with MID/BIF need intensive support in different areas of life and consequently, professionals spend a lot of time on arranging basic conditions and on contacts with community services, a smaller staff/caseload ratio as compared to regular (F)ACT teams was proposed. Thirdly, treatment interventions should be adapted to people with MID/BIF and should contain both systemic and client based interventions. Finally, (F)ACT MID/BIF teams should apply broad admission criteria since the caseload is more mixed than in regular (F)ACT teams, also because of the atypical presentation of mental disorders in individuals with ID.

In chapter 3, we presented the results of a longitudinal study that has been conducted in the Netherlands between 2011 and 2017. During this period, seven FACT MID/BIF teams were established as part of a nationwide implementation project, while one team was already in operation. The caseload of the teams was built up gradually using the admission criteria as described in the (F)ACT MID/BIF model: 18 years or older; with a determined or at least a serious clinical suspicion of MID/BIF in combination with mental health problems or challenging behaviour; and ineligible or unmotivated for regular forms of care. Right from their start the teams were asked to provide data on client characteristics and treatment outcomes, ideally each year for each client. Outcome measures concerned admissions to (mental) health care, social and psychological functioning, (risk) of challenging and criminal behaviour, and social participation. Six year data collection resulted in a data set of 604 unique clients, of whom 281 had at least two measurements. The second and third measurement were performed on average 13.9 months (*SD* = 7.1) and 24.6 months (*SD* = 7.8) after the first, respectively. Data were analysed using descriptive statistics (for the description of the caseload) and linear mixed models (for investigating trends in time). Most of the clients were men between 20 and 40 years old, with an average IQ of 69, living alone and trying to deal with day-to-day stressful situations and potentially harmful impulses, including substances abuse. During their time in FACT, on average clients showed improvement in their social and psychological functioning and living circumstances. The number of admissions to (mental) health care diminished over time, as well as the reported number of contacts with policy and justice, the level of social disturbance and the risk factors for challenging and criminal behaviour. Problems related to finances, work and substances abuse remained unchanged.

In chapter 4, we investigated whether treatment outcome was associated with static and dynamic client variables. We included 281 clients and used linear mixed models as analysis technique. As outcome measure, we chose the sum score on the HoNOS-LD, a standardised instrument that measures social and psychological functioning in individuals with ‘learning disabilities’. As predictor variables we chose demographic variables, IQ-score, judicial measure and the 14 subscales of the short version of the Dynamic Risk Outcome Scale (DROS-SV; Drieschner, 2012). We found that none of the demographic factors influenced treatment outcome significantly, and neither did IQ or having a judicial or civil measure. This implicates that - on group level and thus, on average - all clients showed progression during their time in FACT, regardless their age, gender, ethnicity, living situation, IQ and possible judicial or civil measure. Of the dynamic risk variables, social skills, impulsivity, treatment cooperation and motivation, substance abuse and awareness of the need for treatment had a significant influence on changes in time. Therefore, we recommended the use of motivational interviewing techniques, and to incorporate social skills training and substance use interventions in the treatment program of FACT MID/BIF teams.

For the enrichment of the quantitative studies, a qualitative study was performed to evaluate (F)ACT from the clients' perspective. Chapter 5 is devoted to the experiences of service users with FACT. Fifteen clients of two forensic FACT MID/BIF teams were interviewed on their experiences with FACT. Most of them highly appreciated the involvement of FACT. The positive valuation was attributed to the contact with the staff and the practical and emotional support clients received from FACT. Persistent involvement, availability and humanity, and respect for autonomy were distinguished as core values in the relationship with the staff. Most service users experienced improvement in time, and attributed this to intrapersonal changes and/or less stress in life. We concluded that, from the service user's perspective, FACT appears to have an added value and seems to be able to build up a trusting bond with individuals with MID/BIF and multiple problems, often with a burdened past and a criminal history. An important area of attention for FACT MID/BIF teams is to achieve an optimal balance between professional responsibility, control and structure on the one hand, and client's autonomy, independence and freedom on the other.

6.2 Follow-up Joey

After two years in FACT Joey is doing reasonably well. FACT visits him two times a week at his home, when he is free from work. Besides, when Joey encounters a problem or wants to discuss something, he contacts FACT by telephone or WhatsApp. Since Joey has more structure in life and exchanged his car for a bicycle, he commits no traffic offences anymore. However, his drinking behaviour remains problematic. Under influence of alcohol he started a fight in a café a few weeks ago. Joey was arrested for assault and had to go to jail again. During his detention period FACT visits him every week. His administrator takes care for the payment of rent and other bills.

The case of Joey is an illustration of the results found in our research on (F)ACT MID/BIF. Firstly, the fact that Joey, despite his avoidant and negative attitude in the beginning, still receives care from FACT after two years and regularly even takes the initiative for contact, can be seen as an achievement in itself. It is characteristic for the target group of FACT that many clients have problems with motivation for treatment, and building a trusting relationship may take a lot of time. Secondly, the case shows that Joey has found more structure in his life since FACT has arranged independent housing and meaningful day time occupation for him. Also, since Joey has outsourced his administration and finances to an administrator, he has less problems with authorities and experiences less stress in life. As we presented in chapter 5, it seems to be the combination of the good contact with the staff and the practical and emotional support to which clients attribute the treatment results. However, the case of Joey also illustrates that FACT is not a panacea. Even after a multi-year treatment program many clients still encounter difficulties and problems. As chapter 3 showed, particularly with regard to finances, work and substances abuse, problems are often persistent and hard to handle. Anyhow, relapse of symptoms or adverse results are no reason for FACT teams to give up; as the case shows, FACT stays visiting clients during admissions or incarcerations. This feature of FACT, persistent involvement, is seen as an important working ingredient of FACT by service users.

6.3 Discussion

This thesis covered an important social issue: the (organisation of) care and treatment for a group of vulnerable people with a marginal position in society, who lack the skills to deal with the challenges of everyday life and frequently cause trouble or even danger for themselves and other people. Although composed heterogeneously, this group of people has in common that their problems and behaviour can be traced back to, or are at least associated with limitations in their intellectual, adaptive, and social and emotional functioning. In a society that becomes more and more complex, it becomes increasingly evident that people with MID/BIF can experience severe problems – since they do not have the skills to deal with the challenges of everyday life. When these people are overcharged long term and if there is not sufficient support from informal or formal care givers, mental health problems, psychosocial problems and behavioural problems may occur. It is therefore no coincidence that individuals with MID/BIF are overrepresented in mental health care (Nieuwenhuis, Noorthoorn, Nijman, Naarding & Mulder, 2017), shelters for homeless people (Lougheed & Farrell, 2013; Van Straaten et al., 2014) and in prisons (Hellenbach, Karatzias & Brown, 2015; Kaal, Nijman & Moonen, 2015). Given the fact that self-responsibility, empowerment and social participation are important values in modern western societies, it is plausible that in the near future an increasing number of people with MID/BIF will rely upon health care and social services (also see Woittiez, Putman, Eggink & Ras, 2014).

While regular facilities in mental health care, disability care and addiction care often do not succeed in treating people with MID/BIF and complex problems successfully (see, e.g., Chaplin, 2009; Hurley, 2006; Nieuwenhuis et al., 2017), our research indicates that FACT MID/BIF seems to be effective. Although we cannot establish causal relationships because of the lack of a control group, clients showed - on average - improvement during their treatment in FACT, both with regard to psychological measures (individual functioning), living conditions (housing) and to societal or criminal measures (e.g., social disturbance, burden on the judicial system). The results of our longitudinal study were confirmed by the information drawn from the interviews with clients; most of them experienced improvement in functioning and well-being in time. These positive results are congruent with the results found in previous, predominantly observational studies on ACT for people with (M)ID, performed in the United States, Canada and the United Kingdom. Although the comparability of the studies is limited because of different designs, inclusion criteria and outcome measures, several studies reported a reduction in behavioural problems (i.e., better functioning) (Coelho, Kelley & Deatsman-Kelly, 1993; Douglas & Hurtado, 2013; Van Minnen, Hoogduin & Broekman, 1997) and a decrease in number of admissions (Douglass & Hurtado, 2013; Hassiotis et al., 2001; King et al., 2009; Meisler et al., 2000; Van Minnen, Hoogduin & Broekman, 1997) as well. Hence, we can conclude that our research results strengthen the evidence value of (F)ACT for people with MID/BIF.

Another key conclusion drawn from the results of our research is that demographic variables and level of IQ do not have a significant influence on changes in social and psychological functioning of clients with MID/BIF during their time in FACT. Hence, on group level and on average all clients seem to benefit from FACT, that is, regardless their age, gender, living situation, ethnicity and IQ level. This finding advocates a broad description of the target group of FACT MID/BIF teams. Remarkably, the treatment outcomes of FACT appeared neither to be associated with client's voluntarily or involuntarily status. From research among clients with severe mental illness receiving ACT it is known that clients with an involuntary status experience little or no leverage or coercion (Appelbaum & Le Melle, 2008; Stuen, Rugkäsa, Landheim & Wynn, 2015). Apparently, even if they are obliged to undergo treatment, clients may benefit from the treatment of (F)ACT. This finding was in agreement with the results of our qualitative study, in which we found that receiving compulsory treatment was not related to the valuation of FACT. Indeed, several participants indicated that FACT helped them to break the vicious circle of negative functioning, problems with local authorities and criminality and admitted that they needed FACT as a precaution and to stay on track. In this respect, compulsory treatment can even be seen as beneficial to (some) clients – provided that, as will be discussed below, within the limits set out by the judicial measure, their autonomy is respected and they feel emotionally and practically supported by their caregivers.

Above findings lead us to the next question, namely: Which factors can be identified as the working ingredients of FACT for people with MID/BIF? The conclusion we draw on the basis of our qualitative study is that the positive results of FACT seem to be attributed to 1) the contact with the staff and 2) the practical and emotional support provided by FACT. In the contact with the staff persistent involvement ("Don't let me down"), availability and humanity ("Be there, as a human being"), and respect for client's autonomy ("Let me make my own choices") were identified as the key aspects and might be considered as the most important working ingredients of FACT MID/BIF. The fact that caregivers 'just' do what their clients need the most and 'just' treat them respectfully might be considered as obvious, but is often not in line with clients' experiences with professional care in the past. Both research and practice learn that many general health care facilities have difficulties to fit the needs of individuals with MID/BIF and mental health problems or challenging behaviour. For example, many staff members in mental health care facilities are not equipped to identify clients with MID/BIF and to interact and communicate with them, resulting in false diagnoses, inadequate treatment, more lengthy hospital stays, more use of coercive measures and poor treatment outcome (e.g., Chaplin, 2009; Hurley, 2006; Nieuwenhuis et al., 2017). Conversely, the same holds true for staff members in the ID field: because of their lack of knowledge with regard to mental health issues, mental disorders are missed and treatment facilities adapted to these individuals are insufficient and remain ineffective (e.g., Hassiotis, Tyrer & Oliver, 2003).

With regard to the working ingredients of FACT MID/BIF, again, a parallel may be drawn with the results of studies on experiences of service users suffering from severe mental illness with ACT. A study often referred to is the study by McGrew, Wilson and Bond (1996) who found that non-specific ingredients (such as the relationship with case managers) were reported by clients most frequently when they were asked what they liked best about ACT, followed by content aspects of ACT (e.g. assistance, medical care, housing). Krupa et al. (2005) set up a participatory research to find out how people who receive ACT experienced this service and concluded that, in line with Mc Grew et al. (1996), clients' well-being was mainly determined by the relationship between client and staff members. Also, the results suggested that the relationship was facilitated by structural aspects of the ACT model, such as continuity, long-term involvement, flexibility and accessibility: “In short, the helping relationship appears to be related to the capacity of the model to allow the relationship to ‘be there’ as needed” (p. 23). Appelbaum and Le Melle (2008) focussed on the experiences of clients with coercive techniques within ACT and found that little evidence was found of significant use of leverage or perceptions of coercion. Instead, clients reported that feeling supported by staff (caring, listening, encouraging) were the most helpful ingredients. Lastly, Stuen et al. (2015) set up a qualitative study of clients’ experiences of community treatment orders within an ACT setting. Many clients described the ACT team as a different mental health arena from what they had known before, with another frame of interaction. Especially the focus on unmet needs, the management of future crises and finding solutions to daily life problems were considered positive aspects of ACT.

The results of our qualitative study can be put in a theoretical context. Firstly, our results are in line with the self-determination theory (SDT), that states that all individuals, if they abide in a stimulating, rather structured but non-controlling environment, show personal growth. From the perspective of SDT, professionals should be responsive to the service users’ needs for competence (i.e., perceptions of ability), relatedness (i.e., feeling socially accepted, included, and supported), and autonomy (i.e., exercising responsibility, choice, and decision-making) to facilitate constructive social development and personal well-being (Ryan & Deci, 2017). A second important theory wherein our findings resonate is the theory of presence (Baart, 2001). This theory is based on research on practices of pastoral workers in disadvantaged areas and describes how care-givers can build up a meaningful relationship with individuals who live in the margins of society and are difficult to reach. Presence practitioners are open, unprejudiced, human, authentic, informal, loving, warm and sincere in contact with the other. Instead of being specialised in a certain area of expertise, presence practitioners work comprehensively and without boundaries, and do what is necessary and important for the other. Presence practitioners meet their clients in their own environment, tune their conversation topics and pace to the other and are usually involved for a long period. Their focus is not the ‘hunt on’ the problems, but supporting the other to find a satisfactory attitude regarding life.

Despite the overall positive results of FACT for people with MID/BIF and complex problems, our research has shown that FACT is not a panacea. Firstly, small changes take often a long period of time. The interviews with clients revealed that building up a trusting relationship with professionals takes a lot of time. As a result of life events or negative experiences with professional care in the past, several clients were not motivated to accept help, which made high demands on the patience and persistence of the FACT team members. Secondly, although clients showed improvement on several outcome measures, financial problems, work-related problems and addiction problems often remained. As the case of Joey shows, even if clients do receive long-term support and monitoring from FACT, relapse in symptoms or challenging behaviour is lurking around. For this reason, most clients will be long-term in need of professional support and monitoring, either from FACT or from another ambulant and/or outpatient form of treatment. Thirdly, clients with addiction problems appeared to benefit less from FACT, as did clients with a high score on impulsivity, clients with limited awareness of the need for treatment, clients with limited treatment motivation and cooperation, and clients with limited social skills. In previous studies among clients with severe mental illness (e.g., Kortrijk, Mulder, Roosenschoon, & Wiersma, 2009), low motivation for treatment and substance abuse were found to be associated with worse treatment outcome. It is therefore important that (F)ACT MID/BIF teams keep on improving their treatment programs and investing in ongoing education and training of their team members. To meet the needs of their clients and to achieve better treatment results, motivational interviewing, substance abuse treatment and social skills training should be incorporated in treatment programs of (F)ACT MID/BIF teams structurally. Further, because of the persistency of financial and work-related problems, (F)ACT MID/BIF teams should have expertise on the areas of finances and job coaching.

In contrast with most other health care facilities and social services, (F)ACT MID/BIF teams provide long-term and comprehensive treatment and support to a heterogeneous group of people with complex needs. Also, these teams work across treatment programs, disciplines, health care sectors and funding systems. These features may explain their effectiveness, but conflicts with the current health care organization system and funding structure as well. FACT MID/BIF teams have to deal with different funding systems and legislations, which is a considerable obstacle to deliver continuity of care. For example, in some cases FACT MID/BIF teams feel obliged to unsubscribe their clients prematurely from FACT because of the expiration of the judicial measure and consequently the funding - despite the risks for both the client and society. In other cases FACT MID/BIF teams have to refuse new clients or feel obliged to terminate the treatment prematurely, because of the strict and rigorous policy of the funder.[11] Further, as also mentioned by King et al. (2009), several FACT MID/BIF teams have considerable difficulties with the maintenance of the ‘can-do-all approach’ what assertive outreach stands for – for instance because the funder only compensates ‘treatment interventions’ and not ‘supportive interventions’. Hence, despite the positive results of FACT MID/BIF, the implementation of this type of care has

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[11] For example, to be eligible for funding, organisations should prove that the person concerned has a MID/BIF that has been diagnosed before the age of 18.

appeared to be a major challenge for organisations and the survival of FACT MID/BIF for the long term is not guaranteed. It should be clear that tailored-made care needs tailored-made financing, and that care innovations need investments and support from policy and funders.

6.4 Methodological limitations and strengths

It is relatively difficult to investigate FACT because it is a complex intervention containing several interacting components (Craig et al., 2008). In this research project we chose to combine different research sources (i.e., literature, professionals, clients) and different research methods (i.e., quantitative and qualitative research), which is viewed by researchers as the most adequate approach to study complex interventions. In this paragraph we will discuss some methodological issues on both the quantitative and qualitative studies.

With respect to our quantitative study, we chose for an observational design, making use of data that were collected routinely by eight FACT MID/BIF teams. As a consequence, the results of our study cannot with certainty be attributed to the efforts of the (F)ACT teams. In contrast with randomised clinical controlled trials, observational research does not assess efficacy, as it does not measure whether the intervention has the capacity to achieve a result. It assesses effectiveness, that is, whether the treatment works in real life under circumstances that are sometimes far from ideal (Haynes, 1999). Since we did not use control groups we can not make any statements about what would have happened if clients were being treated 'as usual' or had no treatment at all. Nor did we investigate whether clients would have benefited from other forms of (community) treatment and care. It is important to note that the results of our study can be attributed to factors other than FACT treatment; improvement in social and psychological functioning of clients with MID/BIF could be the result, for instance, of changes in health care policy or changes that go along with increasing prosperity. Also, autonomous changes in clients' private lives or autonomous developments that go along with increasing age (or simply time) could have played a role; in this respect it is important to note that many clients were admitted in FACT when they had reached the bottom of the well.

Also inherent in the design of our research project, is that the data collection was relatively difficult to regulate. Several staff-related and organisational-related obstacles, such as illness, discharge and staff shortage, were met in daily practice that may have influenced the response. Also, most of the data were collected by two of the eight participating teams. Although the statistical technique of Linear Mixed Models deals with missing values and include all available data in the analyses to study trends in time, a bias caused by selective non-response or selective drop-out during the study period cannot be ruled out. It is possible that individuals who are difficult to treat were overrepresented in the non-response or drop-out group. Because of the lack of information, we could not perform a non-response analysis, and neither did we gather information on the reasons for (premature) termination of individual treatment courses.

In view of the foregoing, although the data collection was spread over a period of six years, only 61% of the initially included clients had two measurements or more. The steep decline in the number of repeated measures might be a result of the abovementioned staff-related and organisation-related factors. An on average shorter treatment period of FACT MID/BIF teams as compared to regular (F)ACT teams could be another explanation, amongst others because of the way of funding. In any case, the decline in response can be attributed to the time factor as well: several teams started their data collection just half-way the entire study period because they were not operational yet at the start of it, while data collection ended in May 2017 at the same time for all teams. Given the fact that, especially in this client group, small changes may take much time and effort, and recovery processes are rarely linear, it would have been valuable to extend the duration of the data collection period in order to have access to as much useful information as possible. However, the necessary resources were not available to continue the research project.

While we did investigate the influence of clients' static and dynamic risk variables on the treatment results of FACT MID/BIF, our longitudinal study did not identify which treatment-bound factors were responsible for the changes in social and psychological functioning of clients. Since we had no information on the type and the intensity of treatment on a client level, we were not able to explore associations between the treatment elements of FACT and treatment outcome. It is possible that certain teams achieve better results than others, because they provide more intensive care, have a wider range of therapeutic interventions or have another mix of disciplines or expertise than other teams. Also, it is possible that higher-motivated clients benefit especially from the therapeutic interventions of the FACT team, while lower-motivated clients benefit more from the practical support with regard to housing and daytime activities. Since we were not able to investigate these assumptions, future research could be directed at which clients benefit from which treatment elements in FACT.

With respect to our qualitative study we should make some critical comments as well. Firstly, since the researcher is a central figure in qualitative research, he or she influences and partly constructs the collection, selection, and interpretation of data (Finlay, 2002). In our study, the main researcher had extensive knowledge and experience in the area of (F)ACT MID/BIF, both as a researcher and as a trainer, coach and auditor. To reduce the risk of biased interpretations, we embedded a number of precautions in our study design, such as logbooks, frequent exchange of experiences and ideas between both interviewers, an audit trail performed by a member of the research team who was not involved in the interviews, and critical conversations with an expert group containing both professional and methodological expertise.

To what extent the findings of the qualitative study are representative for the study population (i.e., service users of FACT MID/BIF teams) is hard to determine. The fact that most of the participants (have) had a judicial measure might limit the generalizability of the results. Also, several clients declined to participate with the interviews. It is possible that the non-participants had less positive experiences compared with the participants. Moreover, most of the participants have been in treatment of FACT for quite a long time. It is possible that service users who were admitted in FACT more recently had different or less positive experiences, because they might experience more problems and suffering. However, our findings suggested that the valuation of FACT is not necessarily related to the current level of well-being of the service users. Further, our findings were congruent with the outcomes of earlier studies on the experiences of service users of regular ACT, as well as with the recommendations of Griffith, Hutchinson and Warwick (2013) regarding the preferred attitude and treatment of people with ID and challenging behaviour.

Our qualitative study was aimed at service users' experiences. It is possible that service users did not always gave a correct representation of how things went in the past, and the support they received from FACT. Sometimes participants forgot things to tell or could not make clear in which sequence events had occurred, for what reasons they were referred to FACT or to argue their opinions. Also, some participants may have overestimated themselves, at the expense of the efforts of FACT. It is known that interviewing persons with ID can pose problems in terms of reliability of data (see e.g., Finlay & Lyons, 2001). To optimize the quality of data collection, sentence structures were simplified, questions were adjusted, and answers were summarized and checked. However, what counts for people in general goes for people with MID/BIF as well: they reason, feel and interpret from their own perspectives. Personality, self-insight, level of understanding and experiences in the past colour their perceptions. For a more complete insight in the working ingredients of FACT MID/BIF, it might be useful to extend the research activities to FACT team members as well.

6.5 Policy implications and recommendations for future research

Everything considered and taking into account both the strong and weak points of the separate studies, the results of our research may be seen as encouraging and give rise to continued development and use of (F)ACT MID/BIF in the Netherlands and abroad, as well as to further research.

With regard to policy: the outcomes of the present research indicate that people with MID/BIF and mental health problems or challenging behaviour benefit from a comprehensive, outreaching approach and by long-term, continuous care and monitoring, as provided by FACT teams. Hence, FACT MID/BIF can be considered as an important addition to regular care. Unfortunately, the success of FACT MID/BIF teams could be their deathblow if - as is the case today – systemic problems will continue to be passed on teams and individual professionals. For instance, from clinical experience it is known that team members of FACT MID/BIF teams spend a disproportionate part of their time to administrative bureaucracy in order to secure funding for their efforts. Also, they spend a lot of time to coordinative activities, since realising admissions in psychiatric hospitals, addiction centres or residences in disability care take a lot of time – if there is any capacity at all. From earlier studies in other countries it is known that ACT programs for people with (mild) intellectual disabilities – despite their positive results - had to end prematurely because of budget cuts (Meisler et al., 2000). To guarantee the survival of FACT MID/BIF teams in the future, optimal facilitation through appropriate and cross-sectoral funding and well-equipped staff are prerequisites. Also, since FACT teams cannot function without clinical back-up, responsible parties should guarantee sufficient clinical capacity in mental health care, intellectual disability care and in addiction care.

An issue that often arises in the literature is whether the care for people with MID/BIF and mental health problems should be organized categorically (i.e., in specialized services) or be integrated in mental healthcare. This debate has been started since the de-institutionalisation of services for people with intellectual disabilities in developed countries (Hassiotis, Barron & O’Hara, 2000; O’Hara, 2000). De-institutionalisation has been credited with improving the lives of persons with ID. However, in doing so it has shifted the responsibility of the many specialised healthcare needs to the community without sufficient preparation. Different countries have developed various models of care to deal with this shift in responsibility, but until now, there is very limited evidence on the organisation of healthcare services for people with ID (Balogh et al., 2016). While policy makers in the UK and the United States head for the integrated variant, the categorical variant is adhered to in other countries, like Canada and - to some extent - in the

Netherlands. Specifically with respect to the organisation of (F)ACT for people with MID/BIF and mental health problems or challenging behaviour, the same issue is at hand. In the Netherlands the pilots with specialized (F)ACT MID/BIF teams have been evaluated positively and proponents of specialisation underpin their standpoint by referring to the special needs of clients with MID/BIF and to the fact that regular (F)ACT teams have left this client group aside for a long time. At the same time, the coverage of (F)ACT MID/BIF is still relatively small at the moment. To reach more people with MID/-BIF in the future, it would be advantageous and efficient to make (also) use of the (F)ACT structure that has been set up in Dutch mental healthcare in the past decades, and to add expertise of MID/BIF to the regular (F)ACT teams. The fact that in recent years there has been increasing attention for people with MID/BIF from mental health care is encouraging and could facilitate mutual efforts of rapprochement.

With respect to research, we encourage researchers to undertake comparable research to the treatment outcomes of (F)ACT for people with MID/BIF, using comparable designs, outcome measures and model criteria. Replication of studies on FACT MID/BIF could improve the reliability of the results. Also, new research should include cost-effectiveness analyses to investigate whether the investments and benefits of FACT MID/BIF are in balance, or – as earlier studies suggested (Hassiotis et al., 2001; King et al., 2009; Meisler et al., 2000; Van Minnen, Hoogduin & Broekman, 1997) – to reveal the social returns.

Although in our research the so-called non-specific aspects, that is, the relational aspects were identified as the most important working ingredients of FACT, that does not mean that the therapeutic interventions applied by the FACT team are of less significance. In our view, a fitting approach adjusted to the cognitive and emotional level of the client involved, is a prerequisite to achieve treatment results at all in individuals with MID/BIF. As a next step, future research should focus on the implementation and effectiveness of certain treatment programs within FACT MID/BIF teams. For instance, Van Vugt et al. (2011) focussed on the association between ACT model fidelity, that is, the degree of implementation of ACT, and treatment outcomes in people with SMI and found that aspects of team structure, such as shared caseload and daily briefings, were associated with better outcomes. Also, they found a positive association between consumer-provider presence and, amongst others, improvements in clients' daily functioning (Van Vugt, Kroon, Delespaul & Mulder, 2012). As with regular ACT, it is possible that certain FACT MID/BIF teams achieve better results than others, because they provide more intensive care, have a wider range of therapeutic interventions or have another mix of disciplines or expertise than other teams. It is also possible that certain client groups benefit more from certain components than other; for instance, it is conceivable that higher-motivated clients benefit more from therapeutic interventions, while lower-motivated clients benefit especially from practical care.

After all, research to the working ingredients of FACT MID/BIF requires in our opinion both a quantitative and a qualitative approach. In our qualitative study, we focussed on the experiences of clients. For a more complete insight in the working ingredients of FACT MID/BIF, it might be useful to extend the research activities to FACT team members as well.

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Summary

Samenvatting (Summary in Dutch)

Summary

ACT and FACT

Assertive Community Treatment (ACT) and Flexible Assertive Community Treatment (FACT) are models for the organisation of treatment, support, and recovery for people with severe mental illness (SMI) combined with problems in important domains of life (e.g., housing, finances, work, social functioning). ACT and FACT teams (hereinafter referred to as (F)ACT teams) focus on individuals who cannot (sufficiently) be reached by and treated in regular inpatient or outpatient mental healthcare facilities. (F)ACT teams offer intensive, comprehensive and assertive home treatment and support. (F)ACT teams consist at least of social workers, psychiatric nurses, a psychologist and a psychiatrist and team members take joint responsibility for the whole caseload. Usually (F)ACT teams are involved long-term because of the severity, plurality and chronical course of the problems. Also, (F)ACT teams stay involved in case of admissions in (mental) health care facilities or in case of detentions. The (F)ACT model has been described thoroughly and its effectivity has been studied extensively, with especially in the United States positive outcomes. (F)ACT has been implemented on a wide scale in many countries and has evolved into a form of preferred treatment for people with SMI.

Since the nineties of the last century, (F)ACT has been disseminated to other sectors and client groups as well, including people with mild intellectual disabilities (MID, IQ between 50 and 70) or borderline intellectual functioning (BIF, IQ between 70 and 85) and mental health problems or challenging behaviour. However, as far as known, (F)ACT has not been implemented on a wide-scale in any country. As a result, the research base of (F)ACT MID/BIF is small. Moreover, the studies that have been performed on this subject are difficult to compare because of differences in design, investigated interventions and research population.

In the Netherlands, four organisations that are specialised in the treatment of people with MID/BIF and severe mental health problems and/or challenging behaviour have participated in a nationwide implementation and research project. Between 2011 and 2017, the original (F)ACT model and fidelity scale were adapted to people with MID/BIF. Also, seven new (F)ACT MID/BIF teams were established (one was already existing) and a structure for routine outcome monitoring (ROM) was developed and implemented. Data on client characteristics and outcomes were collected yearly between September 2012 and May 2017 by the eight participating teams and resulted in a data base with more than 600 unique clients.

Research questions

The main research question was: What are the treatment outcomes of (F)ACT for people with MID/BIF and mental health questions or challenging behaviour? This main question comprised the following sub questions:

1. What is known about the effectiveness of (F)ACT for individuals with intellectual disabilities, and how has (F)ACT MID/BIF been developed in the Netherlands?
2. What are the characteristics of the clients who receive treatment in FACT MID/BIF teams, and what are the outcomes of FACT MID/BIF over time, in terms of social and psychological functioning, admissions in (mental) health care, (risk of) challenging and criminal behaviour, and social participation?
3. Is there an association between client variables and treatment outcome of (F)ACT MID/BIF, in terms of social and psychological functioning?
4. How do clients with MID/BIF value the treatment and the results of (F)ACT, in terms of daily functioning and well-being, and which factors are perceived as supportive?

Research methods

Since (F)ACT is not a single intervention, but a model for the organisation of treatment and care consisting of several components, we chose to combine various research methods and research populations – which is known as triangulation. In this research project we combined literature research with a quantitative and a qualitative study. The quantitative research was based on analyses of the database as described above. Linear mixed models (LMM) were used to explore positive or negative trends in a series of outcome measures. The qualitative research consisted of semi-structured interviews with fifteen clients of two forensic FACT MID/BIF teams, using a primarily inductive approach.

Results

Research question 1

On the basis of a critical review we concluded that there are some indications that ACT is effective for individuals with MID/BIF and mental health problems or challenging behaviour, but that more research is needed. To address the need of standardisation of (F)ACT MID/BIF among researchers, we described the (F)ACT MID/BIF model as developed in the Netherlands. (F)ACT MID/BIF teams distinguish from regular (F)ACT teams by, e.g., a lower staff/client ratio and a systemic focus.

Research question 2

The caseload of the participating (F)ACT MID/BIF teams consisted mainly of men. The average age was about 34 years and two-thirds of the clients were born in the Netherlands. The majority were single or divorced, and most clients lived on their own and were dependent of social welfare. About half of the caseload had a criminal or civil measure on admission and most referrals came from the probation service. The average IQ was 69 and the majority had multiple diagnosed psychiatric disorders, including substance abuse.

Over time, clients showed improvement in their social and psychiatric functioning and living circumstances. The number of admissions to (mental) health care diminished as well as the number of contacts with police and justice, the level of social disturbance and the risk factors for challenging and criminal behaviour. Problems related to finances, work and substance abuse remained unchanged.

Research question 3

To identify which client variables were associated with treatment outcome of FACT, demographic variables and dynamic risk variables (derived from of the short version of the Dynamic Risk Outcome Scales (DROS-SV)) were selected as potential predictor variables of social and psychological functioning (measured by the HoNOS-LD). Limited awareness of the need for treatment, limited treatment motivation and cooperation, limited social skills, impulsivity and substance abuse were significantly associated with worse treatment outcome. None of the demographic variables influenced treatment outcome significantly, and neither did IQ level or having a judicial or civil measure.

Research question 4

In addition to the quantitative research, semi-structured interviews were held with fifteen clients to explore how they valued the treatment and their own functioning, and which factors were perceived as supportive. Most clients highly appreciated the contact with the staff and the practical and emotional support. Persistent involvement, availability and humanity, and respect for autonomy were distinguished as core values in the relationship with the staff. Most service users experienced improvement in time, and attributed this to intrapersonal changes and/or less stress in life.

Conclusions and recommendations

Overall, we concluded that (F)ACT MID/BIF seems to be an effective treatment form. Although we could not establish causal relationships because of the longitudinal design of our study, clients showed - on average - improvement during their treatment in FACT, both with regard to psychological measures (individual functioning), living conditions (housing) and to societal or criminal measures (e.g., social disturbance, burden on the judicial system). The results of our longitudinal study were confirmed by the client interviews and were congruent with the results found in previous, predominantly observational studies on ACT for people with (M)ID. However, despite the overall positive results we emphasized that (F)ACT is not a panacea for individuals with MID/BIF. Firstly, small changes often take a long period of time, and financial problems, work-related problems and addiction problems often remain. Secondly, some client groups seemed to benefit less form FACT, such as clients with addiction problems, clients with limited treatment motivation and cooperation, and clients with limited social skills. For these reasons we recommended that FACT MID/BIF teams should keep on improving their treatment programs and investing in ongoing education and training of their team members, amongst others with respect to motivating interviewing. Further research is necessary to strengthen the evidence for the effectivity of (F)ACT MID/BIF and to investigate the effectivity of its substantive components, i.e., treatment programs. To guarantee the survival of (F)ACT MID/BIF teams in the future, adequate and integral funding is necessary.

Samenvatting (Summary in Dutch)

ACT en FACT

Assertive Community Treatment (ACT) en Flexible Assertive Community Treatment (FACT) zijn organisatievormen voor de behandeling, begeleiding en het herstel van mensen met ernstige psychiatrische aandoeningen (EPA) in combinatie met problemen op verschillende levensgebieden (zoals wonen, werken, financiën en sociaal functioneren). ACT- en FACT-teams (hier verder aangeduid als (F) ACT-teams) richten zich op cliënten die niet (voldoende) kunnen worden bereikt door en behandeld in reguliere voorzieningen voor geestelijke gezondheidszorg. (F)ACT teams bieden intensieve, integrale en assertieve behandeling en begeleiding aan huis. (F)ACT teams bestaan ten minste uit maatschappelijk werkers, psychiatrisch verpleegkundigen, een psycholoog en een psychiater, en teamleden zijn gezamenlijk verantwoordelijk voor alle cliënten die in zorg zijn van het team (shared caseload). Omdat de problematiek van cliënten complex en meervoudig is en veelal een chronisch beloop heeft, bieden (F)ACT teams langdurende zorg. Ook blijven zij betrokken in geval van eventuele opnames of detenties. Het (F)ACT model is uitgebreid beschreven en is op effectiviteit onderzocht, met vooral in de Verenigde Staten positieve uitkomsten. (F)ACT is op grote schaal geïmplementeerd in binnen- en buitenland en is uitgegroeid tot standaardbehandeling voor mensen met ernstige psychiatrische problematiek.

Sinds de jaren negentig wordt (F)ACT ook in toenemende mate toegepast op andere doelgroepen dan de EPA-doelgroep, waaronder mensen met een lichte verstandelijke beperking of zwakbegaafdheid (hier verder aangeduid als LVB; IQ tussen 50 en 85) en bijkomende gedrags- of psychiatrische problematiek. Voor zover bekend is deze behandelvorm echter in geen enkel land op grotere schaal ingevoerd voor mensen met een LVB. Onderzoek naar (F)ACT voor mensen met een LVB is dan ook schaars. Het onderzoek dát gedaan is, is bovendien moeilijk vergelijkbaar door verschillen in design, onderzochte interventie en onderzoekspopulatie.

In Nederland hebben vier instellingen die gespecialiseerd zijn in de behandeling van mensen met een LVB en ernstige gedrags- of psychiatrische problematiek (de zgn. Borg-instellingen) tussen 2011 en 2017 deelgenomen aan een landelijk implementatie- en onderzoeksproject. In deze periode werden een modelbeschrijving en een betrouwbaarheidsschaal ontwikkeld, werden zeven nieuwe FACT LVB teams opgericht (één team bestond al) en werd een structuur opgezet voor ‘routine outcome monitoring’ (ROM). Tussen september 2012 en mei 2017 leverden de acht deelnemende teams jaarlijks data aan over de kenmerken en het functioneren van hun cliënten, hetgeen resulteerde in een databestand met meer dan 600 unieke cliënten.

Vraagstellingen van het onderzoek

De hoofdvraagstelling van het onderzoek was: Wat zijn de behandelresultaten van (F)ACT voor mensen met een LVB en ernstige gedrags- of psychiatrische problematiek? Deze hoofdvraag viel uiteen in de volgende sub-vragen:

1. Wat is bekend over de effectiviteit van (F)ACT voor mensen met een (lichte) verstandelijke beperking, en hoe heeft (F)ACT LVB zich ontwikkeld in Nederland?
2. Wat zijn de kenmerken van cliënten die in behandeling zijn (geweest) van (F)ACT LVB teams, en wat zijn de behandelresultaten na verloop van tijd in termen van sociaal en psychologisch functioneren, opnames in de (geestelijke) gezondheidszorg, (risico op) grensoverschrijdend of crimineel gedrag en sociale participatie?
3. Is er een verband tussen cliëntkenmerken en behandelresultaten, in termen van sociaal en psychologisch functioneren?
4. Hoe waarderen cliënten van (F)ACT LVB-teams de behandeling en de resultaten van de zorg in termen van dagelijks functioneren en welbevinden, en welke factoren worden gezien als helpend?

Methoden van onderzoek

Omdat (F)ACT geen enkelvoudige interventie is maar een organisatiemodel bestaande uit verschillende componenten, laat het zich het beste onderzoeken door een combinatie van onderzoeksmethoden (triangulatie). In dit onderzoek is gekozen voor een combinatie van literatuuronderzoek, een kwantitatieve en een kwalitatieve studie. Het kwantitatieve onderzoek was gebaseerd op analyses van het hierboven genoemde databestand. De analysetechniek ‘lineair mixed models’ (LMM) werd gebruikt om positieve dan wel negatieve trends op de verschillende uitkomstmaten te exploreren. Het kwalitatieve onderzoek bestond uit semi-gestructureerde interviews met vijftien cliënten van twee deelnemende forensische FACT teams. We hanteerden een hoofdzakelijk inductieve benadering.

Resultaten

Onderzoeksvraag 1

Op basis van een ‘critical review’ concludeerden we dat er enkele indicaties zijn dat (F)ACT effectief is voor mensen met LVB en psychische en/of gedragsproblemen, maar dat meer onderzoek noodzakelijk was. Om aan de onder onderzoekers gevoelde behoefte aan standaardisatie tegemoet te komen, beschreven we het (F)ACT MID/BIF model zoals ontwikkeld in Nederland. Het (F)ACT LVB model onderscheidt zich van het reguliere (F)ACT model door bijvoorbeeld een lagere staf/caseload ratio en focus op een systeembenadering.

Onderzoeksvraag 2

De caseload van (F)ACT LVB teams bestond met name uit mannen. De gemiddelde leeftijd was bijna 34 jaar en twee derde was geboren in Nederland. De meerderheid was alleenstaand of gescheiden, woonde zelfstandig en had geen betaalde baan. Ongeveer de helft van de cliënten had een juridische titel en de meeste verwijzingen waren afkomstig van de reclassering. Het gemiddelde IQ was 69 en het merendeel van de cliënten had meerdere gediagnostiseerde psychiatrische aandoeningen, waaronder middelenmisbruik.

Het onderzoek liet zien dat cliënten na verloop van tijd gemiddeld beter sociaal en psychisch gingen functioneren en dat hun woonomstandigheden verbeterden. Het aantal opnames in de GGZ of in andere sectoren nam af, evenals het aantal contacten met politie en justitie, de mate van sociale overlast en de risicofactoren voor probleemgedrag en criminaliteit. Geen veranderingen werden waargenomen met betrekking tot financiële problematiek, werk en middelengebruik.

Onderzoeksvraag 3

We hebben onderzocht of de behandelresultaten (in termen van sociaal en psychisch functioneren) samenhingen met statische en dynamische cliëntvariabelen (ontleend aan de verkorte DROS). Er bleek geen samenhang te zijn met demografische kenmerken. Ook bleken de resultaten niet samen te hangen met IQ of (on) vrijwillige status. Wel was er een significant verband met sociale vaardigheden, impulsiviteit, motivatie voor behandeling, middelengebruik en onderkenning van de noodzaak tot zorg.

Onderzoeksvraag 4

In aanvulling op het kwantitatieve onderzoek werd een kwalitatief onderzoek uitgevoerd. Vijftien cliënten werden geïnterviewd over hun ervaringen met de behandeling in (F)ACT, hun waardering van de behandelresultaten en de in hun perspectief werkzame factoren. Cliënten waardeerden vooral het contact met de teamleden en de praktische en emotionele ondersteuning. Langdurende betrokkenheid, beschikbaarheid als hulpverlener én mens, en respect voor de autonomie van de cliënt werden benoemd als de belangrijkste kernwaarden in het contact met de staf. De meeste cliënten gaven aan verbetering te bemerken in hun functioneren, en schreven dit toe aan intra-persoonlijke veranderingen en/of minder dagelijkse stress.

Conclusies en aanbevelingen

Alles overziende concludeerden we dat (F)ACT MID/BIF werkzaam lijkt te zijn. Hoewel we geen causale relaties hebben kunnen vaststellen vanwege de longitudinale opzet van het onderzoek, lieten cliënten op verschillende gebieden (sociaal en psychisch functioneren, woonomstandigheden, sociale overlast, criminogene uitkomstmaten) vooruitgang zien. De resultaten van onze longitudinale studie werden bevestigd door de cliëntinterviews en waren congruent met de resultaten van eerder uitgevoerd onderzoek naar ACT voor mensen met een LVB. Ondanks de positieve resultaten werd benadrukt dat (F)ACT geen wondermiddel is voor mensen met een LVB. Ten eerste kosten kleine verbeteringen vaak veel tijd en blijven er ondanks de inzet van (F)ACT vaak problemen bestaan op het gebied van financiën, werk en verslaving. Ten tweede leken bepaalde groepen cliënten minder van (F)ACT te profiteren, zoals cliënten met verslavingsproblematiek, cliënten met geringe motivatie en medewerking en cliënten met weinig sociale vaardigheden. Om deze redenen bevolen we aan dat (F)ACT LVB teams zich blijven inzetten voor het verbeteren van hun behandelprogramma's en voor systematische deskundigheidsbevordering van hun teamleden. Meer onderzoek is nodig om de bewijskracht van de effectiviteit van (F)ACT voor mensen met een LVB te versterken en om de effectiviteit van de inhoudelijke componenten, d.w.z. de behandelprogramma's binnen (F)ACT, te bestuderen. Om het voortbestaan van (F)ACT teams voor mensen met een LVB te garanderen is passende en integrale financiering van groot belang.

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About the author

- Curriculum Vitae
- Publications

Curriculum Vitae

Laura Neijmeijer was born on June 13, 1969 in Kampen (the Netherlands). After completing her secondary education at the Almere College in 1987 and her higher professional education in nursing (HBO-V) in 1991, she studied Social Sciences (ASW) at the University of Utrecht, where she specialized in health care organisation and policy. During her study she completed an internship at the Netherlands Institute of Mental Health and Addiction (Trimbos-institute) in Utrecht and conducted research on professions in mental health care. She degreed cum laude in 1994 and worked until 1997 as a scientific assistant at the Trimbos-institute.

Since then, Laura has worked in different sectors of mental health care at the intersection of policy, quality, research and development. Until 2000 she worked as a policy staff member at the Ministry of Health Care, with forensic psychiatry as one of her focus areas. Thereafter, she worked as a secretary of the managing director of a mental health care organisation for children and youth and as a senior staff member at a regional sheltered housing institution successively. In 2008 she joined the Trimbos-institute again where she was responsible for several research and implementation projects on different areas, including recovery oriented care, (Flexible) Assertive Community Treatment, forensic psychiatry and the care for people with mild intellectual disabilities or borderline intellectual functioning (MID/BIF) and mental health problems or challenging behaviour. Amongst others, she developed the (F)ACT MID/BIF model and advised and supported several organisations in the care for people with intellectual disabilities with the implementation of (F)ACT MID/BIF. Also, she worked as an auditor and trainer at the Dutch Centre of Certification of ACT and FACT teams (CCAF).

Between 2015 and 2019, Laura has worked as a PhD student at the Radboud University where she continued her research work on (F)ACT for people with MID/BIF and mental health problems or challenging behaviour. Also, she worked as a senior staff member at the Amarant Group and at the expertise centre of Trajectum. Currently she is working as a psychiatric nurse and case manager in one of Trajectum's FACT MID/BIF teams. In 2021 she will start the specialist mental health nursing training at GGZ Centraal.

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