Measures intended to improve guideline adherence in psychotropic medication

for people with intellectual disabilities living in residential accommodation.

Recommendations and ideas from practical experience

TECHNISCHE UNIVERSITÄT DRESDEN

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The catalogue is to be used in practice, the measures are to be tested there and, if necessary, adapted to the structural framework conditions of the actual residential accommodation. The overview is also intended to encourage the development of measures within the facility that are not yet listed in the catalogue. In this regard, the catalogue may and should be edited within the facility and made available to all the staff of the residential accommodation in an edited form. It should be noted that the measures aim to implement a guideline-compliant PTM and that the implementation of the measures is only to be adjusted to the extent that the goal of guideline implementation is maintained.

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Foreword

In its aim to contribute to more guideline-compliant psychotropic medication of people with intellectual disabilities, this catalogue is one of the initiatives that have been undertaken nationally and internationally in view of a practice that is to be assessed as critical overall.

In its conception, the catalogue is based on the consideration that the responsibility for the **development** of guidelines lies in the hands of professional societies and other organisations and that part of the possible measures for guideline implementation can be carried out nationally. However, we are convinced that the responsibility for the **implementation** of the guidelines lies with the persons acting in everyday care, for example, with the treating doctors and the patients, but with regard to the psychotropic medication of people with intellectual disabilities living in institutionalised forms of accommodation, very much also with the staff of the residential accommodation.

Against the background of this basic conviction, the measures listed in this catalogue were developed by the staff from randomly selected residential accommodation in Saxony, Baden-Württemberg and Bavaria, usually in consultation with the doctors responsible for prescribing psychotropic drugs. We would like to thank all those involved sincerely for their commitment, which made this catalogue possible in the first place.

We would also like to thank several organisations who had already agreed to support our project before it began: Liga der freien Wohlfahrtspflege Baden-Württemberg; Landesverband Sachsen der Arbeiterwohlfahrt; Caritasverband für das Bistum Dresden-Meissen e.V.; Diakonisches Werk der Ev.-Luth. Landeskriche Sachsen; Paritätischer Wohlfahrtsverband, Landesverband Sachsen.

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Key

PTM = Psychotropic medication
MZEB = Medical Centre for Adults with Disability
WfbM = Workshop for disabled people

Notes on the designations used

In the institutions involved in creating the catalogue of measures, different terms were used for the groups of people involved in psychotropic medication. Every linguistic designation is accompanied by specific meanings, e.g. related to the term “disability” or to “grammatical gender”. When compiling this catalogue, we have endeavoured to use language sensitively and to make the text easy to read. We apologise for not always being able to do so.
For people with intellectual disabilities living in residential accommodation, we use the terms “person with intellectual disabilities” or, in the appropriate context, “resident”.

Furthermore, we use the word “doctor” in the text, meaning psychiatrists and neurologists who accompany the people with intellectual disabilities living in residential accommodation. However, the term also includes those general practitioners who prescribe psychotropic drugs for this group of people. We refer to doctors who are responsible for basic medical care as general practitioners; they are usually general practitioners or internal medicine specialists.

We use the term “specialist service” to describe staff members who are specifically responsible for organising and coordinating the medical and therapeutic care of the residents.

Chapter 1

Introduction

People with an intellectual disability often have a need for psychiatric or psychotherapeutic care, for example because they are suffering from a mental disorder or because they manifest challenging behaviour for other reasons that imply a need for psychiatric or psychotherapeutic care, for example self-aggressive behaviour or aggressive behaviour towards others, extraordinary social withdrawal or even odd, bizarre behaviour that is inappropriate and distressing to the individual or those around them.

Unfortunately, this need for care is very often insufficiently met. This is not least due to the fact that there are too few psychiatrists or psychotherapists who feel sufficiently qualified to treat persons with intellectual disabilities. The topic is still very rarely the subject of education and training, and research also deals with the issue only to a very limited extent. Studies dealing, for example, with the effectiveness of psychotherapy or even of other non-psychotropic medication interventions for persons with intellectual disabilities are hardly available.

Irrespective of this, psychotropic drugs are also an essential component of the usually multimodal treatment for persons with an intellectual disability. However, they should only be prescribed when clearly indicated and in accordance with basic ethical principles. Challenging behaviour should at best be treated temporarily and not exclusively with psychotropic medication.

However, it is known from current studies that these principles are not sufficiently taken into account in Germany either. Above all, neuroleptics are prescribed too often and despite a lack of evidence, for example for the treatment of challenging behaviour. Not least against this background, various authors have presented guidelines on the use of psychotropic drugs in people with intellectual disabilities, e.g. by the Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V. (AWMF)[1-4].

The objectives of these guideline recommendations, which are shown in table form in *Annex A*, are comprehensive. A central principle, for example, is that the prescription and treatment should be patient-centred and should therefore above all correspond to the well-understood needs and interests of the patient. The relatives and, in the case of people with intellectual disabilities living in residential accommodation, the staff members working there must be included in the treatment and supported. Throughout the course of psychotropic medication, it must be ensured that psychotropic drugs are only prescribed after comprehensive diagnostics and that the indication is regularly reviewed and dose reductions are regularly considered. The physical, instrumental and laboratory chemical examinations required as part of a prescription must be carried out regularly at the required intervals. It must also be ensured that the instructions for use are observed and that effects and side effects are recorded in a standardised manner as far as possible. The options for non-psychotropic medication treatment of the symptoms must be regularly examined.

While the responsibility for the creation of guidelines lies in the hands of specialist societies or other organisations and some possible measures for guideline implementation can be carried out nationally (e.g. the development of versions for users and patients, as well as quality indicators for measuring guideline conformity), according to the general understanding, the

responsibility for the implementation of the guideline recommendations ultimately lies with the stakeholders involved. With a view to psychotropic medication for people with intellectual disabilities living in residential accommodation, the responsibility lies essentially with the treating physicians and the staff in the residential accommodation, whereby the respective specific tasks, as shown in *Annex B*, complement each other.

In order to be able to fulfil this responsibility as comprehensively as possible, those responsible should consider and develop measures that can contribute to psychotropic medication that is as guideline-compliant as possible against the background of the existing structural and personnel conditions in everyday work. This was the subject of a total of 22 workshops, which are reported on in more detail in *Chapter 2*.

Chapter 2

Development of the catalogue of measures

What is the goal of the catalogue of measures?

This catalogue of measures was developed within the framework of a project funded by the Innovation Fund of the Federal Joint Committee (G-BA) at the TUD Dresden University of Technology (Prof. Matthias Schützwohl) and the University of Ulm (Prof. Silvia Krumm). The aim was to develop a catalogue of measures that was as universally valid as possible, based on our own preliminary work, in exchange and in cooperation with experts working in the field. This is intended to contribute nationwide to the guideline-compliant psychotropic medication of people with intellectual disabilities living in institutionalised residential accommodation. The project was implemented between April 2021 and September 2022.

How was this objective implemented?

The project was divided into three sections. In the first stage of the project, interviews were conducted with doctors responsible for the psychotropic medication (PTM) of persons with intellectual disabilities and with managers of residential accommodation for persons with intellectual disabilities in order to identify hindering and facilitating factors for the implementation of the guideline recommendations. The information from these surveys was used to prepare and structure the content of workshops that were held in the second phase of the project with staff members from randomly selected residential accommodation and, mostly, the doctors responsible for medical treatment there. The aim of these workshops was to develop measures that can contribute to a PTM of the residents of their own residential accommodation that is as guideline-compliant as possible. In the third and final phase of the project, the results of these workshops were summarised in a general catalogue of measures. You are now holding this catalogue of measures in your hands.

How were the measures developed in the workshops?

The measures were developed in three facilitated discussions after the presentation of key aspects of guideline-compliant PTM. The main topics were: (i) Patient-centricity of PTM, (ii) Knowledge about PTM and (iii) Exchange and cooperation in PTM. Each of these thematic discussions started with a presentation of the respective question and a gathering of ideas. Each participant was able to name their own ideas. These were then compiled, structured according to thematic priorities and then discussed and specified in a joint exchange between the group of participants. Both new measures and those that are already being implemented in the respective participating residential accommodation were named.
All of the measures described in this catalogue were developed by the participants in the workshops and therefore by specialists who have valuable practical knowledge as part of their daily work and, in some cases, due to many years of experience in supporting people with intellectual disabilities. The practical knowledge of the specialists therefore forms the fundamental basis for this catalogue.

Who took part in the workshops?

The residential accommodations that were asked to take part in the project were selected at random from the total number of residential accommodations in Baden-Württemberg, Bavaria and Saxony, whereby the different structural framework conditions previously surveyed were also taken into account in the selection. This procedure should ensure that the participating residential accommodations reflect the heterogeneous care practice with different medical care models, different degrees of intellectual disability of the residents or different structural framework conditions.

Ultimately, workshops were held in a total of 22 residential accommodations in Bavaria (5), Baden-Württemberg (7) and Saxony (10). On average, six people took part in the workshops (smallest group: 4; largest group: 10). No doctor responsible for PTM could be persuaded to participate in five workshops.
Further characteristics of the residential accommodation can be found in the table in *Annex C*.

Chapter 3

Notes on using the catalogue of measures

You can use the catalogue of measures as information and as a guide to look for answers to the following questions:

(i) What are the characteristics of guideline-compliant PTM for persons with intellectual disabilities?

(ii) Which specific measures could help me to take certain guideline recommendations (e.g. patient-centricity of the prescription and treatment) into account more in my everyday work?

(iii) How can I take the guideline recommendations into account in certain situations in my everyday work (e.g. in contact with a person with an intellectual disability)? What specific measures would support me in this?

(iv) With what specific measures can the doctor responsible for the PTM contribute to a PTM that is more in line with the guidelines?

In Chapters 4 and 5 you will first find an **overview of the measures** that were developed in the workshops. In *Chapter 4* you can **find the measures that contribute to the implementation of a specific guideline recommendation** (e.g. measures to consider non-psychotropic medication treatment options). If you are looking for **measures for a specific area of your everyday work** (e.g. measures to prepare for visits), you can use the tables in *Chapter 5*. These areas of everyday work (so-called practical areas) were developed from the measures developed in the residential accommodation and therefore on the basis of the practical experience of the participants.

Chapters 4 and 5 only list the titles of the measures. You can access the detailed description of the measure, which can be found in Chapters 6 and 7, via the code listed in the tables, which can be clicked on, or via the reference to the page on which the measure is described in detail.

The central part of the document consists of measures for staff members in residential accommodation for people with intellectual disabilities (*Chapter 6*). In addition to this, measures are reported that are largely the responsibility of the doctors (*Chapter 7*). We have included these measures in the catalogue because they were developed in the workshops and because the areas of responsibility of the members of staff in the residential accommodation and the medical colleagues complement each other and also overlap.

Chapters 6 and 7 contain a detailed description of the respective measures. At the beginning of each measure description you will find a paragraph on the **meaning** of the respective measure for a guideline-compliant PTM for people with intellectual disabilities. This paragraph serves to provide a deeper understanding of the effect of this measure on other processes and components of the PTM and therefore also to understand what exactly the intended approach to a guideline-based PTM for people with intellectual disabilities is. The meaning of the measures is partly similar, but they differ in terms of content or the people involved.

In the following explanations on **implementation** you will find suggestions on how a measure could be implemented specifically in your residential accommodation. **You can adapt or develop this suggestion independently to the very individual circumstances in your residential accommodation.** It should be noted that the measures aim to implement a guideline-compliant PTM and that the implementation of the measures is only to be adjusted to the extent that the goal of guideline implementation is maintained.

Chapter 4

Overview of measures according to guideline areas

4.1 Basic principles of psychotropic medication

Patient-centricity of prescription and treatment | Involvement and support of relatives and environment | Information and consent (Patient/Legal Guardian/Relevant)

Of course, people with intellectual disabilities have the right to be recognised and respected for their individual abilities and their different needs for help. The well-understood interests of the person with intellectual disability are therefore at the centre of all considerations regarding the PTM. This also applies in the case of conflicting interests of other persons or institutions.

In view of legal obligations and ethical requirements, the person with an intellectual disability must be informed comprehensively, for example about the rationale for therapy, possible undesirable side effects and alternative treatment options, before starting psychotropic medication treatment, provided they are capable of giving their consent. The treatment can only be started after such comprehensive information has been given and a corresponding consent. If the person with an intellectual disability is not capable of giving consent, they must still be given as much information as possible in a suitable form. Consent must then be obtained from the legal representative.

The staff members of assisted living arrangements and the relatives should also be informed in a suitable form about the treatment concept, for example about the considerations on the indication and the desired effects and limits of the PTM. The aim is to support staff members and their families in their understanding and in their own actions.

Table 4.1 lists the possible measures for implementing the basic principles of psychotropic medication. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 4.1

Quality indicator and measures	Code	Page
Patient-centred prescription and treatment		
Encourage self-determination of the person with intellectual disabilities	*K1*	35
Regular, unprovoked one-on-one talks with people with intellectual disabilities	*K4*	39
Event-related one-on-one talks with people with intellectual disabilities	*K5*	41
Biographical interview with person with intellectual disability	*K7*	43

Quality indicator and measures	Code	Page
Annual meeting as a "celebration" for the person with intellectual disabilities	T6	57
Creation of opportunities for encounters between doctors from the residential accommodation area and residents from the residential accommodation	M3	65
Preparation for visits with a person with an intellectual disability	V4	76
"Me-Book" providing general and treatment specific information about the person with intellectual disability	V5	78
Adjusting the care system to the needs of the person with intellectual disabilities	K8	44
Adaptation of the medical care model to the needs of the person with intellectual disabilities	V1	73
Sitting in with other residential groups	T3	54
Contact of the residential accommodation with the clinic during the stay in the clinic	M5	67
Involvement and support of relatives and environment		
Encouragement for self-reflection by staff members	T1	52
Exchange between staff members and relatives on observations in the home environment	F1	68
Discussions to inform relatives about the PTM	F2	69
Family get-together with a doctor	F3	70
Regular consultation time for relatives	F4	71
Mediation between people with intellectual disabilities and relatives in the event of conflicting interests	F5	72
Medical discussions with relatives	A11	104
Explaining to roommates about changed behaviour	K9	45
Information and consent		
Debriefing of visits with person with intellectual disability	V13	86
Regular PTM basics training for people with intellectual disabilities	K15	51

4.2 Indication, monitoring and review of the prescription in the course

Prescription after comprehensive diagnostics and if there is a corresponding indication | Monitoring of drug-specific laboratory parameters, ECG | Testing of effects and undesirable side effects | Monitoring of environmental factors | Review of the indication in the course of treatment

If there is a clear indication, psychotropic drugs can form an essential component of a generally multimodal treatment for people with intellectual disabilities. The examination of the indication requires a comprehensive psychiatric and, if necessary, multiprofessional diagnostics. The doctor examines and questions the person with an intellectual disability, but is also very much dependent on information from the person's immediate environment, i.e. also information from the staff of a residential care facility for people with an intellectual disability. It not only requires specific information on the underlying problem, which can be obtained from discussions with the person with intellectual disabilities and/or from behavioural observations. As a rule, the diagnosis also requires information, for example on the biography of the person with intellectual disabilities or on changed environmental factors in the immediate living environment of this person.

In order to detect organ damage at an early stage and to record changes in the laboratory parameters and in the ECG and to be able to react to them, the corresponding parameters must be checked continuously during the course of treatment, depending on the type of medication, at individually determined intervals. This is done either independently by the doctor who prescribed the psychotropic drugs or in cooperation with the family doctor.

In the context of subsequent regulations, the indication must be checked regularly and continuously. This requires monitoring the consequences of the PTM, both in terms of the desired and possible undesirable effects. Also in this case, the doctor is dependent on information from the immediate living environment of the person with intellectual disabilities. Conversely, the staff members of residential care must be informed as comprehensively as possible about the effects and side effects of the prescribed psychotropic drugs in order to be able to question or observe the person with an intellectual disability in this regard.

Table 4.2 lists the possible measures for the implementation of an appropriate indication, the monitoring and the review of the prescription in the course. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 4.2

Quality indicator and measures	Code	Page
Prescription after comprehensive diagnosis and if there is a corresponding indication		
Everyday observation without cause	*K2*	36
Event-related everyday observation	*K3*	38
Clarification of possible organic causes for behavioural changes	*A3*	96
Doctor contact without the participation of staff members	*V7*	80
Request and evaluation of previous reports and diagnoses	*A2*	95
First visit without a prescription	*A1*	94
Detailed initial introduction with a focus on getting to know the person with an intellectual disability	*A4*	97
Video recordings to illustrate behaviour	*V9*	82
Cooperation with a medical centre for people with disabilities (MZEB)	*M4*	66
Contact of the residential accommodation with the clinic during the stay in the clinic	*M5*	67
Monitoring of drug-specific laboratory parameters, ECG		
Psychiatric and general medical survey of drug-specific laboratory parameters and ECG	*A9*	102
Testing of effects and undesirable side effects		
Specialist exchange on PTM for people with intellectual disabilities	*A12*	105
Personal overview of the effects and side effects of individual psychotropic drugs	*A7*	100
Medical information for the residential accommodation staff members	*A10*	103
Regular training for staff members on the basics of PTM	*W1*	87
Short lectures on aspects of the PTM by staff members for colleagues	*W6*	92
Compilation of information sources on PTM	*W3*	89

Quality indicator and measures	Code	Page
Overview with general information on side effects	W5	91
Self-compiled reference work on psychotropic drugs	W4	90
Monitoring of environmental factors		
Visit preparation sheet on the status of the PTM, observations and environmental factors	V3	75
Review of the indication in the course of treatment		
Discussion of PTM-relevant aspects when handing over at shift change	T7	58
Regular team meetings to reflect on the observations	T2	53
Regular, unprovoked case discussions	T4	55
Event-related case discussions	T5	56
Fixed contact person in the residential accommodation for visits	V2	74
Visit checklist for staff members	V12	85
Medical formulation and documentation of target agreements	A5	98
Promotion of active participation of the person with intellectual disability in visits	V10	83
Overview of the persons with intellectual disabilities participating in the visit	V6	79
Discussion between staff member and doctor before visits	V11	84
Regular exchange between the residential accommodation and day-structuring offers and facilities	T11	62
Create “communication islands” for staff members	T8	59

4.3 Prescription and administration

Avoidance of polypharmacy; Consideration of possible drug interactions | Compliance with the strict requirements for "off-label" use of psychotropic drugs | Ensuring compliance with the intake regulations | Definition of intake conditions for Pro re nata (PRN; 'as needed') medication

All prescribed drugs should be taken into account when new drugs are prescribed, in order to keep an eye on their interactions and to avoid polypharmacy. With their support, the staff members of the residential accommodation enable the resident to take the psychotropic drug according to the doctor's prescription and thereby ensure the continuity of the intake. If pro re nata (PRN; 'as needed') medication is required, it requires written medical instructions that precisely define the conditions for administering this medication. These instructions form the obligatory basis for the staff members of the residential accommodation to administer pro re nata (PRN; 'as needed') medication.

Table 4.3 lists the possible measures to implement appropriate prescription and administration. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 4.3

Quality indicator and measures	Code	Page
Avoidance of polypharmacy; Consideration of possible drug interactions		
Fixed contact person(s) for questions about the PTM	*M2*	64
Standardised Federal medication plan	*A6*	99
Joint psychiatric and general medical visit	*A8*	101
Specialist exchange on PTM for people with intellectual disabilities	*A12*	105
Ensuring compliance with the intake regulations		
Dual-control principle when administering pro re nata (PRN; 'as needed') medication	*T9*	60
List of internal contacts with specific knowledge of PTM and mental disorders	*T10*	61

Quality indicator and measures	Code	Page
Definition of intake conditions for pro re nata (PRN; 'as needed') medication		
Feedback on the administration of pro re nata (PRN; 'as needed') medication	*V8*	81
Regular training for staff members on the administration of pro re nata (PRN; 'as needed') medication	*W2*	88

4.4 Consideration of non-psychotropic medication treatment options

Consideration of non-psychotropic medication treatment options

Prescribing and implementing non-psychotropic medication treatment options is reviewed and considered prior to treatment initiation. These measures can complement or replace drug therapy.

Table 4.4 lists the possible measures to consider non-psychotropic medication treatment options. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 4.4

Quality indicator and measures	Code	Page
Consideration of non-psychotropic medication treatment options		
Overview of individual non-psychotropic medication coping strategies	K10	46
Reflection on current non-psychotropic medication interventions during visits	K12	48
Implementation of a low-threshold contact to the doctor	M1	63
Involvement of external professionals for non-psychotropic medication interventions	K13	49
"Me-Book" providing general and treatment specific information about the person with intellectual disability	V5	78
"Bag" with individual non-psychotropic medication offers	K11	47
Participation of the person with intellectual disability in outside leisure activities	K14	50
Offer for open exchange in the group	K6	42

Chapter 5

Overview of measures according to practical areas

In this chapter, the measures developed in the residential accommodation are structured according to practical areas. This should enable you to look up specific areas of your everyday work (so-called practical areas) in which the measures developed can be applied or are already being applied.

5.1 Contact with a person with an intellectual disability

Promotion of self-determination | Observations | (individual) talks with people with intellectual disabilities | Additional measures and alternatives to PTM | Imparting knowledge for people with intellectual disabilities

In the practical area (K), all measures are summarised that relate to direct contact with the person with an intellectual disability (e.g. (individual) conversations with a person with an intellectual disability) or in which the person is the focus (e.g. observation). The contact takes place mainly between the person with intellectual disabilities and the staff members. This practical area also includes measures that focus on the needs and interests of the person with intellectual disabilities (e.g. supplementary measures and alternatives to PTM).

Table 5.1 lists the possible measures for contact with the person with intellectual disabilities. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.1

Areas	Measure	Code	Page
Promoting self-determination	Encourage self-determination of the person with intellectual disabilities	K1	35
Observation	Everyday observation without cause	K2	36
	Event-related everyday observation	K3	38
(Individual) conversations with people with intellectual disabilities	Regular, unprovoked one-on-one talks with people with intellectual disabilities	K4	39
	Event-related one-on-one talks with people with intellectual disabilities	K5	41
	Offer for open exchange in the group	K6	42
	Biographical interview with person with intellectual disability	K7	43

Areas	Measure	Code	Page
Supplementary measures and alternatives to PTM	Adjusting the care system to the needs of the person with intellectual disabilities	*K8*	44
	Explaining to roommates about changed behaviour	*K9*	45
	Overview of individual non-psychotropic medication coping strategies	*K10*	46
	"Bag" with individual non-psychotropic medication offers	*K11*	47
	Reflection on current non-psychotropic medication interventions during visits	*K12*	48
	Involvement of external professionals for non-psychotropic medication interventions	*K13*	49
	Participation of the person with intellectual disability in outside leisure activities	*K14*	50
Knowledge transfer for people with intellectual disabilities	Regular PTM basics training for people with intellectual disabilities	*K15*	51

5.2 Visits

Basics | Preparation | Implementation | Follow-up

In the practical area (V), all measures that are used in the visits are summarised. The measures are divided into the basics, preparation, implementation and follow-up of the visit. In this practical area, not only the staff members but also the doctor play an important role. Measures that only concern the doctor can be found in the practical area (A).

Table 5.2 lists the possible measures for the visit. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.2

Areas	Measure	Code	Page
Fundamentals	Adaptation of the medical care model to the needs of the person with intellectual disabilities	*V1*	73
	Fixed contact person in the residential accommodation for visits	*V2*	74
Preparation	Visit preparation sheet on the status of the PTM, observations and environmental factors	*V3*	75
	Preparation for visits with a person with an intellectual disability	*V4*	76
	"Me-Book" providing general and treatment specific information about the person with intellectual disability	*V5*	78
	Overview of the persons with intellectual disabilities participating in the visit	*V6*	79
Carrying out	Doctor contact without the participation of staff members	*V7*	80
	Feedback on the administration of pro re nata (PRN; 'as needed') medication	*V8*	81
	Video recordings to illustrate behaviour	*V9*	82

Areas	Measure	Code	Page
Carrying out	Promotion of active participation of the person with intellectual disability in visits	*V10*	83
	Discussion between staff member and doctor before visits	*V11*	84
	Visit checklist for staff members	*V12*	85
Follow-up	Debriefing of visits with person with intellectual disability	*V13*	86

5.3 Cooperation within the team

In the practical area (T), all measures related to the cooperation of the staff members in the residential accommodation are summarised. Collaboration can take place between two staff members or within the entire team. The term "staff members" here includes all people who have regular contact with the people with intellectual disabilities living in the residential accommodation or in the daily structuring offers (e.g. internal daily structure, care for the elderly).

Table 5.3 lists the possible measures that affect teamwork. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.3

Measure	Code	Page
Encouragement for self-reflection by staff members	T1	52
Regular team meetings to reflect on the observations	T2	53
Sitting in with other residential groups	T3	54
Regular, unprovoked case discussions	T4	55
Event-related case discussions	T5	56
Annual meeting as a "celebration" for the person with intellectual disabilities	T6	57
Discussion of PTM-relevant aspects when handing over at shift change	T7	58
Create "communication islands" for staff members	T8	59
Dual-control principle when administering pro re nata (PRN; 'as needed') medication	T9	60
List of internal contacts with specific knowledge of PTM and mental disorders	T10	61
Regular exchange between the residential accommodation and day-structuring offers and facilities	T11	62

Remark: This practical area is not divided into further areas, so this column is omitted in the table

5.4 Collaboration with healthcare professionals

The practical area (M) includes all measures aimed at the cooperation of staff members of the residential accommodation with medical professionals. The term "medical specialist" means doctors and employees of a pharmacy. Measures relating to cooperation with doctors are only listed in this practical area if the cooperation does not relate to aspects of visits (cf. practical area (V)).

Table 5.4 lists the possible measures that affect collaboration with healthcare professionals. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.4

Measure	Code	Page
Implementation of a low-threshold contact to the doctor	M1	63
Fixed contact person(s) for questions about the PTM	M2	64
Creation of opportunities for encounters between doctors from the residential accommodation area and residents from the residential accommodation	M3	65
Cooperation with a medical centre for people with disabilities (MZEB)	M4	66
Contact of the residential accommodation with the clinic during the stay in the clinic	M5	67

Remark: This practical area is not divided into further areas, so this column is omitted in the table

5.5 Cooperation with family members

The practical area (F) includes all measures relating to cooperation with relatives. Both the staff members of the residential accommodation and the doctor can be involved in the cooperation.

Table 5.5 lists the possible measures relating to cooperation with family members. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.5

Measure	Code	Page
Exchange between staff members and relatives on observations in the home environment	F1	68
Discussions to inform relatives about the PTM	F2	69
Family get-together with a doctor	F3	70
Regular consultation time for relatives	F4	71
Mediation between people with intellectual disabilities and relatives in the event of conflicting interests	F5	72

Remark: This practical area is not divided into further areas, so this column is omitted in the table

5.6 Imparting and making available knowledge about PTM

Training by external people on the basics of PTM | Make information about PTM available that is relevant to everyday life

The practical area (W) summarises measures that contribute to the transfer and availability of specialist knowledge on PTM. The knowledge includes the basics of PTM (e.g. mechanisms of action of psychotropic drugs) as well as information relevant to everyday life (e.g. frequent side effects of the currently administered psychotropic drugs). Both can be guaranteed through training courses carried out by external people (i.e. people who are not staff members of the residential accommodation) and through the preparation of relevant information on PTM for everyday use by staff members.

Table 5.6 lists the possible measures relating to the transfer and making available of knowledge about the PTM. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.6

Areas	Measure	Code	Page
Training by external people on the basics of PTM	Regular training for staff members on the basics of PTM	*W1*	87
	Regular training for staff members on the administration of pro re nata (PRN; 'as needed') medication	*W2*	88
Make everyday relevant information about the PTM available	Compilation of information sources on PTM	*W3*	89
	Self-compiled reference work on psychotropic drugs	*W4*	90
	Overview with general information on side effects	*W5*	91
	Short lectures on aspects of the PTM by staff members for colleagues	*W6*	92

5.7 Medical measures

All of the measures listed in Table 4.7 are measures for which the responsibility largely lies with the doctors responsible for the PTM.

Table 5.7 lists the measures for which doctors are responsible. The detailed description of the respective measure can be accessed in Chapter 6 or 7 via the code or the page number.

Table 5.7

Measure	Code	Page
First visit without a prescription	A1	94
Request and evaluation of previous reports and diagnoses	A2	95
Clarification of possible organic causes for behavioural changes	A3	96
Detailed initial introduction with a focus on getting to know the person with an intellectual disability	A4	97
Medical formulation and documentation of target agreements	A5	98
Standardised Federal medication plan	A6	99
Personal overview of the effects and side effects of individual psychotropic drugs	A7	100
Joint psychiatric and general medical visit	A8	101
Psychiatric and general medical survey of drug-specific laboratory parameters and ECG	A9	102
Medical information for the residential accommodation staff members	A10	103
Medical discussions with relatives	A11	104
Specialist exchange on PTM for people with intellectual disabilities	A12	105

Remark: This practical area is not divided into further areas, so this column is omitted in the table

Chapter 6

Presentation of residential accommodation-specific measures

6.1 Contact with a person with an intellectual disability (K)

Encourage self-determination of the person with intellectual disabilities

K1

Meaning

The needs and interests of the person with an intellectual disability are at the centre of the considerations regarding psychotropic medication treatment. They should be fully complied with and, as far as possible, the person him/herself should be given the opportunity to decide on the recommended measures. An awareness of self-determination and the ability to make one's own decisions are prerequisites for being able to make decisions on one's own responsibility. This also explicitly applies to decisions in connection with the PTM. These skills often require targeted development and support, particularly in the case of people with intellectual disabilities.

Implementation

The ability of the person with intellectual disability to comment on the PTM and to make independent decisions can be supported by stimulating individual self-determination in everyday life. Individual self-determination can be strengthened or developed by enabling them to make specific decisions for themselves throughout their everyday lives (e.g. by choosing food and clothing, choices for leisure activities). This happens depending on their individual level of development, their very individual needs and their communicative skills (e.g. use of yes/no symbols). Specific situations that include a consideration of individual wishes and interests (e.g. contact with a doctor) can also be discussed, planned and practiced in advance.

Responsibility

The staff members of the residential accommodation, the internal daily structure or Workshop for disabled people (WfbM), the legal guardians and the relatives can support the person with intellectual disability in making self-determined decisions for themselves and therefore being able to influence decisions within the framework of the PTM.

Everyday observation without cause

K2

Meaning

Regular observation of people with intellectual disabilities in different everyday contexts enables changes in their behaviour to be recognised quickly and allows conclusions to be drawn about situations in which a certain behaviour occurs more frequently. Everyday observation plays an important role in determining their current condition and needs, especially for people who have severely limited communicative resources.

The regular, structured transmission of the observations enables the most objective, continuous and comprehensive observation of the person possible and possible causes for challenging behaviour can be identified. This gives the doctor a more comprehensive picture of the person concerned. On the one hand, this prevents, for example, important changes in the behaviour of this person from being overlooked. On the other hand, this enables a timely reaction to the changes, possibly with very low-threshold measures. In this way, the need for a PTM may be averted.

Environmental factors, such as the housing situation and the individual living environment or its changes, can have a major impact on the development and maintenance of a behavioural problem and the psychopathological symptoms and therefore require regular consideration.

Implementation

The person with an intellectual disability is observed in different situations in everyday living, with a focus on conspicuous and changed behaviour and the context of this situation. The observations are recorded at least at the end of each shift in the internal documentation of the residential accommodation. A structured observation sheet that is accessible to all staff members can be used for this purpose (see practical tip "Structured observation sheet"). Here, the observations and assessments of several staff members are structured and recorded over a longer period of time.
For example, the observation form can be sent to the doctor before the visit, so that they have the opportunity to find out about the condition and behaviour of the patient in everyday life at different times of the day.

Responsibility

The responsible staff members of the residential group (e.g. reference caregiver) or the internal daily structure document their behaviour-specific observations in the internal documentation system or the specific observation sheet. Information from external specialists, such as occupational therapy, is also documented here by them or by staff members of the residential accommodation. They are thereby made accessible to all staff members and can be discussed within the team.

Practical tip

Structured observation sheet

Create a structured sheet or use a (carrier) internal template in which relevant everyday observations can be recorded as objectively as possible. For example, the sheet may include items on behaviour, mood, physical aspects, and environmental factors. Work out together as a team which points are important for you in the observation. If possible, consult medical professionals (e.g. medical specialist, neurologist, psychiatrist).

Event-related everyday observation

K3

Meaning

The targeted observation and subsequent documentation of changes in the behaviour of the person with intellectual disabilities supports their observation over a certain period of time. A definition of observation focal points aims to record behavioural changes as completely and "compulsorily" as possible and therefore to be able to analyse them comprehensively.

This targeted observation can help, especially in the case of people with intellectual disabilities who have very limited communicative resources, to record their current condition and, if necessary, to reflect on it. In addition, causes for a certain behaviour can be identified with the help of event-related observations. These observations can then be sent to the doctor prescribing the psychotropic drugs and therefore be taken into account when designing the PTM.

Implementation

If a doctor defines observation priorities for an initial prescription or for an adjustment of the treatment in the course of time, staff members observe the person concerned specifically for this behaviour in everyday life. The observation must take place and be documented within the previously defined framework (e.g. setting, time of day).
In the case of special focal points of observation, the "compulsory documentation" function can be used for a previously defined period of time by adapting the internal documentation system. This "obliges" the staff member on duty to answer a previously defined question in writing. This procedure ensures that a complete documentation of an observation focus is carried out within a certain period of time.

Responsibility

The responsible staff members of the residential group (reference caregiver, residential group leader) agree with the doctor on the focal points of the observation and the period of the targeted observation. For a comprehensive consideration of the environmental factors, an exchange with the relatives and/or the employees of the Workshop for disabled people (WfbM) may be necessary.

Practical tip

Individually created observation protocol
Create an individual observation log together as a team in order to be able to document the clearly defined observation focal points (e.g. sociability, irritability) and the observation period.

K4

Regular, unprovoked one-on-one talks with people with intellectual disabilities

Meaning

Talking one-on-one with the person with intellectual disability about themselves is essential to understand their current living environment, needs and behaviour better. Such an understanding is the basic requirement for the interests of that person to be taken into account properly. In addition, listening, perceiving and paying attention to negative emotions (e.g. dissatisfaction, specific fears and anger) can prevent challenging behaviour and provide information on how challenging behaviour that is experienced as problematic or challenging can be positively influenced, e.g. by changes in environmental conditions.

Implementation

A staff member regularly (e.g. daily, but at least once a week) conducts a one-to-one interview with the person with an intellectual disability, in which their current condition and experience are discussed. The discussion takes place in a quiet environment that is relaxed for the person with intellectual disabilities (e.g. in their room, during a walk). It takes place on a fixed date or depending on the individual need for discussion. In the discussion, the individual communicative possibilities of the person with an intellectual disability are taken into account and, if necessary, materials from supported communication are used. Topics that are important either from the point of view of the person with intellectual disabilities or from the point of view of the staff member can be noted and taken up again at the next discussion. In addition to this regular conversation, the person is offered the opportunity to have further one-on-one conversations if necessary.
The offer can be designed individually (e.g. daily changing contact person for further one-on-one discussions).

Responsibility

A person from the residential accommodation with close and trusting contact to the person concerned (e.g. reference caregiver) conducts the conversation. To ensure that these are carried out regularly, a substitute is appointed in the event of absence.

Practical tips

Short questionnaire on current well-being
Use a short questionnaire to record your current condition. This can include the following questions, for example: “How are you today? How would it be if you were better? What would have to change for you to feel better?”. In this way, the well-being can be recorded in a structured way.

Body sketch and symbols to identify ailments
A body sketch can help identify ailments. The person concerned can point to or mark the

body part or area with discomfort. In addition, symbols can be used to describe the nature of the complaint (e.g. lightning bolt for pain).

"Emotion Monster Cards"

"Emotion Monster Cards" are pictograms that represent different emotions. These can be used as an impetus for a conversation about how you are feeling ("Which monster describes how you are feeling?"). The cards are designed in such a way that they can be interpreted individually.

K5

Event-related one-on-one talks with people with intellectual disabilities

Meaning

In an event-related one-on-one interview, staff members reflect on their perception of a change in behaviour or anomalies by comparing this with the self-description of the person concerned. If the person with an intellectual disability shows signs of suffering, the next steps can be discussed and planned together. Here the person with an intellectual disability can communicate their specific interests and needs regarding further action. The person is fully involved in all further decisions.

Implementation

If staff members observe changes/abnormalities in the behaviour of residents, an individual discussion is planned (after consultation with the team) with the person concerned. In the conversation itself, the staff member reports on his or her own perceptions or perceptions of the team members regarding a change in behaviour and compares these with the self-perception of the person concerned. The comparison stimulates reflection on the part of the staff members ("Does the behaviour only bother me or us, or does it also affect the person concerned?"). The next steps are then discussed and planned together (e.g. carrying out a relaxing leisure activity on a regular basis).

Responsibility

A person from the residential accommodation with close and trusting contact to the person concerned (e.g. reference caregiver) conducts the conversation.

Offer for open exchange in the group

K6

Meaning

In regular exchanges in the group, the people with intellectual disabilities are given space in everyday life to exchange information about their current condition and their experiences (e.g. about symptoms, about PTM in general or about non-psychotropic medication alternatives). This can contribute to a more open approach to the issue of mental health.

Implementation

The open exchange among the residents is offered as a regular, low-threshold everyday conversation (e.g. daily after work in the workshop). The residents can talk about various topics here, for example, about the current mood or joyful and stressful events as well as symptoms. This is an open offer in which people with intellectual disabilities are given the opportunity to exchange ideas, for example in the common rooms. The group size is variable and depends on the needs of the residents. As the focus is on informal exchange among the residents, no moderation is needed.

Responsibility

The offer is carried out by the residents themselves, a staff member from the residential accommodation takes over the initiation and organisation of the offer (e.g. encouraging people to exchange ideas, providing premises).

Practical tip

Guided exchange

If residents want support and leadership of the group discussion, the exchange can also be guided. In the case of a guided exchange, the staff member responsible takes over the moderation of the group discussion. It is important that moderating staff members act cautiously, but if necessary also easily control contributions so that everyone has the opportunity to express themselves. If a person expresses psychological strain, staff members offer an event-related one-on-one conversation.

K7

Conversation on the biography with a person with an intellectual disability

Meaning

Knowledge from the biography of the person with intellectual disabilities contributes to a better understanding of their personality, their behaviour and, if necessary, also of challenging behaviour. For example, experiences relevant to therapy, including traumatic ones, can be made visible and communicated to the doctor, provided the person or their legal guardian agrees.

A grouping together of biographical knowledge about the respective person offers valuable information. These can be relevant for the doctor when planning therapy, in order to be able to get an idea of the patient as a person with their own story, even if they are not able to provide information about their life themselves in a conversation. Such information can provide important clues to behaviour-causing factors (e.g. childhood experiences). The knowledge from the biography can further be helpful to offer a suitable choice of therapeutic alternatives or supplements to a PTM for the person.

Implementation

A person from the residential accommodation has regular (e.g. weekly) one-to-one talks with the person with an intellectual disability. In the conversation, the biography and in particular biographical topics that are important for the person him/herself or the staff member are discussed and recorded in writing by the staff member. The content of the conversation is noted and can be taken up again in the next conversation. The conversation takes place in a relaxed setting (e.g. on a walk, in their own room).

Responsibility

A person from the residential accommodation with close and trusting contact to the person concerned (e.g. reference caregiver) conducts the conversation. To ensure that this is carried out regularly, a substitute is appointed in the event of absence.

Practical tip

Biography sheet

Use or create a uniform and structured biography sheet for the long-term documentation of the discussions in the team. The individual points can be gradually filled out in the joint discussions. This can be sent to the doctor if necessary (e.g. as part of the initial PTM presentation).

K8

Adjusting the care system to the needs of the person with intellectual disabilities

Meaning

A reference care system can provide the person with intellectual disabilities with consistency and reliability in their care. The person has a constant contact person at his/her side who knows his/her personality, abilities and interests very well and is in regular contact with him/her. The reference care system also aims to be able to transmit relevant information about the person with intellectual disabilities to the other staff members in the residential accommodation and the treating doctors. In this way, they can pass on information on physical complaints or changes in the living environment, which is relevant, for example, when examining the indication for psychotropic medication treatment. The reference caregivers can support and, if necessary, repeat the informing of the person with an intellectual disability about their therapy.

In addition, 1:1 care can provide particularly intensive support and individual, continuous and reliable support in everyday living. This form of care allows you to react immediately to critical situations and individual peculiarities. This form of care can have a positive effect on the well-being and balance of the person with intellectual disabilities and can therefore complement or even replace a psychotropic medication intervention.

Implementation

The care system is designed according to the individual needs of the person with intellectual disabilities and the structural conditions of the respective residential accommodation.

In the case of longer-lasting, intense abnormalities in the behaviour of the person concerned with a resulting need for very close care or a change in living situation that becomes necessary as a result, 1:1 care can be considered and, if necessary, applied for with the responsible cost bearer for the first time or extended. A targeted behavioural reflection and planning of the changed care situation takes place with several participants (reference caregiver, residential group leader), e.g. in the context of a case discussion.

Responsibility

Staff members discuss the feasibility of a new support system with the person regarding their needs and within the team.

Explaining to roommates about changed behaviour

K9

Meaning

A certain behaviour or individual forms of expression of a person with intellectual disabilities, possibly also as a result of effects and side effects (e.g. increased salivation, changed day-night rhythm) of the psychotropic drugs, can be perceived as disturbing by the roommates in the living area. As a result, there can be reactions on their part that can lead to serious conflicts and possibly intensify the challenging behaviour. Explaining to the roommates about behaviour that is perceived as disruptive or a particular form of expression can contribute to a better understanding and help to classify the behaviour better, bring about a changed "response reaction" and therefore positively influence the behavioural interaction.

Implementation

If the person with intellectual disabilities behaves in a manner that is perceived as disruptive by their living environment, a conversation will be held with the person's roommates. In this conversation, the background for the behaviour shown is explained and the concerns and worries of the roommates are discussed. Before the conversation, the consent of the person being discussed is obtained.

Responsibility

The conversation is planned and conducted by a person from the residential accommodation who is in close contact with the person concerned and their living environment (e.g. reference caregiver). To ensure that the conversation takes place early, i.e. before serious conflicts arise, a deputy should also be appointed.

K10

Overview of individual non-psychotropic medication coping strategies

Meaning

In order to simplify the consideration of non-psychotropic medication alternatives before the start and during the course of PTM, it can be helpful to create an overview of individual coping strategies. The overview encourages staff members to use non-psychotropic medication alternatives in situations that the person with intellectual disability experiences as stressful. This can possibly contribute to a reduced requirement. By creating an overview of coping strategies, individual interests can be taken into account and the person with intellectual disabilities can be given the best possible support, for example with relaxation and behavioural regulation.

Implementation

A written overview describes the typical behaviour of the resident in burdensome and stressful situations as well as possible individual coping strategies, which were identified through observation and exchange in the team and through exchange with the person concerned. A possible coping strategy can be a "timeout" from what is happening in the group (e.g. staying in the Snoezelen room, going for a walk [with or without a companion], retreating into their own room). Longer-term measures such as changing the living environment (e.g. moving to another room) can also be considered. When implementing the non-psychotropic medication alternatives, the doctor's indication for pro re nata (PRN; 'as needed') medication must be observed and the prescribed medication given as needed. The overview is created individually for each resident once together in the team and checked at regular intervals and adjusted if necessary.

Responsibility

Staff members who have frequent and close contact with the person concerned create the overview. The team determines who checks the overview at regular intervals (e.g. reference caregiver).

Practical tip

Table overview

Use a tabular overview in which individual behaviour and possible non-psychotropic medication preventive and acute coping strategies are described. The overview should be accessible to everyone who is in contact with the person with intellectual disabilities (e.g. stored in the documentation).

"Bag" with individual non-psychotropic medication offers

K11

Meaning

Non-drug offers and interventions tailored to the needs and interests of the individual can be used in problem situations and may make the administration of pro re nata (PRN; 'as needed') medication superfluous. The selection of very personal objects and preferences takes place outside of critical situations and serves as a preparation. In such a situation, the person with intellectual disability him/herself or those around him/her can react quickly and use the selected methods of relaxation and coping.

Implementation

Together with the person with intellectual disabilities, objects that are perceived as pleasant and relaxing (e.g. blanket, stress ball, photos, CD) are put together and collected in a specific place (individually designed box, small suitcase). In a burdensome or stressful situation, the person concerned (possibly with the support of staff members) can fall back on these objects, which can contribute to relaxation and therefore to well-being.

Responsibility

A person from the residential accommodation with close and trusting contact with the person concerned (e.g. reference caregiver) compiles the content together with them and regularly checks or adapts it.

K12

Reflection on current non-psychotropic medication interventions during the visit

Meaning

The implementation of non-psychotropic medication measures can have a major impact on the well-being of the person with intellectual disability and therefore on the behaviour shown. In contrast to treatment with psychotropic drugs, non-psychotropic medication measures usually have no side effects that are harmful to the organism. Therefore, before starting and during the course of drug treatment, it is important to consider to what extent such non-psychotropic medication treatment options are available and can be used as an alternative or in addition to PTM.

Implementation

During the course of treatment, it is regularly checked whether current non-psychotropic medication treatments need to be adjusted or whether additional non-psychotropic medication treatments can be used. The following questions can be helpful for this: "Is the individual satisfied with current non-psychotropic medication treatments?"; "Do they support the person in the best possible way?"; "Does the person want to use a different or additional option?". The reflection takes place together with the person concerned, staff members and the doctor regularly during the visits and as required (e.g. in the event of changes in behaviour).

Responsibility

The person responsible for preparing the visits compiles an overview of the current non-psychotropic medication treatments and sends this to the doctor, if necessary in advance.

Practical tip

Structured questionnaire on non-psychotropic medication treatments
Use a structured overview to present the non-psychotropic medication treatments used to date. This can be created together with the doctor or in a team and should be accessible to everyone (e.g. stored in the documentation).

K13

Involvement of external professionals for non-psychotropic medication interventions

Meaning

External specialists (e.g. ergotherapy, psychological specialist service, autism counselling, the organisation's own crisis intervention team) are available to provide individual care and support for the person with an intellectual disability. Their special expertise can be used in the interest of the person with an intellectual disability to improve their well-being, to reflect on conspicuous behaviour and to provide advice on how to deal with it, as well as to implement non-psychotropic medication measures.

Implementation

For an individual and extensive range of non-psychotropic medication alternatives, the person with intellectual disability is able to take advantage of external offers for non-psychotropic medication treatment options (e.g. speech therapy, horseback riding therapy) in addition to internal offers. In addition, external specialists are invited to the residential accommodation to advise the staff members on additional non-psychotropic medication alternatives that can be implemented in the residential accommodation (e.g. advice on supported communication). The selection of a corresponding offer depends on the needs of the person concerned, the need for support and advice of the staff members and the prescriptions of the doctor. Depending on the type of support required, the appropriate measures are integrated into the everyday structure of the residential accommodation.

Responsibility

External specialists are contacted by the people responsible for this in the residential accommodation (e.g. residential group leader, social worker).

K14

Participation of the person with intellectual disability in outside leisure activities

Meaning

The individuality of the person with intellectual disabilities, their interests and needs are already taken into account in everyday life. It can positively influence the mental state of the person with intellectual disabilities, find out and implement their individual hobbies and interests and create positive experiences. Tension may be relieved and challenging behaviour prevented, potentially reducing the need for psychotropic medication treatment.

Implementation

The person with an intellectual disability is given the opportunity to engage in external leisure activities in addition to activities within the residential accommodation. Together with him/her, it is agreed on what he/she would like to try. After that, possible providers are researched and, if necessary, an appointment is made. At regular intervals (e.g. every six months) it is discussed together whether the person concerned would like to continue the activity or take up another activity.

Responsibility

In order to ensure that leisure activities will be possible for the person with an intellectual disability in the foreseeable future, a staff member (e.g. reference caregiver) must be appointed to be responsible for this.

Regular PTM basics training for people with intellectual disabilities

K15

Meaning

Regular training provides people with intellectual disabilities with basic knowledge about mental disorders and possible treatment options. This knowledge gives them more opportunities to design the PTM according to their interests and needs. In this way, the persons concerned can independently communicate relevant complaints at the beginning and during the course of treatment. This can provide essential information during the determination of the indication as well as during the examination of the effect and side effects and in the consideration of possible non-psychotropic medication alternatives.
Knowing how a PTM might work can help the person with intellectual disability to feel more comfortable and participate more actively during the visit.

Implementation

The regular (e.g. twice a year) approx. one-hour training course on the basics of PTM includes content on possible symptoms of a mental disorder ("Where do I feel that?" "How does it feel?"), psychotropic medication and non-psychotropic medication treatment options and the process of a PTM. So that as many residents as possible can take part in the event and benefit from it, it is offered in different versions, each adapted to the cognitive resources.

Responsibility

Staff members compile the content together with a doctor. The training is carried out jointly or by the staff members themselves.

Practical tip

Explanatory video as a project with trainees
Create an explanatory video that can be shown during the training. The video shows the course of a possible PTM ("Which doctor will help me if I feel these symptoms?" "What does the doctor do during the treatment?"). A possible format would be: Short video with pictograms and visualisations that represent practical situations. In terms of content, orientation can be based on information sheets in simple language (see next practical tip). The video can also be used to prepare for an initial presentation.

6.2 Cooperation within the team (T)

Encouragement for self-reflection by staff members

T1

Meaning

Changed behaviour or behaviour that is perceived as conspicuous can have various causes (e.g. organic causes, changed/difficult/disturbing situations in the living environment, mental disorders). The reflective, questioning attitude of the staff members is an important prerequisite for developing a better understanding of certain behaviour and challenging behaviour of the person with intellectual disabilities. By regularly reflecting on and questioning one's own actions, their effect and influence in the interaction with this person can be considered. This can serve to take a different look at previous situations and to derive and implement alternative reactions from this. The reflective attitude of the staff members also forms an important basis for actions and decisions within the framework of the PTM, because they are thereby embedded in a more extensive and profound consideration.

Implementation

As part of the regular team meetings (e.g. monthly team consultation), there is a joint exchange on situations/interactions that staff members experience as difficult. All staff members are given the opportunity or are encouraged to describe selected everyday situations and to consider their own actions. The team colleagues can support this reflection by asking questions and, if necessary, offer an alternative view of the situation described.
By reflecting on one's own actions in the team and establishing this regular exchange (e.g. during team consultation), regular self-reflection of the staff members in everyday care can be stimulated and promoted.
The staff members consider the situations/interactions with the residents as well as their own behaviour/reactions to them. They reflect on their own perceptions of the behaviour of the person with intellectual disabilities and their own actions in interaction with them and look at the person with intellectual disabilities with the most objective, professional "overall view". "Behaviour perceived as disruptive is questioned: "Does it bother the person or maybe just me? In which situations does this behaviour occur? What is the actual background of the behaviour shown? What was the reaction to the behaviour?"

Responsibility

Responsible staff members of the residential accommodation (e.g. residential group leaders) encourage and support an exchange of self-reflection among the staff members. Residential accommodation staff consider, analyse and question their own behaviour in relation to the person with intellectual disabilities.

Practical tip

Carrying out supervision
Use the opportunity for supervision (in a team or individually) to stimulate, accompany and support reflection on your own work.

Regular team meetings to reflect on the observations

T2

Meaning

As part of a regular exchange and the joint reflection of different observations in the team, several perspectives and approaches in relation to the behaviour of the person with intellectual disabilities are considered. This results in a differentiated and comprehensive picture of the specific courses of action. Observation focal points can be jointly defined and analysed and possible interventions can be planned.

It makes sense for staff members on night duty to participate in the team consultations, as they can make statements about changes in the sleeping behaviour of the person with an intellectual disability. Sleep-related abnormalities can, among other things, represent a symptom of a mental disorder or occur as a side effect of a psychotropic drug and should be reported to the doctor.

Implementation

The team meeting takes place at a fixed time (at least once a month) within the residential group. The staff members of the respective residential group and, if necessary, the internal daily structure exchange behaviour-specific observations of each resident over the entire course of the day in the past period. These are reflected on together ("Does this behaviour bother me only or does it also restrict the person concerned?"). In addition, information on medical visits can be communicated as part of the team meeting. The entries of the internal documentation system of the residential accommodation are used to prepare the meeting and to document the results of the meeting. The documentation of the meeting offers the staff who are not present the opportunity to find out about the contents of the meeting and to use it, for example, to prepare for the doctor's visit.

Optionally, cross-group internal meetings can also be held at regular intervals.

Responsibility

The planning and management of the team meeting is carried out by a responsible person from the residential accommodation, e.g. the group leader. If possible, all staff members of the residential group should take part in the team meeting, including the night shift and, if applicable, the staff members of the internal day structure.

Sitting in with other residential groups

T3

Meaning

A regular and systematic exchange as well as cooperation between those responsible for the residential groups within the residential accommodation can enable a more comprehensive consideration of people with intellectual disabilities in their conspicuous behaviour and the underlying causes. The sitting in with another residential group allows different observations and perspectives, so that individual, problematic situations can be analysed together. Changes in the behaviour of the person with intellectual disabilities can possibly be recognised and recorded more quickly and, if necessary, communicated to the doctor. This makes it possible to include these "external" considerations in the decisions made in the context of psychotropic medication.

Implementation

At regular intervals (e.g. once a month), staff members of the residential group management sit in with another residential group. (e.g. hourly work). The participants then share their experiences.

Responsibility

The managers of the residential groups and areas determine the type and implementation of the observation and organise it.

Regular, unprovoked case discussions

T4

Meaning

The information available on a person with intellectual disabilities is discussed with everyone involved in the PTM. This results in an up-to-date, comprehensive and interdisciplinary picture of the person concerned, which takes into account different perspectives and points of view. On this basis, further goals, focal points, procedures and responsibilities for the PTM can be coordinated. The case discussions provide a framework for reviewing the indication and planning further non-drug measures or necessary psychotropic medication interventions.

Implementation

Scheduled case discussions take place at set times throughout the year (min. 1 x per year). The situation of one person is discussed in each appointment. A suitable room in the residential accommodation (e.g. consultation room, dining room) is required to conduct the case discussion with several participants. All persons who are in regular contact with the person concerned take part in the discussion (staff members in the residential area and day care structures, doctor, therapists and legal support if applicable). For people who cannot take part in the conversation in person (e.g. due to a long journey), participation via digital forms of exchange can be considered.

Contents of the internal documentation of the residential accommodation (e.g. observation logs) as well as individual notes of the other participants can be used to prepare the conversation. During this interdisciplinary discussion, all the people involved are given the opportunity to express their priorities and perspectives. Aspects of a PTM (including the need for a new presentation, drug effects and side effects and, if necessary, an adjustment to the medication) can be discussed and coordinated. The results of the case discussion are documented and therefore made accessible to all those involved, but also to the other staff members in the residential accommodation (e.g. in the form of a protocol).

Responsibility

The organisation and implementation is carried out by the group management, the specialist service or the reference caregiver.

Practical tip

Prepare the agenda

Create agenda items for the case discussion. These can be helpful in preparing the content and promote a structured course of the discussion. The PTM should be included as a separate item.

Event-related case discussions

T5

Meaning

In crisis situations that require rapid intervention due to changing behaviour of the person with intellectual disabilities, spontaneous case discussions can enable specific behavioural analysis and reflection and initiate prompt non-drug and drug-based interventions. A clear objective for this exchange supports all those involved in a targeted preparation for the case discussion and a solution-oriented discussion of the current problem.

Implementation

If an acute crisis situation occurs that requires an exchange with several people involved in the PTM, a personal case discussion is initiated promptly. Ideally, everyone who is in contact with the person concerned and who is involved in the PTM takes part in this discussion. A clear objective is formulated and communicated in advance (e.g. reduction of aggressive behaviour towards others). This supports all those involved in a targeted preparation for the case discussion and a solution-oriented discussion of the current problem. During the case discussion, different perspectives are exchanged, reflected upon and subsequent interventions coordinated. The possible need for supervision of the staff members of the residential group can be determined in this exchange process and this can be planned if necessary.

Responsibility

The organisation and implementation is carried out by the group management, the specialist service.

T6

Annual meeting as a "celebration" for the person with intellectual disabilities

Meaning

All supporters and companions who are relevant for the person with an intellectual disability can talk to them about their wishes and needs and also to each other and discuss specific concerns. The person with an intellectual disability and their concerns are the focus of the considerations. An up-to-date, comprehensive and interdisciplinary picture of the respective person with an intellectual disability can result for all those involved.

On this basis, other goals, priorities, procedures and responsibilities in connection with psychotropic medication treatment can also be coordinated.

Implementation

Once a year, at a fixed time (e.g. in the birthday month), a joint exchange takes place with several people involved in supporting the person with intellectual disabilities, provided that the person with intellectual disabilities agrees. The focus of this meeting is on the person being cared for and the framework for this discussion is based on their needs and wishes. This personal exchange should take place in a room where the person with intellectual disabilities feels comfortable and safe (e.g. in the group room of the residential group in the morning).

Responsibility

In addition to the person with an intellectual disability, the responsible staff members of the residential accommodation (including the caregiver, internal daily structure), treating physicians, relatives, legal caregivers, if applicable, therapists and, if applicable, Workshop for disabled people (WfbM) staff members take part in this annual appraisal.

T7

Discussion of PTM-relevant aspects when handing over at shift change

Meaning

The handing over at shift change enables an explicit exchange on resident-related aspects, some of which are obviously PTM-relevant (e.g. observations of possible undesirable effects of a medication), but some are only PTM-relevant in the overall view or in the assessment by the doctor (e.g. sleeping patterns). The timely and structured transmission of everyday observations means that different perspectives and experiences are included in the assessment of the situation and influencing factors for changed behaviour can be identified more easily. This also makes it possible jointly to plan interventions within the framework of PTM and with regard to non-psychotropic medication alternatives and then to implement them uniformly.

If the observations are written down during the handing over at shift change, the information can also be passed on to the treating doctor in comprehensive form for further evaluation. This person can identify abnormalities that are relevant to the PTM but cannot be classified as such by the staff.

Implementation

The regular handing over at shift change offers an opportunity to exchange everyday observations of all residents, which can be directly or indirectly PTM-relevant. An exchange of information specifically on PTM should take place for every person with intellectual disability who is being treated psychotropic medication for the first time or with changed medication. The content of the handover can also be recorded in writing in the internal documentation or in a log, which means that no content is lost and all staff members and doctors receive the information relevant to them.

Responsibility

Responsibility lies with the staff members changing shift.

Create "communication islands" for staff members

T8

Meaning

"Communication islands" can also support the exchange between staff members that does not or cannot take place during everyday work. The exchange can help to understand better the needs, interests and non-psychotropic medication coping strategies of the person with intellectual disability. In addition, the sensitivity to behavioural changes that may be caused by the PTM (e.g. due to possible side effects) is increased.

Implementation

Periods and spaces (so-called "communication islands") are created in a targeted manner, which offer staff members the opportunity to exchange information about the residents informally without being distracted by other work. Examples are coffee breaks or during lunch breaks. The content of the conversations can be everyday observations, for example the increased preoccupation of a resident with a blanket in stressful situations. This information can flow into the PTM (e.g. inclusion of the blanket in the "bag" with individual non-psychotropic medication offers (see *Measure K11*)).

Responsibility

The facility management examines options and, if necessary, creates new "communication islands" for exchange between staff members.

T9

Dual-control principle when administering pro re nata (PRN; 'as needed') medication

Meaning

The administration of pro re nata (PRN; 'as needed') medication must implement the medical instructions, which in turn are based on the interests and needs of the person with intellectual disability.
Interests and needs as well as subjective attitudes towards PTM of staff members must not play a role in the decision for or against a demand response. Mandatory confirmation when administering pro re nata (PRN; 'as needed') medication by a second person can ensure that the physician's instructions are followed.

Implementation

A second person from the residential accommodation must be called in before pro re nata (PRN; 'as needed') medication can be given as needed. The current behaviour of the person concerned or the situation is described. If possible, the second person gets an impression of the behaviour or the situation. In a one-to-one conversation (in person or by telephone), the behaviour manifested or the situation is discussed together and a decision is made regarding the administration of pro re nata (PRN; 'as needed') medication as required. The conversation and the result are documented.

Responsibility

Staff members who are responsible for dispensing pro re nata (PRN; 'as needed') medication.

T10

List of internal contacts with specific knowledge of PTM and mental disorders

Meaning

A list of specific contact persons in the residential accommodation can be used to network and pass on their specific knowledge of PTM or mental illnesses. In addition, the corresponding contact persons can be quickly identified with the help of the list. It should be noted that if you have any medical questions (e.g. on the indication or on assessing the effects and side effects of the medication), the treating doctor should always be contacted first.

Implementation

A list is created of all staff members, including official contact details, who have specific knowledge of PTM or mental disorders. Staff members may have acquired this knowledge, for example, through additional studies or further training. The list is created, stored accessible to everyone (e.g. in the documentation) and checked regularly (e.g. annually) and adjusted if necessary.

Responsibility

The team decides who is responsible for creating and regularly checking the list (e.g. training officer or another person responsible for further training).

T11

Regular exchange between the residential accommodation and day-structuring offers and facilities

Meaning

Through the exchange of knowledge, everyone who is in contact with the person with intellectual disabilities has the same information and can therefore support the person better and more specifically in everyday life and with PTM. In addition, situation-dependent behaviour can be identified, which can provide an indication for the indication and the review of effects and side effects.

Implementation

At regular intervals (e.g. once a quarter) staff members in the residential area meet with staff members from the various daily structure areas (e.g. workshop, care for the elderly) and exchange views on the current behaviour of people with intellectual disabilities. In the conversation, all residents are addressed; the aim is to share the different observations. An additional meeting for a more intensive exchange can be held if necessary.

Responsibility

A manager (e.g. team leader) plans and coordinates the appointment in coordination with the other participants.

Practical tip

List of contact persons of the various structures

Create a list of contact persons for the exchange outside of the above meetings. The list contains the names of the contact persons in the individual areas (e.g. residential area, workshop, care for the elderly) as well as their official contact details. It also contains information on which other specialists the staff members (mainly) have contact with. The overview is created and circulated once and checked at regular intervals and adjusted if necessary. The overview facilitates communication between the individual areas.

6.3 Collaboration with medical professionals (M)

Implementation of a low-threshold contact to the doctor

M1

Meaning

Fast and uncomplicated contact between staff members and doctors is important during the PTM. In this way, information, such as observations made by staff members, can be communicated directly to the doctor before the situation of this person with a intellectual disability deteriorates or negative consequences of treatment occur. In addition, ambiguities on the part of the staff members regarding the PTM (e.g. sudden physical changes) can be clarified during contact and the person with an intellectual disability can be given the best possible support in their treatment. The implementation of low-threshold contact is particularly important in the PTM of people with intellectual disabilities, as they have an increased sensitivity to side effects and an increased potential for complications[6].

Implementation

In a short meeting, staff members and the doctor agree on how to contact them in the future. Defined communication channels are stored in the documentation. Spontaneous telephone calls (mobile number in an emergency), email contact, spontaneous home visits or the short-term introduction of the person with an intellectual disability in the practice are all possible ways of establishing contact. In addition, telemedicine options can be used, such as video calls via tablet. It is possible to involve the person with an intellectual disability actively, e.g. through a short-term digital consultation.

Responsibility

The responsibility for coordinating the short-term contact lies with the specialists responsible for the PTM in the residential accommodation and the doctor.

Practical tips

Discuss contact options at the next visit
Discuss directly during the next visit which contact option you can use and make a note of this in the documentation so that it is accessible to all.

Clarify the possibility of regular telephone consultation time
Ask about the possibility of being available by telephone if necessary (e.g. a period on certain days of the week).

Fixed contact person(s) for questions about the PTM

M2

Meaning

The treating doctor (possibly also the pharmacy staff) is available as a contact person for the individual support of the PTM of a person with an intellectual disability. Their special expertise and experience can be used in the interest of the person with intellectual disabilities to improve their well-being, to reflect on conspicuous behaviour and to provide advice on how to deal with it, as well as to implement psychotropic medication and non-psychotropic medication measures.

Implementation

The doctor and/or pharmacist is the direct contact person for staff members with questions about the basics of PTM and specific questions about individual psychotropic drugs (e.g. possible side effects, interactions). Depending on the urgency, staff members can contact each other in writing or use a personal meeting. Regular visits or regular contact with the pharmacy can also be used to clarify questions. Ideally, the procedure for making contact should be clarified directly with the doctor and pharmacist in advance.

Responsibility

Any staff member can contact the doctor or pharmacist if they have any questions. Communication can also take place with the help of the permanent internal contact person (e.g. the specialist service in the residential accommodation) for PTM.

M3

Creation of opportunities for encounters between doctors from the residential accommodation area and residents from the residential accommodation

Meaning

Getting to know the residential accommodation and the people with intellectual disabilities through other specialists from the living environment can help to reduce fear of contact, mutual understanding and the reduction of the contact threshold. In addition, a direct exchange with staff members on site is made possible, for example for communication between people with intellectual disabilities.

Such an opportunity to meet makes sense for medical specialists who regularly look after people with an intellectual disability and who want to improve communication with these people. In addition, specialists (such as gynaecologists) who treat people with intellectual disabilities only occasionally can overcome fears of contact with this group of people and develop a more intensive understanding for them.

This measure can lead to the expansion or improvement of cooperation with the local medical specialists and thus also have a positive influence on the PTM, for example through simplified doctor finding for the clarification of possible organic causes in the case of challenging behaviour.

Implementation

In the residential accommodation there is an opportunity to meet people with intellectual disabilities and specialists who have their practice in the vicinity of the residential accommodation (e.g. joint summer party, information evening). The event is aimed at all medical specialists in the area, especially those who only have occasional contact with this group of people (e.g. dermatologists). This contact should enable all to get to know each other and exchange ideas. In addition, specific knowledge can also be imparted in the form of short presentations. The specific design is coordinated in the residential accommodation (e.g. regular/one-time, event location).

Responsibility

In order to ensure that such an opportunity to meet with the specialists in the area can be organised, a meeting should take place in advance for joint planning and a clear division of tasks/responsibilities. In advance, the staff should be informed about the importance and usefulness of such a meeting (e.g. future forms of cooperation or possibilities for patient-centred medical care).

Doctors are written to by the managers of the residential accommodation and invited to the event.

M4

Cooperation with a medical centre for people with disabilities (MZEB)

Meaning

Cooperation with other medical specialists specialising in the group of people with intellectual disabilities can facilitate a more targeted assessment of the problematic behaviour and interdisciplinary diagnostics and advice. This can be ensured by cooperating with an MZEB.

Implementation

Depending on the practical feasibility of working with a medical centre for people with disabilities (MZEB), various communication options are conceivable. In addition to a personal introduction to the residents in the MZEB, regular case-related online meetings can be held. MZEB employees can sit in with the residential group and therefore get to know the person with an intellectual disability in their living environment. Another form of cooperation is possible through the participation of MZEB employees in the case discussions in the residential accommodation. This can be done by attending in person or using digital video conferencing. The design and intensity of the cooperation between the residential accommodation and the MZEB is geared primarily to the needs of supporting the person with an intellectual disability, in addition to practical feasibility.

Responsibility

The staff members of the residential accommodation or the legal guardian will contact an MZEB according to the medical prescription.

M5

Contact of the residential accommodation with the clinic during the stay in the clinic

Meaning

If there is a hospital stay, contact and exchange between the residential accommodation and the clinic is important in order to be able to take the interests and needs of the person with intellectual disabilities into account during a hospital stay. Information, for example on communication and/or on non-psychotropic medication coping strategies, can be communicated to the person. Conversely, the residential accommodation receives information about observations and changes in the PTM made in the hospital.

Implementation

During an inpatient stay in the clinic, the responsible residential accommodation staff member is in regular contact with the clinic staff. This can take the form of phone calls, face-to-face meetings or using video calling. The content of the discussions can be relevant information for employees of the clinic (e.g. special features of a person) as well as information on the course of treatment for staff members of the residential accommodation (e.g. diagnosis, medication). The information from the hospital is passed on in the team and noted in the documentation. The exchange takes place upon admission to the hospital, during the course (e.g. once a week) and upon discharge.

Responsibility

A person from the residential accommodation with close and trusting contact to the person concerned (e.g. caregiver, medical specialist service, social service) organises the exchange, conducts the discussions and forwards relevant information to colleagues. In order to ensure a regular exchange, a substitute is appointed in case of absence.

6.4 Cooperation with family members (F)

Exchange between staff members and relatives on observations in the home environment

F1

Meaning

The relatives of the person with an intellectual disability have a special (not always close...) relationship with them. For a comprehensive view, the perspective of the relatives and descriptions of the behaviour in the home environment are important, since different behaviour and behaviour patterns can occur in different contexts. This information can be compared with the observations of the staff in the residential accommodation and can be incorporated into the considerations of the necessity and design of psychotropic medication treatment.

Implementation

Planned (e.g. new admissions, annual case discussion) and spontaneous talks (e.g. after the person concerned has been in the home environment) take place between staff members and relatives in order to exchange behaviour-specific observations of the relatives and the current condition of the person concerned. The conversations take place in person and in the presence of the person concerned in a quiet, undisturbed environment or by telephone. The observations and perspectives of the relatives are stored in the documentation and therefore made accessible to all staff members.

Responsibility

In the case of a planned meeting with relatives, the exchange takes place with the responsible person from the residential accommodation (e.g. reference caregiver, residential group leader, social worker), in the case of a spontaneous exchange (e.g. after a weekend stay) by the person on duty.

Discussions to inform relatives about the PTM

F2

Meaning

The expectations and concerns of relatives with regard to psychotropic medication treatment influence its design and therefore require attention. By being informed about the objective of the treatment, relatives can develop an understanding of it, be supported in their own actions and therefore improve the quality and continuity of the PTM. By means of the discussions, the staff members can respond to the individual needs and questions of the relatives and therefore develop mutual trust.

Implementation

The informational discussions can take place in the context of a planned appointment (e.g. initial consultation with a specialist) as well as spontaneously in the event of acute issues or questions from the relatives or staff members if relatives have specific questions about PTM. In contact, relevant information is passed on to the relatives by the residential accommodation, primarily therapy content, changes in medication, problems occurring with the current medication or information on side effects. Discussions take place in a quiet setting (e.g. consultation room) in order to discuss questions and concerns undisturbed.

Responsibility

A person from the residential accommodation with close and trusting contact to the person concerned (e.g. reference caregiver) or the person on duty plans and conducts the conversation.

Practical tip

Written notification to family members

Staff members inform the relatives regularly (e.g. monthly) briefly about the current status of the PTM by post or email. A person from the residential accommodation with close and trusting contact to the person with intellectual disabilities (e.g. reference caregiver) writes and sends the short messages.

Family get-together with a doctor

F3

Meaning

Within the framework of regular "relatives' get-togethers" with the residential accommodation staff members and the doctor for neurology or psychiatry, there is an opportunity to exchange ideas with other relatives and to discuss questions about drug therapy. This discussion framework gives the doctor additional space to listen to the relatives actively and to be able to respond to their fears in relation to psychotropic medication therapy.

Implementation

Regular and fixed appointments (e.g. once a year) are held with interested relatives, staff members of the residential accommodation and the treating doctor or doctor for psychiatry or neurology. This meeting can be held in a suitable, undisturbed room in the residential accommodation (e.g. dining room) or outside the residential accommodation (e.g. separate room in a restaurant). At the meeting, a follow-up appointment is coordinated and agreed with all participants.

Responsibility

The management of the living group or residential accommodation plan and organise the family get-together in consultation with the doctor.

Regular consultation time for relatives

F4

Meaning

The expectations and concerns of family members about PTM can influence its design. By regularly informing and exchanging information with the relatives about the current status of the treatment, they can develop a better understanding of the PTM and be supported in their own actions. Therefore, the quality and continuity of the PTM can be improved. The aim of the consultation time is to create a regular and reliable period for exchange.

Implementation

The relatives can reach the staff members by telephone at specified times regarding concerns, questions or information. The period of time is based on the daily routine of the residential accommodation (e.g. weekly Wednesday lunchtime). The exact consultation times are communicated, for example, via letters to relatives.

Responsibility

It is determined in the team who will take over the communication with relatives regarding the new consultation times (e.g. group leader). A person from the residential accommodation with close and trusting contact to the person concerned (e.g. reference caregiver) takes over the specific exchange with relatives.

F5

Mediation between people with intellectual disabilities and relatives in the event of conflicting interests

Meaning

Relatives usually have a close relationship with the person with an intellectual disability living in the residential accommodation and want the best possible support for them. Therefore, they often want their own ideas and expectations to be taken into account in a PTM. However, if these appear to deviate from the well-understood interests and needs of the person being cared for, staff at the residential accommodation can take on a mediating role and initiate a meeting with relatives in order to involve the relatives more comprehensively in the considerations of a PTM. This can support a better understanding of the therapy rationale and thereby contribute to the best possible support for the person concerned in the course of treatment.

Implementation

If, from the point of view of the residential accommodation staff, the well-understood interests of the person with intellectual disabilities do not match those of their relatives (e.g. with regard to the basic administration of psychotropic drugs), staff can take on a mediating role and initiate a joint conversation. In this conversation, the person with an intellectual disability can be given the opportunity to present their current situation and their needs (possibly with the support of a staff member they trust). The aim of this discussion is **not** to **"convince" the relatives of the point of view of the residential accommodation staff members**, but to enable an open exchange process.

If this is desirable from the point of view of the person with an intellectual disability or the relatives, a further exchange with staff members of the residential facility, the daily structuring offers or the doctor treating the relatives can take place in addition to this mediating conversation in order to give the relatives comprehensive information about the educational, medical or to inform therapeutic perspectives. It is important to pick up the relatives in their situation (e.g. fears and feelings of guilt). However, the focus is always on the needs and interests of the person concerned.

Responsibility

A person from the residential accommodation facility with close and trusting contact to the person with intellectual disabilities (e.g. reference caregiver) initiates the first conversation. If necessary, other staff members, medical specialists and the specialist service are involved.

6.5 Visits (V)

Adaptation of the medical care model to the needs of the person with intellectual disabilities

V1

Meaning

Visits take place either in the residential accommodation (visiting, follow-up model) or in the doctor's practice or clinic (come-in structure). The setting affects the well-being, communication and behaviour of the person with intellectual disability; it influences the doctor-patient relationship and therefore also has an impact on the PTM. The basis for the design of medical care is formed by the needs of the person with intellectual disabilities.

Implementation

If necessary, the person with an intellectual disability can be asked whether, from their point of view, contact with the doctor should better take place in the residential accommodation or in the doctor's practice or clinic. In addition, observations that show that the person feels more comfortable in a certain setting (the familiar environment of the residential accommodation or the doctor's office), for example by appearing less anxious or communicating more, can be helpful. Both care models have aspects that can be advantageous for the therapy of the respective person with intellectual disability:

If visits take place in the residential accommodation (visiting, follow-up model), the person with intellectual disabilities remains in their familiar, safe environment and it may be easier for them to communicate with the doctor. Less tension is generated, which can be caused by the journey or the waiting time in the doctor's office, for example.

If visits take place in the doctor's office or clinic (come-in structure), the residents have the opportunity to communicate, for example, their physical complaints or their mental state at a distance from the residential accommodation environment.

In order to implement this measure, it may be necessary for an attending doctor to offer both care models or for a doctor to be involved for the other care model.

Responsibility

Staff members discuss their needs with the person concerned with regard to the care model. A manager seeks a discussion with the doctor in order to agree on the type of medical care or possible changes in the care model.

Practical tip

Agree on appointments for visits for a year

Make appointments for unprovoked visits with the doctor at the beginning of the year for the entire year. Regular visits ensure good medical support and continuous monitoring of the treatment. By establishing the appointments in advance, regular visits and optimum preparation on the part of the residential accommodation and the doctor can be ensured. If necessary, event-related visits are also carried out.

V2

Fixed contact person in the residential accommodation for visits

Meaning

A permanent contact person from the residential accommodation is available to the doctor for visits and all related aspects. He/she transmits all necessary information to the doctor and is available for questions. He/she communicates information from the visits to the other staff members.

Implementation

A person from the residential accommodation is responsible for the visits. He/she prepares them (see also *Measure V3* "Visit preparation form on the status of the PTM, observations and environmental factors"), accompanies the person with intellectual disability to the visit, discusses the visit together with this person (see also *Measure V13* "Debriefing of the visit with the person with intellectual disability") and prepares the visit for the team (e.g. short update in the team meeting, enter the summary in the documentation). He/she can also serve as a contact person for questions regarding the PTM.

Responsibility

The residential accommodation management determines who will act as the permanent contact person. In order to ensure that the tasks of the contact person are carried out continuously, a substitute is appointed in case of absence.

Practical tips

Make a note of the contact person
Make a note of the contact person on the visit preparation form (see also *Measure V3* "Visit preparation form on the status of the PTM, observations and environmental factors") so that the responsibilities are clear.

Send information before visit
Send all the relevant information to the doctor in advance, for example using the form to prepare for visits (see also *Measure V3* "Preparation form for visits on the status of the PTM, observations and environmental factors").

V3

Visit preparation sheet on the status of the PTM, observations and environmental factors

Meaning

A structured sheet to prepare for the visits provides the doctor with a comprehensive overview of all areas relevant to therapy. Contents of this sheet can be the current status of the PTM, observations from the living environment and changes in environmental factors. A structured visit preparation form can be used to record all aspects required for the treatment. In addition, the risk is reduced that factors that can lead to the maintenance or worsening of the psychopathological symptoms are overlooked during the visit.

Implementation

Together with the doctor, staff members prepare a visit preparation sheet on the current status of the PTM (e.g. current target behaviour, previous educational interventions, previous medication, individual needs of the person, diagnosis, results of laboratory tests), current observations (regarding possible side effects such as weight, heart rate, blood pressure) and (changed) environmental factors. The continuous documentation of the observations and the environmental factors enables a comprehensive picture of a certain behaviour over a longer period of time (e.g. weeks). The information is summarised in the visit observation form and filtered for the doctor in such a way that relevant information is immediately visible. The visit preparation sheet is clearly laid out (e.g. in bullet points or as a "fact sheet"). The visit preparation form is filled out by the responsible person before the visit and brought to the visit. If necessary, it can also be sent in advance.

Responsibility

The team decides who will prepare and forward the questionnaire (e.g. group leader). In order to ensure a regular exchange, a substitute is appointed in case of absence.

Practical tips

Use existing templates
Use existing templates for recording symptoms and challenging behaviours.

Show the course of behaviour
Make the course of the behaviour recognisable for the doctor by summarising the daily documentation. For this purpose, continuous documentation over days or weeks is important (especially if conspicuous behaviour has been identified).

V4

Preparation for visits with a person with a intellectual disability

Meaning

During the visit, the person with a intellectual disability should be able to communicate their own interests and needs as well as psychological and/or physical complaints as independently as possible, depending on their resources. In order to support him/her in this, staff members prepare for the visit with her, with as many aspects of the visit as possible (e.g. process, location, doctor) being discussed in advance. This is intended to help the person with intellectual disability feel comfortable later in the visit.

Implementation

The preparation of the resident for the visit is designed individually and adapted to the individual resources of the person.

Responsibility

A person from the residential accommodation who accompanies the visit.

Practical tips

Formulation of requests
Discuss with the resident shortly before the visit (e.g. a few days before) which topics or concerns should be discussed during the visit.

Encouragement to self-determination
If people with an intellectual disability need targeted support and development of the ability to express their own needs, you can incorporate suggestions from everyday life (e.g. independent selection of daily activities). This can serve as an exercise for expressing specific wishes during the visits (see also *Measure K1* "Stimulate self-determination of the person with an intellectual disability").

Visit as a role play
Practice the visits together with the resident in a role play, i.e. a person from the residential accommodation takes on the role of the doctor and goes through the visit discussion with the person.

Get to know the doctor
Plan a "get to know meeting" before the doctor's visit if the person concerned does not yet know the doctor (e.g. for new staff, change of doctor). The content of the conversation is just getting to know each other; medical content is not discussed. The conversation can take place in person or via video conference. Alternatively, a person from the residential accommodation and the person with intellectual disabilities look at photos of the doctor together (e.g. via the homepage of the practice or clinic).

Get to know the practice rooms

Before the actual visit, visit the practice or clinic rooms if they are not already known. Alternatively (if possible) photos of the premises can be viewed online together.

V5

"Me-Book" providing general and treatment specific information about the person with intellectual disability

Meaning

The "Me-Book" as a tool to support communication enables people with limited speech to communicate their interests, needs and preferences to their environment. This information can thereby be considered when implementing patient-oriented treatment and/or during crisis discussions.

Implementation

The "Me-Book" serves, among other things, to introduce the person themselves, their environment, their preferences, hobbies and interests as well as their communicative possibilities. The "Me-Book" can be used in everyday life in the residential accommodation and as part of the PTM, e.g. when introducing the person with intellectual disability to a doctor and when planning the PTM and alternative treatment options.
The "Me-Book" is created over a longer period of time together with the person with intellectual disabilities (and possibly with relatives) and is regularly supplemented or revised (e.g. in the birthday month).

Responsibility

A person from the residential accommodation who has close and trusting contact with the person in question works with them to develop the contents of the "Me-Book". The help of relatives is desirable for the compilation of individual information and photos.

V6

Overview of the persons with intellectual disabilities participating in the visit

Meaning

By sending an overview of all the people who will take part in the visit in advance, the doctor can prepare specifically for these patients and their concerns. In addition, the visits for staff members as well as for the doctor are structured and designed to be plannable.

Implementation

Up to a week before the visit, an up-to-date overview of all people who will take part in the visit will be compiled and sent to the doctor. This includes patients who are already undergoing psychotropic medication treatment, patients who would like to visit the doctor's office at short notice and notifications of absence if residents are unable to attend the doctor's office due to holidays. The overview includes: Name and date of birth, main concerns of the visit (check-up appointment, new presentation), estimated duration of the visit, contact person present, any special features of the person with an intellectual disability (e.g. fears).

Responsibility

A manager (e.g. group leader) or the specialist service is ideal for coordinating and gathering the information.

Doctor contact without the participation of staff members

V7

Meaning

The doctor is the direct contact person for the person with intellectual disabilities for their concerns in relation to mental health and psychotropic medication therapy. In the one-to-one discussion between the person and the doctor, topics and concerns of the person can be addressed directly, while respecting their privacy. This gives the person the opportunity to communicate their ideas and interests themselves and to discuss content that they would not discuss in the presence of other people (e.g. staff members, legal guardians). The doctor has the opportunity to exchange ideas directly with the patient and to experience them as an individual person without being accompanied.

Implementation

At the request of the person with an intellectual disability, the doctor can present him/herself during the visits or in the case of acute problems without other (accompanying) people. Before contacting the doctor, the staff at the residential accommodation will ask the person with an intellectual disability whether they want to do this alone or be accompanied by a person they trust. The opportunity to conduct the medical consultation alone is also spontaneously given to him/her during the visits. If the person with an intellectual disability agrees, the doctor can pass on therapy-related information to the residential accommodation staff after the conversation.

Responsibility

The doctor is responsible for the implementation of a "one-to-one discussion" between the doctor and the person with an intellectual disability, as are the staff members of the residential accommodation when preparing for the discussion.

V8

Feedback on the administration of pro re nata (PRN; 'as needed') medication

Meaning

With the help of the documentation on the pro re nata (PRN; 'as needed') medication, the prescribing doctor can reassure him/herself to what extent the medication was administered according to the written instructions, i.e. considering the defined conditions, fixed dose and frequency. In this way, he/she receives information on how often a need existed and on the effect and possible side effects of the pro re nata (PRN; 'as needed') medication used. The doctor can then make changes to the medication or the instructions, for example if it turns out that the need for the current instructions cannot be correctly assessed and should be defined more specifically.

Implementation

The specialist defines a clear need and sets it down in writing. If necessary, the staff members give the medication according to the written instructions of the doctor. The situation and the dose are documented and presented to the specialist at the next visit. At each visit, the specialist asks about the reason and how often the required medication is given.

Responsibility

The person preparing and accompanying the visit takes the relevant information on the administration of pro re nata (PRN; 'as needed') medication from the documentation and presents it during the visit. If necessary, the information can be sent to the doctor in advance.

Video recordings to illustrate behaviour

V9

Meaning

Recording video sequences (with the necessary consent) can enable a more detailed analysis of situations that are difficult to describe and acute behavioural changes of the person with intellectual disability. This applies in particular to those people involved in PTM who only see people with intellectual disabilities selectively, such as doctors. These recordings can be used for visits and for case discussions or requested by the doctor, for example if the description of the individual forms of expression is not clearly possible for the staff members or a more detailed behavioural analysis is required.

Implementation

In order to demonstrate certain behavioural changes or abnormalities to the doctor, the corresponding behaviour is recorded on video in compliance with data protection regulations and discussed together during the round. Before recording, the consent of the person concerned (if necessary the legal guardian) must be obtained. A quiet conversation in advance (before you show the behaviour!) in private, in which the meaning and purpose of the future recording is explained, is suitable for this. The recording is made and saved using a local tablet or mobile phone without a SIM card. The recordings can also be used for case discussions. The recordings may only be used specifically and must be securely deleted after use (e.g. during visits or case discussions).

Responsibility

If consent is given, the staff members can record the video sequence.

V10

Promotion of active participation of the person with intellectual disability in visits

Meaning

All steps in the treatment process should be designed according to the interests and needs of the person with intellectual disability. This can be ensured by him/her being present during visits and taking an active part in them. Being addressed directly by the doctor can contribute to a trusting relationship and make it easier for the person with intellectual disabilities to communicate their mental state and physical complaints during visits.

Implementation

It goes without saying that the person with an intellectual disability is present during visits (at least quarterly). Active participation is encouraged during the discussion with the doctor (e.g. through eye contact, direct questioning). If this is not initiated by the doctor, the accompanying persons direct the focus to the person with intellectual disabilities and point out that the doctor can direct the questions directly to the person; the staff members present can help if necessary the doctor, for example by pointing out a helpful strategy for communicating with this resident.

Responsibility

Active participation is encouraged by the doctor and the accompanying person during the visits.

Discussion between staff member and doctor before visits

V11

Meaning

A preliminary discussion between the doctor and the staff member during the visit is only conducive to **a guideline-compliant and patient-centred PTM in special cases** (see description in the implementation of the measure). In such exceptional cases, the preliminary talk can help to avoid certain questions from the doctor that are distressing for the patient, insofar as he or she was informed by the staff member before the visit.

Implementation

If it makes sense and is expedient for the person with an intellectual disability, the visit can take place in two parts. This can be the case if the doctor needs to be made aware of specific, acute problems in order to prevent the person with an intellectual disability from being placed under too much stress, for example by asking awkward questions. In such a case, a preliminary discussion first takes place between the doctor and the accompanying person from the residential accommodation. Relevant information about the person with intellectual disabilities can be transmitted here (e.g. current mood, fears, stressful topics of conversation). It is **not** the aim of this preliminary talk that staff members bring their needs to bear in the PTM, but rather the optimum preparation of the visits in the interests of the person with an intellectual disability. The consent of the person concerned must be obtained in advance for the interview. In the second part, the conversation between the person with intellectual disabilities and the doctor takes place as usual.

Responsibility

The preliminary discussion is carried out by the person accompanying the visit (e.g. reference caregiver).

Visit checklist for staff members

V12

Meaning

The planning and design of the visit is carried out using a checklist agreed upon in the residential accommodation according to a recurring process known to all those involved. This allows targeted preparation for the visit and its content. Depending on their abilities, the person with an intellectual disability can be included in the preparation of visits. The recurring process and the defined content of the visit makes it easier to understand for everyone involved. The probability decreases that essential therapy-relevant aspects are not considered or are forgotten.

Implementation

Create a checklist that supports the preparation and follow-up of the visit. This includes, for example, concerns of the person with an intellectual disability (see also *Measure V4* "Preparing visits with a person with an intellectual disability"), concerns of the staff members discussed in advance in the team, aspects relevant to treatment (e.g. observed effects and side effects, changes in environmental factors of the resident) and concerns for the doctor (e.g. reminder to check the indication), organisational aspects (e.g. request for the doctor's letter to be forwarded to the general practitioner, arranging a follow-up appointment) and documents to be brought along (e.g. medication plan, preparation sheet - see also *Measure V3* " Visit preparation sheet on the status of the PTM, observations and environmental factors"). In addition, there may be space for notes and more. The accompanying person present at the visit ticks off the points discussed during the visit and notes down what has been discussed. After the visit, the completed checklist is made available to all staff, for example by storing it in the documentation.

Responsibility

The checklist is created together in the team. The person present during the visit is responsible for the preparation and follow-up as well as filling out the discussion guide during the visit.

Debriefing of visits with person with intellectual disability

V13

Meaning

Debriefing the contents of the visit with the person with intellectual disability will help them develop a better understanding of each step in the PTM.

Implementation

After the visit, the accompanying person clarifies open questions and ambiguities regarding the PTM with the person with intellectual disabilities. The time and the premises are chosen appropriately (e.g. in the resident's room). A calm atmosphere and focus on the person are important.

Responsibility

The person accompanying the visit takes over the conversation.

6.6 Communicate knowledge about the PTM and make it available (W)

Regular training for staff members on the basics of PTM

W1

Meaning

With the help of regular training, staff members are taught the basics of PTM. In this way, new staff members receive up-to-date knowledge, while long-term staff members refresh or deepen their knowledge. The knowledge acquired can contribute to better monitoring of the PTM.

Implementation

The content of the training should be relevant to practice, so internally relevant topics are collected before planning/initiating an offer. All skilled and non-skilled workers who come into contact with people with intellectual disabilities take part in the regular training courses. The contents can include: Biological basics (structure and functioning of the brain and neurotransmitters), mental illnesses and frequently used psychotropic drugs including their indication, effects and frequent side effects. The contents (e.g. disease, symptoms, side effects) can be explained specifically using practical examples. Training documents are subsequently made accessible to everyone and, for example, stored in the documentation. The training takes place regularly (e.g. 2-4 times a year), lasts one to two hours and is timed to match the duty rosters. If required, online participation can be made possible.

Responsibility

The team decides who will organise and plan the training (e.g. education officer, specialist service). Possible speakers can be: Pharmacist, person from the specialist clinic or the attending doctor.

Practical tips

Training at the introductory days
Integrate the training into the induction days for new staff members. The basics of psychotropic medication are already known at the start of work.

Training as an extension of pharmacy training
Expand the annual pharmacy training with PTM content.

W2

Regular training for staff members on the administration of pro re nata (PRN; 'as needed') medication

Meaning

Pro re nata (PRN; 'as needed') medication may only be administered on the basis of medical instructions. Interests and needs as well as subjective attitudes towards the PTM of staff members must not play a role in the administering. In addition, staff members should feel safe with the administering. The training provides staff members with a basic understanding of pro re nata (PRN; 'as needed') medication, which can reduce the above-mentioned uncertainties. Through the subsequent exchange, staff members can experience that they are not alone with their experiences and, if necessary, with their concerns and fears.

Implementation

Regular training (e.g. annually) provides content on the basics of pro re nata (PRN; 'as needed') medication. The content can be designed individually, e.g. "What does it mean when a person with intellectual disability receives pro re nata (PRN; 'as needed') medication?" or "Is PRN generally necessary?". The aim of the training is to convey that the pro re nata (PRN; 'as needed') medication is to be given according to the instructions and that the administration should be based on the needs of the person concerned. After the knowledge transfer, the participants can exchange their experiences on the requirement. The training should be attended by all staff members who are responsible for the administration of doses.

Responsibility

The training is led by the doctor. Planning and organisation is carried out by a manager from the residential accommodation.

Compilation of information sources on PTM

W3

Meaning

With the help of various sources of information on PTM, staff members can independently find out about the basics of PTM and relevant information for the course of treatment (e.g. side effects, laboratory parameters). This knowledge can support the staff members in accompanying the PTM in the interest of the person with intellectual disabilities.

Implementation

Sources with information on PTM are researched and made available to all staff members, see practical tips below.

Responsibility

see Practical tips

Practical tips

Overview with internet sources
Gather Internet sources for research on the PTM on a list accessible to all staff members. The overview is created together in the team; the content is checked regularly and updated if necessary.

Material from relevant courses
Make study material accessible to colleagues if staff members are also studying psychological/educational subjects (e.g. social work). Be sure to obtain permission from the author before distributing the material.

Relevant specialist literature
Use relevant specialist literature as a reference work and to read more detailed information about the topic. Specialist books can be ordered from the responsible authorities, for example.

Self-compiled reference work on psychotropic drugs

W4

Meaning

With the help of a reference work they have created themselves, staff members can independently obtain relevant information about a PTM (e.g. side effects, laboratory parameters). By concentrating on practice-relevant information, the staff members are supported in their everyday life and in accompanying the PTM.

Implementation

With the help of specialist literature and the support of medical specialists (e.g. pharmacists, doctors), staff members create an internal reference work on psychotropic drugs. There, the information relevant to the residential accommodation of common psychotropic drugs is listed (e.g. indication, effect, possible side effects, need for drug-specific laboratory parameters). Staff members can use it in their day-to-day work if anything is unclear or to deepen their knowledge. The reference work is accessible to all staff members, for example as a printed version in the office or as a digital version saved in the documentation. Once created, the reference work is regularly reviewed and updated if necessary.

Responsibility

The exact procedure and responsibilities are agreed within the team.

Overview with general information on side effects

W5

Meaning

As part of a PTM, side effects must be checked regularly. Staff members can support the doctor by focusing on the observation of possible side effects of medication during the everyday observation of people with intellectual disabilities. In order to put this into practice in the best possible way, staff members need to know about possible side effects. This can be obtained in different ways.
With the help of the different overviews of possible side effects of psychotropic drugs, staff members can independently inform themselves about everyday issues for the course of treatment and thus support people with intellectual disabilities in the PTM in the best possible way.

Implementation

Overviews of the side effects of PTM and how these can manifest themselves in everyday life (e.g. sleep patterns) are compiled independently by staff members in cooperation with a medical specialist. These overviews can be designed in different ways, see practical tips below. All the practical tips mentioned below are created once together in the team and reviewed and adapted at regular intervals.

Responsibility

It is decided in the team who will be responsible for preparing and producing the overviews.

Practical tips

Folder with package insert
Collect the package inserts of the prescribed psychotropic drugs in a folder. Alternatively, you can collect and save the package inserts digitally.

Colour coding of the intensity of the side effects using a traffic light
Use colours to indicate the intensity of side effects: e.g. green/no to mild side effects, yellow/moderate side effects, red/severe side effects. Coloured dots can be stuck on medicine boxes or used in the medicine overview. Specialist advice (e.g. from a pharmacist) should be sought when assessing side effects.

Poster with the most common psychotropic drugs and their side effects
Create a poster with the most commonly used psychotropic drugs in the facility and the possible side effects of each one. The colour assessment of the intensity of the side effect (see above) can also be used here. The poster is easily accessible for all staff, e.g. office. The content of the poster should be reviewed by a health professional (e.g. pharmacist).

W6

Short lectures on aspects of the PTM by staff members for colleagues

Meaning

Expertise on PTM for persons with intellectual disabilities supports staff in guiding the person through PTM, in recognising possible medication-related side effects and in understanding their own actions in the context of PTM. When staff members take over the lectures, this not only promotes the active acquisition of expertise, but also collegial exchange. Through the short lectures, practical and up-to-date knowledge about PTM is imparted to the staff members, which can be used in everyday life.

Implementation

In the team, specialist knowledge of PTM is presented in short presentations (5-10 minutes) by a resident specialist or, if applicable, a trainee. The content is practice-relevant and up-to-date (e.g. side effects of a certain psychotropic drug). The contents can be written down afterwards, including further information, and made available to all staff members (e.g. by email to all, stored in documentation).

Responsibility

The team decides who will coordinate appointments and content.

Practical tip

Integrate a short talk into the team meeting
Link the short presentations to an already existing team exchange (e.g. after the team meeting).

Chapter 7

Presentation of medical measures (A)

First visit without a prescription

A1

Meaning

The prescription of a psychotropic drug requires a detailed psychiatric diagnosis, the clarification of possible somatic diseases and a clear indication. A precise analysis of the conspicuous behaviour of a person with intellectual disabilities serves to ensure that psychotropic medication treatment is not started prematurely. Observation protocols made after the first specialist appointment with a clear definition of the observation goals can contribute to the understanding of the causes of the displayed conspicuous behaviour of the person with intellectual disability and be decisive for the indication.

The information on the patient's activities/daily structure can be helpful for therapy-relevant decisions, such as the selection of the individually appropriate psychotropic drug.

Implementation

The aim of the first visit is for the doctor to receive all the relevant information for a clear indication; the prescription of a psychotropic drug does not (yet) happen here. The doctor takes an anamnesis. In doing so, he or she also informs himself or herself about the resident's activities/day structure as well as about any non-drug measures that have been carried out so far (see practical tip for *Measure K10* "Overview of individual non-psychotropic medication coping strategies"). During this first appointment, the resident is given initial recommendations ("homework", e.g. increasing the daily fluid intake). The focal points of the observations are determined with the staff members in the residential accommodation. Staff members should pay special attention to these in their daily observation. These are recorded in an observation log until the next visit appointment and submitted to the doctor; if necessary, the observation log is sent to the doctor shortly before the second appointment.

Responsibility

The doctor is responsible for conducting the initial presentation and determining the focal points of observation.

Practical tip

Use of a checklist for non-drug measures

Make a list of various non-drug measures. Go through these with the residential accommodation staff to get an overview of which non-medicinal measures have already been tried in the residential accommodation or are currently being used. This approach reduces the likelihood of overlooking important non-drug measures that should be checked for their effect before starting psychotropic medication therapy. In addition, the overview serves to evaluate which measures could be used in parallel with psychotropic medication therapy.

A2

Request and evaluation of previous reports and diagnoses

Meaning

Consideration of previous indications and diagnoses as well as identified drug intolerances enables a comprehensive, interdisciplinary insight into the medical history of the patient and is decisive for the planning of the current PTM.

Implementation

As part of the initial consultation, the doctor will request information about the medical history of the person with intellectual disabilities. If the relevant documents (e.g. doctor's letters, expert reports, reports from hospital stays) are not stored in the residential accommodation, the legal guardian can be contacted. The requested reports and diagnoses are evaluated by the doctor for therapy planning.

Responsibility

The doctor is responsible for requesting previous reports and diagnoses.

A3

Clarification of possible organic causes for behavioural changes

Meaning

Changed or conspicuous behaviour of the person with intellectual disabilities can also be caused by physical illnesses or complaints. Therefore, in addition to psychiatric diagnostics, clarification of organic factors as a possible reason for the behaviour shown is required as part of the indication and in the course of treatment. Physical complaints and pain can sometimes not be clearly recognised and communicated by people with intellectual disabilities and are therefore often more difficult to identify as such for those around them. They therefore require particularly careful and targeted consideration.

Implementation

Before a psychotropic drug is prescribed for the first time, during the visit and in the event of sudden changes in the behaviour of the person with intellectual disability, possible organic causes are first clarified. The diagnosis of somatic causes that is deemed necessary is discussed by the responsible staff of the residential group in contact with the doctor. The examinations required for this are carried out by the doctor him/herself within the scope of the respective possibilities or a referral to other medical colleagues takes place. For the diagnostic process, the residential accommodation provides documents on the previous medical history (e.g. doctor's letters) and accompanies the resident to any further necessary doctor's appointments.

Responsibility

The staff members of the residential accommodation can address and therefore initiate the clarification of organic causes for the conspicuous behaviour of the person with intellectual disabilities towards the doctor - which they believe is necessary. The doctor is responsible for conducting and planning the relevant examinations. The staff members of the residential accommodation support this process by communicating their observations in the living environment, providing the necessary documents (e.g. doctor's letters, observation logs) and accompanying them to other necessary doctor's appointments.

A4

Detailed initial introduction with a focus on getting to know the person with an intellectual disability

Meaning

In the PTM of persons with intellectual disabilities, the establishment of a trusting doctor-patient relationship is of great importance. It is not uncommon for this group of patients to have negative previous experiences with doctors, so that a visit to the doctor can be accompanied by anxiety. Allowing more time, especially at the first appointment, gives the doctor the opportunity to approach the patient gently, to adjust to the person and to get to know them personally. In this way, trust can be gained and fears can be reduced so that a good basis is created for the entire further course of treatment. On this basis, persons with intellectual disabilities find it easier to communicate their interests and needs as well as their mental state and physical discomfort during PTM. This information can inform both diagnostics and decisions throughout PTM (e.g. selection/adjustment of the medication). By means of the participation of the residential accommodation staff and relatives, they are included in the PTM and can support the person with intellectual disability in the treatment process in the best possible way.

Implementation

For the first presentation of a patient with an intellectual disability at the visit, the doctor reserves sufficient time (about one hour) if possible. In addition to the person with intellectual disabilities, staff members, relatives and, if applicable, the legal guardian or the guardian's representative take part in the interview, if possible and according to the wishes of the person. The focus of the conversation is on getting to know each other and building a trusting doctor-patient relationship. It is a good idea to start the conversation in a relaxed way without medical questions (e.g. ask about hobbies). The doctor addresses the questions directly to the person with intellectual disability. If the accompanying person signals that he/she needs his/her help to answer the question, this person tries to support the patient.

Responsibility

The doctor is responsible for conducting the initial presentation.

A5

Medical formulation and documentation of target agreements

Meaning

The effectiveness of a PTM should be verifiable using criteria that are as objective and standardised as possible. Clearly defined target agreements can contribute to a targeted review of the effect as well as provide important information for a possible dose adjustment. This has a positive influence on the continuity and quality of psychotropic medication treatment.

Implementation

Both during the initial prescription and in the course of treatment, the doctor formulates target agreements for the next visit in consultation with the person with intellectual disabilities and the staff. The goals are adapted to the individual therapy of the person with intellectual disabilities and may include targeted observations, behavioural changes or low-threshold therapeutic measures. The interests and needs of the resident are at the centre of the formulated treatment goals.

The patient is given specific "homework" to achieve the goals. The doctor explains these (taking into account the communicative possibilities of the person with intellectual disabilities) and writes down specific questions about the "homework" for the next visit. The noted questions are asked to the person with intellectual disability at the beginning of the next visit.

If necessary, specific tasks for the period of time until the next visit are also assigned to the staff of the residential accommodation (e.g. targeted observation of sleeping behaviour after a low-threshold therapeutic measure).

The target agreements are recorded in writing (e.g. in the medication plan). At each subsequent visit, the medication is reviewed in relation to the target agreements and adjusted if necessary.

Responsibility

The doctor is responsible for reviewing the target agreements in the course of treatment. Residential accommodation staff can remind of the check if necessary.

Practical tip

Formulate questions for the next visit

During the visit, make a note of questions that you would like to discuss during the next visit. These can relate, for example, to the target agreements set and the implementation of the "homework". The questions are addressed to the patient and, if necessary, to the staff member.

Standardised Federal medication plan

A6

Meaning

Through the Standardised Federal Medication Plan (BMP), all doctors can retrieve information on the current medication of a person with intellectual disabilities and note newly prescribed and adjusted medications on it. In the context of new prescriptions and dose adjustments, possible interactions and contraindications must be considered. This can be ensured by using the Standardised Federal Medication Plan (BMP).

Implementation

The Standardised Federal Medication Plan (BMP) contains information on a patient's current medication (trade name, active substance, dosage, pharmaceutical form and the dose regimen). Doctors can create this medication plan and/or use the 2D barcode to call up the current medication plan, save it, add new medication digitally if necessary and then print out the plan for the residential accommodation. To create, update and save, the technical conditions in the doctor's prescription systems must be checked in advance. A hand-held scanner can facilitate the reading of the 2D barcode. Treated persons are entitled to this Standardised Federal Medication Plan (BMP) if they take at least three medicinal products prescribed at the expense of the statutory health insurance funds at the same time for at least 28 days. The persons treating the patient can view the contents of the medication plan with the help of suitable software (e.g. app). Through the use of this system, the residential accommodation always has the current medication plan available and can take it with them on visits.

Responsibility

The doctor issues the medication plan for the residential accommodation once and updates it at every visit (also possible by other doctors). Staff members can initiate the use.

Practical tip

Further information regarding the Standardised Federal Medication Plan (BMP)
You can find more information on the Standardised Federal Medication Plan here:
https://www.bundesaerztekammer.de/themen/aerzte/digitalisierung/digitale-anwendungen/telematikinfrastruktur/medikationsplan
https://www.kbv.de/html/24910.php

A7

Personal overview of the effects and side effects of individual psychotropic drugs

Meaning

The knowledge of frequent or important side effects of the administered drugs helps to observe them specifically during the course of treatment. The possible side effects of the currently administered psychotropic drugs are compiled in an accessible and clear manner for all staff members. In this way, any side effects that occur can be recognised in good time and communicated to the doctor. Based on these observations, the therapy can be adjusted.

Implementation

For all persons with intellectual disabilities for whom a psychotropic drug is prescribed, the doctor prepares an overview with the desired (or expected) effects and possible side effects of the respective psychotropic drugs. All relevant side effects are described, if necessary with an example ("The possible side effect ... often manifests itself in practice as follows...") as well as estimates of their intensity. The information should be understandable. The overviews are created, stored in the internal documentation and reviewed and, if necessary, adjusted at regular intervals and in the context of new regulations.

Responsibility

The doctor is responsible for the creation. Staff members can initiate the creation.

Practical tip

Recording of side effects in the medication plan
Drug-specific side effects are recorded directly in the medication plan. For example, in the Standardised Federal Medication Plan in the column "Notes".

Joint psychiatric and general medical visit

A8

Meaning

Within the framework of a joint visit with a doctor responsible for general medical treatment, the therapy-relevant information/parameters can be passed on and discussed directly and quickly. Possible interactions between a psychotropic drug and other drugs are controlled. The general medical as well as the psychiatric view, experiences and concerns about effects and side effects of the respective medication can be exchanged and necessary medication adjustments can be discussed together. The avoidance of polypharmacy remains better in focus through direct cooperation.

Implementation

At specified intervals (min. 1 x per year) residential accommodation visits are carried out with the participation of psychiatrists and general practitioners. Here, medical perspectives on effects and side effects can be exchanged and possible interactions and polypharmacy can be discussed.

Responsibility

The psychiatrist and the general practitioner are responsible for conducting the joint visit. Staff members of the residential accommodation can encourage joint visits and, if desired, take over their planning and organisation.

A9

Psychiatric and general medical survey of drug-specific laboratory parameters and ECG

Meaning

Regular monitoring of drug-specific laboratory parameters and the ECG enable early detection of deviating normal values and therefore reduce the risk of these not being detected and subsequent organ damage. A change or adaptation of the PTM can be made if necessary.

Implementation

The psychiatrist coordinates regularly (at least annually) with the general practitioner regarding the collection of drug-specific laboratory parameters in the course of treatment. It can be clarified who is responsible for the review, the frequency of the review and the way in which the results are communicated to the other person.

Responsibility

The participants agree on the type and regularity of the exchange among themselves. Staff members of the residential accommodation can issue reminders about the possibility of coordination, if necessary.

A10

Medical information for the residential accommodation staff members

Meaning

The medical education of the residential accommodation staff on the contents of the psychotropic medication treatment supports them in accompanying the person with intellectual disabilities in the therapy, in recognising possible medication-related side effects and in understanding their own actions within the framework of the treatment. In addition, this gives them the opportunity to explain the medical therapy explanation to colleagues who are not present and, if necessary, to repeat it several times for persons with intellectual disabilities.

Implementation

During the visits, the doctor informs the staff about the rationale of the therapy as well as the expected effects and possible side effects of the medication. Staff members have the opportunity to ask questions. A comprehensive explanation takes place at the first presentation and every change of the PTM. Questions and uncertainties can be clarified at any time during the course of treatment (see Measure M1 "Implementation of a low-threshold contact to the doctor"). Informed staff members in turn pass on the information to other staff members and can help with questions from the residents.

Responsibility

The doctor is responsible for carrying out the explanation. Staff members of the residential accommodation can actively request clarification if necessary.

Medical discussions with relatives

A11

Meaning

Within the framework of medical discussions, an opportunity for exchange is created between the relatives and the doctor responsible for the PTM. Relatives can clarify questions and ambiguities regarding the PTM, which can contribute to a better understanding of the therapy rationale. Since relatives often have close contact with the person with intellectual disabilities and therefore specific knowledge about their interests and needs, the perspective of the relatives gives the doctor the opportunity to obtain a comprehensive, interdisciplinary picture in addition to his or her own diagnosis and to integrate it into the design of the therapy.

Implementation

The doctor offers the relatives regular discussions or discussions on demand if necessary. In the conversation, he or she provides information about the PTM, and questions and ambiguities on the part of the relatives can also be clarified. If interested relatives do not legally represent the person with intellectual disability, the doctor must obtain the consent of the person with intellectual disability or their legal representative before the discussion.

Responsibility

The doctor informs the relatives at which fixed times they can contact him or her outside the visits.

Specialist exchange on PTM for people with intellectual disabilities

A12

Meaning

The use of psychotropic drugs in people with intellectual disabilities requires special knowledge because this group of people has a higher susceptibility to side effects and often an increased potential for complications (Seidel, 2011). A case-related exchange with specialist colleagues who treat persons with intellectual disabilities with psychotropic medication in other residential accommodation offers the opportunity to pass on one's own experiences, e.g. on the use of medication with this group of persons, to colleagues and to obtain the recommendations/experiences of colleagues in case of uncertainty.

Implementation

The doctor looks for opportunities to exchange information with other medical specialists. Case reviews that are regular (e.g. 3-4 times a year) digital, via video conference services with end-to-end encryption, are ideal for this. In the case reviews, experiences/recommendations regarding the selection, dosage, and combination of psychotropic drugs for people with intellectual disabilities are presented.

Responsibility

The exchange is initiated by a doctor. Further steps can then be discussed among the interested parties.

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Annex

Annex A: Overview of guideline-compliant psychotropic medication for people with intellectual disabilities [7,8]

Principle	Explanation
Patient-centred prescription and treatment	Patient-centred prescription and treatment occurs when the well-understood needs and interests of the person with reduced intelligence are fully met and, to the extent possible, they are able to make their own decisions about the recommended actions.
Involvement and support of relatives and environment	Relatives should be informed about the treatment with a psychotropic drug, for example about the expected effects and possible side effects, if the person with reduced intelligence or their legal representative agrees; they should understand the therapeutic rationale and be able to comprehend the therapeutic goal. The aim is, on the one hand, to support the relatives in their understanding as well as in their own actions and, on the other hand, to promote the quality and continuity of psychotropic medication treatment.
Prescription after comprehensive diagnosis and if there is a corresponding indication	A psychotropic drug should only be prescribed after a detailed psychiatric diagnosis and against the background of a clear indication.
Informed consent (patient/legal guardian/ caregivers)	The person with reduced intelligence, if capable of giving consent, must be fully informed about the therapeutic rationale as well as the possible undesirable side effects and alternative treatment options before starting treatment with psychotropic drugs. If the person with reduced intelligence is not capable of giving consent, he or she must still be fully informed in an appropriate form. Consent must be obtained through the legal representative.
Implementation of a "Start low, go slow" strategy	Treatment should be started with the lowest possible dosage and increases in dosage should be slow and with small increases in dose.
Ensuring compliance with the intake regulations	In the psychotropic medication treatment of people with intellectual disabilities, it is particularly important to ensure that the psychotropic drug is taken according to the doctor's prescription.

Consideration of non-psychotropic medication treatment options	Before starting and in the course of psychotropic medication treatment, it should be checked at regular intervals to what extent the prescription and implementation of non-psychotropic medication treatment options appears to be useful as a supplement or alternative to psychotropic medication treatment.
Avoidance of polypharmacy; Consideration of possible drug interactions	Polypharmacy should also be avoided as much as possible in the treatment of people with intellectual disabilities. The possible interactions between a psychotropic drug and other medications must be taken into account in the context of each prescription.
Monitoring of drug-specific laboratory parameters, ECG	Treatment with a psychotropic drug usually involves a certain risk potential that has either already been clinically identified or is probable on the basis of certain biopharmaceutical or preclinical experience, so that monitoring for organ damage is necessary.
Testing of effects and undesirable side effects	The effects and side effects of psychotropic medication treatment must be checked and documented regularly and, if possible, on the basis of objective criteria, for example using suitable standardised survey methods or previously defined target behaviour. The time interval is determined e.g. according to the previous duration of the medication. In the context of long-term medication, an interval of 3 to 6 months should not be exceeded.
Monitoring of environmental factors	Environmental factors can have an influence on the maintenance of psychopathological symptoms or behavioural disorders. Changes in relevant environmental conditions must therefore be regularly checked and documented.
Review of the indication in the course of treatment	The necessity of further treatment with a psychotropic drug must be checked regularly, at the latest within the framework of each continuation prescription.
Observance of the strict requirements for an "off-label" use of psychotropic drugs	"Off-label" use of psychotropic drugs is not negative per se; on the contrary, it can be an indication that the treatment is of particularly high quality. "Off-label" use, however, requires the existence of well-founded empirical evidence and special education of the persons involved and documentation of the "off-label" use.

Definition of intake conditions for pro re nata (PRN; 'as needed') medication	Treatment with a psychotropic drug as a pro re nata (PRN; 'as needed') medication should be avoided if possible. However, if a psychotropic drug is used as a pro re nata (PRN; 'as needed') medication, instructions for action must be available in written form that specify very precisely under what conditions, in what dose and at what frequency the drug is to be administered. The documentation of the frequency of such medication intake must be ordered by the attending physician.

Annex B: Recommendations for improving the support of psychotropic medication [9]

	Tasks of the doctors	Tasks of the staff members
Doctor contacts	The doctor comes to the residential accommodation for regular (e.g. once a quarter) medical visits.	Every resident is presented to the doctor, regardless of whether the person has shown any abnormalities recently or not. The staff members document the doctor's visit.
Diagnosis	The doctor bases him/herself on multiple sources of information to assess bio-psycho-social as well as environmental variables, performs physical examinations (including laboratory parameters) and anamnestic surveys.	The staff members support the doctor in the diagnosis by explaining the underlying problem in detail. The basis for this is a behaviour documentation, prepared by the entire staff team. Staff members allow the doctor access to further information (e.g. the resident's biography or files on previous treatments).
Information and consent of the resident	The doctor explains the resident according to the level of understanding and in plain language. The consent is documented in writing.	Staff members will repeat the doctor's explanation if necessary and support the resident to understand the treatment as best they can.
Explaining to staff in the residential environment	If legally authorised to do so, the doctor informs the staff member in the residential accommodation about the prescription as well as the effects and side effects of the psychotropic drugs, possibly also within the framework of further training.	Staff members have a basic knowledge of psychotropic drugs. They transparently communicate all relevant information and, if necessary, request medical clarification. If you are unsure or in doubt, consult the doctor.
Intake instructions	The doctor puts the intake instructions in writing, ensures that those responsible receive them and enquires about implementation.	The staff members will dispense the medication according to the doctor's instructions. The administering is documented. In case of confusion, acute side effects or refusal to take the medicine, the doctor will be informed.
Drug interactions	The doctor will keep him/herself informed about the entire medication and regularly check possible interactions between the prescribed drugs.	The staff members inform the doctor about the current medication from other medical specialists.

Non-drug treatment options	The doctor regularly considers, especially at the beginning, whether non-drug therapies could usefully complement the psychotropic medication treatment.	The staff members provide guidance if they think non-drug therapies would be helpful. Together with the doctor, they discuss the benefits, offer and implementation.
Effects and side effects	The doctor establishes target behaviour at the beginning of the treatment. He/she checks effects and side effects on the basis of the clinical impression, the resident's feedback and the information from the staff members.	The staff members observe the resident according to certain pre-determined target behaviour, documents these observations in a documentation sheet and discusses them with the doctor. **No independent dose changes!**
Environmental factors of the resident	The doctor obtains information about changes as well as physical aspects from the resident and the staff members at each visit.	Staff members provide information on environmental changes, physical illnesses and what has been on the resident's mind recently.
Review of the indication	The doctor regularly reviews the need for further treatment also based on feedback from the resident and staff member. If the indication is no longer given, attempts to stop taking the drug are considered together, for example in the context of case conferences.	The staff members document the resident's behaviour and pass this information on to the doctor. The further procedure is discussed together, for example in case discussions. **No independent weaning attempts!**
Pro re nata (PRN; 'as needed') medication	The doctor defines a clear case of need and puts it in writing. He/she obtains information from the staff about the reason and frequency of the administering at each contact with the doctor.	The staff only give the psychotropic drugs when necessary. There is a responsible person who decides on this. The situation and the administering are documented and discussed with the doctor at the next doctor's visit.

Annex C: Characteristics of the residential accommodations involved in the development of the measures

	N	%
Target groups of the residential accommodation *(multiple answers possible)*		
People with severe and most severe intellectual disabilities/ multiple disabilities	16	73
People with mild and moderate intellectual disabilities	13	59
People with intellectual disabilities and additional challenging behaviour or chronic mental illness	13	59
Total capacity of the residential accommodation		
24-32 residents	6	29
33-48 residents	9	42
49-120 residents	6	29
Medical care model		
Outreach (i.e. the doctor contact takes place in the residential accommodation)	8	36
Visits in the doctor's office (i.e. the doctor contact takes place in the practice or clinic rooms)	4	18
mixed, i.e. outreach and visits in the doctor's office	10	45
Frequency of contacts with doctors who are responsible for the PTM		
Several times a quarter	6	27
Once a quarter	11	50
once every half year	3	14
as required	2	9
Location of the residential accommodation		
urban	13	59
rural	9	41