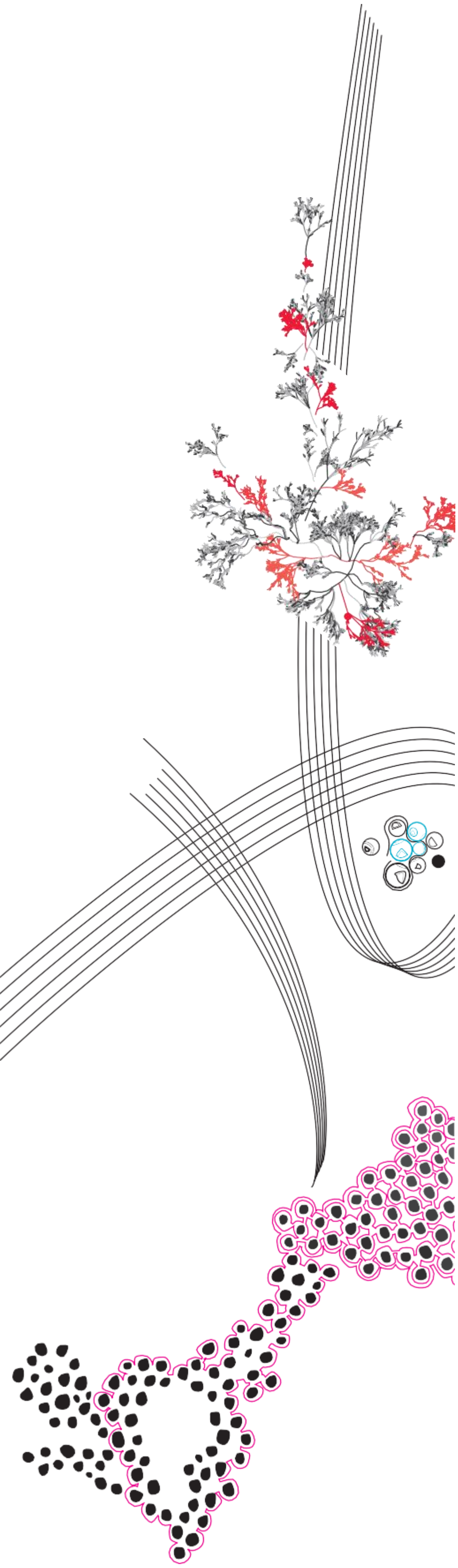

MSc Thesis

Health Psychology &
Technology (25 EC)

German Adaptation of the Psychological Well-Being Scale for Adults with Intellectual and Developmental Disabilities

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Abstract

Although individuals affected by an intellectual and developmental disability (IDD) are more likely to suffer from mental health problems such as depression and anxiety, they face limited access to appropriate health care and trained medical professionals. This gets aggravated by the fact that they have fewer resources to counteract this vulnerability or the linguistic skills to even communicate their mental problems. To support them, such conditions need to be recognised early and treated as such. Unfortunately, several studies concerning the mental health of people with IDD identified a clear lack of standardized assessment tools. Especially psychological well-being seems to be highly disregarded, even if proven necessary and helpful for people with IDD. Therefore, this study aims at building an adapted instrument for assessing the psychological well-being of people with IDD.

The new instrument was adapted from an original scale for psychological well-being (SPWB), including six different dimensions: Positive Relations with Others, Environmental Mastery, Personal Growth, Self-Acceptance, Autonomy, and Purpose in Life. Adaptations were carried out with the help of a focus group with disability carers and semi-structured interviews conducted with an expert for easy language and a psychologist. To consider the special characteristics of people with IDD living within an institution, the assessment criteria of all dimensions and their respective items contained relevance, applicability to everyday life, and comprehensiveness. After a draft version of the instrument was created, two individuals affected by IDD performed a user test to further check on these criteria and provide recommendations. The transcripts of all sessions (interviews, focus group, user test) were analysed utilizing conventional content analysis. By using an inductive coding approach, commonality-based codes were developed to justify the adaptation process and deliver insights into PWB and people with IDD.

The analysis revealed that Environmental Mastery and Positive Relations with Others are the most important dimensions contributing to the PWB of the IDD population. Autonomy and Purpose in Life seem less relevant, according to the experts. Items that were considered relevant represent the need for a social support system, the importance of self-efficacy, and positive reinforcement. Codes that indicated reasons to cut items include a lack of reflection abilities and the institutional structure. Based on the data, the researcher also developed new codes. These cover different aspects of being disabled such as accepting disability as part of the identity, expressing needs instead of opinions, and finding purpose in life within work. Users with IDD found the draft version of the SPWB-IDD relevant, applicable, and generally understandable with the proper support. They delivered useful recommendations such as a colourful response format and orientation points for re-formulating problematic items.

Overall, the adaptation of a SPWB provided a new PWB instrument tailored to the needs of people with IDD, as well as useful insights to expand the knowledge roundabout psychological well-being and intellectual and developmental disabilities. The next step is to validate the new SPWB-IDD.

Content

1.0 Introduction

Evidence is emerging that individuals with intellectual and developmental disabilities (IDD) experience mental health inequalities associated with complex needs and obstacles (Cooper et al., 2015; Trollor, 2014). While facing an increased risk for co-occurring conditions such as depression and anxiety (Hsieh et al., 2020), they also have limited access to appropriate health care and trained medical professionals (Ervin et al., 2014; Pinals et al., 2022b). It seems, that at the same time, people with IDD are more vulnerable to mental health conditions but experience less support. According to Pinal and colleagues (2022a), the key to improving disability care and assisting those affected is the early recognition of such conditions. Unfortunately, several studies, including a systematic review of measurement tools for mental health problems in the IDD population, identified a clear lack of instruments and standardized assessment tools (Flynn et al., 2017; Heras et al., 2021; Kendall & Owen, 2015). Especially measuring the well-being of individuals with IDD appeared to be disregarded even if considered necessary (Cooper et al., 2015; Flynn et al., 2017). In fact, psychological well-being has been found an important contributor to overall health but has not been implemented in disability care yet (Coiffait & Leedham, 2016; Emerson & Hatton, 2008). Therefore, this study intends to build a new instrument covering the well-being of people with IDD.

But before the concept of well-being is elaborated, it might be useful to understand the special characteristics of the target population. Due to cognitive impairment and limited communication, people with IDD have problems in expressing abstract concepts, such as a depressed mood or their emotional state (Hinton, n.d.; Kendall & Owen, 2015). This gets aggravated by the fact that they are less likely to establish active coping skills and have fewer resources to counteract their problems and protect their mental health (Hinton, n.d.). Furthermore, they show highly individual behaviour, that is difficult to categorise or interpret for professionals (Cooper et al., 2015). That might result in the tendency of medical professionals to attribute behavioural and psychological problems to one´s IDD, called diagnostic overshadowing (Reiss et al., 1982). According to an inclusion report of the European Union (EU), persons with intellectual disabilities and complex support needs are most likely to live in institutions, which means they do not share the same living context as the general population (Šiška & Beadle-Brown, 2020). Given these special characteristics of the target population, assessment tools for well-being must be designed to be easy to use, comprehensible, and reflect the institutional environment of individuals with IDD.

Theoretical Framework of Psychological Well-Being

The two-continuum model of mental health states, that mental illness and health are related, but also two distinct dimensions (Westerhof & Keyes, 2010). In the last decades, an impressive number of instruments emerged measuring the psychopathology of people with IDD, thus their mental illness (Matson et al., 2012). More recent studies concentrated rather on the presence of well-being (Fava, 2012). To continue this development, this study applies the concept of **psychological well-being (PWB)**. Established by Professor Ryff, PWB is its own separate construct defined by six core dimensions: Positive Relations with Others, Environmental Mastery, Personal Growth, Self-Acceptance, Autonomy, and Purpose in Life (Ryff, 1995). The 6-factor model focuses on eudaimonic features such as personal fulfillment, meaningful relationships, and direction (Delle Fave et al., 2011). Several studies confirmed the conceptual model of PWB and its positive impact on mental health (Fava, 2012; Wood & Joseph, 2010). A high PWB, for instance, has been associated with a variety of health advantages, such as a lower probability to suffer from major depression and anxiety (Wood & Joseph, 2010). Moreover, a recent meta-analysis concluded that PWB can be enhanced by targeted intervention programs (van Dierendonck & Lam, n.d.). It means that assessing PWB could ultimately lead to concrete orientation points for improving well-being. Implementing PWB in disability care might help the IDD population to benefit from these advantages.

To further elaborate the framework of Psychological Well-Being, this study takes a small excurse in highlighting the actual instrument. Nowadays, Ryff´s scale for psychological well-being (SPWB) is available in several different versions, varying in the number of items. The most common SPWB comprises 42 positively and negatively worded items (Morozink et al., 2010). To ensure the highest possible internal consistency, a 54-item version or even an 84-item version are available, but also an abbreviated version with 18 items (Schmutte & Ryff, 1997). All items are measured on a six-point Likert scale ranging from “Strongly disagree” (1) to “Strongly agree” (6). Examples of items are “*The demands of everyday life often get me down*” (Environmental Mastery), “*I like most aspects of my personality*” (Self-Acceptance), and “*I have a sense of direction and purpose in life*” (Purpose in Life). Results can be interpreted by summing up the total of each scale and comparing it to the possible total of each subscale. Assuming a normal distribution, Ryff and colleagues suggest classifying the lower and upper quartiles (25%) of responses as high and low functioning. Most studies confirm an acceptable internal consistency, high test-retest reliability, and high construct validity (Bayani et al., 2008; Ryff, 1989). Knowing the scientific value and health advantages of psychological well-being, it seems promising to adapt this concept to people with IDD and finally support their mental health.

Adaptation of Psychological Well-Being Scale (SPWB)

Despite being scientifically recognized, Ryff´s PWB scale (SPWB) is not implemented in disability care, yet. The special characteristics discussed earlier impose a great challenge for suitable assessment tools to help the IDD population (Costello & Bouras, 2006; Kendall & Owen, 2015). To overcome this, the literature suggests that special needs could be covered by adapting SPWBs. Several studies investigated the psychometric properties of SPWB tailored to children, adolescents, and the elderly (Gao & McLellan, 2018; Opree et al., 2018; Villar et al., 2010). An original abbreviated version, used for the elderly, has led to inconsistent results. As one study found high internal consistency and no support for a factorial model (Villar et al., 2010), other studies confirmed either a 4- or 6-factor model but no sufficient internal consistency (Clarke et al., 2001; Guindon et al., 2005). On the other hand, adapting or simplifying items to make them suitable for 8–12-year-olds resulted in high reliability and validity (Opree et al., 2018). In fact, one study has been found that pilot-tested an adapted version of the Ryff scale detecting PWB in a population characterized by mild intellectual disability and borderline disorder (van Herwaarden et al., 2022a). Results also have shown high internal consistency, high test-retest reliability, and sufficient construct validity (van Herwaarden et al., 2022a). Overall, the literature supports the idea of adapting Ryff´s scale to assess the psychological well-being of people with IDD.

To substantiate the adaptation process, the researcher got in contact with Herwaarden et al. (2022a), who successfully adapted Ryff´s SPWB to suit the needs of people with mild intellectual disabilities. Based on a German Version of the SPWB (Bartkowiak, 2008; Risch, 2008) the recommended design intended to adapt and cut the original scale with the help of different IDD experts and individuals affected. Given the limited concentration abilities of the target population, an upper limit of 30 items was recommended (van Herwaarden et al., 2022a). Following the guidelines of Finlay and Lyons (2001), measurement instruments for people with IDD must be adapted in terms of language, content, and response options. To avoid difficult wording, metaphors, and negatively worded questions proved to ensure responsiveness among people with IDD (Stancliffe et al., 2014). Items must be relevant, applicable to their special life circumstances, and comprehensible. The targeted stakeholders include different carer(s), psychologist(s) and specialists for easy language, as well as people with IDD[1]. Previous studies confirm that they can give reliable answers to self-reported instruments and that they consider Eudaimonic indicators as important for their well-being (Beernink & Westerhof, 2020; van Herwaarden et al., 2022b). It is intended to let them conduct User-Tests and gain firsthand feedback and considerations to add another adaptation phase. Generally, stakeholder involvement to adapt a SPWB to the IDD population has led to promising results (Opree et al., 2018; Simões & Santos, 2016). The clear need and usefulness for tools assessing psychological well-being in people with IDD lead to the following objective and research questions:

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[1] **Disclaimer**: While conducting this study, the researcher was working (part-time) as a carer for people with IDD at a Diaconal Foundation in Gronau, Germany. The research is not commissioned by the Diaconia. However, the researcher was granted access to the foundation's resources, staff, and clients.

Objective and Research Questions

The objective of this study is to build an adapted instrument for assessing the psychological well-being of people with IDD, tailored to their needs.

The following research questions are divided into two different stages, which will be highlighted in the method section in detail. Stage 1 refers to the development/building stage. Since cognitive impairment and limited communication skills seem to be the most significant factors impeding assessing mental health, a potential new PWB scale must focus on being easy to use and comprehensible by people affected with an IDD. On top of that, it needs to be relevant and applicable to the unique life circumstances of people with IDD living at home or in institutions. Based on these criteria, the intention is to decide on a maximum of 30 items by letting the stakeholders assess each item and identify reasons to either cut or keep them. As some studies did not support a 6-factorial model, the researcher is also interested in how stakeholders evaluate the six dimensions. The gained information could not only help to find the most suitable items for people with IDD but also deliver concrete aspects to improve the quality of mental health care.

The research questions regarding stage 2, the adaptation stage, refer to the User Tests and the gained feedback from people with IDD. Emphasis is laid on how useful and easy/difficult the new questionnaire is perceived. On top of that, people with IDD were also asked to assess all items and dimensions. The researcher intended to combine the feedback given by the experts with the opinion of those affected by IDD. The stage finished with a re-formulation process conducted by the researcher based on all the given suggestions.

Table 1
Research Questions

Research Question Stage 1: Development	Research Question Stage 2: User Test/Adaptation
RQ1: Which dimension(s) of PWB is the most/least important and why?	RQ4: Is the questionnaire relevant, applicable, and comprehensible for someone with an IDD?
RQ2: Which item(s) of each dimension were kept and why?	RQ5: What are recommendations for improving the questionnaire by individuals with IDD?
RQ3: Which item(s) of each dimension were cut and why?	RQ6: What are the new (adapted) items?

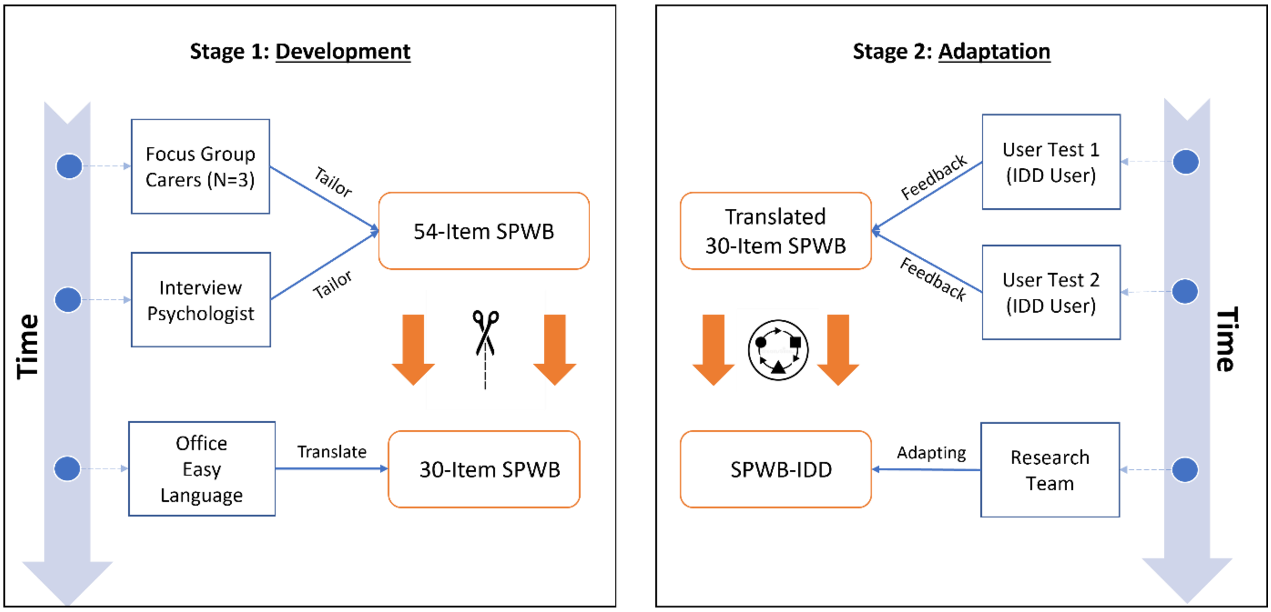
2.0 Methods

2.1 Design

This is a mixed methods study of scale development and qualitative content analysis. It was designed sequentially, by having two different stages. Stage 1, the **development** stage, referred to building a new Psychological Well-Being Scale (SPWB) based on a quantitative ranking system as well as qualitative findings. During semi-structured interviews and a focus group, different experts in the field of disability care were asked to tailor an original 54-Item SPWB by assessing and ranking each item and dimension. Previous studies confirm the combination of quantitative and qualitative data as a valid approach for developing scales (van Herwaarden et al., 2022a; Zhou, 2019). After this assessment, the tailored SPWB was translated into easy language, containing ca. 30 of the highest ranked, thus most relevant, and applicable items. Within the **adaptation** stage 2, participants with intellectual and developmental disabilities (IDD) conducted User Tests going through the tailored SPWB. By thinking out aloud, qualitative first-hand feedback was gathered and used to further adjust the scale. By the end of stage 2, the research team reformulated items and developed new ones with the help of all data and qualitative content analysis. An overview of the study design is given in Graph 1, below. This study finished with a new psychological well-being scale tailored to the needs of people with IDD (the **SPWB-IDD**).

Figure 1

Study Design: Building an adapted version of SPWB for people with IDD



2.2 Participants

Experts for IDD and people affected were identified and recruited in coordination with the diaconal foundation "Wittekindshof" located in Gronau, Germany[2]. As a part-time carer, the researcher contacted potential participants directly at the workplace or via mail and phone. The first stakeholder group approached were carers of a supervised living unit. For various perspectives, the researcher gathered carers with different occupational backgrounds. Three carers agreed on forming a focus group: A geriatric nurse (age 44), the deputy team leader (age 51), and a pedagogue curative teacher (age 49). Two of them identify as female and one as male and each of them has been working as a carer at the Wittekindshof for more than ten years. All work within one team and share the same responsibilities such as supporting apartment-related tasks, formulating SMART-Goals, medication, and facilitating the social and emotional needs of IDD clients. Nonetheless, they provide a unique perspective and their own set of priorities based on their education.

Next, a semi-structured interview was conducted with a psychologist (age 31). He has been working at the psychology department of the Wittekindshof for at least three years and majored in Clinal Health Psychology. His responsibilities include diagnostic, general consulting, advisory support for guardians, and training courses for carers. Being familiar with the respective clinical pictures of IDD clients and having an overview of their cognitive capacities ensures well-founded statements regarding the relevance and potential comprehension of a tailored PWB scale.

For the translation of the tailored SPWB, the researcher got in contact with a specialist from the office for easy language. The 43-year-old female apprenticed as an educator (pedagogue) and has been working as a deacon for the Wittekindshof for more than a decade. Through advanced vocational training, she gained competencies in easy language. "Easy" language could be best explained by a simplified version based on rules such as short sentences, one statement per sentence, and no subjunction. The expert supports the office in translating brochures, websites, and documents to guarantee comprehension and accessibility by IDD clients.

Potential participants for the user tests were recruited within the living unit, in which the researcher worked as a carer. To benefit from techniques such as thinking out aloud, inclusion criteria contained the ability to read, speak understandably and the caring degree. The Wittekindshof categorises its clients in four different "caring" degrees. Clients within degree one mean high independence and low need for care and clients within degree four mean vice versa. In the end, two clients that met the criteria agreed to participate. Both users were male, share a high level of communication, and have been living in the Wittekindshof for more than five years. The first IDD participant (age 21) is listed with a caring degree of one and the second has a caring degree of three (age 20). They were legally allowed to sign documents without the presence of their guardian.

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[2] The Wittekindshof includes different forms of (supervised) living units, a sheltered workshop/factory, schools, and different health services such as a psychology department. The researcher worked as a carer in a supervised living unit. Representatives of the Diaconia had been informed about potential participants.

Table 2
Demographics of Participants

Sample	***N***	***Age (median [interquartile range])***	***Gender (frequencies (%))***
IDD Experts	5	50.00 [47.00;50.50]	M: 2 (40%); F: 3 (60%)
IDD Users	2	20.50 [20.25;20.88]	M: 2 (100%); F: 0 (0%)

2.3 Procedure and Materials

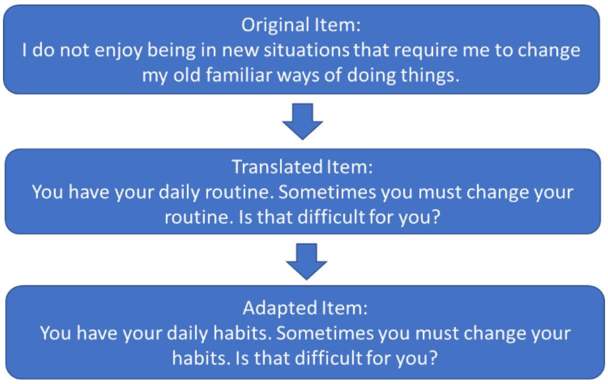
Development Stage: The research started by conducting the focus group and the interview with the psychologist. Both sessions followed the same procedure and were not meant to be in chronological order. After a brief introduction explaining psychological well-being, experts were given six handouts containing all items of the German 54-item version of the SPWB, categorised by its six dimensions. Starting with the first, positive relations with others, each item was discussed in terms of relevance, applicability to the everyday life of people with IDD, and comprehensiveness. Before heading to the next dimension, the experts were asked to rank the items from one to five, while one referring to the most important item. Items that should be cut were marked with an “X”. The ranking system will be explained in the section of Data Analysis in more detail. After the experts evaluated all items, they were induced to also assess the dimensions based on relevance and applicability. Qualitative questions included: *“Which dimension do you consider most relevant/applicable to IDD everyday life and why?”/ “Is this item relevant/applicable to IDD everyday life and why?”/ “Which item would you cut and why?”*. To support this discussion, the researcher prepared a PowerPoint presentation (PPP) explaining the concept of PWB as well as the definitions of its dimensions. Both sessions took approximately two hours. In the end, the researcher collected the handouts for analysing. All materials (informed consent + information sheet, example handout) are added as Appendix A and B.

Together with the specialist for easy language, the five highest-ranked items of each dimension (30 items in total) were translated while also discussing an appropriate response format. Additionally, the language expert assisted in preparing information sheets and informed consent to introduce the construct of PWB and its dimensions to the target group of people with. These documents are added as Appendix C. The development stage ended with a draft version of Ryff´s Psychological Well-Being Scale for people with IDD, the SPWB-IDD (Appendix D).

User Tests/Adaptation Stage: The second stage contained two Users Tests and a final reformulation phase. However, the procedure was like the sessions before. First, the information sheet and the informed consent were read out loud by the researcher and then together with the user. After the questions were cleared, it was pointed out, that the test can be stopped at any given time. Starting the user tests, both participants received the SPWB-IDD and were asked to read the items either themselves or together with the researcher. After each item was read, some time was given for first thoughts or potential questions. The researcher constantly motivated the participants to verbalize their thoughts or ask questions. Given their linguistic skills but also their cognitive limitation, this technique seemed to deliver the most useful data. Previous studies in the field support that choice (Gjertsen, 2019; Grünke et al., 2018). After the researcher felt sure the concept of the item is grasped (or not), the participants were asked to assess the respective item based on relevance and applicability to their life and the life of their housemates (fellow people with IDD). To sum up the user experience, the following questions were added: *“What do you know about PWB?”/ “What do think about this scale?”/” Is the questionnaire too long/short?”/* “What *do you think about the response format?”/” Do you have any suggestions?”* Both user tests took approximately 30 minutes.

During those user tests, all items that were difficult to comprehend or not considered applicable were noted for the upcoming reformulation phase. The procedure of reformulation/adaptation was based on Finlay and Lyons guidelines (2001) and general rules of thumb for easy language. These rules include *1. Short sentences containing one message/idea. 2. Short and easy words instead of technical terms and foreign words. 3. The same words for the same things. 4. Using active and positive words. 5. Using verbs. 6. Avoid abbreviations. 7. Avoid the genitive. 8. Avoid conjunctions. 9. Avoid figures of speech.* To further underpin the reformulation process, suggestions made by the IDD experts regarding wording and adaptation were considered as well. That also led to the development of completely new items, that covered important aspects of the psychological well-being of the target group. An example of how an item was adapted is presented as Figure 2 down below. The study finishes with a new version of Ryff´s SPWB, tailored to the needs of people with IDD.

Figure 2
Example of an Adapted Item



Original Item:
I do not enjoy being in new situations that require me to change my old familiar ways of doing things.

Translated Item:
You have your daily routine. Sometimes you must change your routine. Is that difficult for you?

Adapted Item:
You have your daily habits. Sometimes you must change your habits. Is that difficult for you?

2.4 Data Collection

All sessions (the focus group, the semi-structured interview, and two user tests) had been recorded with two smartphones (one served as a backup). All recordings were uploaded to Trint, an online transcription tool. Due to some discrepancies, the researcher re-listened to each audio file and corrected passages if necessary. Besides transcription, the platform Trint also allows to structure, relevant passages, and download the transcripts as a Word file. While highlighting, special attention was given to any suggestions regarding wording, relevance, and applicability. Item for item, all answers were collected and summarised as tables with the help of Microsoft Word. In total, there were four tables (one for each session), which serve as the significant datasets of this study (attached as Appendix E).

2.5 Data Analysis

Development Stage: The data analysis for the development of a new PWB scale was based on quantitative and qualitative data. The quantitative approach contained a simple ranking system set up by the researcher and the participants of the focus group. It was decided to rank the items from one to five. One refers to the most relevant and applicable item of the respective dimension and five to the least important. Items that should be cut were marked with an" X", counting for six. In the end, the points for each item were summed up and the five items per dimension with the lowest amount were kept within the scale. In that way, a maximum of 30 items were collected and not all items that were marked with an "X" ultimately got cut. If, for instance, three participants rank one item rather low (thus relevant) and one participant decided to cut it (with an X, counted for 6), the item could still find itself on the list. The same approach was used to rank each of the six dimensions. An illustration of that method can be found within the result sections 3.1 and 3.2 in the form of tables. Items coloured in red were cut from the PWB scale.

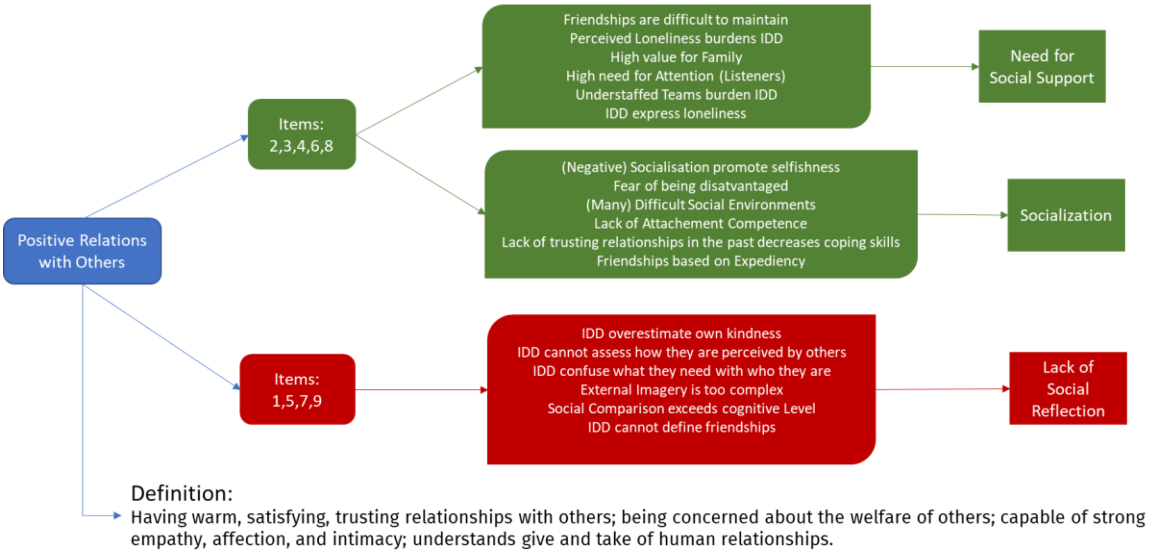
To answer the research questions, the datasets underwent conventional content analysis. This method intends to develop codes that are directly based on the text or data given. It is inductive and meant to create new codes and use them to derive to general conclusions (Hsieh & Shannon, 2005). To do so, each collected statement regarding an item or dimension was broken down to its very essence, or its meaningful unit. These units were analysed and summarised as codes based on commonality. In that sense, codes refer to labels that help to explain the commonality of several units. An example of how quotes turn into meaningful units is portrayed in Table 3. How those units derive to codes is presented in Figure 3 at the end of this section. This just serves as an example. The remaining coding trees are summarised in Appendix F. Speaking of PWB dimensions and their respective items, these codes represent reasons for either cutting or keeping items. In a broader sense, the developed codes also deliver statements describing the IDD population and what is relevant within disability care.

Table 3
Quotes on Items and how they lead to Meaningful Units and Codes

Items + German Translation	Quotes + German Translation	Meaningful Units	Codes
Item1_Pos_Relations *Most people see me as loving and affectionate.* Die meisten Menschen sehen in mir einen liebevollen und zärtlichen Menschen	„Many cannot evaluate themselves and assess how they are perceived by others. They reach their limits there. “CarerB *“Viele können sich ja nicht richtig einschätzen oder sehen sich ja selber nicht, wie sie eigentlich auf andere Menschen wirken. Da stoßen die auch ganz schnell an ihre Grenzen.” CarerB*	IDD cannot assess how they are perceived by others.	Lack of Social Reflection
Item46_Purpose_Life I live life one day at a time and don't really think about the future. Ich lebe von einem Tag in den nächsten und denke nicht wirklich über die Zukunft nach.	„The first I would definitely keep, because everyone does not think about the future, except for a few, but everyone lives one day at a time. “CarerC *„Also den ersten würde ich definitiv drin lassen, weil jeder denkt nicht über die Zukunft nach, außer vielleicht ein oder zwei, aber alle leben so in den Tag für sich hinein“ CarerC*	IDD clients don´t think about the future. IDD clients live for the moment.	Living in the Present

User Tests/Adaptation Stage: The transcripts of the user tests followed the same approach of conventional content analysis as conducted in the development stage. All answers to the user experience specific questions were transformed into meaningful units and summarised as codes. The derived codes represent the user experience in terms of comprehensibility, workload, and usability. Special attention was given to any suggestion for adapting or improving the SPWB-IDD. To have an orientation point for the adaptation process, users with IDD were asked to also assess all 30 items.

Figure 3
Coding Tree of Positive Relations with Others



Definition:
Having warm, satisfying, trusting relationships with others; being concerned about the welfare of others; capable of strong empathy, affection, and intimacy; understands give and take of human relationships.

3.0 Results

For clarification, the section of results is structured in accordance with the research questions. The first part highlights how experts for IDD evaluated the six different dimensions of psychological well-being. To quickly recall, dimensions (and items) were ranked from 1 to 6. A low score/value indicates relevance and applicability. As can be seen in Table 4 e.g., Environmental Mastery has the lowest total score, which means that IDD experts considered this dimension the most relevant for the psychological well-being of the target group. The same principle applies to Table 5 within section 3.2. It displays an overview of all items, their respective value, and if they were cut from the original SPWB or kept. The ranking system is followed by an extensive coding scheme that represents the reasoning for either cutting or keeping items. Since there are multiple codes for each dimension that cannot be generalised, the codes will be presented dimension for dimension. Starting with positive relations with others, the respective codes for keeping items are explained first, and then the codes for cutting items. To share the user experience with the new SPWB, another coding scheme is portrayed under 3.4 and explained in the following. It shows the user´s experience regarding usability and usefulness as well as suggestions for improving the questionnaire, answering research questions 4 and 5. After the user tests have been conducted, the adaptation stage finishes with a reformulation phase. Section 3.5 summarises all items that had been reformulated or newly developed. Based on the user's firsthand feedback, difficult items have been reformulated in accordance with the guidelines for easy language. The newly developed items are presented together with the codes they derived from. The results end by presenting the final SPWB-IDD as 3.6.

3.1 Ranking PWB Dimensions

Table 4
Dimensions of PWB ranked by IDD Experts

Dimension of PWB	Total Score
1. Environmental Mastery	4
2. Positive Relations with Others	6
3. Self-Acceptance	8
4. Personal Growth	13
5. Autonomy	14
6. Purpose of Life	18

Environmental Mastery / Positive Relations with Others / Self-Acceptance

According to the experts for IDD environmental mastery, positive relations with others and self-acceptance are the highest-ranked dimensions and are considered more relevant for disability care and the psychological well-being of their clients. Gaining the competence to manage your everyday life, environmental mastery, is one of the overall goals of disability care and the highest priorities for individuals affected by IDD. These competencies mean independence and a further step towards inclusion. Given the numerous negative experiences of being overburdened or reaching cognitive capacities, people with IDD need a feeling of control and experience self-efficacy. Compared to the general population, people with IDD also seek more intimacy and social support. Especially the absence of positive relations results in poor well-being. Unfortunately, while experiencing this clear necessity, people with IDD have fewer skills to maintain or facilitate social relationships. This dilemma attributes even more importance to the dimension of positive relations. Furthermore, it seems important to develop positive relations with yourself, by accepting your own strengths, weaknesses, and life overall. While people with IDD lack certain abilities in reflecting, the aspect of accepting themselves and especially their disability seems crucial. Experts indicate that there is an association between the number of crises (emotional outbursts) and the degree to which a client accepts his/her disability as part of their identity. Self-Acceptance has a significant impact on PWB and needs to be included.

Personal Growth / Autonomy / Purpose in Life

As can be seen in Table 3, personal growth, autonomy, and purpose in life have been rated less important by the participants. Even though personal growth is considered suitable, experts claim that it applies only to a limited number of clients with IDD. Acquiring new skills and reflecting your life to tap your own potential could exceed the cognitive capacity of most individuals affected. Personal growth needs to be concretised to simpler everyday tasks and combined with positive reinforcement, according to the experts. Autonomy, on the other hand, scores low due to definition discrepancies. According to Ryff, autonomy is defined as the ability to resist pressure and defend your opinion against opposition. In disability care, autonomy is understood as independence, more like environmental mastery. And even if understood as intended, IDD experts argue that clients rather benefit from being persuasive and that it is more important to express needs instead of opinions. Lastly, all experts agreed on assessing purpose in life the least important dimension. It requires potential users to apply abstract constructs such as meaning and direction to themselves and his/her future. Most people with IDD are not capable of such reflection. Even though goal setting is a relevant aspect of PWB, experts stated that most of their clients do not have an active role in planning or reaching these future-related goals. They live completely in the present. To still include this dimension, experts suggest turning abstract concepts into concrete activities that might give meaning, such as work for instance.

3.2 Ranking SPWB Items

Table 5

Ranking of SPWB Items

Items per Dimension	Total Score	Items per Dimension	Total Score	Items per Dimension	Total Score
Items_Pos_Relations		**Items_Self_Acceptance**		**Items_Pers_Growth**	
Item2	8	Item29	7	Item22	10
Item3	6	Item31	9	Item23	7
Item4	10	Item33	9	Item24	8
Item6	14	Item34	11	Item26	9
Item8	7	Item35	10	Item27	11
Cut					
Item1	18	Item28	18	Item19	18
Item5	18	Item30	18	Item20	18
Item7	18	Item32	18	Item21	18
Item9	15	Item36	18	Item25	18
		Item37	17		
Items_Environm_Mastery		**Items_Autonomy**		**Items_Purpose_Life**	
Item11	5	Item38	8	Item47	13
Item12	11	Item39	8	Item48	9
Item14	6	Item40	10	Item49	8
Item15	13	Item41	12	Item55	16
Item16	14	Item46	8		
Cut					
Item10	18	Item42	18	Item50	18
Item13	17	Item43	18	Item51	18
Item17	16	Item44	12	Item52	18
Item18	17	Item45	13	Item53	18
				Item54	17

Table 5 above shows every item of the 54[3]-item version of Ryff´s Psychological Well-Being Scale and their total scores assigned by the experts for IDD. Per each dimension, the five items with the lowest total score were collected and bundled as the first SPWB-IDD draft to translate with the office for easy language. However, there are some irregularities that need to be cleared. For instance, only four items from the dimension purpose of life were kept. That is due to Item 54 and Item 55 being similar. Both items measure the construct of being active in setting goals. The same phenomenon can be seen between Item 41 and 44 within autonomy. Even though they share the same score, Item 44 was cut because of measuring an aspect that has been covered by another (higher ranked) item. It shows that participants picked items not only based on relevance and applicability but also with the intention to include every facet of a dimension. Furthermore, it is striking that most items that were cut show the highest possible score. It means that the experts generally agreed on which items to cut from the scale. The exact reasons why items were cut or kept will be explained in the following section.

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[3] The Original SPWB did not contain 54 items but 55. The dimension of Self-Acceptance counted ten items. The researcher took all items into account.

3.3 Coding Scheme SPWB Items

Table 6

Coding Scheme SPWB Items

Dimension	Example of Items that were kept Items that were cut	Meaningful Units	Codes	Code Definition
Positive Relations With Others	Item3: Maintaining close relationships has been difficult and frustrating for me.	-Perceived loneliness burdens IDD affected -Friends as attachment figures	Need for Social Support	A social support system with deep relationships is crucial to the PWB off IDD. Even within institutions IDD express loneliness. Carers cannot replace friends.
	Item6: I have not experienced many warm and trusting relationships with others.	-Lack of trusting relationships in the past lead to selfishness	Socialization	Most IDD share a troubled (family) background. That negative socialisation causes social inadequacies like a lack of coping skills or attachment competences.
	Item5: People would describe me as a giving person, willing to share my time with others.	-Cannot assess own external image/effect perceived by others	Lack of Social Reflection	Assessing yourself and how you are perceived by others exceeds the cognitive skillset of most IDD.
Environmental Mastery	Item11: The demands of everyday life often get me down.	-Overload leads to Frustration -Frustration leads to resignation	Frustration Tolerance	The potential for frustration is immense and it is inevitable that IDD hit their limits. Facilitating skills to counteract frustration and resignation promises better PWB.
	Item14: I often feel overwhelmed by my responsibilities.	-Implementing Independency	Self-Efficacy	IDD need to recognise/experience a certain degree of power and efficacy within their environment. That usually comes with independence and through positive feedback.
	Item16: I have been able to build a home and a lifestyle for myself that is much to my liking.	- External Structure (institution) determines “Lifestyle” - Structural Compulsion	Institutional Structure	Most environmental decisions are taken over by the institution. IDD require external support to organise their life sufficiently.

Personal Growth	Item23: For me, life has been a continuous process of learning, changing, and growth.	- Recognising own success strengths well-being	Positive Reinforcement	One key component to facilitate personal growth is positive reinforcement. IDD need to be reminded of their development and recognise their own success.
	Item27: You can´t teach an old dog new tricks.	- Stagnation is very present - Age does not influence learning, attitude and personality does	Learning Attitude	Learning or developing is imbedded in the participation plans of IDD institutions. IDD need to constantly learn to avoid stagnation, regardless of age.
	Item21: When I think about it, I haven't really improved much as a person over the years.	-Questioning oneself and whole life exceeds IDD limits -Aspect of time (the past) should be neglected	Lack of Life Reflection	Reflecting personal development over the course of time might exceed the cognitive skills of people with IDD. Generally, reflecting time in a big scope (past, future) seems irrelevant.
Self-Acceptance	Item33: My attitude about myself is probably not as positive as most people feel about themselves.	-IDD care for other people’s opinion -IDD seek for positive feedback (carer)	Other Esteem	IDDs self-acceptance depends to a high degree on how they think they are perceived by others. It is more important to be accepted by others than to accept yourself.
	Item34: When I compare myself to friends and acquaintances, it makes me feel good about who I am.	- Not accepting IDD leads to more crisis - IDD point out other people’s deficits	Accepting Disability	New items need to be developed to measure if IDD accept disability as part of their persona. IDD affected that tend to not accept their disability suffer more crises.
	Item36: I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	- IDD do not regret past mistakes (no reflection)	No Regrets	Experts state that IDD do not regret past mistakes at all. With other words, past mistakes have no influence on the present situation.
	Item30: I feel like many of the people I know have gotten more out of life than I have.	- IDD do not compare themselves with others - No comparison between “me” and “earlier me”	No (Social) Comparison	IDD do not compare themselves with others or with themselves at an earlier stage of life.

Autonomy	Item46: I often change my mind about decisions if my friends or family disagree.	- Communicating needs means Self-Efficacy/Autonomy - IDD learn to first observe and then act	Expressing Needs	Autonomy for people with IDD means to share (communicate) their needs. Due to linguistic inadequacies IDD learn to express themselves non-verbally.
	Item45: I tend to worry about what other people think of me.	-IDD are surrendered to carer - High fear for consequences	Power Imbalance	For someone with IDD, living in an institution means many dependencies. The imbalance of power is always present. In the long-term IDD develop submissive tendencies.
	Item42: I have confidence in my opinions, even if they are contrary to the general consensus.	- Being easily persuaded is positive for IDD well-being	Flexibility is Key	Within disability care, psychological well-being is rather reached through flexibility than sticking by an opinion/conviction. Remaining persistent leads straight into crisis.
Purpose in Life	Item48: My daily activities often seem trivial and unimportant to me.	- This has never been asked - Work as an important anchor/structure	Purpose at work?	Purpose in life seems intertwined with work. It serves as the biggest contributor to structure and give direction to IDDs life. But if people with IDD consider their work meaningful needs further investigation.
	Item54: I used to set goals for myself, but that now seems a waste of time.	-Participation Plans (contain) require SMART Goals	External Goal setting	Most goals and objectives are imbedded in the participation plans of IDD. Experts (carers) and IDD affected set up these goals together but achieving these requires external support. IDD set unrealistic goals.
	Item53: I tend to focus on the present because the future always brings me problems.	- IDD people live in the present - Future thoughts are not prevalent	Living in the Present	Generally, people with IDD live in the present and don´t think about the future. Items were cut because the dimension of time should generally be neglected.

3.3.1 Positive Relations with Others

Need for Social Support

Generally, all experts emphasized the crucial **need for social support**. Although people with IDD usually live in supervised units (24/7), they often express the feeling of loneliness or the need for being heard. The psychologist states that (perceived) loneliness means a huge burden and having many people around does not always mean IDD clients share their worries („*some close friends might be enough to not feel lonely (…) But to have no one with whom you share your worries…Then you feel lonely. And that's something, that burdens many clients.* "). This, as well as high praise for family and friends, indicates that people with IDD seek deep(er) relationships and that items for positive relations need to cover either the availability or its absence.

Socialisation

Unfortunately, the target population seems unable to initiate or maintain the needed relationships. According to the experts, a lack of trusting relationships in the past is causing negative social behaviour and a shortage of social coping skills. Indeed, most IDD biographies are characterised by troubled life and family circumstances. As described in the following quote: **"***Many come from difficult life circumstances, where emotional needs were not covered sufficiently. But they do have it here and here they compete with each other".* This difficult background story resulting in an inadequate social skillset is so common that these meaningful units are summarised as (negative) **socialisation**. The imbalance between desiring positive relations and having insufficient abilities to facilitate such is a significant aspect worth investigating and measuring.

Lack of Social Reflection

Another important aspect of positive relations is to assess yourself and how you are perceived by others, such as friends and peers. Unfortunately, those who are affected with IDD seem not to have the cognitive capacities to do so. All experts described a **lack of social reflection.** External imagery of oneself requires complex thoughts and a high degree of social reflection that is simply not experienced within disability care: "*Many cannot assess themselves or they don´t see/understand how they are perceived by others. They reach their limits*". It doesn´t mean that people with IDD are not capable of reflecting on themselves, it rather means that they struggle to add another point of view. The same applies to the concept of social comparison. People with IDD do compare themselves with others, but they do not compare their social support systems with one another. For this reason, items focusing on social comparison and assessing other people´s opinions were neglected and cut.

3.3.2 Environmental Mastery

Frustration Tolerance

Items of environmental mastery refer to the competence of organising and controlling external activities. For individuals with IDD, these activities include financial affairs as well as simple house chores. According to the carers, any skill or competence in managing everyday life means success and a closer step towards independence. On the contrary, failing these daily tasks entails a considerable potential for frustration: *"We got to see that we support clients in making progress. But overload leads to frustration."* While overstraining situations sometimes result in resignation, more often it causes crises. A crisis in disability care describes any situation of uncontrolled emotional outbursts and/or (auto-)aggressive behaviour. In most cases, carers must react with de-escalating measures. They also state that these episodes have a significant negative impact on the well-being of their clients. To prevent crises, disability care does not only intend to support with daily tasks but also to build up coping skills to tolerate and overcome these moments of frustration. The concept of "**frustration tolerance**" is an important skill and should therefore be embedded in the IDD questionnaire.

Self-Efficacy

A promising way to tackle the frustration of people with IDD is by increasing their **self-efficacy.** The psychologist points out that self-efficacy happens subconsciously and especially for people with IDD it is highly important to experience a certain power and control in their life, considering the number of negative experiences: "*Self-Efficacy is difficult to grasp, because it runs subconsciously*. *They have many frustrating experiences that make them realise that they cannot or that set them back*)." As mentioned earlier, people affected by IDD are constantly confronted with their own inadequacies. That makes self-efficacy a highly relevant aspect of their psychological well-being.

Institutional Structure

Next to controlling and organising, environmental mastery is also applied in the sense of creating a context that suits the needs and values of a person. Unfortunately, living in an institution needs to be characterised as living under structural compulsion. In other words, the living context already has been created and people with IDD must fit their needs and values within these boundaries. The IDD experts put it this way: "*It's about IDD that live in institutions. I arranged my life in a way that it is satisfying for me. How could someone possibly answer that with yes if you live in an institution with that much structural compulsion?"*. On top of that, the **institutional structure** also means that many responsibilities need to be given away. Even on a daily basis, many clients rely on the support of their carers. Items considering the mastery of rather big environmental affairs have been cut since these were undertaken by either the carers or the institution itself.

3.3.3 Personal Growth

Positive Reinforcement

Within disability care, personal growth is strictly embedded in the participation plan of clients with IDD. It means that personal development and facilitating IDD independence are one of the core objectives of IDD institutions. In getting there, experts once again stressed the importance of **positive reinforcement**. The following quote emphasizes how development requires constant mirroring and positive evaluation: "*When it works, and it is recognised: I am developing. To reflect that is important. To mirror/reflect personal growth, because very often it is not recognised".* Recognising own success might be beneficial to anybody's psychological well-being and growth, but given the huge number of negative experiences, moments of success might mean more to people affected by IDD. Items that cover this positive aspect need to be kept within a potential SPWB-IDD.

Learning Attitude

Furthermore, experts underlined the basic concept of learning. The psychologist recommends that new things must be tried regularly, even though clients with IDD tend to avoid new challenges. Unknown situations could mean losing control and a sense of essential structure. But without learning people with IDD stagnate, which is considered worse. Interestingly, carers claimed that age does not influence the likelihood of learning new things, but personality and **attitude** do: "*Not because of the age, because he doesn´t want to (...) It has nothing to do with age."* It indicates that not learning itself but a positive attitude towards learning is an important aspect of IDDs PWB. Items focused on this attitude found their way into the first draft of the SPWB-IDD.

Lack of Life Reflection

Another component of this dimension is reflecting own personal growth over the course of time. Some items intend to measure to which degree potential users of this questionnaire have developed over time or compared to an earlier stage of life. Especially when an overview of the overall life is required, people with IDD might have difficulties in answering: "*No, they reach their limits/capacities. They do not question themselves the way it is intended here.*" This quote explains that questioning oneself and one´s life in terms of maturing exceeds the cognitive limits of people with IDD. Due to this **lack of life reflection**, IDD experts advise neglecting the dimension of time and every item that requires a review or assess own personal growth.

3.2.4 Self-Acceptance

Other Esteem

Discussing the dimension of self-acceptance revealed that people with IDD do not only rely on carers practically but also emotionally. In everyday life, clients tend to crave positive feedback in the sense of confirmation. Experts mentioned that people with IDD do not only want to be accepted by others, but it is also important to be popular and praised: "*I do think, that they want to be popular. I think it is important to them to be liked."* That does not only involve carers but also family, friends, and general contacts outside the institution. This form of **other esteem** is an important point of reference for PWB, and its items need to be included. As soon as detected, people affected by IDD and their carers can take actions to counteract and increase self-acceptance (self-esteem).

Accepting Disability

However, embracing the feeling of accepting yourself and your mistakes is generally difficult. But the aspect of intellectual and developmental disabilities composes an even greater challenge in that context. Many clients affected struggle to **accept** the **IDD** as part of their character or identity. Carer noticed that clients who do not accept their disability face more crises than those who do accept their condition: "*In my experiences, those clients I have supervised from who you know they do not accept their disability, they cause/have more crises*." In one way or another people with IDD are constantly confronted with their inadequacies. Investigating to which degree IDD affected accept this as a part of their persona benefits the overall psychological well-being. Since the original items only touch this matter in a broad sense, the experts advised developing new items accordingly.

No Regrets

According to Ryff´s definition, self-acceptance entails not only accepting oneself but especially one´s past mistakes. However, all experts expressed the concern that this is not applicable to life and work with IDD. Again, the dimension of time proves to be a problem since it requires IDD affected to reflect their past. But even if being confronted directly, people with IDD seem not to regret past mistakes nor to learn from them. One carer describes this as follows: "*I believe many do not think about mistakes that have been made in the past. For them it is just okay."*. In that sense, having **no regrets** can be something positive. It does not influence the present negatively and it is easier to move on. Nevertheless, items referring to the reflection of time and life have been cut.

No (Social) Comparison

Furthermore, some items of self-acceptance let people compare themselves with others and distinguish between their current version and an earlier one. Only a handful of people with IDD can make a distinction like that and evaluate themselves accordingly. Since IDD clients do not compare themselves with other people at all, this component should be excluded fully. Items need to rather ask for concrete and relatable situations, that do not include an overall life or person review.

3.3.5 Autonomy

Expressing Needs

Following the definition by Professor Ryff, autonomy entails the ability to resist social pressure and defend your opinion and values against opposition. However, due to linguistic limitations, most people with IDD cannot have elaborated conversations about opinions and values. It doesn´t mean that they lack those. It means that the focus of those items needs to shift from expressing opinions towards **expressing needs**: "*This item asks political, societal beliefs or superior categories. It is not about: In my opinion we should have spaghetti today…but that would rather be the extent/level our clients should prove their strength of opinion."* The experts describe most of their clients as silent observers. To be able to demand what you want/need also non-verbally can be a sign of psychological well-being. Items that cover that sort of initiative were kept for the new scale.

Flexibility is Key

According to the original questionnaire, sticking by your opinion even if challenged is considered positive and a sign of intact psychological well-being. However, both expert groups, carers, and psychologists, state the exact opposite when it comes to people with IDD. Being easily persuaded and changing mind is beneficial to the well-being of people with IDD: "*But within our job, the disability care, it is positive to influence clients, with for instance the strategy of distraction*. *"*As written before, opinions need to be considered as expressing needs or sometimes wishes. Especially in situations in which those demands cannot be granted, people with IDD who tend to stick by it fall into a crisis. That is why experts stress the importance of **flexibility**. Items measuring opinion strength and persistence are not applicable to people with IDD and were cut.

Power Imbalance

Moreover, carers argue that they must influence their client's opinions for the sake of protecting them. Presumably having the best interests in mind, the fact of being easily persuaded leads to another problem with the items of this dimension. Generally, living in an institution comes with many dependencies. Taking these into account, any form of autonomy seems unrealistic: "*The experience they have is being at somebody's mercy. If a carer is ill at ease, then the client is in a difficult position. The client is situated in many dependencies and is worrying of course."* There is a clear **power imbalance**, that indicates that the autonomy of people with IDD always depends on the institution and how it is either facilitated or limited. It doesn´t mean that (perceived) autonomy is impossible to reach for someone with IDD but it exemplifies that the original questions were not meant for someone with IDD.

3.3.6 Purpose in Life

Purpose at Work

While working through the dimension of purpose in life, it was striking that there are no work-related items. Yet, the discussion with the participants always circled back to the aspect of work. According to IDD experts, work serves as the biggest contributor structuring their client’s life. It gives direction and provides people with IDD the feeling of being needed somewhere. However, if work is perceived as meaningful or not could not be answered. The psychologist admitted that a question like this has never been asked before: “*If I ask: My daily activities often seem trivial to me, then I have asked my clients this question the very first time”*. Items investigating “**Purpose at work?”** might reveal how people with IDD think about their work and if there are eventually other things that are perceived as meaningful. The psychologist also pointed out that feeling needed doesn´t necessarily mean working. It could also entail the fact of going somewhere to have fun or to maintain positive relations with others. Items asking if daily activities are considered important (or meaningful) remained within the scale.

External Goal setting

According to Professor Ryff, one thing that gives life direction is the possession of aims, objectives, and concrete goals. Even though goal setting is embedded in the participation plans of people with IDD, experts cut most goal-related items. It simply requires too much external support. Many people affected by IDD set unrealistic goals like being a football referee at the highest professional level: *“Or another client wants to be a referee or the coach of the National Team.”* To have a realistic and feasible participation plan, carers work out SMART goals. Outsourcing goal setting does not always match the hopes and dreams of their clients. Generally, it is not considered bad that people with IDD dream big. But in the long-term, their well-being benefits from hitting reality and focusing on feasible objectives.

Live in the Present

Speaking of long-term, some items are dedicated to measuring the potential meaning of past and future life. Once again, the experts explained that the dimension of time should be excluded. People with IDD **live in the present** and thoughts about the future, even if connected with concrete goals are not prevalent. The following quote: *“Simply because, so many live in the present. And the aims appear out of nothing… But that there is someone thinking I can´t do this, I have no big visions, that applies to the least here”* states that people with IDD do not reflect their lives in the sense of visions for the future. It was commonly agreed on cutting these items.

3.4 User Experience

Table 7

Coding Scheme User Experience

Criteria for User Experience	User Test Questions	Meaningful Units	Codes
Relevance & Applicability	What do you think/know about PWB? What do you think about SPWB-IDD? Is it relevant? Is it applicable?	- There is a difference between being mentally ill and mentally healthy - (Auto-) aggressive behaviour means being mentally ill or having low psych - Institutions should know if people are mentally ill - Psychology is the cure to improve psych - IDD-SPWB is important to prevent individuals with IDD from hurting themselves or not getting any help at all - More needs to be done to increase the well-being of the soul, considering molested IDD from other places - Such questionnaires need to be done more often	PWB as the "Cure"
Comprehensiveness	Do you understand the items of SPWB-IDD? What is difficult to understand?	- Not all people with IDD need easy language - Original SPWB would be understood as well - External support in understanding is not necessary but preferred - Abstract termina, rather using everyday language	Support Comprehensiveness
Recommendations	What would you improve about this questionnaire? What do you think about the length of this questionnaire?	- IDD-SPWB needs to be filled in with a break in between - Length might overstrain the majority of IDD clients - Reducing items to 20	Managing Resources
	What do you think about the response format?	- Portraying answer options as traffic light system - Using pictograms as response format (pointing at answers)	Traffic Lights & Pictograms

3.4.1 Relevance & Applicability

Psychological Well-Being as the "Cure"

Before discussing the SPWB-IDD in terms of relevance and applicability, the researcher asked about the user´s understanding of the concept of psychological well-being. Interestingly, both users indicated a distinction between people that are mentally ill, and people that are mentally healthy, referring to some extent to the two-continuum model of mental health. Those who are ill show (auto-) aggressive behaviour and require a "**cure**" through psychology, according to the users. Even though not harming yourself is not a sign of mental well-being, the users show some understanding of the matter and its significance. The SPWB-IDD is considered highly important and necessary because it could be a way to find out if someone needs help: *„Of course. There are people hurting themselves or those who can´t get help…That's why it is important to be able to fill in a questionnaire. "*Especially in situations in which people with IDD seem to suffer, the users consider questionnaires like this applicable and wished for: *"When I look at other houses and how clients are treated there. Being yelled at, or molested/bullied etc. There you can do more to make the soul feel better… Yes, that's why these questionnaires need to be done more often. Much more often."* Obviously, a scale for PWB is not the cure for such problems, but these quotations signify the clear need and desire of people with IDD for more assessment tools.

3.4.2 Comprehensiveness

Support Comprehensiveness

Generally, the SPWB-IDD is considered understandable. Both users proved to comprehend the items and the overall goal of the SPWB. Nonetheless, there were major differences in the level of understanding between the two users. While the first user was able to read and understand each item instantly, the second user required support from the researcher. User1 even claimed that it wasn´t necessary to translate the questionnaire into easy language: "*For most people these questions are okay. But there are also people who understand the original questions. No easy language, but normal language. Me, for example.*" In the case of the second user, most of the items needed to be read together and explained in the following. As soon as the problematic items were discussed openly the IDD user could reach a sufficient understanding. Considering that people with IDD differ in their cognitive abilities and caring degrees, it is important to secure a basic level of comprehensiveness through external support and instructions.

Reflection Researcher

While conducting the user tests, the researcher took notes to identify problematic items and distinctive features. Special attention was given to the behavior and body language. The first user appeared to be confident and almost rushing through the questionnaire. As soon as an item was read, it was evaluated immediately. To be able to have a discussion, the researcher had to stop from time to time and circle back. User 2, on the other hand, had to be encouraged and motivated. Whenever an item was perceived as difficult, his body slumped down and he put the handout away. It was clear, that the procedure and especially the understanding was energy consuming.

3.4.3 Recommendations

Managing Resources

The reflection of the researcher indicates that it is necessary to give an eye on the client's **resources**. Reading and thinking about that many items takes great capacities of people with IDD. To prevent exhaustion or overload, users need to have the opportunity for a break to have a drink or a walk to reset their batteries. While discussing the workload of the questionnaire, user1 mentioned that it could also have been more items, whereas user2 found it too long. According to user1, an IDD-SPWB version with 20 items might not exceed the limits of his housemates with IDD: "*It could be 35 questions, but not more. But for others it would be too much. For 1/3 of the people here, 30 questions are fine. For the rest rather 20 questions. "*. Without being too explicit, the users recommend developing an abbreviated version of the SPWB-IDD that might match the resources of more people with IDD.

Traffic Lights & Pictograms

During the correspondence with the office for easy language, special interest was given to the way of letting potential users answer the items. According to the linguistic expert, the Likert scale might be too difficult. That assumption was confirmed within the user tests. Both participants stated that they do know and understand the Likert scale (after the researcher's explanation). However, they were also asked to take the point of view of their housemates and friends in the institution and concluded that most of the clients would not understand the Likert scale. Seeing this problem in advance, the office for easy language created a smiley system for the IDD-SPWB to let users answer (Happy/Neutral/Sad). The users advised to carry on that smiley system but to add colours to it, as a form of a traffic light system (Green=Good, Yellow=Okay, Red=Not Good). Clients are used to this kind of picturing as it is integrated in their everyday life through pictograms. It also gives the opportunity to fill in this questionnaire by pointing at these symbols. That is especially helpful for those who cannot write and might need assistance to fill in the IDD-SPWB. Moreover, results can be interpreted the same way as with the Likert scale as the response format. A green smiley counts for three, a yellow one for two, and a red one for one. Assuming five questions per dimension, potential users could reach 15 points in total within each sub-scale/dimension. As suggested by Ryff and colleagues, the lower and upper quartiles (25%) classify low and high functioning.

3.5 Adaptation Phase

After the user tests were conducted, the study inserted another adaptation phase. Within this phase, the researcher re-formulated already translated items and developed new ones. For clarification, the language expert did not participate, but all the guidelines for easy language were strictly followed. Table 8 down below contains four items that have been considered not clear or applicable by the users. Even though the translated versions were significantly easier to understand, the users suggested having one sentence carrying one message. Also, the new items were formulated accordingly. They cover aspects specifically important for people with IDD and are therefore presented with the respective codes. All adapted items found their way in the final SPWB-IDD, following under section 3.6.

Table 8
Adaptation of SPWB-IDD Items

Original Item	Translated Item	Adapted Item
Maintaining close relationships has been difficult and frustrating for me.	Do you have close friendships? Is it difficult to maintain friendships?	Do you have close friends?
For me, life has been a continues process of learning, changing and growth.	You can always learn new things and develop. Do you believe that?	I can always learn new things.
I enjoy making plans for the future and working to make them a reality.	Do you have plans for the future? Do you do something for those plans?	I like planning for the future.
I tend to worry about what other people think about me.	Do you ask yourself often: What do other people think about me?	It is okay when other people don´t like me.

Table 9
New Developed Items

Code (Dimension)	New Item(s)
Frustration Tolerance (Environmental Mastery)	When I am frustrated, I get angry. When I fail a task, I get angry immediately.
Accepting IDD (Self-Acceptance)	It is okay, that I am disabled. My disability is no weakness/obstacle.
Expressing Needs (Autonomy)	When I want something, I go to other people. I am not afraid to ask for help.
Purpose at work? (Purpose in Life)	My work has a purpose. What do you understand under purpose in life? a. Interesting/Joyful Work. b. A place where I belong. c. Taking part in society.

3.6 The SPWB-IDD

Figure 4

SPWB-IDD Part 1

Fragen und Sätze
zur Gesundheit von der Seele

Bitte wähle zu jeder Frage ein Gesicht aus.

☺ Ja 😐 Ich weiß nicht ☹ Nein

1. Hast du enge Freunde? ☺ 😐 ☹

2. Sind dir deine Aufgaben im Alltag oft zu viel? ☺ 😐 ☹

3. Findest du dich toll? ☺ 😐 ☹

4. Lernst du gern Neues? ☺ 😐 ☹

5. Wenn Andere eine andere Meinung haben:
Kannst du deine Meinung trotzdem sagen? ☺ 😐 ☹

6. Denkst du über deine Zukunft nach? ☺ 😐 ☹

7. Fühlst du dich oft alleine und einsam? ☺ 😐 ☹

8. Du hast im Alltag deine Gewohnheiten.
Manchmal muss man seine Gewohnheiten ändern.
Fällt dir das schwer? ☺ 😐 ☹

9. Du musst eine Entscheidung treffen:
Hörst du dabei sehr auf Andere? ☺ 😐 ☹

10. Hast du oft das Gefühl:
Was du tust, ist **nicht** wichtig? ☺ 😐 ☹

11. Redest du gern mit deiner Familie und deinen Freunden? ☺ 😐 ☹

12. Denkst du oft schlecht über dich? ☺ 😐 ☹

13. Ich kann immer neue Dinge lernen. ☺ 😐 ☹

14. Es ist okay, wenn andere mich nicht mögen. ☺ 😐 ☹

15. Hast du Ideen für dein Leben? ☺ 😐 ☹

Figure 5
SPWB-IDD Part 2

16. Sind deine Freunde immer für dich da?	😊	😐	☹
17. Bist du immer für deine Freunde da? Wissen deine Freunde das?	😊	😐	☹
18. Bist du mit deinem Leben zufrieden?	😊	😐	☹
19. Bist du mit dir als Person zufrieden?	😊	😐	☹
20. Soll in deinem Leben alles so bleiben wie es ist?	😊	😐	☹
21. Können Andere deine Meinung verändern?	😊	😐	☹
22. Ich plane gerne für die Zukunft.	😊	😐	☹
23. Wenn du mal jemanden zum Reden brauchst: Gibt es Personen, die dir zuhören?	😊	😐	☹
24. Hast du im Alltag genug Zeit für deine Aufgaben?	😊	😐	☹
25. Wenn du mal einen Fehler gemacht hast: Kannst du gut damit umgehen?	😊	😐	☹
26. Wenn deine Familie oder deine Freunde eine andere Meinung haben als du: Änderst du dann deine Meinung?	😊	😐	☹
27. Führst du deine Pläne durch?	😊	😐	☹
28. Wenn ich etwas nicht schaffe, dann werde ich wütend.	😊	😐	☹
29. Es ist okay, dass ich behindert bin.	😊	😐	☹
30. Ich habe keine Angst, andere um Hilfe zu bitten.	😊	😐	☹
31. Meine Arbeit ist wichtig.	😊	😐	☹

Zusätzliche Frage:
Was gibt deinem Leben einen Sinn?

A: Arbeit, die spannend ist und Spaß macht.
B: Ein Ort, an dem ich mich zuhause fühle.
C: Freunde und Familie.

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4.0 Discussion

In light of a clear shortage of standardized assessment tools for the mental health of the IDD population (Flynn et al., 2017), this study delivered an adapted version of the psychological well-being scale, the SPWB-IDD. In doing so, we found that Environmental Mastery is considered the most important dimension of Ryff´s framework while Autonomy and Purpose in Life seem less contributing. To justify the process of tailoring, several codes have been developed indicating reasons to cut and keep items. To not exceed, the discussion will focus on codes of Positive Relations with Others as an example of reasons to keep. They appear most striking to the researcher and deliver great reference points across current literature. Since the analysis revealed new aspects regarding the special characteristics of the target population, the discussion will also compare newly developed items with literature. Thanks to the user tests, the SPWB-IDD underwent a first quality control and was assessed as relevant, applicable, and comprehensible. These findings are put into perspective while also reflecting the strengths of this study. This section ends by presenting limitations and implications for future research.

4.1 Current Literature

Reflecting PWB Dimensions

As mentioned in the introduction, several studies investigated the psychometric properties of adapted SPWBs confirming Ryff´s theoretical framework as a 4- or 6-factor model (Clarke et al., 2001; Guindon et al., 2005). Since the current study was not designed to conduct factor analysis, the evaluation of PWB dimensions will only concern the least important dimensions. Experts for IDD commonly agreed on valuing “Personal Growth”, “Autonomy” and “Purpose in Life” rather low. That corresponds with a study by van Herwaarden & Colleagues, who adapted and piloted a SPWB for people with mild intellectual disabilities (MID-ID) (van Herwaarden et al., 2022a). According to their factor analysis, personal growth and purpose in life measure the same construct. Learning new things and working for your own future appear to be similar, thus no separate dimensions. Although the current approach draws conclusions from qualitative data, the results of this study confirm the findings of van Herwaarden et al., as experts pointed out that learning new skills is a key component of IDDs participation plans and future-related SMART goals. Interestingly, IDD experts in this study considered purpose of life the least important dimension, while people with IDD stated otherwise. Both users affected by IDD claimed to strive for purpose in life as intended by Ryff´s framework. Another research concerning eudaimonic well-being among people with ID confirms that purpose in life is an important new indicator for well-being (van Herwaarden et al., 2022b). This discrepancy might be due to the fact, that purpose, direction, or meaning in life cannot be generalised. These termina allow wide interpretation (van Herwaarden et al., 2022b). The psychologist of this research underlined that thought by explaining: “*Purpose could mean to be busy and go somewhere, where people are waiting for you, where you do things together* “.

Further, experts of this study ranked the dimension of autonomy low because people with IDD generally do not show autonomous behaviour by expressing a resilient opinion. They do know what they want but articulating their wishes and remaining persistent in defending their position exceeds most IDD´s cognitive capacities. Wehmeyer & Shogren argue that this low autonomy of people with IDD is predicted by limited opportunities for choice (Wehmeyer & Shogren, 2016). In fact, living in a supervised living unit does limit the opportunities for choices significantly, summarised by the code "Institutional Structure" and "Power Imbalance". However, especially carers state that having a resilient opinion might not be beneficial to the PWB of people with IDD. They rely on behavioural change techniques such as distraction and positive reinforcement to prevent people with IDD from experiencing crisis (Dugdale et al., 2016). The intention is not to call for obedience, but to facilitate a flexible mindset. According to their experience, most crises occur when clients with IDD are forced to change their plans. Overall, the findings of this study neither confirm a 4- nor a 6-factor model of PWB. However, they underpin the approach of adapting the SPWB and its dimensions to suit the needs of a specific target group.

Positive Relations with Others

From the numerous codes that represent aspects that must be covered by a SPWB for people with IDD, the codes of positive relations with others stick out. Starting with "Social Support System" experts as well as people affected by IDD pointed out that living in a supervised living unit does not protect from experiencing loneliness. In fact, the theme of loneliness seems common among several studies covering the subjective well-being of people with IDD (Emerson et al., 2021; van Herwaarden et al., 2022b). A strong social support system as well as intimate relationships prove to be protective against not only loneliness but also the feeling of helplessness (Emerson & Hatton, 2008; van Herwaarden et al., 2022b). According to research concerning children with Special Education Needs, subjective well-being, in general, is associated with social support (Gaspar et al., 2016). Another important factor of positive relations with others was found in people´s "Socialisation". Experts of this study shared that most IDD biographies are characterised by negative experiences such as traumata and stigmatisation, which impede the development of social skills and attachment behaviour. Key statements from van Herwaarden´s eudaimonic well-being study include that people with IDD fight negative stereotypes that keep them from flourishing (van Herwaarden et al., 2022b). Also Nussbaum identified social acceptance as one of the most important elements contributing to well-being (Nussbaum, 2009). Overall, improving socialisation and a well-established social support system seem crucial to the psychological well-being of people with IDD. One way to approach that seems the person-focused model of active support (Lin et al., 2020; Totsika et al., 2008). It intends to facilitate positive relations with others by enhancing meaningful activities and interactions, referring to some degree to the dimension of Purpose in Life.

Developing new Items

The special characteristics of this target group did not only require reformulating items but also developing new ones. The code of “Accepting IDD” represents a good example. Experts, especially carers, described how IDD clients often deny their disabilities or react angrily when confronted with their own inadequacies. Being cognitively impaired could mean constantly feeling overburdened. Such situations often result in a crisis, which has a negative impact on their psychological well-being. Studies elaborating on the concept of Disability Identity Development emphasize the importance of accepting the impairment as part of the own reality without losing a sense of self (Forber-Pratt et al., 2017; Murugami, 2009). The model tries to encourage a positive sense of self and a sense of identity, which helps people with IDD distinct different parts of their self-concepts (Forber-Pratt et al., 2017). That gets backed up by Gaspar & Colleagues who found that personal factors such as self-esteem and a positive self-image are associated with the subjective well-being of children with IDD (Gaspar et al., 2016). It seems crucial to concretize the dimension of self-acceptance and add items that cover the acceptance of IDD.

Further, codes for Purpose in Life indicate the need for concretisation as well. All experts emphasized that most clients with IDD “Live in the present” since reflecting on the future might be cognitively challenging. Generally, termina such as direction, purpose, or meaning had been considered too abstract to fully comprehend by the target population. To specify these concepts, new items could draw upon the workplace. “Purpose at work?” explains that work is the biggest contributor in structuring everyday life, but if it (or other activities) is considered meaningful seems unknown. According to the literature, young adults with IDD experience a lack of meaningful occupation or activities after leaving school, which has a negative impact on their health and well-being (Young-Southward et al., 2017). Another article confirms that adults with IDD seek stability and fulfillment in life, often equated with work (Harwick et al., 2017). Therefore, item(s) covering the workplace and beyond were added to the SPWB-IDD.

4.2 Strengths of this Study

Before heading towards the limitations, it might be convenient to mention the strengths as well as what this study adds to the field of research. Generally, IDD experts agreed on how to tailor or adapt the SPWB. Despite different occupational backgrounds, the evaluation of items and dimensions was consistent among all experts. As it can be seen within section 3.2, the majority of cut items received the highest possible total score. It means that all experts were certain about which items to remove from the questionnaire. Given the fact that qualitative research tends to create subjective information points (Queirós et al., 2017), this consistency appears as a clear strength. Furthermore, the data demonstrate a certain degree of coherence. Using mixed methods sometimes results in qualitative and quantitative data contradicting each other (Malina et al., 2011). Within this study, the coding scheme serves as a great underpinning for the ranking system. Whenever an item was valued either good or bad, the analysis of the qualitative data delivered a thoroughly justification of why.

In terms of added value, this study serves as another positive example of how people with IDD contribute scientifically. Despite their obstacles of limited communication and cognitive capacity, more and more studies emerge that include people affected by IDD not only as the target group but as participants. Within this study, their first-hand impressions gave valuable hints about comprehensibility and usefulness as well as constructive feedback. Suggestions such as "Traffic lights and Pictograms" increased the feasibility of the scale (Daems et al., 2016) and were implemented immediately. Next to scale development, research among disability narratives and mental health interventions are benefiting from their perspective as well. For instance, participants with IDD were able to follow a life story intervention which led to an improvement in psychiatric complaints, well-being, and purpose in life (Beernink & Westerhof, 2020). Another study investigating health narratives as therapeutic tools even listed people with IDD as co-authors, since they provide the most authentic point of view (Caudill et al., 2022). The combination of having complex healthcare needs and a unique set of resources seems particularly challenging (Caudill et al., 2022). To overcome these problems, this study advocates for the approach of human-centered design. The development of methods, instruments, and interventions might benefit from the iterative contribution of people with intellectual and developmental disabilities (Daems et al., 2015).

4.3 Limitations

Although the current study provides a new assessment tool for PWB of people with IDD, results should be interpreted with several limitations in mind. To begin with, the recruitment process missed potentially significant stakeholders such as family and peers. Both Studies from van Herwaarden & Colleagues delivered promising results after inviting people affected by IDD and their family members (van Herwaarden et al., 2022a, 2022b). Even though parts of the results correlate, there are clear differences recognisable. Family and peers praised purpose in life and personal growth, whereas participants of this study prioritised environmental mastery and positive relations with others. This discrepancy could be explained by the professional relationship between carers/psychologists and clients with IDD. Managing their everyday life and facilitating relationships is part of work and even if family and peers do the same it might be considered less of a "job". It appears only natural that having a purpose in life rather reflects the priorities of a family taking care of someone with IDD. It should be noted that this point of view could be covered to a small extent since the researcher has a sister with Trisomy 21 and is familiar with taking care of someone with IDD from the professional perspective as well as the personal. However, future research in scale development for IDD should involve family and peers as stakeholder.

Another limiting aspect has been the sample size. To ensure data saturation within content analysis among qualitative health research Vasileiou & Colleagues (2018) suggest at least twelve participants. Unfortunately, only two people affected by IDD participated in the user tests. Even though they delivered valuable results, two perspectives of IDD cannot guarantee data saturation. As mentioned multiple times, people with IDD are characterised by highly individual behaviour and unique healthcare needs (Caudill et al., 2022; Cooper et al., 2015). Adding more participants with different diagnoses or even recruiting people outside an institution would have enlarged the data and provided different themes for comparison. Especially since a certain "power imbalance" and "institutional structure" has been identified, that influence the (perceived) autonomy and environmental mastery of people with IDD. Considering comprehensibility, users with a more limited skill set could have also improved the data by highlighting difficulties. To accommodate data saturation to some degree the researcher recruited participants that differ in caring degree but are also capable of reflecting the SPWB-IDD on behalf of their housemates and friends with IDD. While testing the scale, both users were specifically asked to give recommendations to suit the needs of as many potential users with IDD as possible. However, since generalisability remains one of the biggest challenges in mental health care for IDD, a bigger sample size with more variations seems necessary.

4.4 Future Recommendations

Even though the user tests seem bright, the implied results allow no conclusion regarding the validity and reliability of the SPWB-IDD. Therefore, the next step is to set up studies measuring psychometric properties. Van Herwaarden and Colleagues delivered a first pilot study assessing internal consistency, test-retest reliability, and construct validity of an adapted PWB scale for people with mild intellectual disability and borderline disorders (van Herwaarden et al., 2022a). The researcher recommends a similar approach but complemented by factor analysis. Investigating underlying factors influencing the outcome or if single items eventually covariate with other dimensions of PWB delivers valuable information for improvement. To further verify and draw conclusions on validity, the researcher suggests following COSMIN´s guidelines on measurement properties for patient-reported outcome measures. These guidelines require a multi-group and/or longitudinal study design (Prinsen et al., 2018). Since research in that regard is rather limited, future study designs need to deliver clear psychometric properties in a larger scope. These might serve as the fundament for further research.

Generally, the results of this study indicate a 6-factor model if items of certain dimensions were adapted accordingly. However, it could also be interpreted that a 4-factor model, leaving out the more challenging purpose in life and autonomy, might be more feasible for more individuals with IDD. To tackle this challenge of generalisability, the researcher suggests developing an abbreviated version of the SPWB-IDD based on the four most applicable dimensions of this research. Depending on the respective caring degree, the abbreviated version could be tested (and developed) among individuals with a high need for care and low(er) cognitive capacities. Psychometric properties will be analysed as described in the previous paragraph and compared. It seems contradictory, but the more assessment tools can be specified/tailored the sooner research might reach generalisability. It may not only improve the quality of disability care but also allow comparison among the general population or specific target groups that live in similar institutions as people with IDD (such as the elderly in retirement homes).

5.0 Conclusion

The objective of this study was to build an adapted instrument for assessing the psychological well-being of people with intellectual and developmental disabilities, tailored to their special characteristics. With the help of experts from the disability field as well as people affected by IDD, this study finishes with a new scale, the SPWB-IDD.

Based on the widely recognised theoretical framework of Psychological Well-Being, the adaptation process produced not only a new scale but also delivered new insights about how the construct and its dimensions are evaluated. According to IDD experts, the ability to manage everyday tasks (Environmental Mastery) and facilitate deep relationships with peers (Positive Relations with Others) are the most important aspects contributing to the PWB of people with IDD. On the other hand, persisting on own opinions (Autonomy) and reflecting an overall meaning in life (Purpose in Life) seems to exceed the cognitive capacity of most people affected and could even have a negative impact on people with IDD. Most items were cut because people with IDD lack the ability to reflect on themselves, social relations, and time. However, their special characteristics and limitations also entailed the opportunity to create new and more concrete items. The dimension of self-acceptance, for instance, was complemented by “accepting disability” as part of their identity and autonomy focuses on “expressing needs” instead of expressing opinions. Assessing all items did not only justify the tailoring process but also delivered great reference points to respond to their special needs and further adapt the SPWB-IDD.

Additionally, the SPWB-IDD underwent its first User Tests which indicated that the new scale is highly relevant, applicable, and generally comprehensible by individuals with IDD. Another finding worth mentioning is that people with IDD prove to be useful participants in mental health research and scale development. Including individuals with IDD as participants seems a promising way to deal with the challenge of generalisability. Their recommendations and suggestions had a positive impact on the development of the scale and their point of view could close the research gap of missing measurement tools.

To put it in a nutshell, this study expands the current knowledge on PWB among people with IDD and even if the SPWB-IDD has not been validated yet, individuals with IDD gained a new assessment tool focusing on their mental health and well-being.

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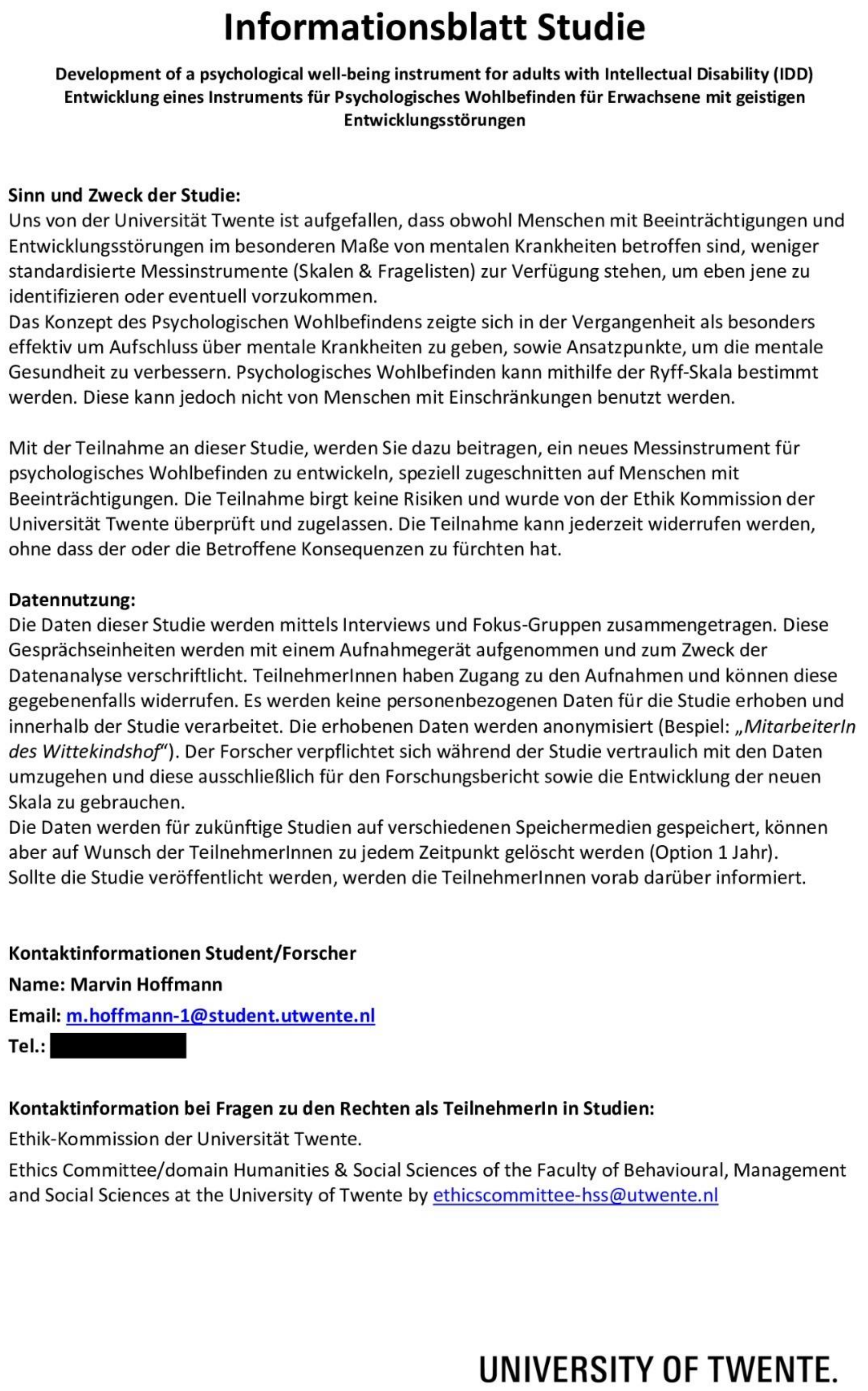
7.0 Appendix

Appendix A Info Sheets + Informed Consent for Experts



Informationsblatt Studie

Development of a psychological well-being instrument for adults with Intellectual Disability (IDD)
Entwicklung eines Instruments für Psychologisches Wohlbefinden für Erwachsene mit geistigen Entwicklungsstörungen

Sinn und Zweck der Studie:
Uns von der Universität Twente ist aufgefallen, dass obwohl Menschen mit Beeinträchtigungen und Entwicklungsstörungen im besonderen Maße von mentalen Krankheiten betroffen sind, weniger standardisierte Messinstrumente (Skalen & Fragelisten) zur Verfügung stehen, um eben jene zu identifizieren oder eventuell vorzukommen.
Das Konzept des Psychologischen Wohlbefindens zeigte sich in der Vergangenheit als besonders effektiv um Aufschluss über mentale Krankheiten zu geben, sowie Ansatzpunkte, um die mentale Gesundheit zu verbessern. Psychologisches Wohlbefinden kann mithilfe der Ryff-Skala bestimmt werden. Diese kann jedoch nicht von Menschen mit Einschränkungen benutzt werden.

Mit der Teilnahme an dieser Studie, werden Sie dazu beitragen, ein neues Messinstrument für psychologisches Wohlbefinden zu entwickeln, speziell zugeschnitten auf Menschen mit Beeinträchtigungen. Die Teilnahme birgt keine Risiken und wurde von der Ethik Kommission der Universität Twente überprüft und zugelassen. Die Teilnahme kann jederzeit widerrufen werden, ohne dass der oder die Betroffene Konsequenzen zu fürchten hat.

Datennutzung:
Die Daten dieser Studie werden mittels Interviews und Fokus-Gruppen zusammengetragen. Diese Gesprächseinheiten werden mit einem Aufnahmegerät aufgenommen und zum Zweck der Datenanalyse verschriftlicht. TeilnehmerInnen haben Zugang zu den Aufnahmen und können diese gegebenenfalls widerrufen. Es werden keine personenbezogenen Daten für die Studie erhoben und innerhalb der Studie verarbeitet. Die erhobenen Daten werden anonymisiert (Bespiel: *„MitarbeiterIn des Wittekindshof“*). Der Forscher verpflichtet sich während der Studie vertraulich mit den Daten umzugehen und diese ausschließlich für den Forschungsbericht sowie die Entwicklung der neuen Skala zu gebrauchen.
Die Daten werden für zukünftige Studien auf verschiedenen Speichermedien gespeichert, können aber auf Wunsch der TeilnehmerInnen zu jedem Zeitpunkt gelöscht werden (Option 1 Jahr).
Sollte die Studie veröffentlicht werden, werden die TeilnehmerInnen vorab darüber informiert.

Kontaktinformationen Student/Forscher
Name: Marvin Hoffmann
Email: m.hoffmann-1@student.utwente.nl
Tel.: [redacted]

Kontaktinformation bei Fragen zu den Rechten als TeilnehmerIn in Studien:

Ethik-Kommission der Universität Twente.

Ethics Committee/domain Humanities & Social Sciences of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-hss@utwente.nl

UNIVERSITY OF TWENTE.

Einverständniserklärung

Development of a psychological well-being instrument for adults with Intellectual Disability (IDD)
Entwicklung eines Instruments für Psychologisches Wohlbefinden für Erwachsene mit geistigen Entwicklungsstörungen

Bitte kreuze die folgenden Boxen an:	**Ja**	**Ne**
Teilnahme an der Studie		
Ich habe das Informationsblatt zu der Studie gelesen und verstanden. Ich habe Fragen stellen können und meine Fragen wurden zu meiner Zufriedenheit beantwortet.	○	○
Hiermit bestätige ich die Teilnahme an der Studie. Die Teilnahme an der Studie ist freiwillig. Das Gespräch kann zu jedem Zeitpunkt abgebrochen werden, ohne Begründung.	○	○
Hiermit bestätige ich, dass die Daten im Rahmen eines mündlichen Gesprächs mit einem Aufnahmegerät aufgenommen werden. Zum Zweck der Analyse werden die erhobenen Daten verschriftlicht.	○	○
Datennutzung		
Ich verstehe, dass die erhobenen Daten zur Fertigstellung eines Studienberichts (Master-These) genutzt werden und eventuell veröffentlicht werden.	○	○
Ich verstehe, dass die personenbezogenen Daten über mich nicht über das Forschungsteam hinaus geteilt werden. Es werden darüber hinaus keine personenbezogenen Daten innerhalb des Studienberichts geteilt.	○	○
Hiermit bestätige ich, dass ich (anonymisiert) zitiert werden darf.	○	○
Zukünftige Datennutzung		
Hiermit bestätige ich, dass die erhobenen Daten für zukünftige Studien und Forschung gespeichert werden. Diese Daten werden anonymisiert gespeichert.	○	○

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Unterschriften

_____________________ _____________________ ________

Name Teilnehmer/In

Unterschrift Datum

Ich habe das Informationsblatt zu der Studie laut gelesen und den TeilnehmerInnen nach bestem Wissen und Gewissen verständlich gemacht.

________________________ __________________ ________

Forscher/Student Unterschrift Datum

Kontaktinformationen Student/Forscher
Name: Marvin Hoffmann
Email: m.hoffmann-1@student.utwente.nl
Tel.: [redacted]

Kontaktinformation bei Fragen zu den Rechten als TeilnehmerIn in Studien:

Ethik-Kommission der Universität Twente.

Ethics Committee/domain Humanities & Social Sciences of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-hss@utwente.nl

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Appendix B Focus Group/Interview Handout Example

☐ Positive Beziehungen zu anderen

Bewerte bitte die folgenden Items hinsichtlich Relevanz, Anwendbarkeit im Alltag und Verständnis. Erstelle dabei eine Rangliste (1= Gut/Relevant…) und/oder lösche Items mit X.

☐ Die meisten Menschen sehen in mir einen liebevollen und zärtlichen Menschen.

☐ Enge Beziehungen aufrecht zu erhalten ist für mich schwierig und frustrierend.

☐ Ich fühle mich oft einsam, weil ich nur wenige enge Freunde habe, mit denen ich meine Sorgen teilen kann.

☐ Ich mag persönliche Gespräche und Austausch mit Familie und Freunden.

☐ Andere Menschen würden mich als Person beschreiben, die viel für andere tut und die bereit ist ihre Zeit mit anderen zu teilen.

☐ Ich habe nicht viele warmherzige und vertrauensvolle Beziehungen mit anderen erlebt.

☐ Ich weiß, dass ich mich auf meine Freunde verlassen kann und sie wissen, dass sie sich auf mich verlassen können.

☐ Ich habe nicht viele Menschen, die mir zuhören wollen, wenn ich das Bedürfnis habe zu reden.

☐ Mir scheint, dass die meisten anderen mehr Freunde haben als ich.

Appendix C Info Sheets + Informed Consent IDD Users

Gespräch über die Gesundheit von der Seele

Ich bin Marvin Hoffmann.

Ich studiere an der Universität in Twente in Holland.

Menschen lernen an einer Universität für ihren späteren Beruf.

Ich schreibe einen Bericht für mein Studium.

Der Bericht ist über die Gesundheit von der Seele.

Das heißt auch:

Psy-cho-lo-gisch-es Wohlbefinden.

Du kannst mich anrufen.

Meine Telefon-Nummer ist: [redacted]

Du kannst mir eine E-Mail schreiben.

Meine E-Mail-Adresse ist: m.hoffmann-1@student.utwente.nl

Warum führen wir das Gespräch?

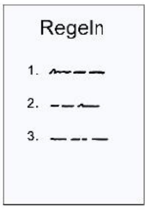
Alle haben eine Seele.

Die Seele meint:

- alle Gefühle und
- das eigene Verhalten.

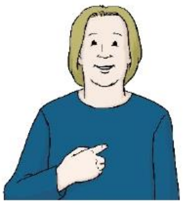
Wir müssen gut auf unsere Seele aufpassen.

Denn auch unsere Seele kann krank werden.



Regeln für das Gespräch

Das Gespräch ist freiwillig.



Du bestimmst:

- Ich bleibe bis zum Ende bei dem Gespräch.

Oder:

- Ich bleibe **nicht** bis zum Ende bei dem Gespräch.

Wenn Du etwas **nicht** verstehst:

Du kannst immer fragen.

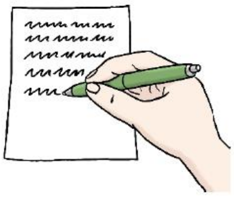
Ich mache eine Ton-Aufnahme von dem Gespräch.

Das bedeutet:

Man kann das Gespräch wieder hören.

Wenn Du möchtest:

Du kannst das Gespräch noch einmal hören.



Ich schreibe die Antworten bei dem Gespräch auf.

Du kannst deine Antworten lesen.

So führen wir das Gespräch

Das Gespräch dauert ungefähr eine halbe Stunde.

Ich lese Fragen zur Gesundheit von der Seele vor.

Du musst die Fragen **nicht** beantworten.

Bilder © Lebenshilfe für Menschen mit geistiger Behinderung Bremen e.V., Illustrator Stefan Albers, Atelier Fleetinsel, 2013

Die Gesundheit von der Seele ist genauso wichtig

wie die Gesundheit vom Körper.

Ich möchte heraus-finden:

Wie geht es deiner Seele?

Ich spreche mit vielen Menschen,

die ein Wohn-Angebot vom Wittekindshof nutzen.

Ich schreibe einen Bericht über alle Gespräche.

Aber ich schreibe **nicht**:

Wer hat was gesagt.

Der Bericht ist für mein Studium.

Ich bekomme eine Note für den Bericht.

Woran merkst du:

Ist deine Seele gesund?

- Du fühlst dich gut.
- Du schaffst deinen Alltag gut.
- Du hast Ideen:
  ➔ Was kann ich allein unternehmen.
  ➔ Was kann ich mit anderen unternehmen.

Ich möchte wissen:

- Verstehst du die Fragen?
- Was denkst du über die Fragen?
- Kennst du manche Fragen aus Deinem Alltag?

Wenn du möchtest:

Dann machen wir eine Pause.

Einverständnis-Erklärung zum Gespräch:
Gesundheit der Seele

Bitte lies die Informationen auf diesem Blatt.
Du bist einverstanden:
Mach ein Kreuz bei **Ja**.
Du bist **nicht** einverstanden:
Mach ein Kreuz bei **Nein**.

	Ja	**Nein**
Ich habe die Informationen über die Gesundheit der Seele gelesen und verstanden.	☐	☐
Ich erlaube: Marvin darf das Gespräch aufnehmen. Nur Marvin hört die Aufnahme und kennt meine Antworten. Wenn ich möchte: Ich kann mir die Aufnahme anhören und meine Antworten lesen.	☐	☐
Marvin schreibt einen Bericht. Ich erlaube: Den Bericht dürfen lesen: • die Lehrerinnen/Lehrer von Marvin von der Universität, • die Leitung vom Team 18 vom Wittekindshof, • die Geschäfts-Bereichs-Leitung vom Geschäfts-Bereich 1 vom Wittekindshof.	☐	☐

Wenn später noch andere Personen
den Bericht oder das Heft lesen:
Marvin muss mich vorher fragen.

Unterschrift Klient

Unterschrift Marvin Hoffmann

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Appendix D Draft Version IDD-SPWB

Fragen und Sätze zur Gesundheit von der Seele

Bitte wähle zu jeder Frage ein Gesicht aus.

🙂 Ja

😐 Ich weiß **nicht**

🙁 Nein

---

1. Hast du enge Freundschaften? Ist es für dich schwer, dich um die Freundschaften zu kümmern?	🙂 😐 🙁
2. Ist dir der Alltag oft zu viel?	🙂 😐 🙁
3. Findest du dich toll?	🙂 😐 🙁
4. Lernst du gern Neues?	🙂 😐 🙁
5. Wenn Andere eine andere Meinung haben: Kannst du deine Meinung trotzdem sagen?	🙂 😐 🙁

6. Denkst du über deine Zukunft nach?	🙂	😐	🙁
7. Fühlst du dich oft alleine und einsam?	🙂	😐	🙁
8. Schaffst du alle deine Aufgaben im Alltag gut?	🙂	😐	🙁
9. Magst du dich?	🙂	😐	🙁
10. Du hast im Alltag deine Gewohnheiten. Manchmal muss man seine Gewohnheiten ändern. Fällt dir das schwer?	🙂	😐	🙁
11. Du musst eine Entscheidung treffen: Hörst du dabei sehr auf Andere?	🙂	😐	🙁
12. Hast du oft das Gefühl: Was du tust, ist **nicht** wichtig?	🙂	😐	🙁
13. Redest du gern mit deiner Familie und deinen Freunden?	🙂	😐	🙁
14. Sind dir deine Aufgaben im Alltag oft zu viel?	🙂	😐	🙁
15. Denkst du oft schlecht über dich?	🙂	😐	🙁

16. Du kannst immer wieder Neues lernen und entwickelst dich immer weiter. Glaubst du das?	🙂	😐	🙁
17. Fragst du dich oft: Was denken Andere über dich?	🙂	😐	🙁
18. Hast du Ideen für dein Leben?	🙂	😐	🙁
19. Sind deine Freunde immer für dich da?	🙂	😐	🙁
20. Bist du immer für deine Freunde da? Wissen deine Freunde das?	🙂	😐	🙁
21. Bist du mit deinem Leben zufrieden?	🙂	😐	🙁
22. Bist du mit dir als Person zufrieden? Egal, was Andere von dir denken?	🙂	😐	🙁
23. Soll in deinem Leben alles so bleiben wie es ist?	🙂	😐	🙁
24. Können Andere deine Meinung verändern?	🙂	😐	🙁

25. Hast du Pläne für deine Zukunft?
Und tust du etwas für die Pläne? ☺ 😐 ☹

26. Wenn du mal jemanden
zum Reden brauchst:
Gibt es Personen, die dir zuhören? ☺ 😐 ☹

27. Hast du im Alltag
genug Zeit für deine Aufgaben? ☺ 😐 ☹

28. Wenn du mal einen Fehler gemacht hast:
Kannst du gut damit umgehen? ☺ 😐 ☹

29. Wenn deine Familie oder deine Freunde
eine andere Meinung haben als du:
Änderst du dann deine Meinung? ☺ 😐 ☹

30. Führst du deine Pläne durch? ☺ 😐 ☹

31. Du kannst in deinem Leben
nichts Neues mehr lernen.
Glaubst du das? ☺ 😐 ☹

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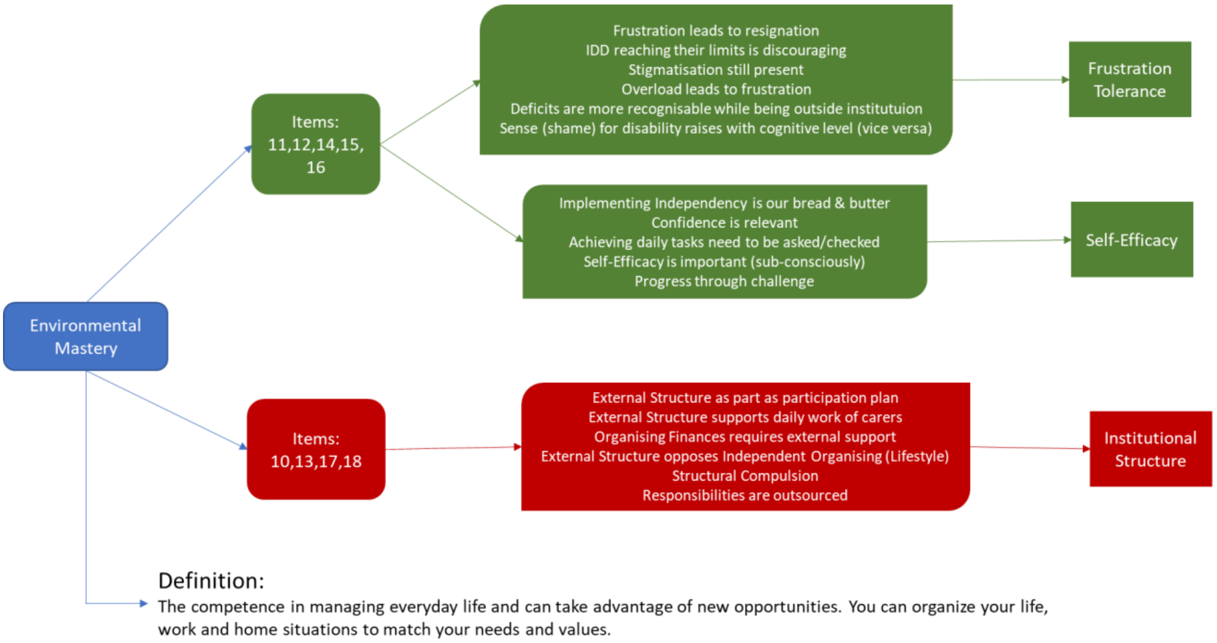
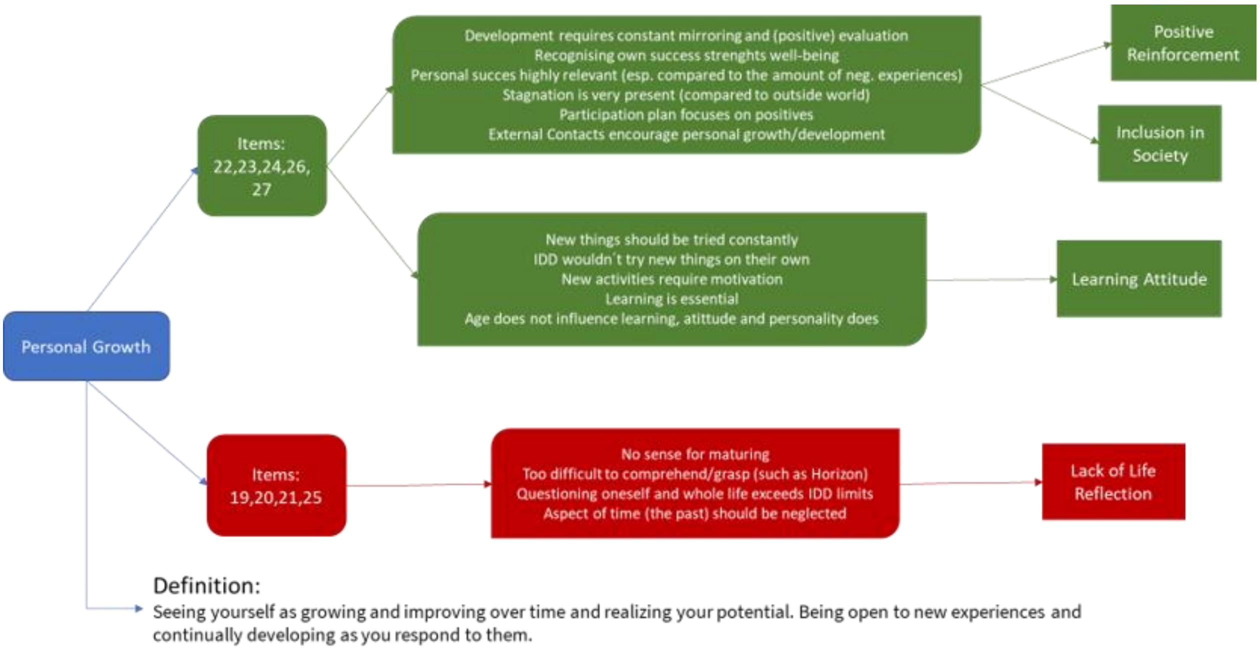
Appendix E Significant Datasets

User2_Part2.docx User2_Part1.docx User1.docx Raw_Data_Psy.docx Raw_Data_Focus.docx

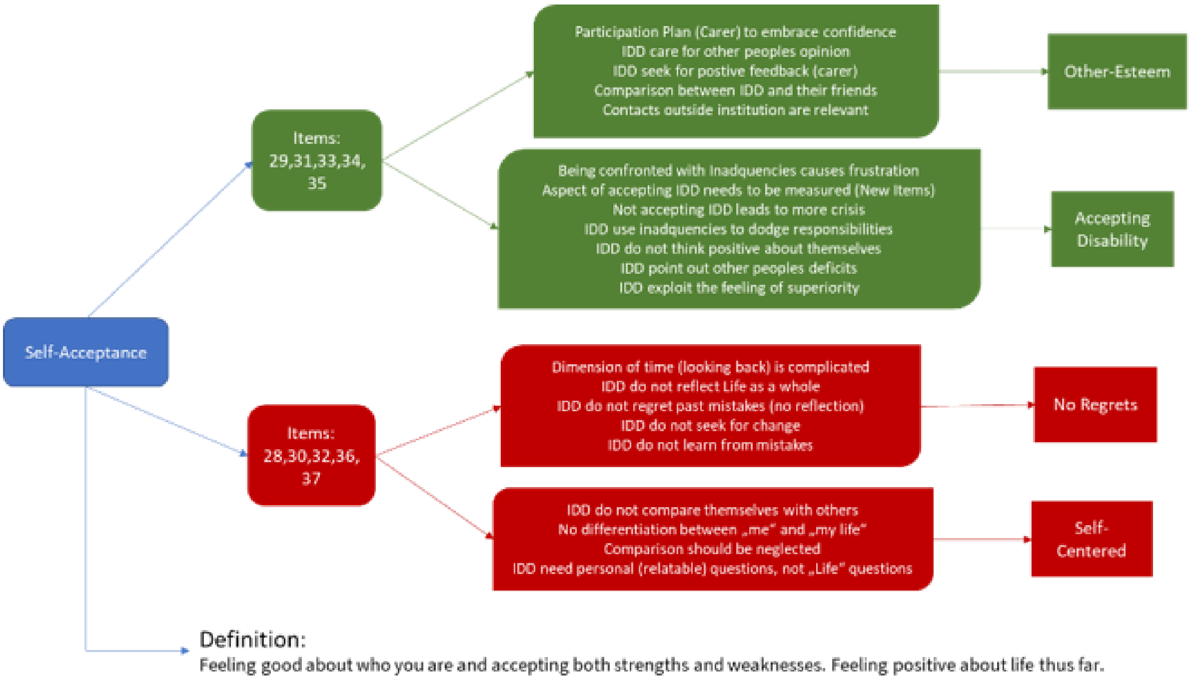
Appendix F Coding Trees for each Dimension



Definition:
The competence in managing everyday life and can take advantage of new opportunities. You can organize your life, work and home situations to match your needs and values.

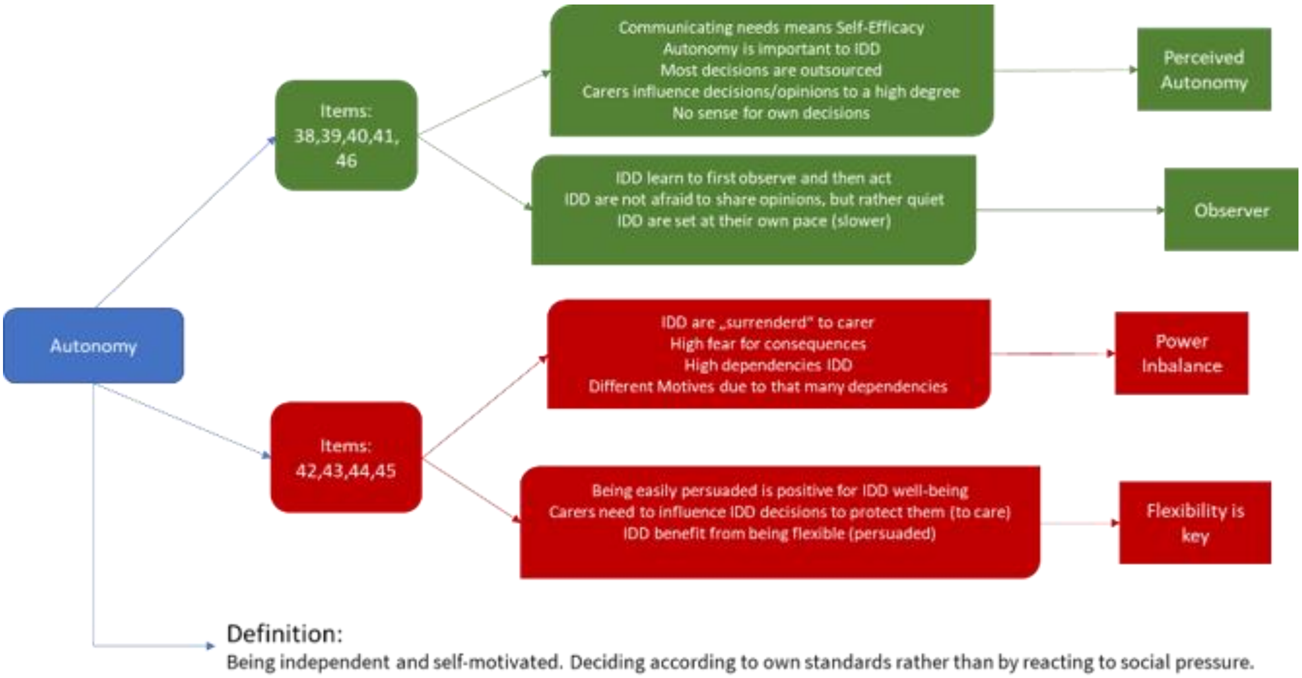


Definition:
Seeing yourself as growing and improving over time and realizing your potential. Being open to new experiences and continually developing as you respond to them.



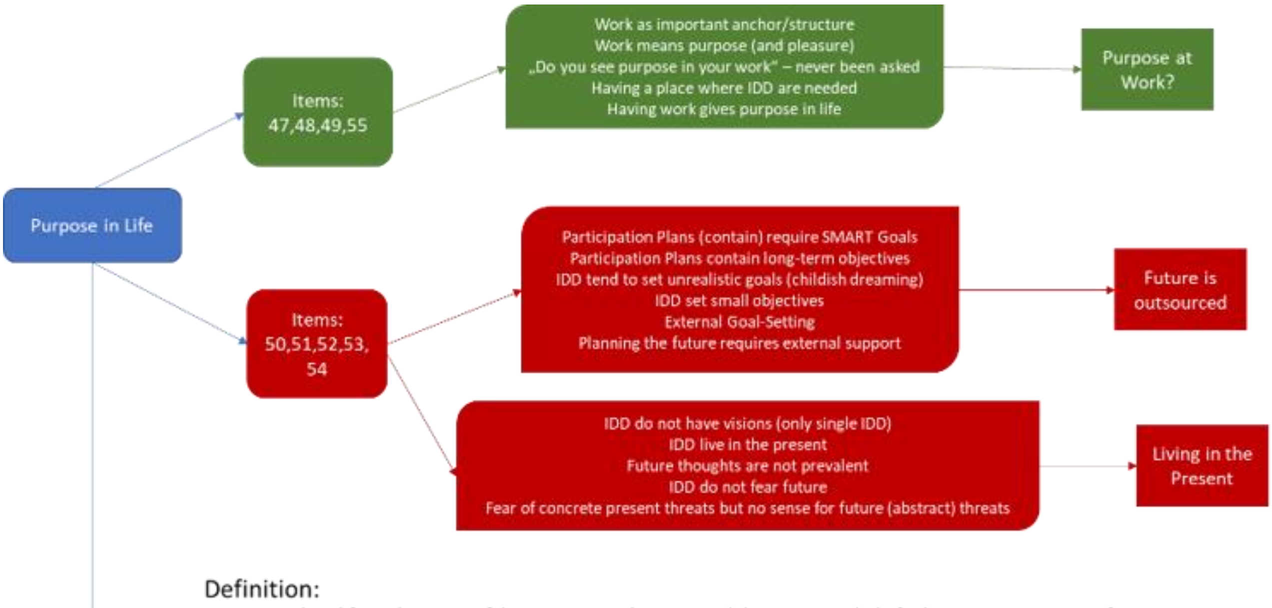
Definition:

Feeling good about who you are and accepting both strengths and weaknesses. Feeling positive about life thus far.



Definition:

Being independent and self-motivated. Deciding according to own standards rather than by reacting to social pressure.



Definition:

Having goals in life and a sense of direction in working toward them. Having beliefs that support a sense of purpose in your own life and life generally.