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DEUTSCHES ABSTRACT

Gesundheitsverhalten und Gesundheitswissen von Menschen mit intellektueller Beeinträchtigung

Menschen mit intellektueller Beeinträchtigung (IB) stehen in unserer Gesellschaft großen Herausforderungen gegenüber. So scheint zum Beispiel das Gesundheitswesen in vieler Hinsicht nicht flexibel genug, um die individuellen und gesundheitlichen Bedürfnisse von Menschen mit IB zu versorgen. Diese Dissertation versuchte auf zwei Ebenen diese Tatsache zu beleuchten: einerseits wurden die sozial-politischen Aspekte der Gesundheitsversorgung von Menschen mit IB näher analysiert, andererseits wurde ein besonderes, gesundheitspsychologisches Problem, das des häufigen Risikoverhaltens dieser Population, beleuchtet. Die Kombination beider Ebenen ist wesentlich. Die Feststellung fehlender Strukturen im Gesundheitswesen, wie jene der Prävention, die für eine gute Versorgung essentiell sind, geben einem gesundheitspsychologischen Projekt den entscheidenden Gestaltungsrahmen. Umgekehrt können gesundheitspsychologische Forschungsergebnisse der Politik notwendige Veränderungsimpulse liefern.

In einem ersten Schritt wurden die Fortschritte europäischer Länder in der Umsetzung der Gesundheitsartikel der Behindertenmenschenrechtskonvention analysiert. Neben der Erkenntnis, dass europäische Staaten mehrheitlich die Berichterstattungsrichtlinien nicht befolgen, werden auch kaum Gesundheitsdaten erwähnt. Der Fokus der Staatenberichte liegt auf der physischen Barrierefreiheit von öffentlichen Gebäuden, dabei bleiben andere Punkte, wie die Kompetenz von Gesundheitspersonal in der Versorgung von Menschen mit Behinderungen, unreflektiert. Um die Konvention vollständig zu implementieren, bedarf es aber einer genauen und detaillierten Analyse des Status-quo.

In einem zweiten Schritt wurde gesundheitspsychologische Forschungsliteratur zu den Themen Gesundheitsstatus, -verhalten sowie Gesundheitsinterventionen für Menschen mit IB gesichtet und analysiert. Auf diese Bewertung aufbauend wurden Kriterien für die

Entwicklung eines Gesundheitsmodells bestimmt und in der Folge ein Modell (*the General Health Circuit*) entworfen und an einer Stichprobe von Menschen mit/ohne IB überprüft. Zwischen den Gruppen konnten zahlreiche Unterschiede festgestellt werden: Menschen mit IB verstehen die Begriffe *Gesundheit, Krankheit* und *Behinderung* anders, nehmen sich und ihren Körper anders wahr und zeigen andere Risikoverhaltensweisen.

Die neugewonnenen Erkenntnisse könnten zukünftig helfen passende Gesundheitsinterventionen für Menschen mit IB zu entwickeln als auch notwendige gesundheitspolitische Änderungen animieren, um weitere Benachteiligungen für Menschen mit IB zu verhindern.

ENGLISH ABSTRACT

Health behaviour and health knowledge project for persons with intellectual disabilities

Persons with intellectual disabilities (ID) face enormous challenges when engaging in our society. Some of these challenges are due to their health status. The objective of this thesis was twofold: on the one hand, to specify the social-policy challenges for their health status and on the other hand to review one specific health psychological context, health behaviour, in this population in more detail.

In a first step, the initial achievements in the process of implementation of the Convention on Rights of Persons with Disabilities (CRPD) in the European Union, with a special focus on health of persons with intellectual disabilities (ID), were explored. It was found that the reports designed to represent official state comments on the situation of persons with disabilities often do not follow the reporting requirements of the Convention when it comes to data required. Besides, access to health is generally understood in a purely physical sense of availability and accessibility of services, while no attention is paid to specific expectations and needs of persons with disabilities or to the competence of health staff to work with vulnerable groups. In order to implement the Convention, governments need to carefully assess their country's status quo with regard to disability policies and politics, and at the same time need to develop action plans to implement the CRPD fully.

In a second step, the current status of research on health status and health behaviours and health interventions for persons with ID was described. Based on this review, criteria for the development of a health model were identified. After designing a health model, called the General Health Circuit, it was tested in a sample of persons with and without ID. Findings indicate that persons with ID perceive health and their bodies differently and therefore act differently when it comes to health. While stress, alcohol consumption and smoking were the

most frequent risk behaviours in persons without ID, unhealthy nutrition, bad oral health, less physical activities and few social resources were found in the ID sample.

The results of the conducted psychological study as well as previous research findings imply necessary policy changes concerning health regulations to protect persons with ID from further human rights violations and to empower persons with ID to act more autonomously in health matters.

1. INTRODUCTION

Persons with intellectual disabilities (ID) face numerous challenges and barriers to active engagement in our society. Some of these challenges are due to their health status and some of the barriers are linked to stereotypes encountered on the grounds of disability. As the author is a member of the interdisciplinary initiative college 'Empowerment through Human Rights', the objective of this thesis was twofold: a) to specify these social-policy challenges for their health status and b) to review one specific health psychological context, health behaviour, more precisely in this population. It will be demonstrated that it is of high relevance to review these two aspects, the social-policy and the psychological, in combination.

In the first chapter, the population of persons with ID will be described together with recent epidemiological developments. These trends will be portrayed in order to give a thorough picture on the background of this dissertation project, which will be delineated in the second chapter. Finally, results and future prospects will be discussed.

The results of the conducted psychological study as well as previous research findings imply necessary policy changes concerning health regulations to protect persons with ID from further human rights violations and to empower persons with ID to be able to act more autonomously in health matters. The epidemiological transformations and immense health status variations, which will be described in the next chapter, also demand such policy changes.

1.1. Persons with intellectual disabilities

The population of persons with intellectual disabilities is defined by significant limitations both in intellectual functioning (e.g., reasoning, planning, solving problems, abstract thinking) and adaptive behaviours (conceptual, social and practical skills that have

been learned and performed in everyday lives), still in the developmental phase of the individual's life (American Association on Intellectual and Developmental Disabilities, 2011).

In a meta-analysis, which included 52 studies published between 1980 and 2009 by Maulik, Mascarenhas, Mathers, Dua and Saxena (2011), the prevalence rate of persons with ID was stated to amount to 1.037%. This estimate was known to vary according to study design (cross-sectional vs. cohort), origin of data (national register, register of care providers), population characteristics (e.g., age group) and country specifics (low income vs. high income countries). Besides, the definition of ID used to identify persons with ID also affected the prevalence estimate. Prevalence rates were in general higher in males than in females in all age groups. Half of all diagnosed ID cases were related to antenatal (e.g., Down Syndrome), perinatal (e.g., anoxia) and postnatal causes (e.g., accidents), whereas for the rest their ID aetiology was unknown (Maulik et al., 2011).

1.2. Epidemiological trends

Recent research studies report on epidemiological changes with respect to the ID population and their impact on the organisation of health and social services providing support to persons with ID. Due to advances in medicine, two trends for this population can be observed: babies born prematurely or with birth defects survive more often and life expectancy figures of persons with ID are approaching those of the general population (Köhncke, 2009). Besides, methods of prenatal diagnosis are constantly advancing, which in turn affects the number of live births with certain syndromes related to intellectual disabilities. Following these developments, the composition of the ID population seems to be changing: Brosco, Mattingly and Sanders (2006) evaluated the impact of specific medical interventions on reducing the prevalence of ID. They concluded that the prevalence figures caused by a number of specific biological conditions (e.g., congenital syphilis, rhesus haemolytic disease of the newborn, measles, haemophilus influenzae type b meningitis, congenital

hypothyroidism, phenylketonuria and congenital rubella syndrome) have decreased sharply over the last 50 years. According to Köhncke (2009), the availability of prenatal diagnosis is related to the discovered decrease in the number of children born with Down Syndrome in Western European countries. Köhncke (2009) provides figures for Germany, Denmark and France. Similar to her report, Brajenovic-Milic et al. (2008) found a decreasing but non-significant trend for the period 1996-2005 in Croatia. They mentioned that the application of diagnostics like amniocentesis was too low to demonstrate any significant impact on the prevalence of Down syndrome in live births. On the contrary, other researchers have discovered an upward trend in the number of live births with Down syndrome due to the increase in age of pregnant women (e.g., Siffel, Correa, Cragan & Alverson, 2004; Irving, Basu, Richmond, Burn & Wren, 2008; De Graaf et al., 2011). As there seem to be different conflicting trends, further research needs to focus on the impact of prenatal diagnosis on the prevalence rates of ID. Figures and research on the changes concerning other syndromes, which are known to be related to the prevalence of ID, are generally missing.

1.2.1. Ageing of persons with ID

In addition to the changes related to the composition of the ID population, the age structure is shifting as the life expectancy of persons with ID is rising. This trend is of special interest as the availability of information on current and future demands is essential for the strategic planning of social services, but also for future research projects dealing with the ID population. There are only a few studies which published data on the changing age structure of the ID population: Köhncke (2009) mentioned an increase of the number of 60+ persons with ID by between 14% and 31%, depending on different statistical presumptions. Emerson (2009) also reported a sustained and accelerating growth in the number of adults with profound ID and calculated an average annual increase of 1.8% for the ID population. Dieckmann and Giovis (2012) depicted future trends for the period 2010-2030 in Germany.

They highlighted that, as life expectancy is rising and the baby-boomer generation of the 1960s is ageing, the age group 60+ will increase by 21%. The authors emphasised that public services, health provisions and policy regulations will need to adapt to this trend since those who care for persons with ID are ageing as well. Eley, Boyes, Young and Hegney (2009) stated that the number of carers over 65 will have grown by 110% by 2031 and, at the same time, the number of persons with profound disabilities due to unhealthy ageing will increase by 160%. Parrott, Wolstenholme and Tilley (2008) describe this negative trend of age-related health changes for persons with ID. In this respect, Janicki et al. (2002) found that diagnoses of cardiovascular, musculoskeletal, respiratory conditions as well as sensory impairments increased with age. In the whole sample of 1371 adults between 40 and 79 years 49% had problems seeing well and 27% had problems hearing well. In addition to this, the rate of skin diseases (20-25% of the sample), gastro intestinal problems (12%) and dementia (less than 2%) increases with age.

All these findings imply necessary adaptations of existing services structures and governmental provisions to make them able to provide the best possible support to the growing and unhealthily ageing population of persons with ID.

1.3. Health status of persons with ID

The next chapter will in brief summarise international literature concerning the mental and physical health of persons with ID to illustrate their current health situation.

1.3.1. Mental health

In general, research results show an increased actual prevalence of mental health problems in children and adolescents with ID with a reported figure of 36% (Emerson & Hatton, 2007). Boys manifest more behavioural problems than girls, especially in the form of disruptive, self-absorbed and antisocial behaviours (Molteno, Molteno, Finchilescu & Dawes,

2001). Besides, behavioural difficulties are more frequently diagnosed in children with severe and profound ID than in children with mild or moderate ID (Molteno et al., 2001).

Similarly to this data on children and adolescents, prevalence figures of psychiatric disorders in adults with ID are high, although figures differ according to the used diagnostic instruments/strategies and the composition of the sample (inclusion of certain syndromes, age, country) (e.g., Myrbakk & Von Tetzchner, 2008; Mantry et al., 2008; Moss, Oliver, Arron, Burbidge & Berg, 2009). Myrbakk and von Tetzchner (2008) underline the strong correlation between behavioural problems (e.g., aggressive, self-injurious behaviour) and psychiatric disorders (e.g., anxiety disorder, Autistic Spectrum disorder, depression, dementia): 69% showed both behavioural problems and psychiatric symptoms, while 29% have only psychiatric problems. Adults with mild ID are more likely to suffer from psychosis and depression than people with severe/profound ID, who more frequently display behavioural disorders and autistic spectrum disorders (Bhaumik, Tyrer, McGrother & Ganghadaran, 2008).

1.3.2. Physical health

In addition to the data on mental health, studies show that the health status of persons with ID is more prone to physical illnesses than the general population. With respect to varying prevalence figures, Jansen, Krol, Groothoff and Post (2004) emphasised the importance of distinguishing objective data gathered through medical records or medical examinations and subjective data gained in interviews. Prevalence figures differ between carer reports of health issues and examinations by health professionals, for example.

Results demonstrated that persons with ID are at an increased risk of developing sensory problems (Owens, Kerker, Zigler & Horwitz, 2006; Van den Broek, Janssen, van Ramshorst & Deen, 2006; Meuwese-Jongejeugd et al., 2006; Mantry et al., 2008), suffering from bad oral health (Reid, Chenette & Macek, 2003; Pradhan, Slade & Spencer, 2009),

epilepsy (McGrother et al., 2006; Morgan, Baxter, Kerr & MacLean, 2003), chronic diseases (Draheim, 2006; Wallace & Schluter, 2008; De Winter, Magilsen, van Alfen, Penning & Evenhuis, 2009; Van de Louw, Vorstenbosch, Vinck, Penning & Evenhuis, 2009), constipation (Böhmer, Taminiau, Klinkenberg-Knol & Meuwissen, 2001; Morad, Nelson, Merrick, Davidson & Carmeli, 2007), incontinence (Mantry et al., 2008) and cancer in the gallbladder and the thyroid gland (Patja, Eero & Iivanainen, 2001). Certain health risks are related to the aetiology of the disability (Mantry et al., 2008) and the severity of the ID (Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001). In connection to these major influencing factors, the place of residence or the type of received support (e.g., community based living, family supported living, institutionalised living; Morgan et al., 2003) was also reported as influencing factor of certain health risks. In addition to this, the risk of impairments increases with age (Evenhuis et al., 2001; Janicki et al., 2002).

In conclusion, ID provides various challenges to a society '*whether because of its prevalence, the costs to the public health system, the families and society in general or due to related health complications, ID should be a priority area of study and action in the health field*' (Salvador-Carulla, Rodríguez-Blázquez & Martorell, 2008, p.142). For this reason, not only service providers and governments need to use the information on epidemiological transformations and health issues for their strategic planning and upcoming policy changes, but research also needs to focus on the growing population of unhealthily ageing persons with ID to develop supportive measures for services, carers as well as for persons with ID themselves. The aim of the present thesis, thus, consists in providing support in this respect by explaining which factors influence healthy behaviours of persons with mild/moderate ID.

2. THE HEALTH BEHAVIOUR AND HEALTH KNOWLEDGE PROJECT

The objective of this thesis was to present two aspects of the topic '*health of persons with ID*': the general social-policy view and the specific, psychological aspect, concentrating on the health behaviour of persons with ID.

2.1. The social-policy perspective

With respect to the social-policy perspective, regulations concerning health provisions and health services were reviewed to identify support systems, which are able to improve the health status of persons with ID. However, the literature dealing with health provision measures for persons with ID contained information on human rights violations: a lack of trainings for health professionals on how to communicate with patients with ID or on how to treat ID-related diseases, refused treatments on the ground of disabilities, a lack of preventive interventions and health information in easy-to-read language (e.g., Krahn, Hammond & Turner, 2006; Carpenter, 2008; European Union Agency for Fundamental Rights, 2013).

Bearing in mind these descriptions by researchers, NGO's and health professionals who are working with persons with ID, European governmental reports were then reviewed with respect to the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which deals with the topic of health in two articles (Article 25 Health, Article 26 Habilitation and Rehabilitation). The objective of the CRPD is to act upon enabling optimal care for and support of persons with disabilities through the use of strong international monitoring mechanisms. This major human rights instrument of the United Nations was adopted in 2006 and has so far (October 2012) been ratified by 124 states worldwide, including 21 member states of the European Union and the European Union itself (United Nations Treaty Collection, 2012).

The first paper of this thesis provides a detailed description of the current implementation process of Article 25 and 26 in two European countries (Spain and Hungary)

and information on the status of implementation in the 19 other member states (Brehmer-Rinderer, Zigrovic, Naue & Weber, 2013). Finally, as governmental reports often do not follow the reporting requirements of the Convention, implications and suggestions for improvement are discussed.

2.1.1. Dissertation article published in Journal of Policy and Practice in Intellectual Disabilities

See Annex II for publication history

Journal of **Policy and Practice in Intellectual Disabilities**

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Promoting Health of Persons With Intellectual Disabilities Using the UN Convention on the Rights of Persons With Disabilities: Early Implementation Assessment in Spain and Hungary

Barbara Brehmer-Rinderer*, Lucija Zigrovic*, Ursula Naue†, and Germain Weber‡
*Doctoral College "Empowerment through Human Rights," †Department of Political Science, and ‡Faculty of Psychology, University of Vienna, Vienna, Austria

Abstract The article explores the initial achievements in the process of implementation of the Convention on Rights of Persons with Disabilities (CRPD) with a special focus on health of persons with intellectual disabilities (ID) in Spain and Hungary, the first countries to submit and receive a review for their report in the European Union. The CRPD is a major human rights instrument of the United Nations that was adopted in 2006 with the goal of ensuring protection of rights of persons with disabilities by holding governments accountable for the services they provide to this population. It was found that the reports designed to represent official state comments on the situation of human rights of persons with disabilities often do not follow the reporting requirements of the Convention in terms of required data. Moreover, they do not use a unified understanding of disability promoted by the Convention and make no mention of many important health-related issues. Access to health is generally understood in a purely physical sense of availability and accessibility of services, while no attention is given to specific expectations and needs of persons with disabilities or to the competence of health staff to work with vulnerable groups. In order to be able to implement the Convention, governments need to carefully assess their country's status quo with regard to disability policies and politics, and at the same time need to develop action plans to implement the CRPD.

Keywords: Article 25 (Health), Article 26 (Habilitation and Rehabilitation), Convention on the Rights of Persons with Disabilities (CRPD), intellectual disabilities

INTRODUCTION

Health constitutes a major human rights issue. The preamble to the World Health Organization's (WHO) constitution declares that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (WHO, 2006, p. 1). Today there is strong proof that health is not only determined by an individual's genetic makeup and lifestyle, but also profoundly shaped by the broad social environment in which an individual lives (Coreil, 2010). In the social model of health, health is believed to be subject to several layers of influence (Dahlgren & Whitehead, 1991). The farthest outer layer of the health determinants is made up of general socioeconomic, cultural, and environmental conditions. For vulnerable persons such as persons with disabilities, these conditions require extra attention and frequently additional effort on behalf of the society. It is exactly the aim of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to act upon enabling optimal care for and support of persons with disabilities by influencing these outer layers of determinants of health through the use of strong international monitoring mechanisms.

The Convention is a major human rights instrument of the United Nations that was adopted in 2006 and that as of January 2013 has been signed onto by 155 states worldwide (United Nations Treaty Collection, 2012a). Article 1 of the Convention summarizes the purpose, which is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (Ghandhi, 2008, p. 200). Further, the target group of the CRPD includes persons with disabilities "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in

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Correspondence: Barbara Brehmer-Rinderer, Clinical and Health Psychologist, Doctoral College "Empowerment through Human Rights," University of Vienna, Hörlgasse 6, 1090 Vienna, Austria. Tel: +43 1 4277 22347; Fax: +43 1 4277 27429; E-mail: barbara.brehmer@univie.ac.at

society on an equal basis with others" (Ghandhi, 2008, p. 200). This understanding of disability obviously comprises not only children, young, and adult persons with disabilities, but also persons with age-related impairments including persons diagnosed with dementia (see Naue & Kroll, 2010; WHO, 2012a). The goal of this article is to explore the initial achievements in the process of implementation of the CRPD, in the field of health of persons with intellectual disabilities (ID). To date, a total of 21 countries of the European Union have adopted and ratified the Convention, out of which only nine had so far submitted the initial State Report (see Table 1). The Committee on the Rights of Persons with Disabilities, a body of 18 elected independent, international experts (most of them are persons with disabilities themselves) that monitors the implementation of the Convention, has so far commented on two of them: those of Spain and Hungary. The availability of both the State Reports and the comments by the Committee of these two countries formed the basis for this analysis. The insights are however supplemented by information obtained from the remaining available reports (see Table 1).

The objective of this paper is to investigate the documents related to the implementation of the CRPD concerning health of persons with disabilities in order to explore the initial achievements of this important document in two European countries. The paper aims to serve as a preliminary and unfolding assessment of this issue. Obviously, sustainable policy change cannot be analyzed within this short period of time the CRPD has been ratified. However, this paper can be seen as a policy-relevant basis for discussing the status of early implementation of the CRPD in the European context as first national reports may be used as an orientation by other countries. On the basis of this momentary assessment, future steps necessary to improve the health situation of persons with disabilities using mechanisms such as the CRPD are outlined and discussed.

TABLE 1
Status of CRPD ratification and reporting by EU member states (United Nations Treaty Collection, 2012a; 2012b)

EU member states	Status CRPD ratification	Status optional protocol ratification	Status initial state report
Austria	September 26, 2008	September 26, 2008	Submitted
Belgium	July 2, 2009	July 2, 2009	Submitted, not available
Bulgaria	March 22, 2012	None, but signed	Due 2014
Cyprus	June 27, 2011	June 27, 2011	Due 2013
Czech Republic	September 28, 2009	None, but signed	Submitted
Denmark	July 24, 2009	None	Submitted
Estonia	None, but signed	May 30, 2012	—
Finland	None, but signed	None, but signed	—
France	February 18, 2010	February 18, 2010	Due 2012
Germany	February 24, 2009	February 24, 2009	Submitted
Greece	None, but signed	May 31, 2012	—
Hungary	July 20, 2007	July 20, 2007	Committee report
Ireland	None, but signed	None	—
Italy	May 15, 2009	May 15, 2009	Overdue
Latvia	March 1, 2010	August 31, 2010	Due 2012
Lithuania	August 18, 2010	August 18, 2010	Due 2012
Luxembourg	September 26, 2011	September 26, 2011	Due 2013
Malta	October 10, 2012	October 10, 2012	Due 2014
Netherlands	None, but signed	None	—
Poland	None, but signed	None	—
Portugal	September 23, 2009	September 23, 2009	Overdue
Rumania	January 31, 2011	None, but signed	Due 2013
Slovakia	May 26, 2010	May 26, 2010	Due 2012
Slovenia	April 24, 2008	April 24, 2008	Overdue
Spain	December 3, 2007	December 3, 2007	Committee report
Sweden	December 15, 2008	December 15, 2008	Submitted
United Kingdom	June 8, 2009	August 7, 2009	Submitted

Note. *Ratification*, unlike *signature*, refers to the act through which a State establishes its consent to be bound by a treaty. The Convention thus becomes part of the legal system of the State. States which only signed a Convention have only an obligation to refrain, in good faith, from acts that would defeat the object and purpose of the treaty (UN Enable, 2012).
CRPD, Convention on Rights of Persons with Disabilities

HEALTH OF PERSONS WITH ID

Research has shown that persons with ID face numerous health-related challenges (O'Hara, McCarthy, & Bouras, 2010; Ouellette-Kuntz, 2005). To demonstrate this, Table 2 lists examples of physical, mental, and social health issues that persons with ID experience more frequently than persons without disabilities.

It has been observed that weight problems are more common among people with ID than in the general population (McGuire, Daly, & Smyth, 2007; Martínez-Leal, Salvador-Carulla, Linehan, Walsh, Weber, Van Hove et al., 2011). Some groups of persons with ID are more likely to be underweight (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008; De, Small, & Baur, 2008; Emerson, 2005). This is especially common in the group of severely/profound disabled persons due to feeding difficulties and often leads to additional health problems, for example, increased susceptibility to infections (Kennedy, McCombie, Dawes, McConnell, & Dunnigan, 1997). At the same time, obesity is frequently found in persons with mild/moderate ID living with their families (George, Shacter, & Johnson, 2011). A quarter to one-third of all persons with ID are obese—with related health issues such as diabetes or gastrointestinal diseases found to be frequent as well (see Table 2).

Another physical health issue raised in research on persons with ID is oral health. International research shows that teeth decay and parodonthosis are found more frequently among persons with ID than in the general population (Owens, Kerker, Zigler, & Horwitz, 2006). It also seems that dental problems of persons with ID are usually treated more invasively: Tooth extractions occur more often than tooth preservative treatments (Anders & Davis, 2010).

International research has revealed that mental health problems and behavioral disorders are also more common among adults with ID compared with the general population (see Table 2). Emerson and Hatton (2007) determined the prevalence of psychiatric disorders in children and adolescents with ID as well as in children without ID. Some 36% of children with ID fulfilled criteria for at least one psychiatric disorder. The prevalence rate among nondisabled children was only 8%.

The European project POMONA II focusing on health issues in adults with ID revealed that health disparities in persons with ID exist all over Europe (Perry et al., 2010). Although countries differ with respect to their national history and economic development, the health status of persons with ID is adverse across the countries. Additional research findings also indicate major health disparities for people with ID when compared with the general population (Jansen, Krol, Groothoff, & Post, 2004; Krahn, Hammond, & Turner, 2006). Various studies have proven that due to the sensitive health status of persons with ID, their hospitalization rate is higher than in persons without ID (Balogh, Brownell, Ouellette-Kuntz, & Colantonio, 2010).

Also, most directly connected to the issues addressed by the CRPD, persons with ID face substantial barriers when accessing existing health services that are generally designed for the general population (e.g., provision of medical information in accessible formats; O'Regan & Drummond, 2008), partly also because persons with ID are disproportionately represented among the poorer sections of the population, due to their limited ability to engage in gainful employment and the elevated costs of their care (see Table 2). The vulnerable socioeconomic position of persons with ID is a crucial, yet often neglected aspect influencing their health: "It points to evidence that socioeconomic position is the fundamental determinant of health, drawing on longitudinal studies to highlight how it exerts its influence on health from before birth and across the life-course" (Graham, 2005, p. 101).

THE CRPD AND THE REPORTING PROCEDURE

In order to better understand the possibilities of CRPD in addressing the health-related needs of persons with ID, it is necessary to know the official procedure tied to the implementation of the Convention. Two years after ratifying the CRPD, a State Party is obliged to submit the first National Report on the situation of persons with disabilities to the UN-based Committee on the Rights of Persons with Disabilities (Committee on the Rights of Persons with Disabilities, 2009). The working procedures and competences of the Committee are described in the Optional Protocol of the CRPD. A State Party can sign or ratify this Protocol likewise to the Convention itself, but can in addition declare reservations to certain Articles of this Protocol and thereby not recognize entirely the competence of the Committee provided. The reports must adhere to formal standards required by the Committee. These reports are then discussed in the session of the Committee on the Rights of Persons with Disabilities. The Committee convenes twice a year for sessions of 1 week in duration, normally in February and October at the offices of the United Nations in Geneva. The Committee comments and criticizes the information provided in these reports and can give recommendations to the countries. These recommendations are however not binding in nature. Not only State Parties submit official national reports, but reports are also received from representatives of the civil society, in order to serve as a non-governmental, complementary view on the matter.

To be able to analyze the State Reports accurately, it is necessary to have a good knowledge of the Reporting Guidelines compiled by the Committee on the Rights of Persons with Disabilities. According to these, the initial report should deal with every article of the CRPD and give "a detailed analysis of the impact of legal norms on persons with disabilities' factual situation and the practical availability, implementation and effect of remedies for violations" (Committee on the Rights of Persons with Disabilities, 2009, p. 4). It should be indicated which policies and laws have been adopted since ratification. On a number of occasions, it is stressed in the Reporting Guidelines that States Parties shall ensure that their document is "specific to different types of disability" (Committee on the Rights of Persons with Disabilities, 2009, p. 2).

Additionally, this treaty document should illustrate "statistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories, on an annual comparative basis over the past four years" (Committee on the Rights of Persons with Disabilities, 2009, p. 4). States Parties should not only provide statistical

TABLE 2
Examples of research demonstrating health-related challenges faced by persons with intellectual disability (ID)

Health domain				
Health domain				
Physical health	Weight status	Bhaumik et al. (2008): 18.6% underweight, 28% overweight, 20.7% obese	De et al. (2008): 24% overweight, 15% obese Stewart et al. (2009): 36% obese	Gazizova, Puri, Singh, and Dhaliwal (2011) 28% overweight, 41% obese
	Weight-related physical problems	De Winter, Magilsen, van Alfen, Penning, and Evenhuis (2009): 8.7% diabetes	Galli-Carminati, Chauvet, and Deriaz (2006): 48.8% gastrointestinal disorders	Van de Louw, Vorstenbosch, Vinck, Penning, and Evenhuis (2009): 17.4% hypertension De Winter et al. (2009): 36.8% hypertension
Psychological Health	General psychiatric problems	Bakken et al. (2010): 17.4% psychiatric disorders	Morgan, Leonard, Bourke, and Jablensky (2008): 31.7% psychiatric disorders	Deb, Thomas, and Bright (2001): 14.4% psychiatric disorder
	Psychotic disorder/ Schizophrenia	De Kuijper et al. (2010): 11.7% psychotic disorder	Morgan et al. (2008): 3.7–5.2% schizophrenia	Deb et al. (2001): 4.4% schizophrenia
Health provision barriers	Structural/financial	Krahn et al. (2006): inadequate access to quality healthcare services	Drainoni et al. (2006): financial barriers for equipment, repairs, supplies, prescription, etc.	Nocon (2006) described different hindrances that led to health inequalities experienced by persons with ID
	Information	O'Regan and Drummond (2008): Substantial dearth of services exists, including the lack of appropriate cancer information. This presents an alarming obstacle to high-quality cancer care.		
	Personal	Slevin and Sines (1996): • Fifty percent of the nurses do not feel competent enough to care for a patient with ID. • Most nurses fear behavior disturbances by a patient with ID. Werner and Stawski (2012): Review findings stress the need to improve knowledge, competence, and attitudes of practitioners.	Hart (1998) reported similar findings for England concerning the availability of specialized training of health professionals. Robertson, Roberts, Emerson, Turner, and Greig (2011): importance of experts and health checks to detect unmet health needs and targeted actions to address these	Drainoni et al. (2006): Personal or cultural barriers like • negative attitudes • misperceptions • lack of knowledge or respect • unwillingness to provide care, which is often followed by the withholding of a treatment or the provision of inferior treatment
	Communication	Iacono and Davis (2003): Lack of knowledge, skills, and confidence in health professionals who are working with disabled people	D. Brooks (2001): • poor communication skills of health professional and clients • problems obtaining histories and examination of clients	Similar reports by Kerr (1998)

data, but also describe how they were collected and if persons with disabilities participated in the process (Committee on the Rights of Persons with Disabilities, 2009, p. 18f). Further, the modes of dissemination of statistical data and their accessibility for persons with disabilities should be specified (Committee on the Rights of Persons with Disabilities, 2009, p. 18). Apart from these general reporting guidelines, States Parties are expected to comment on all aspects of the Conventions' articles in their initial report.

For the purpose of this article, we will focus on how this Convention can be used to promote individual health and adequate health provisions for persons with ID. These two elements are addressed in the Articles 25 (Health) and 26 (Habilitation and Rehabilitation) of the CRPD. Article 25 of the CRPD summarizes the States Parties' obligations relating to health provision (Ghandhi, 2008). It notes that States Parties are expected to ensure that the persons with ID receive "the same range, quality and standard of free or affordable health care" (Ghandhi, 2008, p. 208) as provided for persons without disabilities. Discrimination in the provision of health insurance must be prohibited and health services that are specialized on disability including preventive programs must be available. These health services must be "as close as possible to people's own communities" (Ghandhi, 2008, p. 208). Health professionals must adhere and not deny the needs of persons with disabilities. Additionally, health professionals must be trained to offer care, free of any kind of discrimination.

Article 26 of the CRPD outlines the States Parties' obligations pertaining to habilitation and rehabilitation in the areas of health, employment, education, and social services. These measures, "based on the multidisciplinary assessment of individual needs and strengths" (Ghandhi, 2008, p. 208), should "begin at the earliest possible stage" (Ghandhi, 2008, p. 208) and lead to "maximum independence, full physical, mental, social and vocational ability" (Ghandhi, 2008, p. 208). Here, a special focus lies on the availability of special technological devices. Apart from that, the States Parties should ensure continuous training of professionals working in the field of habilitation and rehabilitation.

ANALYZING THE INITIAL ACHIEVEMENTS IN CRPD IMPLEMENTATION BASED ON STATE REPORTS AND COMMENTS BY THE COMMITTEE

As of October 2012, nine initial European State Reports on the implementation process have been submitted (see Table 1). Only Spain and Hungary have so far received comments of the Committee on the Rights of Persons with Disabilities (see Table 3, Spain in the 6th Session in 2011 and Hungary in the 8th Session in 2012). Critical documents by national nongovernmental organizations (Hungarian Disability Caucus and the Comité Español de Representantes de Personas Con Discapacidad) on their State Reports, so called Civil Society Reports, were also considered by the Committee before it published its comments on the UN website. In the following section, features of these documents will be presented with a focus on Articles 25 and 26 of the CRPD.

In terms of CRPD background in the mentioned countries, it is to be noted that Hungary ratified the UN Convention on the Rights of Persons with Disabilities on the July 20, 2007, as one of the first countries (see Table 1).

Based on the Hungarian state report, it can be concluded that in Hungary, the definition of disability that is used in provision of social services is based on the medical model of disability (see Table 3). It seems that disabilities that are due to natural aging are excluded from the group of persons with disabilities addressed by the Convention. Besides, people with psychosocial disabilities (i.e., persons with psychological disorders and impaired social function) are explicitly excluded (see Table 3). With respect to this group, the Committee asked for information on the measures that are taken to provide them with protection of their rights (Committee on the Rights of Persons with Disabilities, 2012a, p. 1). In their second statement in September 2012, the Committee addressed their concern directly: "The Committee notes with concern that definitions of disability and persons with disabilities in the State Party's legislation focus on the impairments of an individual rather than on the barriers he/she faces. The Committee expresses its concern that such definitions fail to encompass all persons with disabilities, including those with psychosocial disabilities" (Committee on the Rights of Persons with Disabilities, 2012b, p. 2).

Hungary is currently focusing on increasing the accessibility of buildings to people with physical disabilities, with the December 31, 2012, as the deadline for the completion of this project. The Committee asked for more information on whether the deadline can be achieve especially for building of educational, health, and social services (Committee on the Rights of Persons with Disabilities, 2012a, p. 2). Throughout the report, various supportive programs for different disabilities are noted, whereas the only explicit reference to persons with ID can be found in the description of a Program "Accept It and Accept Me" (Hungary National Report, 2010, p. 13). However, this program is primarily an awareness raising program (cited in response to Article 8 of the CRPD "Awareness Raising"), not a program working directly with persons with ID.

Relating to Articles 25 and 26, the state report refers to several elements: general health programs for Hungarian citizens, special measures for persons with disabilities, as well as certain procedures in the health sector are outlined (Hungary National Report, 2010). However, neither the usage of these services by persons with disabilities has been evaluated, nor are research results on their health status presented. It is indicated that the legal regulations differ for different categories of patients in terms of acting capacity (Hungary National Report, 2010, p. 43), but no further details are given. The Committee is further interested if tools and services on sexual and reproductive health are accessible and available to persons with disabilities (Committee on the Rights of Persons with Disabilities, 2012a, p. 3).

Spain ratified the UN Convention on the Rights of Persons with Disabilities on December 3, 2007 (see Table 1). In Spain, the CRPD implementation is being monitored by the "Comite Espanol de representantes de personas con discapacidad" (CERMI). CERMI is responsible for the Spanish civil society report. As of October 2012, the Spanish documents had been reviewed by the Committee on the Rights of Persons with

TABLE 3
Content of States Parties' Reports and comments by the Committee

	Reports on Hungary	Reports on Spain	Other submitted EU State Reports
Article 1 (Purpose including disability definition)	Individuals with psychosocial disabilities are not considered persons belonging to the group of disabled people, but after ratification they were invited to the National Council of Disability (Hungary National Report, 2010, p. 3). It is not mentioned precisely, but it seems that disabilities caused by aging are excluded from the Conventions' target group as well. Definitions are based upon the medical model. Therefore, the Committee asks how the definition is going to be brought in compliance with Article 1 of the UN Convention (Committee on the Rights of Persons with Disabilities, 2012a; 2012b, p. 1; p. 2).	It is stated that definitions used follow the social model of disability (Spain National Report, 2010, p. 3). The Committee asked for further information "on the steps being taken to revise existing legislation in order to comply with the Convention" (Committee on the Rights of Persons with Disabilities, 2011, p. 1).	Denmark (Denmark National Report, 2011, p. 5) and the United Kingdom (United Kingdom National Report, 2011, p. 7) point out that their definition of disability confirm to the social model of disability. Germany (Bundesministerium für Arbeit und Soziales, 2011, p. 6) and Sweden's definition (Ministry of Health and Social Affairs, 2011, p. 6) apply to the International Classification of Functioning, Disability and Health (WHO, 2001). Like Hungary, Sweden (Ministry of Health and Social Affairs, 2011, p. 6) excludes persons who become disabled through ageing from the CRPD target group. Both Austria (Federal Ministry of Labour, Social Affairs and Consumer, 2010, p. 3f) and the Czech Republic (Czech Republic National Report, 2011, p. 4) have no unified understanding, but numerous definitions existing, mainly representing the medical model of disability.
Article 25 (Health)	The Committee asked for "data as to whether tools and services on sexual and reproductive health are accessible and available to persons with disabilities in accessible formats and technologies, and in augmentative and alternative mode" (Committee on the Rights of Persons with Disabilities, 2012a, p. 3), because these questions were not answered by the State Report. A national nongovernmental organization voiced a critique in their report to the Committee, stating that this right is not properly respected for persons with ID due to the following reasons: "geographical inequalities, lack of personal and material conditions, especially the lack of special training of medical staff, and the lack of specialised health care providers" (Hungarian Disability Caucus, 2012, p. 7).	More information is requested on how many health facilities provide accessible modes of communication (Committee on the Rights of Persons with Disabilities, 2011, p. 3). As the State report does not mention protection against discrimination in health insurance matters, the Committee asked for more details on legal prevention measures in this domain (Committee on the Rights of Persons with Disabilities, 2011, p. 3). The Spanish State report claims that general protection against discrimination of persons with disabilities exists (Spain National Report, 2010, p. 3) as well as same access to quality health services. Other specific questions as outlined in the Reporting Guidelines are not answered.	The United Kingdom followed the Reporting Guidelines quite closely, also stating that "the UK is committed to reducing the difference in health outcomes between disabled and non-disabled people, to enabling disabled people to have the same health care choices as non-disabled people and to meeting additional needs, including access needs" (United Kingdom National Report, 2011, p. 42). With respect to physical access to health care, only Germany (Bundesministerium für Arbeit und Soziales, 2011, p. 39) and Austria (Federal Ministry of Labour, Social Affairs and Consumer, 2010, p. 38) admit that improvements are still necessary. Apart from Denmark, no other country highlights differences between disability types (Denmark National Report, 2011, p. 29). Like Spain, three other EU countries (Czech Republic, Denmark, and Sweden) did not report on protection from discrimination in health insurance matters, whereas the rest highlight their protection measures. No country reports on training for health professionals.

Article 26 (Habilitation and Rehabilitation)	Currently no comments by the Committee. Generally no differentiation is made according to disability type, in the report. Most descriptions depict the situation with regard to the general population, not focusing on any kinds of disabilities.	In this State Report, Article 25 and 26 are treated as one topic and no details are given on Article 26. Therefore, the Committee asked for further information on community-based rehabilitation and measures that are taken to increase habilitation and rehabilitation benefits (Committee on the Rights of Persons with Disabilities, 2011, p. 3).	Few reporting guidelines are met: Whereas the training of health professionals is only commented by the United Kingdom (United Kingdom National Report, 2011, p. 46), even four states (Austria (p. 40), Czech Republic (p. 59f), Sweden (p. 38f), United Kingdom (p. 46)) highlight the point "assistive devices and technologies." Austria (Federal Ministry of Labour, Social Affairs and Consumer, 2010, p. 40), Denmark (Denmark National Report, 2011, p. 33), and Sweden (Ministry of Health and Social Affairs, 2011, p. 38f) describe mainly existing forms of rehabilitation with no specific information given to certain disabilities. Likewise, Germany mentions general legal regulations and its goal to strengthen people's self-determination (Bundesministerium für Arbeit und Soziales, 2011, p. 42). Both countries do not comment on the guidelines specifically.
Article 31 (Statistics and data gathering)	Data differentiated according to disability form are given for Article 24. Generally, a need for more data on persons with disabilities is mentioned (Hungary National Report, 2010, p. 69). The Committee explicitly regrets the low level of disaggregated data on persons with disabilities and recommends systematizing the collection, analysis, and dissemination of data (Committee on the Rights of Persons with Disabilities, 2012a, p. 7). It is not mentioned whether persons with disabilities are included in the data-gathering process.	In total, very little data are provided in the report. Different surveys by the National Statistical Institute are described in the report. No differentiation between forms of disability is made in the report. It is not mentioned whether persons with disabilities are included in the data-gathering process.	All countries provide very little data. None presents health facts. Denmark mentions that "no common norm exists for data processing of specific statistics in the disability area, and no permanent norms exist in terms of highlighting the disability aspect in relation to statistics on the individual sectors." (Denmark National Report, 2011, p. 45). The Czech Republic describes a national study on characteristics of disabled persons and mentions their participation in an EU project collecting data, excluding the topic health, on persons with disabilities (Czech Republic National Report, 2011, p. 87).

Disabilities. The Spanish State Report specifies almost no implementation difficulties and paints a positive picture of the living situation of persons with disabilities. It is stated that "the treatment of disability had already developed into a social model in Spanish law before the Convention came into force on 3 May 2008" (Spain National Report, 2010, p. 3). "However, adjustment and amendment of a number of provisions in the different branches of law will be required in order to permit formal incorporation of the Convention into the domestic legal system" (Spain National Report, 2010, p. 4).

With reference to Articles 25 and 26, the Spanish government did not follow the CRPD reporting guidelines (see Table 3). They describe general regulations and physical accessibility of health services, but do not present any statistics on the health status of persons with ID. The depiction of the implementation process predominantly consists of a catalogue of public health services, which are not specifically related to persons with disabilities. Therefore, the Committee asked for further information concerning the accessibility of health services (including accessibility of information) and additional descriptions of health insurance schemes (Committee on the Rights of Persons with Disabilities, 2011, p. 3). At the same time, the CERMI report has shown that existing Spanish legislation does not guarantee nondiscrimination in insurance matters (CERMI, 2011, p. 28). With respect to Article 26, the Committee requested more information on community-based rehabilitation services and other habilitation measures (Committee on the Rights of Persons with Disabilities, 2011, p. 3). In their report, CERMI outlined the need for early care for children with disabilities as well as services for persons with mental disorders (CERMI, 2011, p. 26). Persons with ID are not explicitly mentioned in any of these papers.

GENERAL COMMENTS ON THE STATES PARTIES' REPORTS

All of the currently submitted and available States Parties' Reports, those of Austria (Federal Ministry of Labour, Social Affairs and Consumer, 2010), Belgium (currently not available), Czech Republic (Czech Republic National Report, 2011), Denmark (Denmark National Report, 2011), Germany (Bundesministerium für Arbeit und Soziales, 2011), United Kingdom of Great Britain and Northern Ireland (United Kingdom National Report, 2011), Hungary (Hungary National Report, 2010), Spain (Spain National Report, 2010), and Sweden (Ministry of Health and Social Affairs, 2011), seem to predominantly emphasize accessibility in every way and form. Health appears not to be on their main agenda. When reporting with respect to Articles 25 and 26, all States Parties explain their health system and its regulations only in broad and general terms (see Table 3). As Table 3 shows, most reporting directives are therefore not or are only partially met. For example, no precise answer is given to the question whether all health services are equally available to the persons with disabilities (e.g., pregnancy care for a woman with ID; see Hungary National Report, 2010, p. 43). Furthermore, it is not clearly stated and exemplified whether the availability of information in accessible language (easy-to-read, Braille) actually exists.

Most reports lack differentiation between forms of disabilities (except for Denmark National Report, 2011, p. 29 or p. 31). In general, people with ID are scarcely addressed, in analogy to the observed underrepresentation of this group in national public health surveillance (Linehan, Walsh, Van Schrojenstein Lantman-de Valk, Kerr & Dawson, 2009). The reporting countries greatly differ in their understanding of *disability* and the designated CRPD target group (see Table 3). Some include aging and elderly persons while others exclude persons with mental disorders. The heterogeneity of this target "group" is tremendous, making it difficult to draw relevant conclusions based on general descriptions and provisions. People with ID usually demand substantially different facilitating measures than persons with predominantly physical disabilities or with disabilities associated with age.

No impact analysis of national legislation on the lives of persons with disabilities, as required by the Reporting Guidelines, is currently conducted by the States Parties that reported (see Table 3). Therefore, no infringements or sensitive areas with respect to the implementation of the UN Convention can be observed. Additionally, all States Parties' Reports lack health statistics on persons with disabilities. If no data are gathered, no problems are identified and thus no actions or precautions have to be taken by the government. In words of Stone (2002, p. 127): "Like metaphors, numbers make normative leaps. Measures imply a need for action, because we do not measure things except when we want to change them or change our behavior in response to them."

The reporting countries have signed and ratified the Convention that stresses the importance of strong statistics and research findings as grounds for policy making, thereby recognizing the contribution of health research to establishing adequate health provisions and ensuring high standards of health to their citizens, but no State Report has used existing research data to fill the knowledge gap concerning the health status of persons with disabilities.

Based on the apparent discrepancy between expected and actual reporting, a question can be raised whether it is in fact possible for States Parties to meet the reporting guidelines, based on the kind and scope of data available to them. Some States Parties might be willing to, but are unable to provide the required details because the corresponding data are either not available or not adequately presented and used. It should be noted that the countries that have ratified the Convention were familiar with the Convention requirements at the time of signing, as well as that the Convention and its accompanying documents are a result of several years of consultations with distinguished experts and policymakers in the field. There is therefore no reason to assume that the requested data are in principle unobtainable or that meeting the guidelines' requirements is *a priori* impossible. Because of that, it is possible to conclude that either there are still strong deficiencies in domestic systems when it comes to collecting and presenting statistical health-related data, or that some reporting countries simply do not want to mention insufficient health provision and therefore ignore the reporting guidelines. Even if it is impossible to fully meet all of the requirements for whatever reason, the research findings presented in the section two of this article prove that there is additional knowledge on this topic available, but not addressed

on a governmental level. A further analysis focusing on whether States Parties do not keep to the reporting guidelines because they are either technically unable to, insufficiently aware of the scope of existing data, or are trying to keep deficiencies secret might be necessary. If the Reporting Guidelines are really overly ambitious with regard to the current capabilities of Governments in terms of collecting and presenting data, they either need to be renegotiated or further effort should be put into improving national statistical records. However, it could simply be that the information obtained from research in academic and health institutions does not receive adequate attention of governmental actors.

In their key points and definitions of disabilities used, the European State Reports build strongly on the European Disability Strategy (European Commission, 2010). States Parties report mainly about goals like site accessibility, which are set by this Strategy. It seems that other reporting tasks (such as analyzing the health situation of persons with disabilities according to disability types) are not seen as a priority by the Governments, possibly due to a lack of understanding of importance of health-related research data on a political level or technical shortcomings considered previously.

Furthermore, the documents submitted by the European states lack an impact analysis of the countries' legislation on the lives of persons with disabilities. More data concerning all articles of the Convention need to be gathered, so that precise actions (e.g., the adaptation of insurance policies and the accessibility of information) can be taken by States Parties to ensure high quality of life of persons with disabilities. It is important that persons with disabilities are involved in the planning, conduction, and evaluation of these policy changes. This is a fact that was also highlighted by the Committee in their comment to the Hungarian State Report, where it "regrets the insufficient participation of persons with disabilities and their representation organisations in the review and design of disability-related legislation and policies" (Committee on the Rights of Persons with Disabilities, 2012b, p. 2). User involvement and participation clearly constitute one of the main pillars of this Convention. In addition to this, the WHO (2012b) has published a toolkit, the WHO QualityRights Tool Kit, for this purpose. Two facts observable from the state reports demonstrate in which way problems related to health provision and regarding violations of Articles 25 and 26 of the CRPD can happen:

1. Almost no European Country offers specific education on health needs of persons with ID or provides specialized health centers. Although EU-funded projects such as TRIADD (2005, for frontline staff), CARERS (2009, for caring relatives), or CONTINUA (2010, eHealth) developed information material and trainings, none of these are performed on a regular basis. Consequently, health professionals may lack expertise, and misdiagnose and even unintentionally mistreat people with ID (see Table 2).
2. Health services are expensive and therefore need to work cost-effectively. However, care and support of a patient with ID often include continuous observation and lead to extra tasks for health professionals. This can result in negative attitudes toward persons with ID and in potentially harmful treatments (e.g., inappropriate sedation, failure to meet particular dietary requirements; Iacono & Davis, 2003).

As required by Articles 25 and 26, specialized health services need to be available in every country. A potential solution to this would be allowing these services to be monitored by their users in order to guarantee the best care possible. Further research projects are necessary in order to obtain more information and develop, for instance, communication guidelines for health professionals. Trainings that have already been developed for frontline staff or family carers should be applied on a regular basis. Additionally, educational curricula for health professionals should be revised and the topic *disability* as well as health-improving strategies especially for persons with disabilities better integrated within them.

Krahn et al. (2006) summarized other steps necessary in order to reduce health disparities between persons with disabilities and the general population, including the promotion of healthy behaviors in accessible information and the empowerment of professional and family carers of persons with disabilities. All these measures can improve not only the quality of life of persons with disabilities, but also of nondisabled people who are in different ways related to or working with persons with disabilities.

The implementation of the CRPD is a long-term process that will significantly influence the way the situation of persons with disabilities is addressed in participating countries. State Reports, Civil Society Reports, and Comments of the UN Committee represent dialogical instruments that comprehensively contribute to the promotion and fulfillment of goals of the CRPD. The possibility to compare situations in different countries based on equal and objective criteria agreed upon by the international community creates the possibility to advocate for improvement in those countries and those areas that are lagging behind. Critical examination and comparison of these documents can be a stimulating challenge for scholars and experts working in this field and wanting to contribute to this process.

CONCLUSION AND RECOMMENDATIONS

In this article, we assessed the initial European State Reports on the CRPD implementation and their reception by the Committee on the Rights of Persons with Disabilities. It was demonstrated that the governmental reports currently do not contain all the information necessary to develop strategies for ameliorating the situation of persons with disabilities. From the content of State Reports, it can be concluded that in the studied countries, health-related research on the population of persons with disabilities does not reach the relevant political actors in this field. Definitions of disability applied by the states do not always reflect the understanding of disability in the Convention (informed by the social model of disability) and little attention is paid to specific vulnerabilities of subgroups of persons with disabilities. Moreover, access to health is understood in a purely physical sense of availability and accessibility of services, while no attention is given to specific expectations and needs of

persons with disabilities or to the competence of health staff to work with vulnerable groups.

The picture of persons with disabilities as helpless individuals, currently conveyed by many governments and lived in everyday life by large parts of society, needs to be transformed into an image of self-determined persons with disabilities (Article 8 of the CRPD). This is not only relevant for governments, but also each and every citizen of a given country. With the help of sensitive campaigns, negative attitudes of health professionals and the society itself could be altered. Awareness raising should not only change the image of persons with disabilities, but also prevent human rights violations and therefore improve the quality of life of persons with disabilities. States Parties need to show more proof that they are considering relevant health-related research findings during the implementation process of the UN CRPD.

In the light of the principles of the UN CRPD, the goal of policy making cannot be separated from the implementation process as such. The so far discussed State Reports by the UN Committee for the Rights of Persons with Disabilities show that governments need to comply with the principles of the CRPD, and that is not an easy task in the context of long-established and mainly negative perceptions of persons with disabilities. Therefore, in order to be able to implement the Convention, governments need to carefully assess their country's status quo with regard to disability policies and politics, and at the same time need to develop action plans to implement the CRPD (complying with the general principles of the CRPD) and change this status quo for the better. The Committee for the Rights of Persons of Disabilities will assess individual countries in a second round 4 years after the First State Reports. This will be the crucial assessment for sustainable and "real" policy change, based upon the CRPD's general principles. In this assessment phase, failures to comply with the general principles of the CRPD will be directly addressed by the Committee for the Rights of Persons with Disabilities.

The CRPD marks a paradigm shift in the understanding of disability and hence, demands from states that have ratified the Convention and civil society in these states not only to rethink current disability policies but to change them by adapting them to the CRPD. If this does not happen to a sufficient extent, the objective of equal opportunities for persons with disabilities cannot be achieved.

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2.2. The psychological perspective

2.2.1. Aim and structure of the health psychological project

After looking at the health situation of persons with ID from the social-policy level, the aim of the present psychological contribution was twofold: first, to review previous health psychological research in the field of ID and analyse existing health models with respect to their practicability to describe risk behaviours in persons with ID and second, to test one health model in this specific population.

Table 1 *Title and content of psychological publications*

Publication	Title	Content
1	*Gesundheitsförderung von Menschen mit intellektueller Behinderung: Stand der Forschung und aktuelle Problembereiche*	literature review and analysis of previous health research in the field of ID analysis of applicability of health models in the general population criteria to define a new health model fitting the characteristics of the ID population
2	*Evaluating a health behaviour model for persons with and without intellectual disabilities*	description of a health model, the General Health Circuit sample, procedure, materials results presented for ID and non-ID sample 1) satisfying psychometric properties of questionnaires 2) GHC findings
3	*The relation of an individual's health knowledge and the personal perception of one's body and disabilities to reported health behaviours in persons with intellectual disabilities*	description of previous literature on health influencing variables in ID population sample, procedure, materials results concerning influencing factors on health behaviour (health/disability perception; body perception; health knowledge)

Following, in a first step the status of health research with respect to the health status and health behaviours of as well as health interventions for persons with ID was depicted (see table 1). Health behaviours were defined as behaviours that are frequently deliberately and autonomously demonstrated by persons with ID. Findings of an extensive literature review were described in a health psychological article ('*Gesundheitsförderung von Menschen mit intellektueller Behinderung: Stand der Forschung und aktuelle Problembereiche';* Brehmer-Rinderer & Weber, accepted for publication). In addition, theoretical health models designed for the general population, their pros and cons as well as their applicability to persons with ID

were illustrated and analysed. Finally, criteria for the development of a new model fitting the characteristics of this specific group were proposed. These criteria also aim to facilitate the development of useful evaluation strategies for existing health behaviour studies, as well as define potentially future care measures (Brehmer-Rinderer, Zigrovic & Weber, 2013). The second psychological contribution ('*Evaluating a health behaviour model for persons with and without intellectual disabilities*', Brehmer-Rinderer et al., 2013) focused on two aspects: a) to illustrate the definition and operationalisation of the suggested theory, *the General Health Circuit* (GHC, see figure 1), fitting the characteristics of an ID population that is able to communicate verbally and b) to describe its testing in a mixed sample, consisting of persons with ID, carers of persons with ID and a comparative sample from the GP, in order to explore systematic differences.

The third publication summarizes additional findings on factors influencing (health/disability perception; body perception; health knowledge) the health behaviour of persons with ID (see table 1; Brehmer-Rinderer, Zigrovic, Zeilinger & Weber, submitted).

2.2.2. Health Model, the General Health Circuit

According to Brehmer-Rinderer et al. (2013), the key proposal of this model is that the personal understanding of *health/illness/disability* influences the individual perception of oneself and the way someone perceive him/herself defines the behavioural approach that is taken (see figure 1). This theory was designed on the basis of proposed criteria, which resulted from extensive literature review (see first and second psychological publication, table 1).

Figure 1 *General Health Circuit*

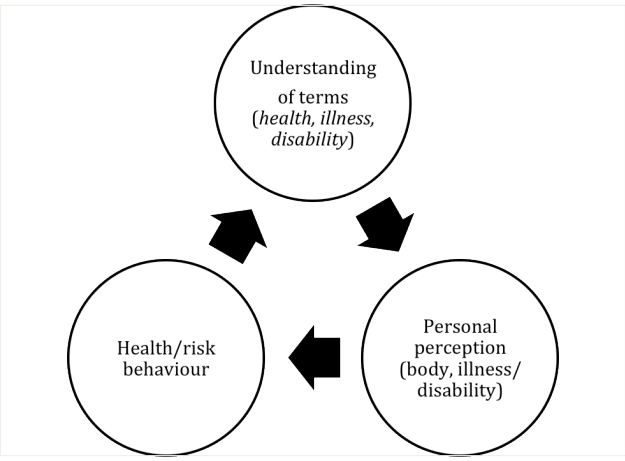

Illustration published in Brehmer-Rinderer, Zigrovic & Weber (Journal of Intellectual Disability Research)

2.2.2.1. Dissertation article accepted for publication in Zeitschrift für Gesundheitspsychologie

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GESUNDHEITSFÖRDERUNG VON MENSCHEN MIT INTELLEKTUELLER BEHINDERUNG: STAND DER FORSCHUNG UND AKTUELLE PROBLEMBEREICHE

Mag. Barbara Brehmer-Rinderer
Universität Wien, Initiativkolleg "Empowerment through Human Rights"
barbara.brehmer@univie.ac.at

a.o.Univ.-Prof. Dr. Germain Weber
Universität Wien, Fakultät für Psychologie, Institut für Angewandte Psychologie: Gesundheit, Entwicklung und Förderung
germain.weber@univie.ac.at

Deutsches Abstract

Zahlreiche Publikationen belegen, dass die Gesundheit von Menschen mit intellektueller Behinderung (IB) für Krankheiten und Störungen anfälliger ist als die der Allgemeinbevölkerung. Zudem sind bestimmte Risikoverhaltensweisen (z.B. schlechte Ernährung und wenig Bewegung) häufiger bei dieser Personengruppe zu finden. Trotz der sensibleren Gesundheitssituation steht die gesundheitspsychologische Forschung für Menschen mit IB noch am Anfang.

Für diesen Überblicksartikel wurde Fachliteratur über Menschen mit IB nach gesundheitspsychologischen Konzeptionen durchsucht und bestehende Forschungsarbeiten analysiert. Des Weiteren wurden rezente Gesundheitsmodelle sowie Kontinuitäts- und Stadienmodelle für die Allgemeinbevölkerung und ihre einzelnen Bestandteile hinsichtlich ihrer Übertragbarkeit auf diese spezielle Population untersucht.

Eine Generalisierung von Gesundheitsmodellen der Allgemeinbevölkerung auf die Gruppe von Menschen mit IB erscheint aus verschiedenen Gründen problematisch. So erweist sich z.B. die Erfassung einzelner Bestandteile durch ihre Abstraktheit als zu komplex für Menschen mit IB. Dieses und ähnliche Forschungshindernisse werden in diesem Artikel besprochen. Diese genaue Analyse hilft jedoch notwendige Kriterien für die Entwicklung eines theoretischen Gesundheitsmodells speziell für Menschen mit IB zu erstellen.

Schlussendlich werden relevante Modellbausteine für Menschen mit IB, die auf den präsentierten Forschungsergebnissen aufbauen, vorgestellt und diskutiert. Schließlich werden zukünftige Forschungsfragen erörtert.

Keywords: Intellektuelle Behinderung, Gesundheitsverhalten, Gesundheitsmodelle, Gesundheitsprävention

English Abstract

Numerous research studies report that health status and health behaviour of people with intellectual disability (ID) is worse than in persons without disabilities. For the general population, different health theories exist, which explain how healthy behaviours develop and how risky behaviours can be effectively treated. Although their health status is worse, it seems that health psychology is not a prominent research topic among studies in the field of ID.

For this article scientific literature on health psychology and persons with ID was reviewed. First, this paper presents current research on health status, health behaviour and health interventions conducted in the ID population. Second, as no health theories, which have been especially designed to measure health behaviours among persons with ID, exist, the applicability of prominent health psychological models for the general population with respect to the ID population is analysed and described. For various reasons, a transfer of health models as developed for the general population to the ID population seems to be problematic. One example is the complex measurement strategy most health models use: questionnaires contain hypothetical situations or abstract topics, which are hard to answer for persons with cognitive impairments. However, the analysis of variables, which hinder the usage of these theories in persons with ID helps to identify necessary criteria for the development of a theoretical health model for the ID population.

Finally, the elements necessary for a theoretical health model based on the research results as described are suggested and discussed. Additionally, future research perspectives are presented.

Keywords: Intellectual disability, health behaviour, health psychological models, health prevention

1. Einleitung

Gesundheitsförderung, gesundes Verhalten und wie dies die Lebensqualität von Kindern und Erwachsenen stärken kann, finden zunehmend Aufmerksamkeit. In der Ottawa Charta der Weltgesundheitsorganisation von 1986 wird Gesundheitsförderung als ein Prozess beschrieben, der Menschen dazu befähigt, ihre Gesundheit selbst zu bestimmen und zu verbessern. Das Hauptziel gesundheitsfördernder Maßnahmen ist über eine gesunde Lebensweise eine Stärkung des geistigen und körperlichen Wohlbefindens zu erreichen. Hierbei wird Gesundheit als Ressource für den Alltag verstanden, die es dem Einzelnen oder der Gruppe erlaubt eigene Ziele zu entwickeln und zu verwirklichen bzw. ihre Bedürfnisse zu befriedigen sowie ihre Umwelt zu gestalten. Die europäische Gesundheitspolitik setzt an diesen Zielsetzungen einer so verstandenen Gesundheitsförderung an. So werden Maßnahmen gegen zunehmendes Rauchverhalten und mangelhafte oder zu üppige Ernährung eingesetzt, aber auch der ansteigende Bewegungsmangel rückt als Gesundheitsthematik vermehrt in das öffentliche Interesse. Präventionsprogramme werden immer zahlreicher finanziert und durchgeführt, um einerseits Gesundheitsverhaltensweisen wie Sonnenschutz, gesunde Ernährung und Bewegung zu fördern und folglich die Lebensqualität der BürgerInnen zu erhöhen. Anderseits belasten gesunde BürgerInnen ihre Gesundheitssysteme kaum und somit können präventive Maßnahmen dazu beitragen langfristig Kosten zu reduzieren (Reitan, 2011).

Doch gilt diese große Aufmerksamkeit für gesundes Verhalten auch Personen, die eine intellektuelle Behinderung (IB) haben? Welche Präventionsmaßnahmen sind für sie passend und wie sieht das aktuelle Angebot für sie aus? In diesem Artikel wird zunächst die gesundheitliche Situation von Menschen mit intellektueller Behinderung betrachtet und versucht dem/der LeserIn einen Überblick über den aktuellen Forschungsstand in dieser Population zu liefern, der durch eine umfangreiche Literatursuche und Literaturanalyse gewonnen wurde. Daran anschließend werden gängige gesundheitspsychologische Modelle und einzelne Bausteine auf ihre Anwendbarkeit bei Personen mit IB analysiert und mögliche zukünftige Forschungsansätze zum Thema Gesundheit und Gesundheitsverhalten von Menschen mit IB diskutiert.

1.1. Zur Definition der Zielgruppe

Als Menschen mit *intellektueller Behinderung* (IB; früher auch *geistige Behinderung*) werden Personen bezeichnet, die eine Intelligenzminderung gemäß der Definition der

Internationalen Klassifikation der Krankheiten der Weltgesundheitsorganisation, der ICD-10 (Dilling, Mombour & Schmidt, 2000), aufweisen. Vielfach, aber nicht immer, liegen dieser Intelligenzminderung biologische Ursachen (z.B. genetische oder Stoffwechselstörungen) zugrunde und daher wird bei der Feststellung der in der Entwicklung stehen gebliebenen oder unvollständig entwickelten, höheren kognitiven Fähigkeiten (z. B. Kognitionen, Sprache, motorische und soziale Fertigkeiten) auf die psychologische Diagnostik zurückgegriffen. Die American Association on Intellectual and Developmental Disabilities (AAIDD, 2010) nennt ebenso drei Kriterien, deren Vorliegen die Diagnose „Intellektuelle Behinderung" begründen: ein Intelligenzquotient unter 70 sowie ein beeinträchtiges sozial-adaptives Verhalten, das innerhalb der Entwicklungsphase der ersten 18 Lebensjahre auftritt.

2. Stand der Gesundheitsforschung

Die aktuelle Forschungsliteratur, die sich auf Menschen mit IB bezieht, kann nach verschiedenen Gesundheitsbereichen und Aspekten strukturiert werden.

2.1. Studien zu Gesundheitsstatus und Epidemiologie

Die Gesundheitsforschung im Bereich von Menschen mit intellektueller Behinderung konzentriert sich derzeit vornehmlich auf den aktuellen Gesundheitsstatus. Zahlreiche Publikationen belegen Unterschiede im Gesundheitsstatus zwischen Menschen mit und ohne IB (Jansen, Krol, Groothoff & Post, 2004; Krahn, Hammond & Turner, 2006). Neben psychischen Störungen sind auch Verhaltensauffälligkeiten und neurophysiologische Erkrankungen wie beispielsweise Epilepsie (McGrother et al., 2006; Morgan, Baxter & Kerr, 2003) oder Erkrankungen der Atemwege (Lennox & Kerr, 1997), Hautkrankheiten (Beange, 1995), hormonelle Störungen (Beange, 1995) und anderes wie Sinnesbeeinträchtigungen (Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001; Mantry et al., 2008) bei Menschen mit IB häufiger.

2.2. Studien zu Gesundheits- und Risikoverhaltensweisen

Demgegenüber ist die Forschung bei Personen mit IB über Gesundheits- bzw. Risikoverhaltensweisen, die selbstständig und bewusst von Menschen mit IB gezeigt werden können, weit nicht so umfangreich und sie konzentriert sich zudem auf wenige Gesundheitsbereiche wie Tabelle 1 zeigt. Diese werden im Folgenden knapp besprochen, um anschließend umfassender die Forschungsbefunde zum Ernährungs- und

Bewegungsverhalten von Menschen mit IB darzustellen, da zu dieser Thematik in den letzten Jahren eine hohe Publikationsdichte vorzufinden ist. In der Regel handelt es sich bei den hier referierten Studien um Forschungsarbeiten, in denen die Ergebnisse auf einer deskriptiv-komparativen Ebene dargestellt werden. Schlussendlich werden in diesem Kapitel bisherige Interventionsstudien und deren theoretische Fundierung analysiert.

>> Tabelle 1 hier einfügen <<

Während manche gesundheitsrelevante Bereiche, wie Sonnenschutzverhalten oder Schutzimpfungen, gemäß den Ergebnissen der Literaturrecherche noch nie empirisch bearbeitet wurden, liegen zu anderen Themenfeldern wie dem Sexualverhalten zwar eine Reihe von Arbeiten vor, diese konzentrieren sich mehrheitlich nicht auf gesundheitspsychologische Aspekte wie Krankheitsprävention. Ähnlich verhält es sich mit dem Forschungsbereich Mundgesundheit: Zwar wurde der schlechte Zahnstatus bei Personen mit IB mehrmals belegt (Anders & Davis, 2010; Gabre, 2000; s. Tabelle 1), das Gesundheitsverhalten selbst, das „Zähne putzen“ sowie deren Frequenz, wurde jedoch bislang nicht eingehend untersucht (Kantor, 2011).

Dagegen finden sich sehr wohl Erhebungen zum Thema Rauchen (Kennedy, Mc Combie, Dawes, McConnell & Dunnigan, 1997; McGillicuddy, 2006; Minihan, 1999; Robertson et al., 2000; Rustin, 1998; s. Tabelle 1). Zusammenfassend belegen diese Studien, dass im Vergleich zur Allgemeinbevölkerung deutlich weniger Personen mit IB rauchen. Wenn eine Person mit IB raucht, dann handelt es sich mit hoher Wahrscheinlichkeit um einen Mann mit leichter intellektueller Behinderung (Tracy & Hosken, 1997). Natürlich gibt es hier auch kulturelle Unterschiede: beispielsweise ist außer in den Niederlanden der Konsum von Cannabis unter Menschen mit IB mehrheitlich kein Thema in der Gesundheitsliteratur (Didden, Embregts, Van der Toorn & Laarhoven, 2009).

2.2.1. Studien zu Ernährungs- und Bewegungsverhalten

Jüngste Fachpublikationen, die das Gesundheitsverhalten von Menschen mit IB berücksichtigen, konzentrieren sich vornehmlich auf die Themen Ernährung (Geller & Crowley, 2009; Humphries, Traci & Seekins, 2009), Körpergewicht (Maaskant, Van Knijff-Raeven, Van Schrojenstein Lantman-de Valk & Veenstra, 2009; Salaun & Berhouze-Aranda, 2011) und Bewegung (Lin et al., 2010; McGuire, Daly & Smyth, 2007), denn Übergewicht bzw. Adipositas, Bewegungsmangel und daraus resultierende Erkrankungen sind bei

Menschen mit IB häufig zu finden (s. Tabelle 1): Je nach Ursprungsland und Alter der Stichprobe erfüllen 20-36% aller Personen mit intellektueller Behinderung die WHO-Kriterien einer Adipositas und ein weiteres Drittel gilt als übergewichtig. Doch auch Untergewicht ist v.a. bei Personen mit schweren Behinderungsformen aufgrund einer erschwerten Nahrungsaufnahme oft anzutreffen. Somit sind zwei Drittel aller Personen mit IB nicht normalgewichtig (Brehmer, 2008; Kantor, 2011).

Als Ursachen für diese schlechte Ernährungssituation werden verschiedene Umstände wie Wohnsituation, Behinderungsursache, aber auch die Bedeutung des betreuenden Umfeldes sowie die Wissensstrukturen über die Menschen mit IB zum Thema „gesunde Ernährung" verfügen, erforscht.

Rimmer und Yamaki (2006) sehen einen Zusammenhang zwischen der Zunahme von Adipositas und den Veränderungen der Lebenssituation, der zunehmenden Deinstitutionalisierung sowie der (in teilbetreuten Wohnformen vorzufindenden) Eigenverantwortlichkeit von Menschen mit IB. Denn Übergewicht ist vornehmlich ein Problem von Personen mit IB, die gemeindeintegriert leben und nicht jener, die in traditionellen Großeinrichtungen untergebracht sind (Rimmer & Yamaki, 2006).

Weiter wird ein Zusammenhang zwischen der Ätiologie der intellektuellen Behinderung und der Adipositas diskutiert. Dabei werden mit der Behinderungsursache einhergehende genetische oder physiologische Veränderungen in direkter Beziehung zum Übergewicht gesehen. So scheinen Frauen mit Trisomie 21 für Gewichtsprobleme anfälliger zu sein (Maaskant et al., 2009). Auch Untergewicht ist häufig mit der Behinderungsursache verbunden und wird vorwiegend bei Personen mit schweren/schwersten Formen von IB beobachtet (Kantor, 2011).

Zudem werden die Bezugspersonen ohne Behinderung als Einflussfaktoren in Betracht gezogen. So konnten Lin et al. (2010) in ihrer Studie einen Zusammenhang zwischen dem Bildungsgrad der Bezugsperson sowie deren persönlichen Präferenzen und dem Gesundheitsverhalten der KlientInnen mit Behinderung feststellen.

Schlussendlich erforschten Illingworth, Moore und McGillivray (2003) und Golden und Hatcher (1997) auch das persönliche Wissen von Menschen mit IB über Nahrungsmittel und Ernährung und stellten fest, dass dieses allgemein nur in geringem Ausmaß vorhanden ist. Personen mit höherer Intelligenz sowie Personen mit einem in der Norm liegenden Body Mass Index waren demgegenüber informierter.

2.3. Studien zur Gesundheitsförderung und deren theoretische Fundierung

Die wenigen Interventionsstudien zur Gesundheitsförderung zeigen, dass sich Veränderungen im gesundheitsbezogenen Wissen bei Menschen mit IB erzielen lassen (Illingworth et al., 2003) oder beschreiben selbstberichtete Verhaltensänderungen (Tracy & Hosken, 1997). Auch hier liegt das Augenmerk vornehmlich auf den Verhaltensweisen Essen und Bewegung sowie Rauchen. Zu Themen wie Sexualität oder Sonnenschutzverhalten liegen bisher keine Ergebnisse von Präventionsprogrammen vor.

Da diese Studien allerdings keine expliziten theoretischen Modellannahmen über Gesundheitsverhalten benutzen, bleiben die Beziehungen zwischen jenen Faktoren, von denen angenommen werden kann, dass sie in Zusammenhang mit Gesundheitsverhalten von Relevanz sind, empirisch ungeklärt. Aus einer evidenzbasierten Perspektive führt dies wiederum zur Frage der Qualität und Effektivität von Präventions- und Interventionsprogrammen: sind die Wechselwirkungen zwischen den Faktoren eines Gesundheitsverhaltens nicht bekannt, stellt sich zwangsläufig die Frage der Relevanz der vorliegenden Berichte präventiver Programme und deren Effektivität.

Der Bedarf an Gesundheitsförderung und entsprechenden, auf Menschen mit IB abgestimmten Präventionsprogrammen wird durch die vorliegenden deskriptiv-komparativen Gesundheitsstudien deutlich belegt. Bislang liegen jedoch keine theoretischen Modelle vor, die erläutern wie sich gesundes Verhalten bei Menschen mit IB entwickelt bzw. wie gesundheitsförderliche Verhaltensweisen aufrecht erhalten werden. Theoretische Modellannahmen und deren empirische Überprüfung sind allerdings die Voraussetzung für den Aufbau von Wissensstrukturen zu Wechselwirkungen zwischen den für Gesundheitsverhalten relevanten Faktoren. Zudem könnten aus entsprechenden Modellen beispielsweise begründete Gesundheitspräventionsprogramme für die Zielgruppe abgeleitet werden.

Stam (2000) macht deutlich, dass in Zusammenhang mit gesundheitspsychologischen Interventionen und deren Evaluation theoretische Konzepte essentiell sind. Ohne überprüftes, theoretisches Modell fehlen die begründeten und messbaren Ergebnisvariablen, die eigentlichen Interventionsziele. Neben diesen aus gesundheitspsychologischen Theorien ableitbaren Interventionszielen bietet ein theoretisches Modell gleichzeitig eine Basis für Inhalte von Kommunikationsprozessen und deren psychologischen Ausgestaltung mit KlientInnen, die ihre Gesundheit gefährden, und die über diese Intervention zu einem anderen Verhalten motiviert und angeleitet werden sollen (DeRidder, Theunissen &

VanDulmen, 2007; Insel, Meek & Leventhal, 2005; Theunissen, DeRidder, Bensing & Rutten, 2003). Ein gutes Beispiel für eine theoriegeleitete Vorgangsweise in der Allgemeinpopulation stellt das Transtheoretische Modell von Prochaska und DiClemente (1983) dar, das erfolgreich im Suchtbereich eingesetzt wird. Den Betroffenen wird hier über einen bildhaften Ansatz ein Veränderungsprozess zu gesundem Verhalten vermittelt (Schwarzer, 2004). Auch in der gesundheitspsychologischen Begleitung von Menschen mit IB könnte ein bildhaftes Gesundheitsmodell nützlich sein, Gespräche über Gesundheit und gesundes Verhalten zu gestalten und zu strukturieren. Ein derartiges Gesundheitsmodell für Menschen mit IB muss leicht verständlich sein. Der Komplexitätsgrad des Modells sollte sich demnach gemäß dem Prinzip der Parsimonie in ein einfaches Modell transferieren lassen, damit es für den einzelnen Menschen mit IB nachvollziehbar wird und entsprechend in leicht verständlicher Sprache kommuniziert werden kann. Ein solches Modell wurde bislang nicht entworfen, wäre aber für die gesundheitspsychologische Begleitung von Menschen mit IB eine Voraussetzung, wenn man die Kommunikation zu Gesundheitsthemen zwischen ihnen und den VertreterInnen der Gesundheitsprofessionen optimieren will. So könnte die Selbstverantwortung und die Selbststeuerung zu Fragen der Gesundheit bei den KlientInnen nachhaltig gestärkt werden.

3. Zur Generalisierung existierender gesundheitspsychologischer Theoriemodelle auf Menschen mit intellektueller Behinderung

Da bislang keine auf „Intellektuelle Behinderung“ abgestimmten, gesundheitspsychologischen Theorien vorliegen, sollen in der Folge anerkannte gesundheitspsychologische Modelle für die erwachsene Allgemeinpopulation auf ihre etwaige inhaltliche Passung zu Menschen mit IB analysiert werden (s. Tabelle 2). Gesundheitsförderung setzt an der Selbstbefähigung eines Individuums gegenüber seinem Gesundheitsverhalten und entsprechendem Veränderungspotential an. Im Kontext der Veränderung, des Umlernens, spielen motivationale, emotionale, kognitive und soziale Prozesse eine besondere Rolle. Diese Aspekte gilt es in einem gesundheitspsychologischen Modell für Menschen mit IB spezifisch zu bestimmen.

In einem ersten Schritt werden zunächst allgemeine theoretischen Eckpunkte sowie die Annahmen gängiger Gesundheitsmodelle, wie beispielsweise Kontinuitäts- und Stadienmodelle, bestimmt. Weiter wird berichtet, inwiefern diese Modelle bzw. auch einzelne Bausteine aus diesen Modellen bereits für diese Zielgruppe überprüft wurden und

wie diese Ergebnisse bewertet werden können. Abschließend soll die Generalisierbarkeit bzw. Übertragbarkeit einzelner Theorien oder Teilbereiche dieser auf die Population „Menschen mit IB“ diskutiert und allgemeine Problembereiche in der Messung bisheriger Modelle zusammengefasst werden.

3.1. Passung der theoretischen Eckpunkte gängiger Gesundheitsmodelle auf die Zielgruppe

Gängige Gesundheitstheorien sind durch zwei zentrale Annahmen charakterisiert, erstens, dass der Einzelne grundsätzlich sein Gesundheitsverhalten selbst verändern kann und zweitens, dass der Einzelne ein Wissen über den Ist- und den Sollzustand von Gesundheit hat.

Gesundheitspsychologische Modelle gehen typischerweise von einer Anthropologie eines selbstbestimmten, unabhängigen, stets reflexiv denkenden und rational entscheidenden Menschen aus (Cameron & Leventhal, 2003). Folglich lassen sich einige gesundheitspsychologische Theorien schwer auf Kinder und Jugendliche umlegen, die in Gesundheitsfragen noch von ihren Eltern begleitet werden (Lohaus, Jerusalem & Klein-Heßling, 2006; s. Tabelle 2). Diese Feststellung trifft auch auf erwachsene Menschen mit IB zu, die in der Regel in ihrer Lebensführung und Alltagsgestaltung in unterschiedlichem Ausmaß auf Unterstützung durch Dritte angewiesen sind (s. Tabelle 2). Erkrankt eine Person mit IB, ist häufig eine Vielzahl an Menschen, von Familienmitgliedern über BetreuerInnen bis hin zu rechtlichen VertreterInnen, an der Lösung der Situation beteiligt. Somit treffen verschiedenste vergangene Erfahrungen und Erwartungen von Drittpersonen aufeinander, die in bisherigen Gesundheitstheorien als Einflussfaktoren kaum enthalten sind. Die Einbindung dieses komplexen, sozialen Netzwerkes, in welcher die einzelne Person mit IB lebt, gilt es im Sinne leicht operationalisierbarer Variablen in ein entsprechendes gesundheitspsychologisches Modell zu integrieren.

In der zweiten typischen Annahme wird davon ausgegangen, dass Ist- und Sollzustand von Gesundheit bestimmbar sind. Auch dies wäre in der Entwicklung eines gesundheitspsychologischen Modells für Menschen mit IB zu berücksichtigen (s. Tabelle 2). In der aktuellen Forschung zum Gesundheitszustand von Menschen mit IB finden sich vermehrt Ergebnisse über spezifische Gesundheitsherausforderungen und Krankheiten, die mit bestimmten Syndromen gehäuft einhergehen, wobei die genauen Wirkzusammenhänge häufig noch ungeklärt sind. So sind beispielsweise für Mädchen mit Rett Syndrom, die

überdurchschnittlich oft Untergewicht aufzeigen, andere präventive Interventionen notwendig als für Personen mit Prader Willi Syndrom, die häufig übergewichtig sind. An diesem Beispiel wird deutlich, dass sowohl der Istzustand der Gesundheit, der in hohem Ausmaß durch die biologische Ätiologie der Beeinträchtigung bedingt ist sowie der Sollzustand spezifisch bestimmbar zu gestalten sind. Für ein gesundheitspsychologisches Modell ebenfalls von Relevanz ist die Berücksichtigung von geschlechtsspezifischen Gesundheitsherausforderungen bzw. Erkrankungsrisiken wie sie die geschilderten Forschungsergebnisse schon dargelegt haben. Diese komplexe Ausgangslage wäre bei der Formulierung eines für die IB Population gültigen gesundheitspsychologischen Theoriemodells zu berücksichtigen.

3.2. Passung von Kontinuitätsmodellen auf die Zielgruppe

Kontinuitätsmodelle, wie das „Health Belief" Modell von Becker (1974), die Theorie der „Reasoned Action" von Fishbein und Ajzen (1975) oder die „Social Cognitive" Theorie von Bandura (1977), erklären wie bestimmte Variablen gesundes bzw. schädliches Verhalten beeinflussen und vorhersagen. Bislang wurde jedoch keines dieser Modelle bei Menschen mit IB überprüft. Lediglich Jenkins und McKenzie (2011) schätzen die Theorie des „Planned Behaviour" von Ajzen für die Vorhersage der Intention von BehindertenbetreuerInnen, gesundes Essverhalten zu unterstützen, als nützlich ein. Empirisch untersucht wurde bei Personen mit IB der Faktor Selbstwirksamkeit, ein Bestandteil der „Social Cognitive" Theorie (Peterson, Peterson, Lowe & Nothwehr, 2009).

Allgemein werden Kontinuitätsmodelle häufig für ihre Operationalisierung kritisiert (s. Tabelle 2), vor allem wenn es um die Bestimmung des Übergangs von Verhaltensintention zu tatsächlichen Verhaltensweisen geht (Sheeran, 2002). Auch die Definitionen einzelner Modellkomponenten werden häufig kritisch analysiert (s. Tabelle 2). So argumentieren Suls und Wallston (2003) beispielsweise, dass oft selbstberichtetes Verhalten erfasst wird und nicht tatsächliches Verhalten oder es werden lediglich Verhaltensintentionen erfasst (s. Tabelle 2). Weiter wird angeführt, dass Faktoren, die irrationale, impulsive oder sozial unerwünschte Verhaltensweisen abdecken, in Kontinuitätstheorien nicht integriert, aber in Zusammenhang mit Gesundheitsförderung von hoher Relevanz sind (Suls & Wallston, 2003). Da das betreuende Umfeld einer Person mit IB für den Gesundheitszustand der beeinträchtigten Person mitverantwortlich ist, scheint eine Anwendung von Kontinuitätsmodellen, die von einem sich selbstbestimmenden

Individuum ausgehen, nicht zweckmäßig um das Gesundheitsverhalten von Menschen mit IB zu beschreiben und zu verstehen.

3.3. Passung von Stadienmodellen auf die Zielgruppe

Stadienmodelle wiederum, wie z.B. das Transtheoretische Modell von Prochaska und DiClemente, charakterisieren verschiedene Phasen, die ein Mensch durchläuft, wenn er/sie sein/ihr Verhalten ändert (Schwarzer, 2004). Da emotionale, soziale und umweltbedingte Einflüsse auf eine Verhaltensweise im Allgemeinen von Stadienmodellen nicht erfasst werden, scheint die Anwendbarkeit dieser Modelle für Menschen mit IB nicht direkt zweckdienlich (s. Tabelle 2). Neben allgemeinen Kritikpunkten, wie jener der Zuweisungsmethodik von ProbandInnen zu den einzelnen Veränderungsstadien oder jener der Operationalisierung der Zielkriterien (Thyrian¸ Rumpf, Meyer & Hapke, 2004), bedarf die längsschnittliche Überprüfung von Stadienmodellen großer, repräsentativer Stichproben (s. Tabelle 2). Solche Studienanforderungen stellen in der Regel bereits bezogen auf die Allgemeinbevölkerung hohe Hürden in der Realisierung entsprechender Forschungsprojekte dar und sind mit zusätzlichen Herausforderungen in der Gruppe der Personen mit IB versehen (z.B. Klärung der Frage der Repräsentativität innerhalb dieser Population). Aus dieser Perspektive ist es nicht überraschend, dass weder das erwähnte Transtheoretische Modell, das „Health Action Process Approach“ Modell von Schwarzer (2002), noch das „Information-Motivation-Behavioural Skills“ Modell von Suls und Wallston (2003) oder das „Prototype-Willingness“ Modell von Gibbons, Gerrard und Lane (2003) bislang an Menschen mit IB untersucht wurden.

3.4. Passung der Konzepte Health Literacy und Health Competence auf die Zielgruppe

Im Gegensatz zu den bisher beschriebenen Modellen erscheinen andere rezentere gesundheitspsychologische Konzepte wie „Health Competence“ (Söllner, Huber, Lenartz & Rudinger, 2009) oder „Health Literacy“ (Paasche-Orlow & Wolf, 2007) passender. Dabei wird die Kompetenz eines Individuums beschrieben, Gesundheitsinformationen zu erlangen, zu verarbeiten und sie zu verstehen, um im Gesundheitswesen selbstständig agieren zu können und passende Gesundheitsentscheidungen treffen zu können. Die beschriebenen, negativen Gesundheitsauswirkungen für Personen mit einer geringen „Gesundheitskompetenz“ (mangelhafter Zugang zu Gesundheitseinrichtung, Probleme in der Patient-Arzt-Kommunikation, Selbstpflege; Paasche-Orlow & Wolf, 2007) gleichen einigen

Forschungsergebnissen aus dem Bereich „Intellektuelle Behinderung“. Daher könnten Adaptionen im Gesundheitswesen sowie Gesundheitsinterventionen, die auf diesen theoretischen Konzeptionen beruhen, auch für diese Population von großem Nutzen sein. Vor einer Überprüfung bei Menschen mit IB sollten diese theoretischen Konzepte (Health Competence und Health Literacy) jedoch noch genauer auf die Zielpopulation „IB“ abgestimmt werden, eine Gruppe, die bislang aufgrund ihrer Bildungssozialisation sowie ihren Institutionalisierungserfahrungen kaum die Möglichkeiten hatte, eine Gesundheitskompetenz zu entwickeln. Die Begründung für die noch fehlende Testung könnte darin liegen, dass bei der Erfassung von diesen beiden Konzepten u.a. auf Teile typischer Intelligenzmessungen (z.B. „listening, verbal fluency, memory span“ (S. 22) wie von Paasche-Orlow & Wolf (2007) erwähnt) zurückgegriffen wird, bei denen Personen mit IB erwartungsgemäß nicht gut abschneiden würden (s. Tabelle 2). Mit der Messung würde die vorliegende Intelligenzminderung bestätigt werden aber die Frage, ob eine Intelligenzminderung einer geringen Health Literacy gleichzusetzen ist, könnte nicht wirklich beantwortet werden. Dementsprechend wäre einerseits die Testung zu adaptieren, um diese Konzepte bei Menschen mit IB zu überprüfen. Andererseits wären ebenso entwickelte Schulungen zur Steigerung von Gesundheitskompetenz an bestehende Fähigkeiten und besondere Bedürfnisse von Menschen mit IB anzupassen.

3.5. Passung des Common Sense Model of Illness Representation und der Konzepte zu Gesundheit und Krankheit von Lohaus auf die Zielgruppe

Abschließend sollen noch das „Common Sense Model of Illness Representations“ von Leventhal (1984) sowie Konzepte von Lohaus (1990) zu Gesundheit und Krankheit über die Lebensspanne diskutiert werden, die auch eine interessante Ausgangslage für ein, diese zwei Ansätze integrierendes Modell darstellen könnten (siehe Kapitel 4). Der Kernpunkt des Modells von Leventhal ist das Konstrukt der „illness representations“. Diese Krankheitsvorstellungen bestehen aus fünf Komponenten (Leventhal, Brissette & Leventhal, 2003): Identität der Krankheit, Verlauf der Krankheit, Konsequenzen der Krankheit, Ursache der Krankheit, Kontrolle/Heilung der Krankheit. Weinman und Petrie (1996) ergänzten diese fünf noch durch die Komponente Krankheitskohärenz. Diese Attribute von Krankheitsvorstellungen werden als miteinander verbunden gesehen und ergeben so ein Krankheitsprofil (Förster, 2003). Dieses Profil entsteht sobald man ein Symptom entdeckt und diesbezügliche Assoziationen in existierende Konzepte und

Erfahrungen integriert (Suls & Wallston, 2003). Man verhält sich in Folge, so das Modell, entsprechend der persönlichen Einschätzung der Krankheitssituation. Auch eine Überprüfung dieser Theorie bei Menschen mit IB erscheint zunächst durch die Komplexität der Theorie und die Charakteristika der IB Zielgruppe problematisch. In der Regel wissen Menschen mit IB recht wenig über ihre eigenen Erkrankungen bzw. gesundheitlichen Einschränkungen (Brehmer, Zeilinger & Weber, 2008). Mit dem „Brief Illness Perception Questionnaire“ (Broadbent, Petrie, Main & Weinman, 2006) liegt allerdings ein einfach und knapp formulierter Fragebogen vor, der kaum abstrakte Gedankenoperationen verlangt, wodurch eine Untersuchung von Krankheitsvorstellungen bei Menschen mit IB durchaus realistisch erscheint (siehe auch Moss-Morris et al., 2002).

Lohaus (1990) beschrieb, wie sich Gesundheits- und Krankheitskonzepte über die Lebensspanne verändern: von der reinen subjektiven Interpretation ohne Ursachenverständnis über die Erkenntnis von Zusammenhängen bis hin zu abstrakten Gedankenoperationen. Diese Theorie wurde bislang auf die unterschiedlichsten Themen übertragen: die Definitionen von Gesundheit und Krankheit, das Körperbild, das Wissen über Körperfunktionen, die Wahrnehmung und Relevanz von gesundem Verhalten, die Vorstellungen zu Tod und Sterben, das Wissen von Behandlungsmethoden und der Arbeit von ÄrztInnen und Pflegepersonal. Interessant für einen Entwurf eines Gesundheitsmodells für Personen mit IB ist, dass sich Krankheitskonzepte aufgrund von persönlichen Erlebnissen, Erfahrungen anderer und vermittelten Informationen auch nicht adäquat weiterentwickeln können. Auch emotionale Prozesse und das soziale Netzwerk haben einen großen Einfluss auf die Ausbildung persönlicher Gesundheitstheorien (Lohaus, 1990).

Zusätzlich können zwei Forschungsergebnisse die wissenschaftliche Relevanz einer Anwendbarkeit der Vorschläge von Leventhal und Lohaus bei Personen mit IB hervorheben: zum einen wurde mehrfach belegt, dass subjektive Krankheitsvorstellungen von anderen Personen beeinflusst werden können (Cameron & Leventhal, 2003; Rüdell & Bhui, 2010; Suls & Wallston, 2003). Dies könnte helfen die Wirkung von Bezugspersonen auf die Wahrnehmung von gesundheitsbezogenen Risiken zu dokumentieren, wie es die Studie von Tracy und Hosken (1997) andeutet. Zum anderen konnten Paterson, Moss-Morris und Butler (1999, zitiert nach Salewski 2002) einen Nachweis erbringen, dass verbale Intelligenz ein signifikanter Prädiktor für die Bandbreite an subjektiven Krankheitsvorstellungen ist. Ein Ergebnis, das ebenso wie jene von Lohaus helfen könnte, die Untersuchung der Gesundheitsvorstellungen von Personen mit IB zu planen. Zudem konnte das Modell von

Leventhal schon in unterschiedlichen Patientengruppen überprüft und auch auf weitere Themen wie Behandlungswahrnehmung übertragen werden (Cameron & Leventhal, 2003).

3.6. Analyse einzelner Modellbausteine hinsichtlich ihrer Übertragbarkeit auf die Zielgruppe

Betrachtet man einzelne Bausteine von gesundheitspsychologischen Modellen, lassen sich, wie schon erwähnt, vorwiegend emotionale, verhaltensbezogene, kognitive und soziale Elemente lokalisieren (Schwarzer, 2004).

Emotionale Regulierungsprozesse und verhaltensbezogene Elemente (z.B. selbstregulierte Verhaltensplanung und Stabilisierung von Verhaltensweisen) sind im Bereich von Gesundheitsverhalten, gemäß der durchgeführten Literaturrecherche, noch nicht an Personen mit IB evaluiert worden.

Kognitive Elemente wie Einstellungen, Absichten, Informationsverarbeitung, Zielsetzung und Zielverfolgung wurden bisher ebenfalls nicht im Kontext von Gesundheitsverhalten bei Menschen mit IB geprüft. Auch Optimismus sowie Copingtechniken (siehe Muthny, 1990) bleiben in dieser Population unerforscht.

Die kognitiven Elemente, wie Risikowahrnehmung und wahrgenommene, persönliche Verwundbarkeit sind in verschiedenen Gesundheitsmodellen enthalten. Und es gibt Hinweise darauf, dass Personen mit IB solche Risiken scheinbar anders einschätzen (Illingworth et al, 2003). Explizit erforscht wurde dieses Thema aber bislang noch nicht. Zur Risikowahrnehmung bei anderen kann die Studie von Tracy und Hosken (1997) hervorgehoben werden. Sie beobachteten, dass nur diejenigen Personen mit IB über ihren Zigarettenkonsum besorgt waren, die diesbezüglich kritische Aussagen von ihren Bezugspersonen zu hören bekommen hatten. Ungeklärt ist, ob dieser Befund auf andere Risikoverhaltensweisen übertragbar ist und ob Risiken von Bezugspersonen häufiger wahrgenommen werden als von den Personen mit IB selbst.

Festingers kognitives Konzept der Sozialen Vergleiche (1954) kam im Gesundheitsbereich bereits vielfach zur Anwendung (Suls & Wallston 2003; Martin, Haskard-Zolnierek & DiMatteo 2010). Brehmer (2008) adaptierte ein Instrument von Filipp und Ferring (1998) um temporale und soziale Vergleiche bei Menschen mit IB zu messen. Die meisten TeilnehmerInnen mit IB wurden durch die Aufgabenstellung, sich mit sich selbst oder einer anderen Person zu vergleichen, aber kognitiv überfordert und reagierten

akquieszent, d.h. beantworteten die Mehrheit der Fragen, gemäß einer sozial erwünschten Haltung mit „Ja“.

Für die Allgemeinbevölkerung werden soziale und Umwelteinflüsse auf gesundes Verhalten als gering geschätzt (Suls & Wallston, 2003). Obwohl Menschen mit IB mehrheitlich im Alltag Assistenz erfahren, ist das Thema “soziale Unterstützung“ in Gesundheitsfragen im Forschungsbereich IB überschaubar: Lippold und Burns (2009) erfragten soziale Unterstützungsformen von Menschen mit IB und stellten fest, dass sie insgesamt weniger Freundschaften als nicht behinderte Personen führen. Ihre Freunde haben zumeist auch eine intellektuelle Behinderung. Häufig werden soziale Kontakte von Personen mit IB inniger beschrieben als sie es tatsächlich sind, da das Prinzip der Reziprozität nicht bedacht wird. So sehen viele ihr Verhältnis zu BetreuerInnen als Freundschaft, was umgekehrt in der Regel nicht so gewertet wird (Lippold & Burns, 2009).

Peterson et al. (2009) erforschten die Auswirkungen von Selbstwirksamkeit und sozialer Unterstützung durch Freunde, Familie und BetreuerInnen auf das Ausmaß an körperlicher Bewegung von Menschen mit IB. Intensive soziale Unterstützung korrelierte mit Selbstwirksamkeitserwartung positiv. Beide Elemente wiederum waren mit einem höheren Bewegungsausmaß verbunden.

Generell steht fest, dass sich Menschen mit IB in ihren Sozialisationserfahrungen von Menschen ohne Behinderung deutlich unterscheiden. Einige sind institutionalisiert und ohne kontinuierliche Bezugsperson aufgewachsen bzw. haben mehrheitlich Sonderschulen besucht oder sammelten in Integrationsklassen andere Bildungs- und Sozialisationserfahrungen. Der Einfluss solcher Sozialisationserfahrungen ist im Zusammenhang mit der Entwicklung von gesunden Verhaltensweisen ebenso ungeklärt wie das jeweilige Ausmaß an Selbstbestimmung, das einer Person mit IB ermöglicht wird.

In der Allgemeinbevölkerung wurde hauptsächlich der Rückhalt zwischen Ehepartnern untersucht. Eine Bewertung der Übertragbarkeit dieser Befunde auf andere Beziehungsformen, wie z.B. zwischen BetreuerIn und KlientIn, ist jedoch ausständig (Suls & Wallston, 2003). Auch der Einfluss erziehungsberechtigter Personen, die für eine betroffene Person Absichten und Ziele entwickeln, wie Schwarzer (2004) vermutet, ist im Bereich IB unerforscht.

3.7. Erfassung gesundheitspsychologischer Modelle bei der Zielgruppe

Wie in den vorigen Abschnitten gezeigt werden konnte, ist allen beschriebenen Gesundheitsmodellen ihre große Komplexität und Abstraktheit durch die Vielzahl an, vor allem kognitiven, Variablen gemein (Flick, 2000). Die Erfassung der verschiedenen, beschriebenen Bausteine aus gesundheitspsychologischen Modellen erfolgt in der Regel schriftlich durch die StudienteilnehmerInnen, wobei häufig hypothetische Problemstellungen präsentiert werden. Bisherige Fragebögen liegen fast nie in einfacher Sprache und psychometrisch überprüft vor, um sie bei Personen mit leichteren Formen von IB zur Anwendung zu bringen. Auch adaptierte Fragebögen müssten wahrscheinlich in Form von Interviews bearbeitet werden, damit der Großteil der Zielgruppe aufgrund der vorliegenden, eingeschränkten Lese- und Schreibkenntnisse in Gesundheitsstudien berücksichtigt werden könnte. Manche Modellkomponenten (z.B. Zielsetzung, Einstellungen) könnten sicherlich, wenn in einem konkreten Kontext in einfachen, qualitativen Fragen formuliert, umgewandelt und dadurch „messbar“ werden. Einen Ansatz, der vielleicht die Erfassung einzelner Bausteine ermöglicht, wäre auf v.a. bildhaftes Material (Bildergeschichte, Symbolkarten) oder Erfassungstechniken zurückzugreifen, wie Lohaus (1990) es in seinen Untersuchungen mit Kindern vorgeschlagen und etabliert hat. Ähnliche Materialien wären auch in Präventionsprogrammen selbst von Nutzen.

Eine weitere Hürde der Erhebung gesundheitspsychologischer Bausteine stellt die häufig abstrakte Aufgabenstellung für Menschen mit IB dar. Eine fehlende Antwort auf eine solche herausfordernde Aufgabe könnte in der Folge nicht genau interpretiert werden: Es wäre nicht klar, ob der/die TeilnehmerIn mit IB die entsprechende Frage z.B. über eine Copingtechnik nicht verstanden hat oder ob er/sie die entsprechende Copingtechnik oder Verhaltensweise nicht für sich benutzt. Somit zeigt sich, dass mit den üblichen Erfassungsverfahren bestimmte kognitive Operationen oder emotionale Prozesse bei Menschen mit IB nicht eindeutig erfasst werden können. Diese Feststellung könnte durchaus ein zentraler Grund dafür sein, dass so wenige empirische Forschungsarbeiten zu dieser Thematik für die Gruppe mit IB vorliegen.

4. Überlegungen zu einem Gesundheitsmodell für Menschen mit intellektueller Behinderung

Da die einfache inhaltliche Übertragung gängiger Gesundheitsmodelle auf Menschen mit IB, wie aufgezeigt wurde, kaum gegeben ist und vorliegende Verfahren zur Erfassung

von gesundheitspsychologischen Daten für Personen mit IB mehrheitlich nicht wirklich passend erscheinen, sollen vor diesem Hintergrund Eckpunkte gesammelt werden, die die Entwicklung eines für diese Gruppe adäquateren und praktikablen gesundheitspsychologischen Modells ermöglichen sollten. Mit einem solchen Modell würde Gesundheitsverhalten der IB Zielgruppe erklärbar.

Für diese Vorgangsweise erscheint, wie bereits angeführt, ein Rückgriff auf das „Common Sense Model of Illness Representations" von Leventhal (1984) sowie die Konzepte von Lohaus (1990) zu Gesundheit und Krankheit über die Lebensspanne durchaus zweckmäßig. Unter Berücksichtigung einiger Forschungsergebnisse von Leventhal und Lohaus, wie die nicht adäquate Entwicklung von Krankheitskonzepten aufgrund von persönlichen Erlebnissen, Erfahrungen anderer und vermittelten Informationen (siehe Abschnitt 3.5.), stellt sich die Frage, in wie fern Menschen mit IB Krankheiten von einem früheren Konzeptstadium aus interpretieren? Demnach könnten Menschen mit IB über andere Vorstellungen von Gesundheit, Krankheit und Behinderung verfügen und würden somit ihren aktuellen Gesundheitszustand/ihren Körper anders wahrnehmen und würden folglich bestimmte Risikoverhaltensweisen gehäuft zeigen. Diese Hypothese könnte auch jene Forschungsbefunde erklären, die ergaben, dass StudienteilnehmerInnen mit IB ihre Gesundheit positiver beurteilen als ihre Bezugspersonen und viele chronisch kranke TeilnehmerInnen mit IB ihren Gesundheitsstatus als „sehr gut" bezeichneten (Brehmer et al., 2008). Möglicherweise übernehmen Personen mit IB die Betrachtungsweise und das Verhalten nahestehender Bezugspersonen.

Zwei Einflussfaktoren auf das gezeigte Gesundheitsverhalten scheinen somit im Bezug auf die Konstruktion eines Modells für Menschen mit IB ausschlaggebend: kognitive Faktoren, wie Vorstellungen und Wahrnehmung der eigenen Gesundheit sowie soziale Faktoren, wie Einfluss der Bezugspersonen, soziales Netz und Sozialisation. Die Wirkungsrichtungen und Abhängigkeiten dieser Elemente können zunächst vielfältig sein und wären zukünftig in Forschungsarbeiten zu bestimmen und zu präzisieren. Bei der Erfassung dieser Komponenten könnte neben einfachen, offenen Fragen z.B. zu persönlichen Vorstellungen (z.B. „Was verstehst du unter Gesundheit?") auch auf Fragen bögen wie den „Brief Illness Perception Questionnaire" (Broadbent et al., 2006) für die Erfassung der persönlichen Wahrnehmung eigener Krankheiten/ der eigenen Behinderung sowie auf Methoden von Lohaus, die für Kinder entwickelt wurden, zurückgegriffen werden. Für die Messung von gezeigten Gesundheits-/Risikoverhaltensweisen gibt es Modelle in den

erwähnten, deskriptiven Untersuchungen (siehe Abschnitt 2). Zusätzlich zu beachten ist, dass keine abstrakten Bestandteile in der Erfassung eines solchen Modells enthalten sind.

Weiter sollte sich ein Modell für Menschen mit IB auf kein spezifisches Risiko-/Gesundheitsverhalten konzentrieren und keinen Ist-/Soll-Zustand von Gesundheit erfragen. Denn das würde eine Anwendung nur in bestimmten Gruppen der Population „Intellektuelle Behinderung“, wie z.B. Personen mit Prader Willi Syndrom, zur Folge haben (s. Tabelle 2) und keine allgemeine Darstellung des Gesundheitsverhaltens bei Menschen mit IB ermöglichen.

5. Zusammenfassung und Schlussfolgerungen

In diesem Beitrag wird überblicksartig und zusammenfassend zum Stand der Gesundheit und gesundheitspsychologischen Forschung und deren Herausforderungen bei Menschen mit intellektueller Behinderung berichtet. Es gibt bislang keine Gesundheitstheorien, welche die Entstehung oder Veränderung von gesunden bzw. schädlichen Verhaltensweisen bei Personen mit IB befriedigend beschreiben können.

Die Analyse der theoretischen Eckpunkte bestehender gesundheitspsychologischer Modelle ergab zunächst das Problem der Bestimmung eines der Zielgruppe gemeinsamen Ist-und Sollzustandes von Gesundheit. Zum anderen verhindern die inhaltliche Komplexität aktueller Gesundheitsmodelle und ihre abstrakte Erfassung eine einfache Übertragung dieser Erklärungsmodelle auf diese spezielle Personengruppe. Und schließlich werden die genannten Gesundheitsmodelle der speziellen sozialen Situation und ihrer Bildungssozialisation der meisten Menschen mit IB mehrheitlich nicht gerecht.

Zudem wurde durch die Analyse bekannter Gesundheitsmodelle und ihrer Bestandteile klar, dass für ein gesundheitspsychologisches Modell für Menschen mit IB die Abstraktheit und Komplexität bestehender Modelle vereinfacht und die Operationalisierung auf die Bedürfnisse von Menschen mit IB zugeschnitten werden muss, damit die Theorie überprüfbar wird.

Um eine solche integrierte Gesundheitstheorie für Menschen mit intellektueller Behinderung zu entwickeln, wird vorgeschlagen auf Forschungsarbeiten von Lohaus und Leventhal zurückzugreifen. Die Annahme, ob sich die vermehrte Häufung bestimmter Risikoverhaltensweisen bei Menschen mit IB durch ihre unterschiedlichen Vorstellungen von Gesundheit, Krankheit und Behinderung erklären lässt, scheint überprüfungswürdig. Die Ergebnisse aus vorliegenden Studien, dass Menschen mit IB ihre Gesundheit anders

wahrnehmen (Brehmer et al., 2008) und sich möglicherweise deshalb anders verhalten, legen dies vorerst nahe.

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Tabelle 1

Ausgewählte Studienergebnisse: Gesundheitsverhalten von Menschen mit intellektueller Behinderung

Gesundheits-verhalten	Studie 1:	Studie 2:	Studie 3:	Studie 4:	Studie 5:
Körpergewicht/ Ernährung [a]	10.3% untergewichtig, 33.3% übergewichtig, 28.2% adipös (Kantor, 2011: n=92 Erwachsene; AUT)	36% adipös (Stewart et al., 2009: n=206 Kinder; GB)	24% übergewichtig, 15% adipös (De et al., 2008: n=98 Kinder; AUS)	18.6% untergewichtig, 28% übergewichtig, 20.7% adipös (Bhaumik et al., 2008: n=1119 Erwachsene; GB)	Review by Rimmer & Yamaki, 2006: 36% adipös (n=321 Erwachsene; IRL) 27% adipös (n=1304 Erwachsene; GB) 29.2% adipös (n=350 Erwachsene; USA)
Bewegung [b]	52% machen ausschließlich passive Freizeitaktivitäten (Brehmer et al., 2008: n=190; AUT)	47% Männer und 51% Frauen beschäftigen sich ausschließlich passiv in ihrer Freizeit (Draheim et al., *2002*: n=150)	80-93% inaktives Freizeitverhalten (Robertson et al., 2000 n=500; GB)		
Mundgesundheit	30.4% unbehandelter Karies (Reid et al., 2003: n= 9620; Special Olympics)	82-96% Karies, 18-58% unbehandelter Karies, 45.1% Probleme mit Mundhygiene (Owens et al., 2006)	16.9% Verfall, 76.3% Karies (Pradhan et al., 2009: n= 485; AUS)	63.3% der BetreuerInnen geben an, dass ihre KlientInnen gute Zähne haben, obwohl bei 42.7% Zähne fehlen (Kantor, 2011: n=92 Erwachsene; AUT)	
Rauchen	64% Nichtraucher (Tracy & Hosken, 1997; AUS)	82% Nichtraucher (Hymowitz *et al.,*1997: n=136)	90% Nichtraucher (Rimmer et al., 1995:n= 186; US)	96% Nichtraucher (Peine et al.,1998: n=400)	86% Nichtraucher (Emerson & Turnbull, 2005: n=95; GB)
Alkohol	12% trinkt mindestens einmal pro Monat Alkohol (Emerson & Turnbull, 2005: n=95; GB)	Keine moderate bis hohe Konsumation! 76-96% Nichttrinker unter Frauen und 45-73% bei Männern je nach Wohnform/ Selbstständigkeitsgrad (Robertson et al., 2000: n=500; GB)			

Anmerkungen. Tabelle 1 listet Forschungsergebnisse zu Gesundheits-/Risikoverhaltensweisen, die selbstständig und bewusst von Menschen mit IB gezeigt werden können. Dadurch finden sich in dieser Aufstellung keine Resultate über Menschen mit schweren oder mehrfachen Beeinträchtigungen wider, da ihre gängigen Gesundheitsrisiken wie Untergewicht vielfach mit ihrer Behinderungsätiologie zusammenhängen und nicht bewusst gesetzt Handlungen darstellen.

[a] Die Stichproben dieser Studien wurden in jeweils vier Gruppen (untergewichtig, normal gewichtig, übergewichtig und adipös) unterteilt. Die adipösen TeilnehmerInnen sind somit nicht gleichzeitig auch Teil des übergewichtigen Stichprobenanteils.

[b] Bei Eintragungen, die keine Stichprobengröße oder Länderangaben enthalten, war dies aus den bestehenden Unterlagen nicht zu schließen.

Tabelle 2

Übersicht zur Anwendbarkeit der beschriebenen Gesundheitstheorien im Bereich „Intellektuelle Behinderung“

Bereich	Kritikpunkte
Allgemeine inhaltliche Kritikpunkte	- Definitionen der Modellkomponenten - Fehlende emotionale, soziale und umweltbedingte Modellkomponenten inkl. irrationalem und sozialerwünschtem Verhalten
Inhaltliche Kritik, die eine Anwendung des Modells im Bereich IB erschweren	- Zugrundeliegendes Menschenbild (immer rational denkend) - Bestimmbarer IST/SOLL-Zustand von Gesundheit - Berücksichtigung von Drittpersonen, die Gesundheitsverhalten beeinflussen
Allgemeine Kritikpunkte an Modellevaluationen	- Operationalisierung der Modellbausteine - Erfassung von selbstberichtetem vs. tatsächlichem Verhalten - Zuteilung der TeilnehmerInnen zu den Modellstadien
Kritik an Messungen, die eine Anwendung des Modells im Bereich IB erschweren	- Erfassung von kognitiven, abstrakten Inhalten per Fragebogen - Große, repräsentative Stichproben

2.2.3. Conduction of the health psychological project

The procedure of the present psychological study is depicted in table 2. In a first step, the study's proceedings were presented to the ethics committee asking for consent to the planned conduction. Following the committee's agreement, we started the sampling and data collection process. By the end of July 2012, sufficient data had been gathered to test a theoretical health model.

Table 2 *Process and sample of psychological study*

Step 1: agreement by ethics committee to the study's procedure	
Step 2: sampling and data collection	
ID sample (personal interviews)	non-ID sample (online survey)
contact service providers for persons with ID and self-advocates	snowball sampling starting with University employees invitation email to service providers to reach carers of persons with ID
final sample of 230 ID respondents age 16-71 (median 38,5); 43.5% women and 56.5% men	final sample of 533 non-ID respondents age 17-69 (median 35); 69% women and 31% men
Step 3: analysing data and documentation of findings	

Table 3 illustrates the structure of the interview protocols for both participant groups (see Annex I). While the parts 1 and 5 aim at gathering health information on the participants themselves, the parts 2 to 4 contain the questionnaires for operationalising the health model.

Table 3 *Structure of the interview protocol for ID and non-ID participants*

Protocol for ID participants	
Part	Content
1a	person related information: age, sex, aetiology of disability, place of residence (province, actual living situation, previous residence), intensity of family contact, years of education activities of daily living (washing, dressing, eating), health contact person subjective health status (*healthy, illness and/or disability*)
1b	reading abilities and knowledge of the human body
2	personal definition of the terms *health*, *illness* and *disability*
3	3 questionnaires dealing with the personal perception of one's body (PPQ), the perception of one's illness and/or disability
4	health behaviour questionnaire (HBQ)
5	'objective' health data: body weight and height, number of smoked cigarettes per day, medication

Protocol for non-ID participants	
Part	Content
1	Person related information: age, sex, province of residence highest educational degree, only for carers: number of years working as carer, completed carer training subjective health status (*healthy, illness and/or disability*)
2	personal definition of the terms *health*, *illness* and *disability*
3	3 questionnaires dealing with the personal perception of one's body (PPQ), the perception of one's illness and/or disability
4	health behaviour questionnaire (HBQ)
5	'objective' health data: body weight and height, number of smoked cigarettes per day, medication

The rationale behind these protocols including its differences concerning part 1 is mainly delineated in the second psychological paper (see table 1), which presented the evaluation of the GHC. In addition to this, this study's protocol also contained items to test *health knowledge* (part 1b, see table 3 and Annex I) in persons with ID and *health perception*s (part 2 and 3, see table 3 and Annex I) in both groups. The findings in connection with these topics are delineated and linked to figures on reported health behaviours and personal health facts (part 1a, 4 and 5, see table 3 and Annex I) in a third psychological paper ('*The relation*

of an individual's health knowledge and the personal perception of one's body and disabilities to reported health behaviours in persons with intellectual disabilities'; Brehmer-Rinderer et al, submitted). Like the second paper, this third article also contains short descriptions of this study's proceedings (sample, procedure and instruments), and results of both participant groups (ID, non-ID) are compared.

2.2.3.1. Dissertation article accepted for publication in Journal of Intellectual Disability Research

Date of acceptance: 02.04.2013 (see Annex II for publication history)

2.2.3.2. Dissertation article submitted in Journal of Applied Research in Intellectual Disabilities

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Evaluating a health behaviour model for persons with and without an intellectual disability

B. Brehmer-Rinderer,[1] L. Zigrovic[1] & G. Weber[2]

1 *Doctoral College 'Empowerment through Human Rights', University of Vienna, Vienna, Austria*
2 *Faculty of Psychology, University of Vienna, Vienna, Austria*

Abstract

Background Based on the idea of the Common Sense Model of Illness Representations by Leventhal as well as Lohaus's concepts of health and illness, a health behaviour model was designed to explain health behaviours applied by persons with intellectual disabilities (ID). The key proposal of this model is that the way someone understands the concepts of health, illness and disability influences the way they perceive themselves and what behavioural approaches to them they take.
Method To test this model and explain health differences between the general population and person with ID, 230 people with ID and a comparative sample of 533 persons without ID were included in this Austrian study. Data were collected on general socio-demographics, personal perceptions of illness and disability, perceptions of oneself and health-related behaviours.
Results Psychometric analysis of the instruments used showed that they were valid and reliable and hence can provide a valuable tool for studying health-related issues in persons with and without ID. With respect to the testing of the suggested health model, two latent variables were defined in accordance to the theory. The general model fit was evaluated by calculating different absolute and descriptive fit indices. Most indices indicated an acceptable model fit for all samples.
Conclusions This study presents the first attempt to explore the systematic differences in health behaviour between people with and without ID based on a suggested health model. Limitations of the study as well as implications for practice and future research are discussed.

Keywords disability perception, health behaviour model, health behaviour, illness perception, intellectual disabilities, personal perception

Correspondence: Ms Barbara Brehmer-Rinderer, Doctoral College 'Empowerment through Human Rights', University of Vienna, Hörlgasse 6, 1090 Vienna, Austria (e-mail: barbara.brehmer@univie.ac.at).

Introduction

Numerous research studies have documented the existence of significant health disparities between people with and without intellectual disabilities (ID; Jansen *et al.* 2004). In their systematic literature review, Krahn *et al.* (2006) illustrated that adverse health conditions (e.g. epilepsy, respiratory disorders) are more common among people with ID. Furthermore, an increasing number of publications deal with health/risk behaviours that are frequently, deliberately and autonomously demonstrated by persons with ID. The majority of these publications highlights *nutrition*, *weight status* and *physical activities*, pointing to an observable lack of adequate health behaviours in persons with disabilities in relation to these aspects (Robertson *et al.* 2000;

Humphries *et al.* 2009; Maaskant *et al.* 2009; Lin *et al.* 2010; Salaun & Berthouze-Aranda 2011). A significant number of projects explored other risk behaviours, such as *smoking* or *alcohol consumption* (Kennedy *et al.* 1997; Tracy & Hosken 1997). Further health behaviours, such as *sun protection* and *immunisations*, still need to be systematically investigated (Brehmer-Rinderer & Weber, in press).

Brehmer-Rinderer and Weber (in press) reviewed and analysed previously published literature on health psychology for the general and ID populations. They argue that there are no theories on how health behaviours develop in persons with ID. This knowledge gap includes causes and variables affecting certain health/risk behaviours, such as the role of the aetiology of ID, the individual's social network, past experiences of persons with ID and their expectations. Additionally, they describe various reasons that hinder the application of well-known health models, such as the Transtheoretical Model of Prochaska & DiClemente (1983; e.g. large representative samples are needed) or the Social Cognitive Theory by Bandura (1977; e.g. difficulty of measuring cognitive constructs in persons with ID) to the ID population. Finally, they suggest criteria for the development of a health model that is equally applicable to persons with and without ID, to enable valid comparison between these two groups. These criteria for the creation of a health model aim at facilitating the development of useful evaluation strategies for existing health behaviour studies. Following these recommendations, the aim of this research paper is twofold: (1) to illustrate the definition and operationalisation of such a health model, the general health circuit (GHC), fitting the characteristics of an ID population that is able to communicate verbally, and (2) to describe its testing in a mixed sample, consisting of persons with ID, carers of persons with ID and a comparative sample from the general population, to explore differences concerning the GHC between these groups.

The general health circuit for persons with and without ID

The key proposal of this model is that the personal understanding of *health/illness/disability* influences the individual perception of oneself and the way someone perceives himself or herself defines the behavioural approach that is taken.

This theory is based on the idea of the Common Sense Model of Illness Representations by Leventhal (1984) as well as Lohaus's (1990) concepts of health and illness. Based on their work, the question arises whether persons with ID interpret *health/illness/disability* in another way than the general population, which in turn leads to different personal concepts and behavioural patterns related to these aspects. This may be the reason why some research studies found that individuals with ID perceive their health as better than it is according to the estimations of their caretakers, as well as that many chronically ill persons with ID describe their health status as very good (Brehmer *et al.* 2008). Additionally, previous research has focused mainly on the (negative) perception of persons with ID by others (Slevin & Sines 1996; Gillmann *et al.* 2000; McConkey & Truesdale 2000), while positive perceptions of disabilities by persons with disabilities have not yet been studied. All past research studies have demonstrated that the predominantly negative perception of disability affected the disabled persons' potential to participate in various societal settings. Possibly, a negative perception of *health/illness/disability* also leads to a higher rate of displayed risk behaviours.

This proposed theory presents a step forward from existing health psychological models by paying attention to the following five aspects and thereby enabling the theory's operationalisation and application in an ID sample:

The first aspect concentrates on cognitive elements. Previous health models contain cognitive elements such as optimism and attitudes (e.g. Social Cognitive Theory). They involve a high level of abstract thinking and visualisations of hypothetical situations, which can be overwhelming for a person with ID (Brehmer-Rinderer & Weber, in press). Therefore, these elements themselves and in particular the strategy for measuring them seem to be inappropriate for persons with ID. Their results cannot be interpreted accurately, as it is impossible to say whether the people with ID simply use different strategies or do not use the measured cognitive strategies at all. Overreliance on cognitive strategies in health models may make the same inappropriate for use in a sample of persons with ID.

Furthermore, previous models do not contain social elements (e.g. interpersonal relations), even though they are highly relevant for the ID population. Persons with ID generally do not act independently in health situations, but are monitored or instructed by carers, who can influence their behaviour. This interaction of personal, biological and environmental elements is also highlighted by the *International Classification of Functioning, Disability and Health* (ICF; World Health Organisation 2001), which makes the ICF a valuable resource for defining variables which influence persons with ID in acting healthily. Until today the influence of carers on the health behaviours of persons with ID has remained unexplored. Only the substantial influence of the family environment on children and the disabled individual's body weight was previously documented (Birch & Fisher 1998; Schreck & Williams 2006).

The key problem with previous models is that they rely on a certain pre-existing concept of the human being as an active, independent actor consciously choosing the best behavioural options, i.e. irrational choices are not taken into account. This concept cannot be applied to persons with ID, who often do not have the opportunity to choose the best options for themselves independently and based on sufficient knowledge of all alternatives (Brehmer-Rinderer & Weber, in press).

Additionally, a health behaviour model for persons with ID should not concentrate on specific behaviours, because it is known that specific risk behaviours are linked to the aetiology of certain ID (e.g. persons with Prader–Willi syndrome are frequently overweight, whereas women with Rett syndrome have an increased risk of being underweight). Such differing health issues require different modifications (losing weight vs. gaining weight). It is important to have a health model fitting the characteristics of the overall population of persons with ID to be able to design appropriate health interventions and provide the best possible medical care.

Finally, a health model in general should aim at facilitating health interactions and enable patients with ID to become more independent in health consultations. A theoretical model describing simple, general factors which influence the individual's health status may be used to explain to patients with ID in an easy language how healthy behaviours can be developed. If the medical professional understands how patients with ID perceive their health status, they will be able to adequately guide the patients towards healthier behaviours (Dysch *et al.* 2012). Likewise, a greater awareness of the interconnections between different aspects of health will help patients with ID understand influences on their health status and behaviour. Therefore, health models can contribute to making the consultation of health professionals more effective for patients with ID and can thus facilitate compliant behaviour (Kaptein *et al.* 2010).

Method

Participants

Two groups were included in this study: people with ID and a comparative sample without ID, including carers of persons with ID ($n = 226$). In total, 253 persons with ID who were able to communicate verbally participated. Respondents who did not answer all the questions of the main questionnaires were excluded from the analysis, resulting in a final sample of 230 persons with ID.

For the majority of the group of persons with ID the aetiology of disability was unknown (67%), 13% had Down syndrome, 10% reported birth related events and another 10% some other causes (Prader–Willi syndrome, Autism, etc.). Forty per cent of our respondents with ID were currently living in an institutional setting, 36% were living with their families, and 24% were living more or less independently. Only 24% of participants in this group had always lived in an institutional setting, the rest had spent most of their lives with their families.

Though this ID sample included persons from all over Austria, it was not representative on variables such as the level of ID. Persons with ID who were not able to communicate verbally could not participate as data were collected through personal interviews. Accordingly, this high level of independence was not surprising: 94% were able to get dressed without support, 80% could prepare little meals, and 91% could wash themselves without assistance. Only 67 of these participants (29%) asked their carers for help during the interview, the rest wanted to proceed with the researcher without any support.

For persons without ID the interview protocol was published online. The questionnaire for the carers had 616 page views, and 127 persons stopped answering questions before having completed the interview. The final data set consisted of 226 carers. To be able to compare findings to a group unaffected by ID, additional people from the general population were surveyed. Their questionnaire registered 735 page views. A total of 88 persons left the homepage without having completed the interview. Finally, 307 respondents answered all the questions of the main questionnaires.

A total of 144 participating carers (78%) were specially trained to work with persons with ID, another 13 (7%) were currently in training, and the remaining 15% had enduring experiences in working as carers, but had no record of formal training in this area. All of the nine Austrian provinces were represented in the study.

Procedure

Before starting with the sampling procedure, ethical approval was received from the University of Vienna's ethics committee.

Personal interviews with persons with ID

First of all, organisations employing or accommodating persons with ID were contacted in February 2012 and invited to inform their clients with ID about this research project. Additionally, this study was presented at a large national self-advocates conference to directly recruit further participants with ID.

All persons who voluntarily stated their interest in participating by contacting the principal researcher (first author) were offered a face-to-face meeting in order to be provided with information in easy-to-understand language on the project. They learned about their rights during the interview: all answers would be analysed anonymously, breaks and questions were allowed anytime. Respondents were told that they could stop the interview any time without stating any reasons and that the researcher was bound to observe confidentiality. Besides, all interviewees were free to decide whether they wanted to be supported by one of their carers or family members during the interview. All rights were documented in an easy-to-read information letter, which was handed to the participants.

Interviews were carried out between March and July 2012. The first author of this article, a trained clinical and health psychologist, conducted all the interviews. On average, the whole interview took 15 min.

Online survey for persons without ID

The same interview protocol with adapted socio-demographics was published on a homepage for online surveys. Respondents could answer these questions when and where they wanted to, offering better conditions for administration of the questionnaire (Batinic 2003).

Carers were contacted via email and invited to participate between March and July 2012. To gather data in the general population snowball sampling was used starting with university employees. This interview protocol was open to public and remained online from November 2011 until June 2012. To obviate missing data in both groups, the online survey only allowed submission after all questions of the main questionnaires had been answered.

Interview protocol

The GHC described above was operationalised mainly by simplifying and shortening psychometrically well-established and well-known tools either for the general population or persons with ID. Based on the designed model, this protocol included questions on the subjective definitions of the terms *health/disability/illness* as well as a questionnaire measuring the individuals' self-perception. Additionally, the personal view of the individual's own disability/illness and their health behaviour was explored.

General structure of the protocol

The first part contained all socio-demographic information appropriate for the respective population. For persons with ID, the following data had to be specified: age, sex, aetiology of disability, current place of residence, years of school education and activities of daily living (washing, dressing, eating). All persons with ID were asked to specify their medication. People without ID were also asked for

their educational level and their daily medication. Carers needed to specify the length of their employment and whether they had been trained and certified to work as a carer.

Health model element '*understanding of health, illness and disability*'

In the next section, the first element of the health model (see Fig. 1), the subjective understanding of *health/illness/disability*, was operationalised in a quantitative way based on studies by Schulte (1998) and Gembris-Nübel (2005). For each of the three terms four sentences illustrating four different approaches were given to our respondents: (1) *behavioural approach* (e.g. when I'm disabled, I cannot do everything I want); (2) *environment approach* (e.g. to be/stay healthy, the environment must be.); (3) *cognitive approach* (e.g. when I'm ill, I have a fever . . .); (4) *emotional approach* (e.g. when I'm ill, I do not feel well . . .). They were asked to make a ranking list of these four approaches, starting with the one that mirrored their understanding of *health/illness/disability* best. These approaches were chosen with respect to their applicability in medical consultations: When a person perceives illness/disability mainly as a reduction of one's scope of action, then health-related advice should contain information on actions that can be taken. By knowing the personal preferences regarding *health/illness/disability* of a patient the health professional can adapt their advice to the needs of the patient (DeRidder *et al.* 2007).

Additionally, this part was operationalised with three qualitative questions in case persons with ID were unable to perform the ranking. They were asked to describe their personal definition of health, illness and disability. Qualitative answers that could be obtained were divided into four categories by an independent researcher evaluating this data: (1) *emotional* answers were all those that referred to the personal experience or positive/negative views of (own) disability; (2) *cognitive* answers were those that featured for example health-related advice or specific illnesses and disabilities; (3) *behavioural* answers were those that referred to specific behavioural rules; (4) *subjective* answers were those that factually referred to the person's own disability or illness without any emotional emphasis.

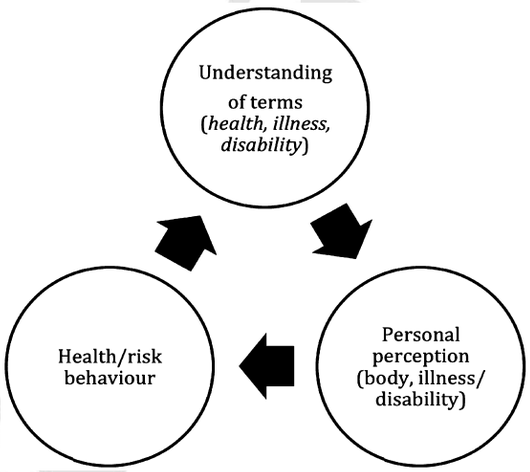

Figure 1 General health circuit.

Health model element 'personal perception'

The next two components illustrated the second element – the *perception* of the GHC (see Fig. 1): the *personal perception* and the *perception of one's disability and illness*. First, to operationalise the variable *personal perception* of the health model, the interview protocol contained sixteen questions with a 4-point Likert scale response format (Personal Perception Questionnaire, PPQ). The PPQ was based on two psychometrically well-established questionnaires for adults of the general population: the Questionnaire on Body Image (Fragebogen zum Körperbild, FBK-20; for details see Clement & Löwe 1996) and the Frankfurter Body Concept Scale (Frankfurter Körperkonzeptskala, FKKS; Deusinger 1998). Items in these two instruments that measure the perception of one's body and one's fitness were selected for the PPQ, similar items were deleted and the wordings and response format were simplified to fit the needs of the majority of persons with ID. Additionally, seven people with ID checked items for comprehensibility in a pilot – some negative wordings had to be rephrased using positive constructions.

Second, all our participants were asked if they had any kind of disability and/or illness. Respondents reporting an illness/disability were given eight

additional questions based on the Brief Illness Perception Questionnaire by Broadbent *et al.* (2006), measuring their personal perception and their knowledge of their illness/disability.

Health model element 'health behaviour'

The third element of the GHC was operationalised by listing fifteen health/risk behaviours which may be displayed deliberately and autonomously by persons with ID (Health Behaviour Questionnaire, HBQ; see Fig. 1). This section consisted of four items (medicational compliance, safe sex, safety regulations, social network) of the Support Intensity Scale (Thompson *et al.* 2004) as well as the already mentioned FKKS (six items: watching personal health in general, looking after one's appearance, sleep, nutrition, oral health, physical activity) and known health behaviours, such as sun protective behaviour, looking after one's personal hygiene, stress, alcohol consumption and smoking habits, named by Schwarzer (2004). Respondents were asked to indicate the personal accuracy of the respective behaviour on a 4-point Likert scale.

Methods of analysis

SPSS version 17 and AMOS Graphics 18.0.0 were used for the following evaluations of the compiled data set: (1) tests for data completeness in the total samples for socio-demographics; (2) tests of rating scaling assumptions, including skewness, distribution of item and scale responses and item–total correlations. All negatively worded items were recoded before used in calculations. Thereafter, (3) the internal consistency reliability (Cronbach's alpha and Guttman's split-half) for the two scales included in the assumed health model was computed, and (4) a structural equation model (SEM) was calculated to test the GHC.

Results

Differences between samples

In the total sample, the youngest respondent was 16 years old, and the oldest was 71 years old. The median age was 35 years, and 62% of our participants were female. Age and sex characteristics of the samples are illustrated in Table 1. The variables *highest attained educational degree* (e.g. compulsory school: 55% ID sample, 5% carers and 1% general population) and *subjective health status* (e.g. current illness: 13.5% ID vs. 31% non-ID; current disability: 54% ID vs. 25% non-ID) differed greatly between samples.

Table 1 Sample characteristics

		Non-ID sample ($n = 533$)	
	ID sample ($n = 230$)	**Carers ($n = 226$)**	**General population ($n = 307$)**
Age	16–71 (median 38.5)	17–61 (median 39)	18–69 (median 30)
Sex	43.5% women	68% women	71% women
	56.5% men	32% men	29% men
Educational degree	44.8% missing data	5% compulsory school	1% compulsory school
	55% compulsory school	35% completed vocational training	6% completed vocational training
	0.2% completed vocational training	30% high school graduates	36% high school graduates
		8.5% bachelor	10% bachelor
		20% master	40% master
		0.5% PhD/doctor	7% PhD/doctor
Subjective health status	47% disabled	15% disabled	
	39.5% healthy	54% healthy	
	7% disabled and ill	10% disabled and ill	
	6.5% currently ill	21% currently ill	

ID, intellectual disabilities.

Data collection characteristics

There were no missing data for the main questionnaires; the GHC could therefore be tested with SEM for all samples. Still, some persons with ID were not able to answer all socio-demographic questions. Nearly half of the ID sample (103 participants, 44.8%) was not able to name their highest attained educational degree. On the other hand, 307 participants (57.6%) of the non-ID sample did not answer questions about the number of medications they were taking on a daily basis, either because they did not take any or because they refused to answer. Few participants commented on this item, making it impossible to distinguish between these two options.

These two variables (medication and education) could not be used as influencing variables when calculating the GHC with AMOS for two reasons: First, the percentage of missing values was very high. Second, although AMOS enables the imputation of missing values of normally distributed variables, Weiber & Mühlhaus (2010, p. 143) advise against such procedures in cases where missing values occurred for unknown, unsystematic reasons.

Finally, the percentage of respondents who reported an illness (17%, $n = 130$) and/or a disability (25%, $n = 191$) was too small to test the GHC for these two groups (ill/disabled) separately.

Scaling assumptions

The ratio of skewness and kurtosis to its standard error and the Kolmogorov–Smirnov test were used to test the normal distribution of variables in all groups of respondents (total sample, ID and non-ID groups). As the distribution of item responses was skewed in all three samples, normal distribution was rejected. The Kolmogorov–Smirnov test confirmed that data were non-normally distributed.

Mardia's coefficient was computed to assess multivariate normal distribution. Consequently, the model fit and parameters of the GHC were estimated using the asymptotically distribution-free method to ascertain the loadings between variables as data were neither univariately nor multivariately normally distributed.

Reliability of the Personal Perception Questionnaire and the Health Behaviour Questionnaire

Reliability coefficients were estimated by computing Cronbach's alpha and Guttman's split-half (Bortz & Döring 2002). Item–total correlations were analysed, referring to the extent to which each item contributes to the measure. Items with scores lower than 0.30 have a low correlation with the overall scale and were therefore excluded from further psychometric analysis (Bortz & Döring 2002). Measures with a reliability score higher than 0.50 were considered sufficient (Helmsteader 1964), and values over 0.90 were stated to indicate a very high reliability (Bortz & Döring 2002).

The results for the total sample, the ID sample and the non-ID group are shown in Table 2 for the PPQ and the HBQ. Both Cronbach's alpha and Guttman's split-half coefficient illustrated a high

Table 2 Reliability coefficients of the PPQ and the HBQ for all samples

	PPQ		HBQ	
	Cronbach's alpha	**Guttman's split half coefficient**	**Cronbach's alpha**	**Guttman's split half coefficient**
Total sample ($n = 763$)	0.923 (6 items)	0.918	0.550 (7 items)	0.574
ID sample ($n = 230$)	0.694 (7 items)	0.790	0.725 (6 items)	0.740
Non-ID sample ($n = 533$)	0.847 (6 items)	0.798	0.649 (7 items)	0.583

The number of items used for calculations is indicated in brackets.
ID, intellectual disabilities; PPQ, Personal Perception Questionnaire; HBQ, Health Behaviour Questionnaire.

reliability of the PPQ for the non-ID group and the total sample. Given that the HBQ contained a list of different behaviours, it was expected that internal consistency values would be lower than for the PPQ. Results were similar for the two samples (ID, non-ID). Many HBQ items needed to be excluded due to low item–scale correlations, resulting in a sufficient Cronbach's alpha and Guttman's split-half coefficient (see Table 2). Concluding, the operationalisation of two GHC components (personal perception, health behaviour) did work for both samples.

Personal definition of health, disability and illness

Approximately one-third of respondents with ID were unable to answer even the modified, qualitative questions (30–41%). As described earlier, qualitative answers that could be obtained were divided into four categories by an independent researcher: *emotional*, *cognitive*, *behavioural* and *subjective* answers. All categories except for the category *subjective answer* matched those provided to the non-ID sample. Measurement strategies and results, however, differed greatly between samples, and for this reason the latent variables *personal definition of health, illness and disability* was eliminated from further statistical analysis of the GHC.

Testing of the general health circuit

The GHC was tested separately for the total sample, the ID sample and the non-ID sample to illustrate model differences between groups. An explorative analysis approach was taken as no previous research results could be used to define manifest, latent or influencing variables and parameters.

First, two latent variables (personal perception, health behaviour) were defined by using the most reliable items of the PPQ and the HBQ as manifest variables. Manifest variables with non-significant parameters, with regression weights below 0.2 (Chin 1998) and critical ratios under 1.96 (Weiber & Mühlhaus 2010, p. 180) and demonstrating low relevance for the model structure (Backhaus *et al.* 2006) were excluded from further calculations. When specifying the measurement models, the parameter of the first manifest variable in each of the two latent factors was fixed to 1. Additionally, based on a suggestion of health moderating variables by Wagner *et al.* (2004), a set of items (age, sex, subjective health status) was considered to assess their influence on the relationship between personal perception and health behaviour. To define the variables having a meaningful influence on the latent variables, the same three criteria as for the selection of manifest variables were followed. After having eliminated redundant variables the GHC was estimated.

The general model fit is illustrated in Table 3 by presenting absolute and descriptive fit indices (Hair *et al.* 1998). As the criterion of normal distribution could not be fulfilled the X^2 statistics was not used to interpret the model fit. The *root mean square error of approximation* (RMSEA) determines how well the model fits a population covariance matrix. Values less than 0.05 suggest a good fit, while those between 0.05 and 0.08 indicate a reasonable fit (Weiber & Mühlhaus 2010). Except for the ID sample with a reasonable fit slightly below the cut-off, each model suggested a good fit. The *goodness-of-fit index* (GFI) is a measure of fit between the hypothesised model and the observed covariance matrix. It ranges between 0 and 1 inclusive, with a

Table 3 General model fit values for all samples

Sample	RMSEA (≤0.05)	GFI (≥0.9)	CFI (≥0.9)	SRMR (≤0.1)	CMIN/DF (≤3)
Total sample ($n = 763$)	0.029	0.991	0.980	0.0304	1.622
ID sample ($n = 230$)	0.052	0.990	0.892	0.0664	1.621
non-ID sample ($n = 533$)	0.034	0.986	0.964	0.0372	1.597

RMSEA, root mean square error of approximation; GFI, goodness-of-fit index; CFI, comparative fit index; SRMR, standardised root mean square residual; X^2/d.f. values (CMIN/DF).

cut-off value of 0.9 generally indicating an acceptable model fit (Baumgartner & Hombur 1996). Values for all samples indicated an acceptable fit. The *comparative fit index* (CFI) shows how much better the specified target model fits in comparison to a baseline model. This value should be above 0.90 to demonstrate a good fit (Byrne 2001). While the total sample and non-ID group indicated a good fit, the CFI of the ID sample scored slightly below the cut-off.

Finally, results of two descriptive indices supported the acceptable model fit: The *standardised root mean square residual* (SRMR) is the square root of the average squared residuals. Weiber & Mühlhaus (2010) state that values ≤0.10 indicate a good model fit (p. 165). Additionally, the X^2/d.f. values (CMIN/DF) were below the cut-off of 3 and therefore supported the acceptable model fit (Weiber & Mühlhaus 2010, p. 176). With respect to the results for the ID sample, it must be noted that fit indices are underestimated in small samples. Samples with less than 250 participants are considered small (Hu & Bentler 1999).

Table 4 depicts direct effects between latent variables and parameters of influencing variables. In the non-ID sample, the latent variable *personal perception* was strongly related to the variable *health behaviour*, thereby supporting our theory: the better the individual's personal perception, the more healthy behaviours the person reports (see Table 4). This relation appeared to be different in persons with ID. No significant relationship existed between the latent variables. Thus, the direct effect between the latent variables *personal perception* and *health behaviour* in the total sample was highly negative (see Fig. 2). Including persons with and without ID in one sample led to the result that persons with a negative perception of themselves more frequently mentioned healthy behaviours. Additional analysis proved that persons who reported a disability perceived their bodies more negatively than persons without a disability ($X^2 = 45.809$, d.f. = 3, $P < 0.000$).

With respect to influencing factors, age had to be eliminated from all model calculations due to the fact that the three mentioned criteria were not met.

Table 4 Standardised path coefficients for latent variables and influencing factors

Sample	Path	Standardised path coefficient
Total sample	Personal perception – health behaviour	–0.69***
	Subjective health status – personal perception	0.25***
ID sample	Personal perception – health behaviour	0.07
	Sex – health behaviour	0.26***
Non-ID sample	Personal perception – health behaviour	0.41***
	Sex – health behaviour	0.30***

*** $P < 0.001$.
ID, intellectual disabilities.

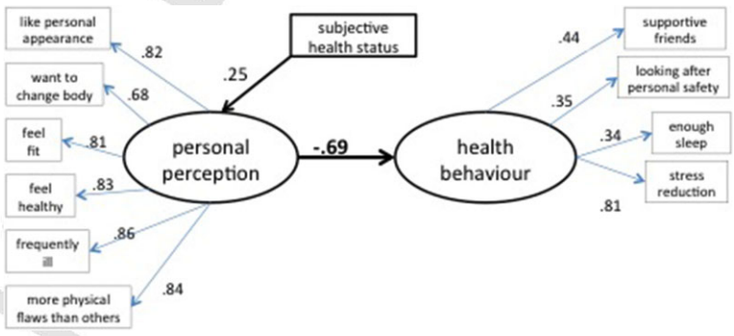

Figure 2 AMOS Graphics output – results for the total sample.

Colour online, B&W in print

For the total sample, the subjective health status (healthy, ill, disabled) had a small, but meaningful influence on the variable *personal perception*. The participant's sex had a significant effect on health behaviour in the ID and the non-ID model. This effect seemed mainly due to two different items: In the non-ID sample the standardised residual covariance of the item *body change* was large (–4.376), exceeding the value of 2.58 (Byrne 2001, p. 86). Men did not wish to change their bodies as frequently as women did. For the ID sample, the standardised residual covariance of the item *body weight* was higher than the Byrne's cut-off (–2.602), which means that men were more satisfied with their body weight than women were. As both items (body change, body weight) were not reliable for the total sample, this effect by sex was not found in the total sample. As in numerous other studies, a general stress reducing behaviour was found to be the most important health behaviour (e.g. Ng & Jeffery 2003; Schwarzer 2004; see Fig. 2).

Discussion

This article illustrates the definition and operationalisation of a health model fitting the characteristics of an ID population able to communicate verbally and describes the evaluation of differences in health behaviour between people with and without ID based on this suggested health model. The GHC was explored with regard to existing research findings and in particular consideration of the critique of Suls & Wallston (2003), which states that authors of new models seldom seek to address limitations of previous models. As explained before, a common problem in health research with persons with ID is that the operationalisation of variables that is customary for other populations may be inappropriate for a person with ID and may, thus, hinder accurate measurement. The usage of overly abstract concepts and the assumption of an independent, rational decision-making agent that are common in health models and related measures seem inappropriate for persons with ID. For these reasons, new instruments were developed. Psychometric analysis of the instruments used showed that they were reliable and hence can provide a valuable tool for studying health-related issues and the GHC in the population with ID.

There were some limitations to the study. The samples used were not entirely representative. The data for the non-ID participants was gathered online, and online populations are known to differ from offline populations (e.g. with respect to age, ethnicity and economic status, Andrews *et al.* 2003). The applied sampling procedures resulted in an unusually high educational level of the non-ID population. As far as the ID population is concerned, these findings are only valid for individuals who demonstrate a high functional ability, as no severely disabled persons were included because of the data collection procedure which required a personal interview. With respect to this missing group, it may be called into question whether this model on health behaviours that are deliberately and autonomously demonstrated can be used to describe the health situation of this group. It needs to be discussed how 'risk behaviours' can be defined in the context of persons with severe/profound ID. When focusing on individuals with ID who are able to express themselves verbally the potential of generalising the findings to the overall population with ID is limited.

Furthermore, in view of a global generalisation of the present findings, previous research (e.g. Perry *et al.* 2010) has shown that Austrian health data on persons with ID are similar to health data collected in Western European and North American countries. Cross-national studies are, however, required to evaluate whether analogue findings of personal perceptions influencing health behaviour can also be expected. For instance, the impact of the *personal understanding of terms* such as *health/illness/disability* may be different in other non-German speaking countries. In German-speaking countries, the medical model of disability is still very prominent in personal reflections made by self-advocates (Felkendorff 2003), whereas in English-speaking countries the social model of disability and its implementation in the context of the UN Convention on the 'Rights of Persons with Disabilities' seems to be discussed more frequently and in more detail, especially among self-advocates (Sprague & Hayes 2000), which might affect their perception of the term *disability*. Concluding, results show that our aim to define and operationalise a health model did work well with the exception of the model's first element. In general, future research should focus on

personal definitions of health/illness/disability to clarify the impact of these definitions on personal perception and health behaviour.

With respect to testing the GHC, two latent variables (personal perception, health behaviour) were defined in accordance with the theory by using the most reliable items of the PPQ and the HBQ as the manifest variables. The general model fit was evaluated by calculating different absolute and descriptive fit indices (Hair *et al.* 1998). Most indices indicated an acceptable model fit for all samples. Two indices (RMSEA and CFI) suggested only a reasonable fit for the ID sample, which can be related to the smaller sample size compared with the non-ID group. When looking at the relation between the latent variables, a high direct effect was found for the non-ID sample. In the ID sample, this relation was not significant, thereby answering our second research question and supporting our theory that persons with ID perceive their health differently from persons without ID and therefore may act differently.

Concerning influencing factors, age had to be eliminated from all model calculations due to the fact that the three mentioned criteria were not met. Further research on moderators of health, such as *medicational compliance*, *education* (see sample distinctions in Table 1) and/or *health knowledge*, *personality and social status*, that may influence health disparities between people with and without ID is necessary for a better understanding of our findings. Similarly, results concerning sex differences have been reported in previous studies for the general population (Feingold & Mazzella 1998). Research on variations in health behaviours and attitudes toward healthy living between sexes and non-ID and ID populations should be expanded, because our findings indicate that different interventions will be necessary for these groups.

The results of our study clearly imply a need to improve the strategies of medical professionals working with persons with ID. Self and health perceptions differ between ID and non-ID groups, resulting in different health behaviours. This implies different priorities in assessing preventive and risk factors for persons with ID as compared with the general population. Our findings support the need for new communicative approaches in health practices involving persons with ID and will hopefully inspire further work aiming to provide appropriate and well-adapted medical care.

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The relation of an individual's health knowledge and the personal perception of one's body and disabilities to reported health behaviours in persons with intellectual disabilities

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Keywords:	health perception, health knowledge, health behaviour, intellectual disabilities

Abstract:	Background: The aim of the study was to explore subjective factors affecting health behaviour in persons with intellectual disabilities (ID). The study therefore focused on their self-perception, their perception of their disabilities and their knowledge of the human body. Materials and Methods: A total sample of 230 persons with ID and 533 persons without ID was surveyed. Socio-demographic data and information on the individuals' health status, personal health perceptions and behaviours were collected. Results: Findings revealed significant differences between the ID and non-ID populations in terms of perceptions and behaviours regarding health, leading to different health outcomes. Additionally, knowledge of the composition and functions of the human body as well as personal medication and illnesses was limited among the ID sample. On the contrary, they demonstrated profound knowledge of nutrition and other health behaviours. Conclusions: Results are discussed with respect to enabling persons with ID to act more autonomously in areas relevant for their health.

The relation of an individual's health knowledge and the personal perception of one's body and disabilities to reported health behaviours in persons with intellectual disabilities

Introduction

Health studies presenting data on the poor health of persons with intellectual disabilities (ID) were published throughout the past decade (Kennedy *et al.* 1997; Robertson *et al.* 2000; Krahn *et al.* 2006; Maaskant *et al.* 2009; Lin *et al.* 2010; Finlayson *et al.* 2011). Current publications focus predominantly on specific health behaviours (e.g., physical activity, alcohol consumption or smoking; Carmeli *et al.* 2008; Melville *et al.* 2008; Finlayson *et al.* 2009), knowledge of specific health risks (e.g., nutritional knowledge; Golden & Hatcher, 1997; Illingworth *et al.* 2003; Jobling & Cuskelly, 2006; Maïano *et al.* 2010) or provide data on the actual health status of persons with ID for a specific health area (e.g., oral health, body weight; Bhaumik *et al.* 2008; Anders & Davis, 2010).

Still, little is known about the factors that influence these persons' health status and lead to the frequently reported disparities between the health status of people with ID and that of the general population. On the one hand, existing research focuses on biological causes of health deterioration in persons from specific ID syndrome groups (for example, overweight as a result of Trisomy 21; Jobling & Cuskelly, 2006), while ignoring psychological and social elements that affect health behaviours and outcomes. On the other hand, previous studies highlight specific factors influencing certain health behaviours (e.g., reasons for obesity; Illingworth *et al.* 2003) or define health risks in general (Hahn & Aronow, 2011). Following an analysis of general and psychological elements which had not been considered so far, Brehmer-Rinderer and Weber (in press) suggest a health model, the General Health Circuit (GHC), describing mainly subjective factors (e.g., personal perception of health) influencing

health behaviours. This means that the elements included in this GHC do not focus on specific health behaviours or biological factors, but on the above-mentioned subjective elements. Besides, objective components can also be added to this model and its measurement, such as the way in which an individual's social network influences the individual's health behaviours. This health theory was previously tested in an ID and a non-ID sample and proved its validity in both samples (Brehmer-Rinderer *et al.*, in press).

In continuation to the research findings with respect to the GHC, the aim of the present contribution is to focus on the model components, i.e. subjective factors affecting health outcomes. Three elements are considered: the individual's view of his or her body, the individual's perception of disability and the individual's knowledge of health/ the human body in persons with ID.

It is possible that perceptions of health/disability are different in persons with ID compared to the general population. Previous research dealing with disability perception focused mainly on the (negative) perception of persons with ID by others (e.g., Slevin & Sines, 1996; Gillmann *et al.* 2000) and demonstrated its effect on person's with ID potential to participate in various areas of society. Following, it may be possible that a negative perception of *health/illness/disability* leads to a higher rate of risk behaviours.

In addition, persons with ID may be unaware of certain health behaviours and therefore engage in risk behaviours. Illingworth *et al.* (2003) demonstrated that knowledge of nutrition is limited among persons with ID. The fact that front-line staff caring for adults with ID often lack knowledge of healthy lifestyles too (Melville *et al.* 2009) may be a socially determined cause of insufficient health related information among persons with ID.

The present study will thus focus on possible effects the three above mentioned elements (health/disability perception, health knowledge, body perception) might have on health behaviours in people with ID.

Health knowledge, health perception and health behaviour

Materials and Methods

Materials

All questionnaires included in this interview protocol were designed to measure the GHC in persons with ID and without ID. Their construction was described in detail in Brehmer-Rinderer *et al.* (in press).

Please insert table 1 here

Table 1 indicates the structure of our interview protocol and highlights differences between the protocols used for the two samples (ID, non-ID) in boldface. In the first part, personal information including subjective health status (healthy, ill and/or disabled) was collected. Information on aetiology was either gained directly from the participants with ID or from the main carer after the participants had given their consent. Additionally, the respondents' knowledge of the human body (composition and functions) was recorded in the second part of the protocol for ID participants. Respondents were given a drawing of the human body and asked to point to the knees, the heart, the stomach and the lungs. Furthermore, they were asked to name the functions of the stomach and the lungs.

The third part considered the individuals' theories related to health, illness, and disability. These concepts were operationalised according to Schulte (1998) and Gembris - Nübel (2005), using three qualitative questions: *What is your personal definition of health? What is your personal definition of illness? What is your personal definition of disability?* In this paper, we will only refer to the perception of the term *health*.

Part four consisted of three short questionnaires (see table1). The first addressed personal body perception (Personal Perception Questionnaire, PPQ), while the others focus on the individuals' perception of their illnesses and/or disabilities. The latter questionnaires were only answered by those respondents who stated to have an illness and/or a disability in the

beginning of the interview (part 1 *subjective health status*). In this article, results will only be presented for the PPQ and the individuals' perception of their disabilities.

The fifth part featured a health behaviour questionnaire (HBQ), consisting of a list of fifteen different health behaviours which a person can engage in independently from others and which therefore may improve or worsen their health status. Finally, all participants were asked to specify objective health-related data (see table 1): body height, body weight, the number of cigarettes smoked per day and prescribed medication they take on a regular basis.

Participants

Table 2 illustrates the sample characteristics of the 230 participants with ID. Our participants could all speak for themselves; it is therefore obvious that the composition of this ID sample is not representative for the whole Austrian ID population. Still, as 80-85% of all persons with ID are considered to be mildly/moderately disabled (AAIDD, 2010), results gained from this study do represent the majority of the ID population. This project was designed to gather data through interviews, which is why no information was obtained from persons unable to communicate verbally. Accordingly, the high level of independence of our sample was not surprising: 94% did not need assistance to get dressed, 80% were able to prepare simple meals and 91% were able to wash themselves. Only 67 of our 230 respondents asked for assistance during the interview.

With respect to ID aetiology, 13% had Down syndrome, 10% mentioned birth related events and another 10% some other causes (e.g. Prader-Willi syndrome, autism; see table 2). Two thirds of this sample (67%) could not specify the aetiology of their disabilities. 40% of our sample were currently residing in an institutional setting, 36% were living with their families, and 24% lived more or less independently (see table 2). Only 24% of our respondents had always lived in an institutional setting, the rest had spent most of their lives with their families.

Health knowledge, health perception and health behaviour

Please insert table 2 here

In addition to this ID sample, data from 533 persons without ID was collected through an online survey. 70% of this group were women and the participants in this sample were about five years younger than those in the ID sample (age span: 17-69 years; median age 33).

Procedure

After the University's ethics committee had considered all project documents and agreed to the project's goals and procedures as well as to the future use of gathered data, the researchers contacted organisations employing or accommodating persons with ID. Additionally, this study was also presented at a large national self-advocates conference in December 2011 to recruit interested participants with ID.

The first author met all persons with ID who voluntarily stated their interest in participation individually in order to provide them with information on the project in easy-to-understand language. In this face-to-face situation, interested participants learned about their rights in relation to the interviews: all answers would be analysed anonymously, breaks and questions by the interviewee were permitted at any time. Besides, interviewees were informed that they were allowed to stop the interview at any point without stating any reasons and that the researcher was bound by confidentiality. Additionally, it was possible for respondents to decide to proceed with the interview with the support of one of their carers/family members or not. All interviewees' rights were documented in an easy-to-read information letter, which was handed over to the participants. All interviews with persons with ID were conducted between March and July 2012 by the first author of this article, a specially trained clinical and health psychologist. The interviews took 15 minutes on average.

Health knowledge, health perception and health behaviour

The participants of the non-ID sample were informed of their rights and presented with the interview protocol online. Details on this online survey are described in Brehmer-Rinderer *et al.* (in press).

Data Analysis

SPSS version 17 was used to evaluate the collected health data. Internal consistency figures will be presented for the two questionnaires (PPQ and HBQ) that are of interest for this article. Since the questionnaire describing the individuals' personal perception of their disabilities only consisted of five items dealing with different aspects, no reliability scores were calculated. Scores were computed to describe the general direction (negative, neutral or positive) of the individuals' personal perception of their bodies and disabilities. Subjective and 'objective' health data for the ID and the non-ID sample and the prevalence of the measured health/risk behaviours will be illustrated. Furthermore, the perception of health as expressed by persons with ID and their health knowledge will be characterised. Finally, when testing hypotheses, only non-parametric tests were used, since no variables confirmed the prerequisite of normal distribution (for describing differences between samples: Mann Whitney U-Test or Kruscal Wallis Test; Spearman's rank order correlation for describing relations between variables). Results will be presented comparatively for the two groups (ID, non-ID).

Results

Internal Consistency of PPQ and HBQ

Reliability coefficients were determined by calculating Cronbach's Alpha and Guttman's split-half coefficient for the total sample. Item-total correlations of items were analysed, and items with scores lower than 0.30, i.e. demonstrating remote correlation with the overall scale,

were excluded from further psychometric analysis (Bortz & Döring, 2002). Reliability scores higher than 0.50 were considered sufficient (Helmsteader, 1964). For the PPQ, a Cronbach's Alpha of 0.923 and a Guttman's split-half coefficient of 0.918 resulted. With respect to the HBQ, internal consistency values (Cronbach's Alpha of 0.550; Guttman's split-half coefficient of 0.574) were lower than for the homogenously constructed PPQ, as the HBQ contained a list of different health and risk behaviours. Reliability figures were similar when calculated separately for the two groups (ID and non-ID) (Brehmer-Rinderer *et al.*, in press).

Health status and participants' perception of their disabilities

39.5% of our respondents with ID considered themselves to be healthy, compared to 54% of the non-ID group, and 13.5% of the ID participants named an illness from which they suffered (in contrast to 31% of the non-ID sample, see table 3).

Please insert table 3 here

In the ID sample, 125 persons (54%) mentioned to have a disability; only 39.2 % of these named intellectual disabilities (see table 3). It was surprising that persons with Down syndrome gave negative answers to the question whether they suffered from a disability significantly more often than persons with known or unknown ID causes ($X^2 = 26.7$, df= 3, $p < 0.000$). On the other hand, persons whose disabilities were due to birth related events confirmed that they suffered from a disability more often than persons with an unknown disability cause. Out of these 125 respondents with ID who defined themselves as a person with a disability, 57% perceived this as something positive, whereas only 9% considered their disabilities as something negative (see table 3).

Furthermore, a small, significant correlation between age and disability perception was found for the total sample ($R= 0.142$, $p < 0.032$): the older a person with a disability was, the more

likely he/she was to think of his/her disability as something positive. Additionally, a moderate correlation was found between body weight and disability perception ($R= 0.352$, $p < 0.004$): the higher the body weight, the more positively the disability was perceived. Persons who reported a disability perceived their bodies more negatively than persons who gave a negative answer to the question concerning an existing disability ($X^2 = 45.809$, $df= 3$, $p < 0.000$).

Body weight and body perception

With respect to the 'objective' health data, persons without ID significantly differed from the ID group regarding their Body Mass Indices (BMIs) ($p < 0.000$), with two thirds of the non-ID sample being of normal weight according to World Health Organisations' criteria (World Health Organisation, 2000). Table 4 also illustrates the distribution of the BMIs in our ID sample: 57% were overweight, while 6% were underweight. Nearly half of the ID sample (113 persons) were unable to report their body height or body weight. We also found a significant disparity in the BMI scores according to the actual living situation ($X^2= 6.012$, $df= 2$, $p < 0.049$): persons with ID living alone showed the highest BMI scores followed by participants living with their families. Institutionalised respondents had the lowest BMIs.

Please insert table 4 here

Although the figures on body weight would suggest otherwise for the ID group, 95% had a neutral view of their bodies and 5% even perceived their bodies positively. Overweight and obese persons with ID did not perceive their appearances differently from normal weight persons with ID. In contrast to the ID sample, 83% of the non-ID participants perceived their bodies positively, 15% neutrally and only 2% negatively. Contrary to the ID group, non-ID respondents with normal body weight perceived their bodies significantly more positively than overweight or obese participants of the non-ID sample ($X^2= 28.814$, $df= 3$, $p < 0.000$). In

addition, women perceived their bodies more positively than the male respondents ($p < 0.000$).

Health behaviours

Table 5 depicts the descriptive results of the HBQ as well as the findings of the Mann Whitney U-Test to detect significant differences between the two groups: Persons with ID reported to eat unhealthy food more often ($p < 0.000$) and were more infrequently physically active than persons without ID ($p < 0.001$). Additionally, the participants with ID mentioned to take less care of their oral health than the non-ID sample ($p < 0.000$). On the contrary, our ID respondents stated lower alcohol consumption rates ($p < 0.000$) and experienced less stress ($p < 0.000$). The percentage of persons with ID (37%) who reported not to have any friends was remarkably high. In addition to this, 78% stated that they currently had no sexual relationship compared to 20% of the non-ID sample. Of those persons with ID who indicated to engage in sexual activity, the majority did not protect themselves from contracting diseases. With respect to this figure, no differences were found between places of residence of persons with ID (family, alone, institutional setting).

Please insert table 5 here

Relating to the item *sun protection*, in both groups no kind of sun protection was used on a regular basis. In general, women reported more healthy behaviours than men ($p < 0.000$). Additionally, the number of health behaviours showed a very low correlation with age ($R= 0.088$, $p < 0.015$) and a negative one with the BMI ($R= -0.081$, $p < 0.038$): the older the respondents were, the more likely they were to mention to act healthily; the lower the BMI, the higher the number of health behaviours by the respective respondent. Finally, the more

cigarettes a participant smoked per the day, the lower the number of other health behaviours reported by this person ($R= -0.463$, $p < 0.000$).

With reference to *smoking behaviour*, we also found a significant difference between our samples: Even though more respondents without ID smoked, participants with ID reported to smoke more cigarettes per day than non-ID smokers (see table 4). Besides, women mentioned smoking significantly less often than men ($p < 0.032$). Neither the results concerning smoking nor the findings relating to the perception of personal appearances and disabilities differed according to the educational level of the participants.

Personal perception of the term *health*

While only two thirds of the ID respondents (68.7%) were able to answer this question, there were no missing answers in the non-ID group as it was only possible to submit the online survey after having answered all the questions. Nearly half of the ID participants (110 persons, 47.8%) spontaneously demonstrated their knowledge of healthy nutrition when asked how they perceived the term *health*: they named healthy foods and drinks, described the food guide pyramid and presented 'health rules', such as the importance of being physically active for staying healthy. The rest of this sample's answers (20.9%) contained information on the respondents' personal health status. On the contrary, only 10.1% of the respondents without ID talked about any kind of health related advice. The majority of this group mentioned the importance of health for personal wellbeing (89.9%).

Knowledge of the human body and general health facts

The following description only refers to the ID sample, as it was only possible to include these questions in the personal interviews. Similarly to the missing data on body height and body weight, only 33% of the ID sample were able to answer all questions on the human body, while an additional 56% were able to solve at least two tasks correctly. When looking at

this exercise in more detail, we found differences according to the respondents' respective level of independence from others: the more dependent our respondents were in their activities of daily living (preparing meals, dressing and hygiene), the less they knew about the human body (X^2= 7.259, df= 2, p < 0.027). Nevertheless, there was no relation to the past and current place of residence: persons living with their families knew as much as persons living in institutionalised settings. Furthermore, persons whose disability aetiology was unknown knew less about the human body than persons, who knew the cause of their disability (p < 0.000). Additionally, we found that respondents who successfully answered all questions on the human body were more likely to present their knowledge of healthy nutrition and other health behaviours spontaneously when asked for their perception of the term *health*. The very same participants also reported more healthy behaviours (p < 0.000).

Besides, we detected that participants with Down syndrome were most likely to spontaneously present their knowledge of health behaviours when asked for their personal perception of the term *health*.

Knowledge of personal medication

61% of the ID group (140 persons) took prescribed medication on a daily basis: 72 named psychotropic medications (31%), eighteen mentioned medication for blood pressure regulation and five took tablets for muscle relaxation and sleep stimulation. Eighteen participants with ID were not able to specify their medication. Those persons who had stated before that they suffered from an illness knew their medication very well: all participants with a mental disorder, epilepsy or diabetes were able to specify the reason for prescription, the name and the dosage of the respective medication. Conversely, only a minority of 23 persons who had to take medication perceived themselves as ill. This implies that some illnesses are not recognised as such by persons with ID: out of 23 persons stating epilepsy as the reason for taking medication, only eight had named this illness when asked about it (part 1 *person*

related information, table 1). Additional 25 persons with ID took thyroid medication, but none mentioned any kind of thyroid disease. Similarly, persons with prescribed medication for other organs/body functions (e.g. heart, stomach, prostate and bladder) answered the question concerning illnesses negatively.

Discussion of findings and suggestions for future research

This study looked at various health aspects in persons with ID: it provides a first insight into subjective and objective data on the health status of respondents from a group of persons with ID and a non-ID group. Their body and disability perceptions were measured as well. On top of that, data on the factual knowledge of the human body and other medical features were gathered from persons with ID. This way, we were able to accomplish the study's aim to collect more information on factors which might affect health behaviour and, thus, contribute to the unfavourable health status of persons with ID.

Results on health status and health behaviour

In accordance with previously published health studies (e.g., Bhaumik *et al.* 2008; De *et al.* 2008; Carmeli *et al.* 2008; Melville *et al.* 2008; Humphries *et al.* 2009; Finlayson *et al.* 2009), this study has demonstrated once again that it is of high relevance to focus on the health status of persons with ID and to develop strategies to at least prevent further deteriorations: most participants with ID were either overweight or obese and in that significantly differed from the non-ID sample. Contrary to the study of Robertson *et al*. (2000), the BMI level of our participants with ID was higher in persons living in a more independent setting.

Besides, a higher frequency of unhealthy nutrition and a lower rate of sport activities were reported by our respondents with ID. Studies by Stanish *et al.* (2006) and Robertson and Emerson (2010) have led to similar results. Some researchers defined various barriers that hinder persons with ID from engaging in physical activities (Bodde & Seo, 2009; Carmeli *et*

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al. 2012). They highlighted that the development of policies for agencies that serve individuals with ID by minimising transport related, financial, policy related and educational barriers are of primary importance for promoting physical activity. In addition, the influence of an individual's social network on the respective individual's physical activities needs further investigation.

In accordance with Anders and Davis (2010), who found inferior oral health in patients with ID, the participants in this study admitted that oral health was not so important to them. With respect to this finding and data gathered on sun protection and contraception, more data and intensified awareness training concerning the risks involved are needed.

Previous studies (e.g., Tracy & Hosken, 1997; Kennedy *et al.* 1997; Rurangirwa *et al.* 2006; McGuire *et al.* 2007) found lower rates of smoking and alcohol consumption in samples with ID compared to the general population. These results were also observed in this project. Contrary to findings for the general population (Statistik Austria, 1997), women participating in this study reported to smoke less than men.

Results on participants' body and disability perceptions

Not only the health status, but also the individuals' body and disability perceptions differed between persons with and those without ID. While most participants without ID liked their bodies, the majority of ID respondents perceived their body neither positively nor negatively. We found that, although most persons with ID were overweight, they did not perceive themselves in a negative way, unlike the non-ID group, where the BMI did influence the individual's body perception. Following this line of thought, persons who are pleased with their appearance will not realise the need to change their behaviours to stay healthy. Hence, new motivational approaches and specific research projects should be designed to convince affected persons with ID to change their unhealthy behaviours.

Besides, contrary to the meta-analysis by Feingold and Mazzella (1998), the women in this study perceived their bodies more positively than the male respondents. We found that persons with disabilities were more likely to be satisfied with their appearance than persons without a disability. Depending on their disability aetiology, persons with ID did not only perceive their bodies and disabilities differently, but were also more likely to deny or admit their ID. With reference to Brehmer-Rinderer *et al.* (in press), who showed that an individual's self-perception influences health behaviour, future research should focus on the determined dissimilarities between disability types. This variation of one's disability perception may partly explain the discovered health difference.

Results on health related knowledge and the individuals' perception of the term *health*

Various aspects of health knowledge were encountered in this study: First, we found that the knowledge of personal health facts, such as body weight, body height, personal medication and individual illnesses, among persons with ID was only fragmentary. Second, unlike previous results of Illingworth *et al.* (2003) or Jobling and Cuskelly (2006), participants with ID in this study had a satisfactory level of knowledge of nutrition. When asked for their personal definition of *health,* the vast majority of the ID group talked about the food guide pyramid, the distinction between healthy and unhealthy foods as well as the importance of being physically active and other 'health rules'. Third, the knowledge of the structure of the human body and the functions of its various organs was generally limited among respondents with ID and differed according to disability aetiology and level of independence in the activities of daily living.

Besides, we found that a profound knowledge of one of the measured health topics was related to profound knowledge in other health areas: participants who knew the human body well demonstrated their general health knowledge when asked for their perception of the term *health* and reported to act healthier.

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Finally, we also found that persons with and without ID perceived the term *health* differently. Similar to this finding, Brehmer-Rinderer *et al.* (in press) described that the individual understanding of *illness* and *disability* varied between participants with and those without ID.

Limitations and future focus

Although the instruments worked well in both groups and reliability results were satisfying, this study had some limitations that can be addressed in future research. The sample used cannot be deemed representative of the entire ID population, because only those who could personally do the interview were included in the study. This excludes people who are less independent and are, thus, probably at an even higher risk of poor health. In addition to this, results of the non-ID sample cannot be called representative either, as it is known that online populations differ from offline populations (Andrews *et al.* 2003). The fact that persons with ID had problems answering many of the open-ended questions demonstrates the need to develop even more sensitive methods for capturing the views and ideas related to health and disability of persons with ID.

Besides, our findings necessitate substantial health research as well as health interventions in the future: First, our results concerning which risk behaviours are most common among persons with ID (being physical inactive, eating unhealthy foods and irregular oral health) support the current research focus. Moreover, we found that an important resource for handling difficult health situations was widely missing for most persons with ID – persons with ID normally have very few or no friends. This finding can be described as alarming, when the result of a recent study is considered: having a small social network is related to poorer psychological wellbeing (Cable *et al.* 2012). Future projects should therefore also highlight possible health resources in the social environment of persons with ID. Besides, the influence of age needs to be further investigated as older participants stated more health

behaviours. They may use different motivational and psychological strategies to stay healthy compared to younger persons.

Second, persons with ID need to be adequately informed about their health status and illnesses, the proper administration and the reasons for prescription of their medication. The finding that only eight out of 23 persons taking prescribed medication for epilepsy mentioned to have epilepsy when asked for an existing illness supports this need.

Besides, educational resources on the human body and its functions have to be made available. It should be highlighted why this kind of knowledge is so extremely important: it means one big step towards independence from others. Health interventions providing persons with ID with this essential information in an easy-to-understand language could help improve this situation.

Fourth, future research projects need to check whether persons with ID who do not know the human body well are still able to understand the health related advice of health professionals. It seems that patients with ID do not adequately understand medical information and therefore continue their risk behaviours.

Fifth, the respective levels of familiarity with health behaviours, the human body and effects of behaviours/illnesses should be taken into account when designing new health interventions or planning medical consultations. Based on this study, health professionals should, for example, be advised to not only ask for current and previous diseases in medical consultations, but also to ask specifically for prescribed medication. In addition to this, the findings that individual body and disability perceptions are of importance when dealing with persons who do not act healthily and that terms like *health*, *illness* and *disability* are perceived differently by persons with and those without ID support the need for new communicative approaches to gather the correct and complete medical history of a patient with ID directly from the respective person.

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In conclusion, the results from this study imply that there is a great potential for developing and enhancing health interventions adjusted to the needs and characteristics of persons with ID in order to enable persons to engage in healthy behaviours.

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Table 1

Structure of interview protocol

Part	Content
1	Person related information: age, sex, **aetiology of disability,** place of residence (province, **actual living situation, previous residence**), **intensity of family contact,** years of education, highest educational degree **activities of daily living (washing, dressing, eating),** **health contact person** subjective health status (*healthy, ill and/or disabled*)
2	**reading abilities and knowledge of the human body**
3	subjective definition of the terms *health*, *illness* and *disability*
4	3 questionnaires dealing with the personal perception of one's body (PPQ), the perception of one's illness and/or disability
5	health behaviour questionnaire (HBQ)
6	objective health data: medication, body weight and height, number of smoked cigarettes per day

Note. Contents marked in boldface were only measured in the ID sample.

Table 2

Characteristics of the ID sample (N=230)

age	sex	ID aetiology	actual residence
16-71 age span median age 38.5	43.5% women 56.5% men	67% unknown 13% Down synrome, 10% birth related events 10% other causes (e.g. accident, Prader-Willi syndrome).	40% high level of institutional support 36% family and 24% living independently with low level of support

Table 3

Subjective health status and perception of disability

	Question	ID sample (N=230)	non-ID sample (N=533)
A	I have a disability	47% disabled	15% disabled
	I am healthy	39.5% healthy	54% healthy
	I have a disability and an illness	7% disabled and ill	10% disabled and ill
	I am currently ill	6.5% currently ill	21% currently ill
B	How do you perceive your disability?	57% positive 34% neutral 9% negative Answered by 125 persons.	23.8% positive 62.3% neutral 13.9% negative Answered by 122 persons.
C	What kind of disability do you have?	24.8% unknown 39.2% ID 16% physical 11.2% sensory 8% neurological 0.8% mental Answered by 125 persons.	1.5% unknown 15% physical 80% sensory 2.2% neurological 0.7% mental 0.6% learning difficulty Answered by 134 persons.

Note. Question B and C were only given to those who admitted to have a disability (Question A).

Table 4

Objective health data and body perception (PPQ)

	ID sample (N= 230)	non-ID sample (N= 533)
smoking	81% do not smoke (N= 187) 19% smoke (N= 43; mean 14 cigarettes/day, SD 7.7)	70% do not smoke (N= 371) 30% smoke (N= 162; mean 10 cigarettes/day, SD 7.3)
medication	90 participants negated question prescribed medication for 140 persons	missing answers for 307 participants and negative answers for 223 respondents
Body Mass Index (BMI)	missing data for 113 persons BMI 16-61 (mean 28.8; SD 7.6) 6% underweight 37% normal 43% overweight 14% obesity	no missing data BMI 15-44 (mean 23.9; SD 4.1) 3% underweight 65% normal 22% overweight 10% obesity
body perception (PPQ)	5% positive 95% neutral 0% negative	83% positive 15% neutral 2% negative

Table 5

Health behaviour: descriptive and test on differences between samples (Mann Whitney U-Test)

item	ID sample (N=230)	non-ID sample (N=533)	Mann Whitney U-Test
being active, sports	39% yes 61% no	48% yes 52% no	ID mean rank: 344.14 non-ID mean rank: 398.34 ($p < 0.001$)
healthy nutrition	53 % yes 47% no	93% yes 7% no	ID mean rank: 496.00 non-ID mean rank: 332.81 ($p < 0.000$)
medication compliance	61% yes 2% no 37% no medication	38% yes 4% no 58% no medication	ID mean rank: 317.69 non-ID mean rank: 409.75 ($p < 0.000$)
oral care	76% yes 24% no	98% yes 2% no	ID mean rank: 503.96 non-ID mean rank: 329.37 ($p < 0.000$)
reduction of alcohol consumption	3% yes 32% no 65% no consumption of alcohol	24% yes 39% no 37% no consumption of alcohol	ID mean rank: 483.87 non-ID mean rank: 338.04 ($p < 0.000$)
safer sex	10% yes 12% no 78% no sex	70% yes 10% no 20% no sex	ID mean rank: 552.85 non-ID mean rank: 308.27 ($p < 0.000$)
stress reduction	24% yes 7% no 69% no stress	71% yes 25% no 4% no stress	ID mean rank: 541.19 non-ID mean rank: 313.31 ($p < 0.000$)
sun protection	67% yes 33% no	60% yes 40% no	ID mean rank: 400.30 non-ID mean rank: 374.10 not significant
supportive friends	58% yes 5% no 37% no friends	93% yes 5% no 2% no friends	ID mean rank: 447.01 non-ID mean rank: 353.95 ($p < 0.000$)

2.2.4. Summary of findings in the health psychological study

In this chapter, only the main results of the psychological health study, which are of relevance to evaluate the study's pros and cons and were published elsewhere, will be summarised. Table 1 illustrates in which article the results are depicted.

2.2.4.1. Health status and health behaviour

Results concerning the subjective and objective health status are depicted in detail in the third paper (see table 1, Brehmer-Rinderer et al., submitted) and generally support previous research outcomes.

In total, 125 persons of the ID sample stated to be disabled, whereas only 39.2% of them mentioning an *intellectual disability*. Depending on their disability aetiology, persons with ID negate or admit their ID: for example, persons with Down Syndrome more often negated having a disability, persons with birth-related ID aetiology more often confirmed to have a disability.

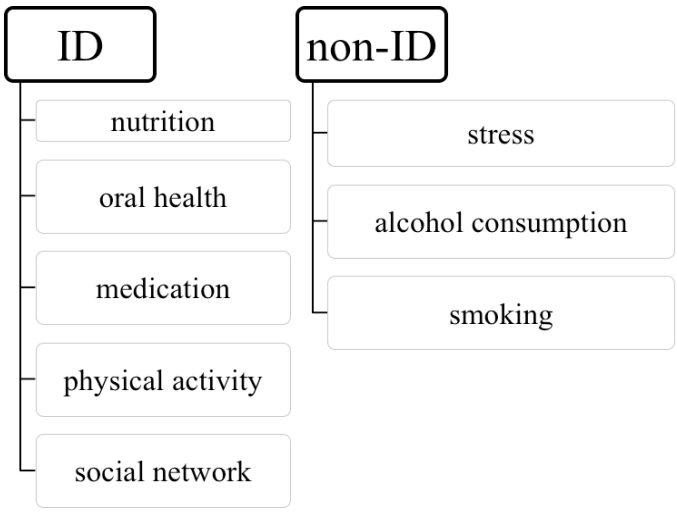
In addition to these subjective health questions, participants were asked for 'objective' figures (see table 3). Health facts uncovered in this study were in accordance with the previously published health studies (e.g., Bhaumik et al., 2008; De, Small & Baur, 2008; Carmeli, Orbach, Zinger-Vaknin, Morad & Merrick 2008; Melville et al., 2008; Humphries, Traci & Seekins, 2009; Finlayson et al., 2009). Most participants with ID were either overweight or obese and in that significantly differed from the non-ID sample. Contrary to the study of Robertson et al. (2000), the BMI level in this study was higher in respondents, who are living in a more independent setting.

With respect to health behaviours, women, persons with lower BMI and older persons report significantly more healthy behaviours. Findings, illustrated in figure 2, suggest that the most common risk behaviours in the general population are smoking, alcohol consumption and stress. Similar results were obtained in previous studies (e.g., Tracy & Hosken, 1997;

Kennedy, McCombie, Dawes, McConnell & Dunnigan, 1997; Rurangirwa, Braun, Schendel, & Yeargin-Allsopp, 2006; McGuire, Daly & Smyth, 2007). Women in this study reported to smoke less, whereas results for the general population indicate that smoking rates are higher in women than in men (Statistik Austria, 2006). Besides, the more cigarettes a person smokes per day, the less often he or she mentioned other health behaviours.

Although these risk behaviours are less frequently found in the ID population, this group reports unhealthy nutrition, worse oral health and a lower rate of sports activities (see figure 2 and 4). These findings have already been described before (e.g., Stanish, Temple & Frey, 2006; Anders & Davis, 2010; Robertson & Emerson, 2010). Besides, results concerning safer sex/contraception (low rate) and medication (high frequency) as well as supportive elements such as friendships and social networks (low rate) in the ID population are alarming.

Figure 2 *Differences in health risks between non-ID and ID*



2.2.4.2. Perception of one's body, disability and/or illness

In accordance with the differences in health status and health behaviours between the ID and the non-ID group, their body perceptions also differed (see figure 4):

While most participants without ID liked their bodies, the majority of the ID respondents perceived their bodies neutrally. Although most persons with ID are overweight,

they do not perceive themselves in a negative way - unlike the non-ID group in which the BMI had a significant influence on the individuals' body perception. The higher the BMI was, the more negative the own body was perceived by the participant without ID.

For the total sample, we found that persons who reported to have a disability were more likely to be dissatisfied with their appearance. Besides, the women in this study perceived their bodies more positively than the male respondents did, in opposition to the meta-analysis by Feingold and Mazzella (1998).

With regard to the individuals' perception of an existing disability, participants with ID perceived themselves and their disabilities differently depending on their ID aetiology and body weight: for example, overweight persons with ID perceived their disabilities more positively compared to normal-weight participants with ID.

2.2.4.3. Perception of the terms health/illness/disability

The twofold measurement strategy (qualitative and quantitative) is described in the second paper ('*Evaluating a health behaviour model for persons with and without intellectual disabilities*', see table 1). The results depicted in the following section have not been reported previously in the psychological publications as they focused on different aspects of the study's analysis.

No ID respondent was able to complete the ranking and approximately a third of them was unable to answer even the modified, qualitative questions (*health* 30.8% no answer; *illness* 35.2% no answer; *disability* 41.7% no answer). Only a third of the non-ID group did answer the qualitative questions, but there were no missing answers in the non-ID group as it was only possible to submit the online survey after having completed all rankings.

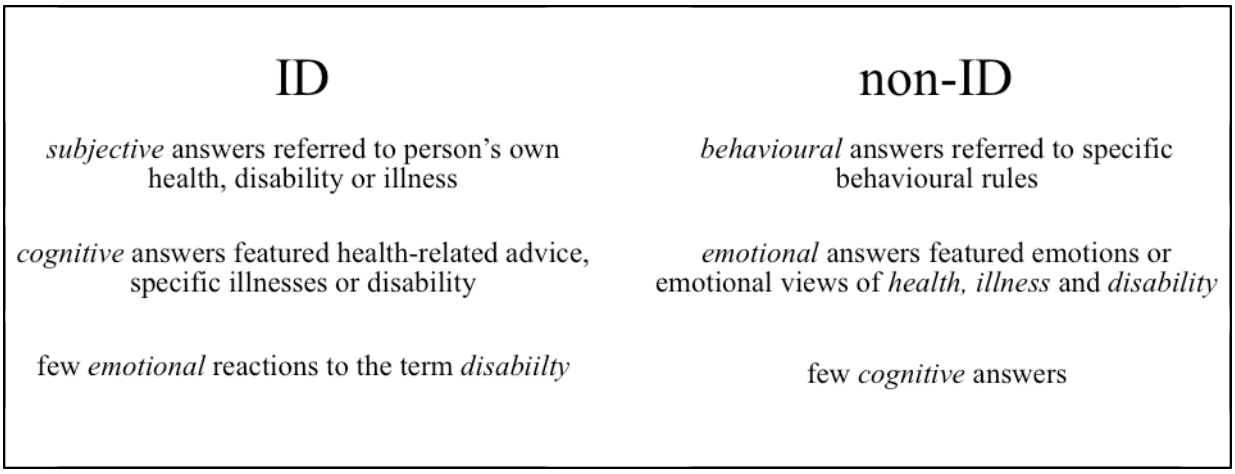
Qualitative answers were analysed and divided into four categories by an independent researcher – *cognitive, behavioural, emotional* and *subjective* answers. While *subjective* answers factually referred to a person's own health, disability or illness, *cognitive* answers

were those that featured health-related advice (e.g., naming healthy foods, explaining the food guide pyramid) or specific illnesses and disabilities, for example. Only persons with ID gave *subjective* answers, describing their illnesses (13%) and/or disabilities (22%). However, the majority of their answers belong to the *cognitive* category: 68% of our participants with ID spontaneously demonstrated their knowledge of healthy nutrition and the importance of being physically active to stay healthy, when asked how they perceived *health*. In contrast, none of the respondents without ID recounted any kind of health-related advice. With respect to this *cognitive* category, nearly a quarter of the non-ID group mentioned certain illnesses/disabilities, and 39.6% of the ID participants described causes/symptoms of illnesses or named types of disabilities.

Answers that referred to specific behavioural rules (e.g., 'when you are sick, you should stay in bed') were coded as *behavioural*. Half of the non-ID sample perceptions of the terms *health*, *illness* and *disability* contained behavioural information. The descriptions of the word *disability* of non-ID participants, for instance, focussed on the negative effects for disabled persons (90.8%), such as being excluded from society or being dependent on others. Only two persons from the general population mentioned the word *disability* in a positive context.

Finally, answers were coded as *emotional*, when they referred to emotions or emotional views of *health, illness* and *disability*. Seventeen respondents with ID clearly argumented how much they disliked the term *disability* due to its discriminative implications, for example, and 94 even refused to answer this question. In addition to this, half of the non-ID sample mentioned emotions relating to the terms *health* (e.g., feeling well, strong) and *illness* (e.g., feeling unwell, exhausted).

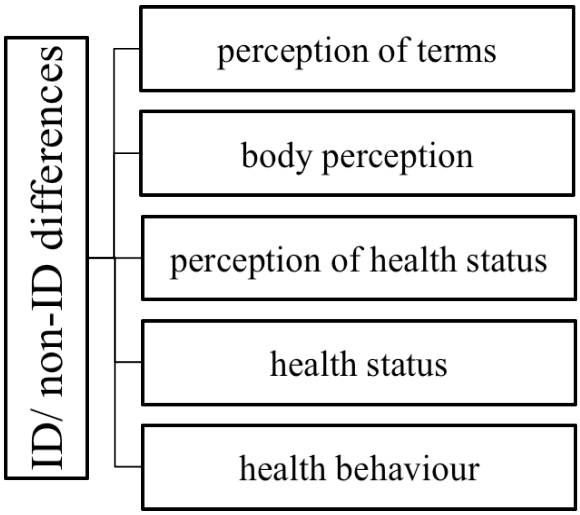
Figure 3 *Differences in perception of terms between non-ID and ID*



In summary, it was found that persons with and without ID perceive terms like *health*, *illness* and *disability* differently (see figure 3). On the one hand, persons with ID rather think of these words from a *subjective* perspective by mentioning their personal situation, whereas persons without ID tend to refer to these terms on an *emotional* level by highlighting effects on the personal wellbeing. On the other hand, persons with ID demonstrated their knowledge of the respective term (*cognitive* answers), whereas persons without ID mainly described behavioural effects (see figure 3). Although, all the categories found in the ID population (except for the category *subjective answer*) did match those provided by the non-ID sample, measurement strategies and results differed greatly between samples (see figure 3 and 4) and, therefore, the latent variable *personal definition of health, illness and disability* was no longer considered for further statistical analyses of the theoretical health model.

To summarize, figure 4 illustrates all differences concerning perceptions and behaviours between the ID and non-ID samples included in this study.

Figure 4 *Summary of the differences encountered between ID and non-ID*



2.2.4.4. Health knowledge

Results concerning this section were depicted in the third publication (see table 1; Brehmer-Rinderer et al., submitted). On the one hand, it was found that the knowledge of personal health facts such as body weight, body height, personal medication and individual illnesses in persons with ID is only fragmentary. Besides, the knowledge of the structure of the human body as well as the functions of its various organs was generally low among respondents with ID and differed according to disability aetiology and level of independence in the activities of daily living. On the other hand, participants with ID in this study, contrary to previous findings, had a satisfactory level of knowledge on the topic of nutrition. The vast majority of the ID group talked about the food guide pyramid, the difference between healthy and unhealthy foods as well as the importance of being physically active and other 'health rules' when asked for their perception of *health*.

Profound knowledge of one of the measured health topics was related to profound knowledge in other health areas and healthier behaviours: Participants who knew the human body well demonstrated their general health knowledge when asked for their perception of the term *health* and reported to act in a healthier way.

2.2.4.5. Health behaviour model – the general health circuit

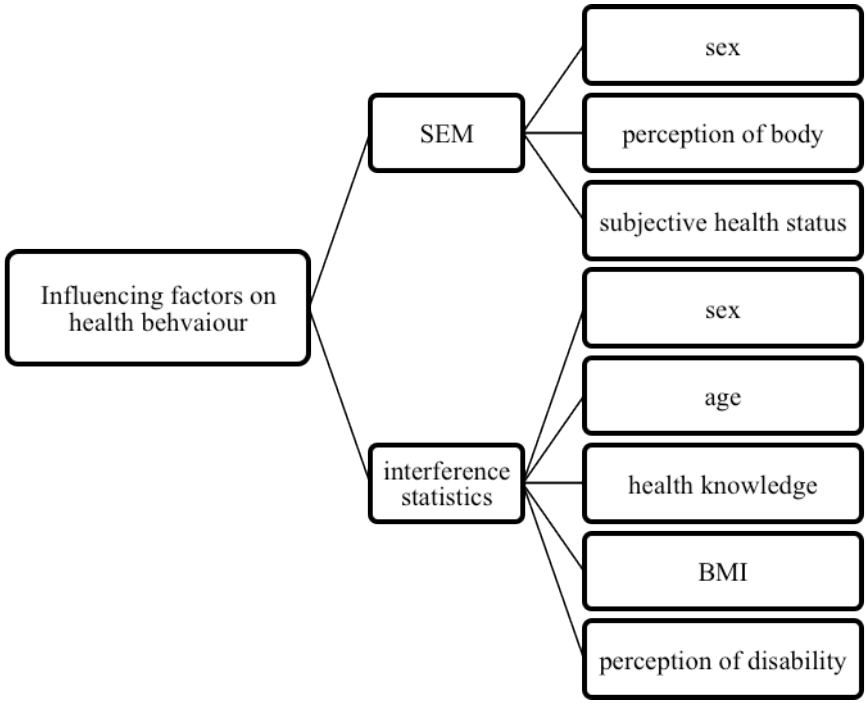
Based on a suggested health model, the second paper delineated (see figure 1 and table 1), systematic differences in personal perceptions and health behaviours between people with and without ID by calculating absolute and descriptive fit indices (Hair, Anderson, Tatham & Black, 1998). Most indices demonstrated an acceptable model fit for all groups (ID, non-ID and total sample). While a high direct effect between the latent variables was found for the non-ID sample, this relation was not significant in the ID group. This result supports our theory that persons with ID perceive their health differently than persons without ID and may therefore act differently.

The GHC comprises three components (understanding of terms, personal perception, health behaviour; see figure 1). As already mentioned, the operationalisation of the first element (understanding of the terms *health*/*illness* and *disability*) led to missing data. Besides, qualitative results differed greatly between ID and non-ID participants and therefore this latent variable had to be excluded from further calculations.

With respect to influencing factors, we considered age, sex, subjective health status, educational level and medication. Of these factors, some had to be excluded because of missing data and others (e.g., age) had to be eliminated from all model calculations due to unmet inclusion criteria. We also tried to identify each individuals' level of socialisation (see table 3, part 1 and Annex I), but this strategy did not result in reliable quantitative information. Depending on the respective sample, sex and the subjective health status were important influencing factors (see figure 5).

Figure 5 summarizes all findings concerning factors influencing health behaviours in persons with ID differentiated by statistical analysis used in the evaluation. It includes information on all influencing factors as well as on elements that needed to be excluded from further analysis, which was delineated in this chapter and the second paper (see table 1).

Figure 5 *Factors influencing health behaviour in persons with ID differentiated by statistical method used*



Note. SEM: structural equation model, BMI: Body Mass Index

2.2.5. Discussion of the study's strengths

This study a) reviews previous health psychological research in the field of ID and analyse existing health models with respect to their practicability in persons with ID and b) explores systematic differences in health behaviour between people with and without ID based on a suggested health model.

The GHC was analysed with regard to existing research findings and in particular consideration of the critique of Suls and Wallston (2003) who stated that authors of new models seldom seek to address limitations of previous models. As delineated in the first psychological paper, a common problem in health research with persons with ID is that the operationalisation of variables that is customary for other populations presents too much of a challenge to a person with ID and, thus, impedes accurate measurement. The usage of overly abstract concepts and the assumption of an independent, rational decision-making agent, which are common in health models and related measures, seem inappropriate for persons with ID. Based on the analysis of previously designed measurement strategies, new instruments for analysing health behaviour (HBQ), the perception of one's body (PPQ), illness and disability were developed. The second psychological paper illustrated this operationalisation and presented the satisfying psychometric properties of all instruments used in both groups (ID, non-ID). Hence, this interview protocol is a valuable tool for studying health-related issues in the population with ID and for comparing findings between populations. In general, health results are in accordance with previous findings, although differences were encountered with respect to sex. For example, women in general smoked less than men in this study (including ID and non-ID sample), whereas the opposite has been reported for studies conducted in the general population.

In addition to these results, the general model fit of the GHC also indicated an acceptable model fit for all samples as described in the second psychological paper (see table 1). The presumption that the personal perception of one's body influences the way people

report to act and is different in persons with ID compared to the general population is supported by the findings concerning the direct relations between the latent variables of the GHC.

2.2.6. Limitations of this study

This study also had some limitations. In the following chapter these limitations and how they can be addressed in future research will be discussed.

First, two facts lead to a limited generalisation potential of the findings:

On the one hand, it may be questioned whether this model on health behaviours, which are deliberately and autonomously demonstrated, can be used to described the health situation of severely disabled persons. The ID sample used cannot be deemed representative of the entire population, because only those who could personally do the interview were included in the study. This measurement strategy excludes people who are less independent and are, thus, probably at an even higher risk of poor health. Still, as 80-85% of the ID population are only mildly to moderately disabled (see chapter 1), this study provides some insight with respect to the health of the majority of this population.

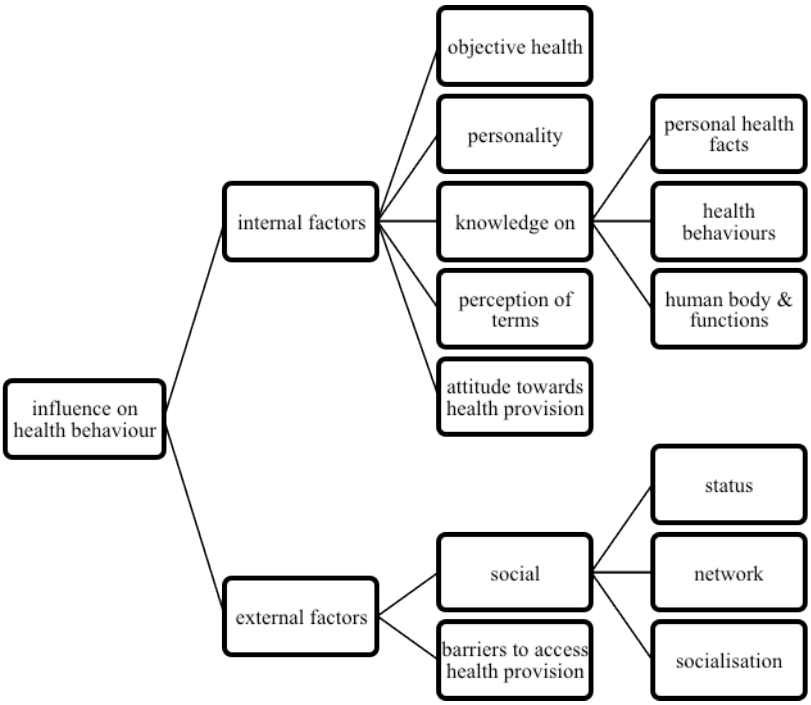
On the other hand, results for the non-ID sample cannot be called representative either, as it is known that online populations differ from offline populations (Andrews, Nonnecke & Preece, 2003). Besides, the sampling procedure used also resulted in an unusually high educational level of the non-ID population. The international generalizability of all findings is widely discussed in the second article (see table 1).

Second, the fact that persons with ID had problems completing the ranking of four different aspects and answering many of the open-ended questions (e.g., personal perception of the three terms, educational level, and body height) raises the need to develop even more sensitive methods and evaluation strategies to capture their views and ideas related to health and disability.

Third, as a consequence, the measurement of the latent variable *personal definition of terms* differed between samples. Although results demonstrated that persons with ID perceive *health, illness* and *disability* differently, future research needs to prove this element's significance for explaining prevailing differences in health behaviours. Otherwise this component should be eliminated from this health model.

Fourth, only few influencing factors were considered. Wagner, Singer, Woll, Tittlbach and Bös (2004) named four moderators of health: *personality, age, sex and social status*. In a structural analysis of essential components of health models, Cummings, Becker and Maile (1980) found that *the personal perception of the health threat, the knowledge on this health threat, the person's social network, the person's ability to access health services as well as his/her attitude towards health provision in general* is of relevance when designing a health model. Following their findings, the elements *personality, social status* as well as the *social network* and the *ability to access health services and attitude towards health provision in general* need to be assessed in future research as influencing factors (see figure 6). With respect to influencing elements, figure 6 illustrates this discussion by displaying factors, which are distinguished between internal characteristics demonstrating qualities lying within the person, and external characteristics affecting the person.

Figure 6 *Internal and external factors influencing health behaviour*



Future research should especially focus on the *social network*: the role of carers, friends and family. Previous studies have focused on defining the barriers that hinder persons with ID from being/becoming physically active (Bodde & Seo, 2009; Carmeli, Merrick, Imam & Levy, 2012). In addition to financial, policy and educational barriers, the influence of the individual's social network on engaging in physical activities needs to be further investigated. It is possible that persons with ID copy risk behaviours from their social network. Besides, possible health resources in the social community of persons with ID should be highlighted by future projects since we found that most persons with ID lack friends. Recently, Cable, Bartley, Chandola and Sacker (2012) concluded that having a small social network is related to poorer psychological wellbeing. Besides, the influence of *age* needs to be further investigated (see figure 5); as older participants mentioned more healthy behaviours, they may use different motivational and psychological strategies to stay healthy than younger persons. Although this variable had to be excluded during the model evaluation process, it cannot be deemed irrelevant when defining risk behaviours, its exclusion can solely be due to statistical reasons, e.g., missing normal distribution of this variable. Finally, research on differences

(e.g. concerning body perception) between *sexes* should be expanded since we gained different results compared to the general population (see chapters 2.2.4.1. and 2.2.4.2.).

2.2.7. Further recommendations for future research

In spite of any limitations, the current project has some further implications for future research:

First, as the literature review presented in the first psychological paper suggested, other health models or aspects of certain theories need to be investigated: for example, the so called (health) *locus of control*, the perceived suggestibility of health/illness as well as the *health competence/health literacy* model can be of interest when exploring health behaviours in persons with ID.

Second, future research should focus on the determined differences between types of disabilities. If some aetiologies are experienced as stigmatising, people with the same aetiologies may be more likely to negate the disability itself and comorbid illnesses. Hence, their compliance in dealing with these medical conditions could be low. The differing ways in which individuals perceive their disabilities may explain a fraction of the discovered health differences. In addition to this, a more sensible usage of the term *disability* is necessary to reduce stigmas. It was frequently reported to have a negative meaning to persons with ID.

Third, with respect to the data gathered on sun protection and contraception, more data and intensified awareness training concerning the risks involved are needed.

Fourth, overweight persons with ID were still pleased with their appearance and therefore are not likely to realise the need to change their behaviours to stay healthy. Hence, new motivational approaches should be designed to convince overweight persons with ID who are still satisfied with their bodies to change their unhealthy behaviours.

In the third psychological paper we already mentioned some developments to improve the health status of persons with ID:

Persons with ID need to be adequately informed on their illnesses, the usage and the reason for prescription of their medication. Thus, education on the human body and its functions is important. Additionally, it should be highlighted why this kind of knowledge is so extremely important: it is one big step towards independence from others. Health interventions containing this essential information in a language that is easy to understand for persons with ID could help ameliorate their health situations.

Besides, data should be gathered to check whether persons with ID who do not know the human body well are still able to understand the health-related advice given by health professionals to them. It seems as if medical information is not understood adequately by patients with ID and, following misinterpretations of medical information, persons with ID continue their risk behaviours. This is supported by the fact that only eight out of 23 respondents with prescribed medication for epilepsy report to have epilepsy when asked for an existing illness.

Finally, the respective levels of familiarity with risk/health behaviours, the human body and effects of behaviours/illnesses should be taken into account when designing new health interventions or planning medical consultations.

3. CONCLUSION

This cumulative dissertation describes challenges that persons with intellectual disabilities (ID) face when engaging in the society. In the introduction, epidemiological and health challenges of this specific population as well as their impact on the provision of service structures were delineated. This combination of two perspectives (the general social-policy view and the specific, psychological aspect, concentrating on the health behaviour of persons with ID) was chosen to present a thorough picture on the topic health of persons with ID.

The first publication dealt with the social-policy perspective describing actual human rights violations of persons with disabilities in connection with health provisions. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its potential to prevent further violations was delineated. A detailed description of the current implementation process of Article 25 and 26 of the CRPD in two European countries (Spain and Hungary) and information on the status of implementation in the 19 other member states is provided in this first publication. Among other social-policy amendments, it is of importance to improve the accessibility of health services (physical, informational and social accessibility), to define special health services fitting the health needs of persons with ID and to develop curricula dealing with ID to enhance the skills of health professionals (Carpenter, 2008; European Union Agency for Fundamental Rights, 2013).

Psychological aspects of health were presented in three subsequent articles describing the actual health situation of persons with ID based on the previous social-policy analysis and a literature review of international health studies. Results showed that persons with ID perceive health differently and demonstrate different health behaviours when compared to persons without ID. As it was outlined in the previous chapter, future research needs to define new preventive strategies focusing on their specific needs (e.g., communicational, informational needs) in order to improve the health of persons with ID. There is a large potential for development and optimisation of health interventions adjusted to the needs and

characteristics of persons with ID that can empower these persons to adopt healthy behaviours and be able to act more autonomously in health matters.

Both, the results of the conducted psychological study as well as previous research findings imply and may facilitate necessary policy changes concerning health regulations to protect persons with ID from further human rights violations. Future amendments therefore need to consider these two aspects: the respective social-policy situation as well as earlier and current research findings.

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5. TABLES AND FIGURES

6. ANNEX I: Questionnaires

Fragbogen für Personen mit intellektueller Behinderung:

Soziodemografische Fragen und Vortest

CODE:				
SD_1	Alter			
SD_2	Geschlecht	Mann	Frau	
SD_3	Ätiologie	unbekannt	bekannt	
SD_4	Bundesland	Wien	Niederösterreich	Steiermark
		Kärnten	Burgenland	Tirol
		Oberösterreich	Salzburg	Vorarlberg
SD_5	Wohnverhältnisse	mehrheitlich institutionalisiert aufgewachsen	gleichmäßig	mehrheitlich familiär aufgewachsen
SD_6	Familienbezug	kein Bezug	etwas Verbindung mit Familie	starke Verbindung zur Familie
SD_7	Bildungsweg	Ausbildungsjahre_____	Höchster Ausbildungsgrad	
SD_8	Ansprechpartner in Gesundheitsfragen	BetreuerIn	Familienangehörige/r	Freund/In mit Behinderung
		Freund/In ohne Behinderung	Niemand	
ADL_1	Essen	Selbstständig	Mit Hilfe	Nicht alleine möglich
ADL_2	Anziehen	Selbstständig	Mit Hilfe	Nicht alleine möglich
ADL_3	Hygiene	Selbstständig	Mit Hilfe	Nicht alleine möglich
VT_1	Wissen über Körper (Körperteile, Organe, Körperfunktionen)	4 richtig	2 richtig	Keines richtig
VT_2	Leselupe	Kann lesen	Erfüllt die Mindestanforderung (erkennt Buchstaben, synthetisierendes Lesen, kann Bildrezepte erfassen)	Erfüllt die Mindestanforderung nicht

TEIL 1: Subjektive Definition von Gesundheit, Krankheit und Behinderung

Was fällt Ihnen zu den Begriffen ein?
Gesundheit
Krankheit
Behinderung
Unterschied Krankheit und Behinderung

RATING:
Reihen Sie die genannten Vorstellungen nach ihrer persönlichen Wichtigkeit (1= sehr wichtig, 4 bzw. 5 = nicht so wichtig)?
Jeder Wert 1-4 kann nur einmal UND muss einmal vergeben werden!

DEF_1	Gesundheit …	…beeinflusst mein Verhalten. Ich bin leistungsfähiger, kreativer und ausdauernder	**Rangplatz:**
		…bedeutet das Fehlen von Krankheit, beeinträchtigenden Symptomen,....	**Rangplatz:**
		…bedeutet emotionales Wohlbefinden	**Rangplatz:**
		…wird durch die Umwelt bedingt (z.B. durch die Nahrung, Luft)	**Rangplatz:**
DEF_2	Krankheit …	…beeinflusst mein Verhalten. Ich bin weniger leistungsfähig	**Rangplatz:**
		…bedeutet die Anwesenheit von beeinträchtigenden Symptomen,...	**Rangplatz:**
		…bedeutet emotionales Unwohlsein (z.B. Traurigkeit)	**Rangplatz:**
		…wird durch die Umwelt bedingt (z.B. durch die Nahrung, Luft)	**Rangplatz:**
DEF_3	Behinderung …	…beeinflusst mein Verhalten. Ich bin dauerhaft weniger leistungsfähig	**Rangplatz:**
		…bedeutet die dauerhafte Anwesenheit von beeinträchtigenden Symptomen	**Rangplatz:**
		…bedeutet emotionales Unwohlsein	**Rangplatz:**
		…wird durch die Umwelt bedingt.	**Rangplatz:**
		…beeinflusst die eigenen Emotionen NICHT	**Rangplatz:**

Achtung es folgt ein Perspektivenwechsel!

TEIL 2a: Wahrnehmung des eigenen Befindens/Körpers

		Diese Aussage TRIFFT SEHR auf mich zu	Diese Aussage TRIFFT ETWAS auf mich zu	Diese Aussage trifft KAUM auf mich zu	Dieses Aussage trifft GAR NICHT auf mich zu
FBK_1	Ich bin robust und stark				
FBK_15	Meine körperlichen Mängel stören mich				
FBK_18	Manchmal wünsche ich mir, völlig anders auszusehen				
FK_SGKB_1	Meistens fühle ich mich körperlich wohl				
FBK_14	Ich fühle mich topfit				
FK_SGKB_3	Ich bin häufiger krank				
FK_SGKB_4	Ich stoße manchmal an meine körperlichen Grenzen				
FK_SGKB_6	Ich fühle mich gesund				
FK_SSAK_1	Wenn es möglich wäre, würde ich Teile meines Körpers austauschen				
FK_SSAK_2	Ich habe mehr körperliche Mängel als andere				
FK_SSAK_4	Ich bin mit meinem Aussehen zufrieden				
FK_SASE_2	Ich bin mit meinem Körpergewicht zufrieden				
FK_SASE_3	Ich mag meine Haare				
FK_SASE_4	Ich mag meine Gesichtsform				
FK_SASE_5	Meine Stimme passt zu mir				
FK_SASE_6	Ich habe eine gute Figur				
FK_SASE_9	Ich bin mit meiner Körpergröße zufrieden				

TEIL 2b: Wahrnehmung Gesundheit, Krankheit und Behinderung

		AF 1	AF 2	AF 3	AF 4	Freier Kommentar
GHWN_2	Können Sie Ihre Gesundheit kontrollieren?	Ja, vollständig	Etwas	Kaum	Gar nicht	
KWN_1	Haben Sie aktuell eine Erkrankung?	Ja		Nein		Wenn ja, welche? (chronisch, Infektionskrankheit,..)
KWN _2	Wie stark beeinträchtigt Sie Ihre Erkrankung?	Sehr	Etwas	Wenig	Gar Nicht	
KWN _3	Wie lange wird Ihre Krankheit noch andauern?	Für immer	Noch länger	Nur mehr kurz	Nicht mehr krank	
KWN _4	Können Sie Ihre Krankheit kontrollieren?	Ja vollständig	Etwas	Kaum	Gar Nicht	
KWN _5	Kann Ihnen eine Behandlung helfen?	Ja	Etwas	Kaum	Gar Nicht	
KWN _6	Wie viele Beschwerden haben Sie durch Ihre Krankheit?	Viele	So manche	Wenige	Keine	
KWN _7	Machen Sie sich Sorgen wegen Ihrer Erkrankung?	Viele	So manche	Wenige	Keine	
KWN _8	Wie motiviert sind Sie Ihre Krankheit zu bekämpfen?	Meistens/ Sehr	Häufig/etwas	Selten/Kaum	Nie	
KWN _9	Kennen Sie die Ursachen Ihrer Erkrankung?	Ja, alle	Manche	Wenige	Keine	Warum sind Sie krank? Ursachen..
BHIWN _1	Haben Sie eine Behinderung?	Ja		Nein		Wenn ja, welche?
BHIWN _2	Wie stark beeinträchtigt Sie Ihre Behinderung?	Sehr	Etwas	Wenig	Gar Nicht	
BHIWN _3	Können Sie Ihre Behinderung kontrollieren?	Ja, vollständig	Etwas	Kaum	Gar Nicht	
BHIWN _4	Kann Ihnen eine Behandlung helfen?	Ja	Etwas	Kaum	Gar Nicht	
BHIWN _5	Wie viele Beschwerden haben Sie durch Ihre Behinderung?	Viele	So manche	Wenige	Keine	
BHIWN _6	Machen Sie sich Sorgen wegen Ihrer Behinderung?	Viele	So manche	Wenige	Keine	
BHIWN _7	Wie motiviert sind Sie Ihre Behinderung zu bekämpfen?	Meistens/ Sehr	Häufig/etwas	Selten/Kaum	Nie	

BHIWN _8	Kennen Sie die Ursachen Ihrer Behinderung?	Ja, alle	Manche	Wenige	Keine	Ursachen/ Funktionsweise

TEIL 3: Risikoverhalten bzw. Gesundheitsverhalten

		AF 1	AF 2	AF 3	AF 4	AF 5
FK_SPKF_1	Ich achte auf meine Gesundheit	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_2	Ich tue wenig für mein Aussehen	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_3	Ich achte darauf, ausreichend Schlaf zu bekommen	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_6	Ich achte auf eine gesunde Ernährung	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_7	Auf meine Zahnpflege lege ich Wert	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SKEF_8	Ich bewege mich nicht regelmäßig (Sport)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
GV_1	Ich achte kaum darauf meine Haut vor der Sonne zu schützen (Kleidung, Creme)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
GV_2	Ich pflege meinen Körper (waschen, ..)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
SIS_2	Ich vermeide Verletzungen in dem ich mich an Sicherheitsvorschriften halte (z.B. Autogurt, Fahrradhelm)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
SIS_1	Ich nehme meine verschriebene Medikation ein	Immer	Meistens	Selten	Nie	Ich nehme keine Medikamente
SIS_4	Ich schütze mich beim Geschlechtsverkehr vor Krankheiten	Immer	Meistens	Selten	Nie	Ich habe keinen Geschlechts-verkehr
SIS_5	Ich habe Freunde, die mir helfen können, wenn es mir nicht gut geht (Soziales Netzwerk: innerhalb/außerhalb WG)	Immer	Meistens	Selten	Nie	Ich habe keine Freunde
GV_3	Ich tue etwas gegen meinen stressigen Alltag (Stressreduktion/ Therapie/ Massage).	Immer	Meistens	Selten	Nie	Ich habe keinen Stress
GV_4	Ich sollte weniger Alkohol trinken.	Ja	Manchmal	Selten	Nein	Ich trinke keinen Alkohol
GV_5	Ich sollte weniger rauchen.	Ja	Manchmal	Selten	Nein	Ich rauche nicht

TEIL 4: objektive Daten

OD_1	Körpergewicht in kg
OD_2	Körpergröße in cm
OD_3	Zigaretten pro Tag
OD_4	Medikation

Fragbogen für BetreuerInnen von Personen mit intellektueller Behinderung:

Soziodemografische Fragen und Vortest

CODE:				
SD_1	Alter			
SD_2	Geschlecht	Mann	Frau	
SD_3	Bundesland	Wien	Niederösterreich	Steiermark
		Kärnten	Burgenland	Tirol
		Oberösterreich	Salzburg	Vorarlberg
SD_4	Höchster Ausbildungsgrad	Pflichtschule	Lehrabschluss	Matura
		Bachelor	Master/Magister	pHD/Doktor
SD_6	Dauer BetreuerInnentätigkeit			
SD_7	Ausbildung BetreuerIn	Ausbildung abgeschlossen	Derzeit in Ausbildung	Ohne spezielle Ausbildung tätig

TEIL 1: Subjektive Definition von Gesundheit, Krankheit und Behinderung

Was fällt Ihnen zu den Begriffen ein?
Gesundheit
Krankheit
Behinderung
Unterschied Krankheit und Behinderung

RATING:
Reihen Sie die genannten Vorstellungen nach ihrer persönlichen Wichtigkeit (1= sehr wichtig, 4 bzw. 5 = nicht so wichtig)?
Jeder Wert 1-4 kann nur einmal UND muss einmal vergeben werden!

DEF_1	Gesundheit …	…beeinflusst mein Verhalten. Ich bin leistungsfähiger, kreativer und ausdauernder	**Rangplatz:**
		…bedeutet das Fehlen von Krankheit, beeinträchtigenden Symptomen,….	**Rangplatz:**
		…bedeutet emotionales Wohlbefinden	**Rangplatz:**
		…wird durch die Umwelt bedingt (z.B. durch die Nahrung, Luft)	**Rangplatz:**
DEF_2	Krankheit …	…beeinflusst mein Verhalten. Ich bin weniger leistungsfähig	**Rangplatz:**
		…bedeutet die Anwesenheit von beeinträchtigenden Symptomen,…	**Rangplatz:**
		…bedeutet emotionales Unwohlsein (z.B. Traurigkeit)	**Rangplatz:**
		…wird durch die Umwelt bedingt (z.B. durch die Nahrung, Luft)	**Rangplatz:**
DEF_3	Behinderung …	…beeinflusst mein Verhalten. Ich bin dauerhaft weniger leistungsfähig	**Rangplatz:**
		…bedeutet die dauerhafte Anwesenheit von beeinträchtigenden Symptomen	**Rangplatz:**
		…bedeutet emotionales Unwohlsein	**Rangplatz:**
		…wird durch die Umwelt bedingt.	**Rangplatz:**
		…beeinflusst die eigenen Emotionen NICHT	**Rangplatz:**

TEIL 2a: Wahrnehmung des eigenen Befindens/Körpers

		Diese Aussage TRIFFT SEHR auf mich zu	Diese Aussage TRIFFT ETWAS auf mich zu	Diese Aussage trifft KAUM auf mich zu	Dieses Aussage trifft GAR NICHT auf mich zu
FBK_1	Ich bin robust und stark				
FBK_15	Meine körperlichen Mängel stören mich				
FBK_18	Manchmal wünsche ich mir, völlig anders auszusehen				
FK_SGKB_1	Meistens fühle ich mich körperlich wohl				
FBK_14	Ich fühle mich topfit				
FK_SGKB_3	Ich bin häufiger krank				
FK_SGKB_4	Ich stoße manchmal an meine körperlichen Grenzen				
FK_SGKB_6	Ich fühle mich gesund				
FK_SSAK_1	Wenn es möglich wäre, würde ich Teile meines Körpers austauschen				
FK_SSAK_2	Ich habe mehr körperliche Mängel als andere				
FK_SSAK_4	Ich bin mit meinem Aussehen zufrieden				
FK_SASE_2	Ich bin mit meinem Körpergewicht zufrieden				
FK_SASE_3	Ich mag meine Haare				
FK_SASE_4	Ich mag meine Gesichtsform				
FK_SASE_5	Meine Stimme passt zu mir				
FK_SASE_6	Ich habe eine gute Figur				
FK_SASE_9	Ich bin mit meiner Körpergröße zufrieden				

TEIL 2b: Wahrnehmung Gesundheit, Krankheit und Behinderung

		AF 1	AF 2	AF 3	AF 4	Freier Kommentar
GHWN_2	Können Sie Ihre Gesundheit kontrollieren?	Ja, vollständig	Etwas	Kaum	Gar nicht	
KWN_1	Haben Sie aktuell eine Erkrankung?	Ja		Nein		Wenn ja, welche? (chronisch, Infektionskrankheit,..)
KWN _2	Wie stark beeinträchtigt Sie Ihre Erkrankung?	Sehr	Etwas	Wenig	Gar Nicht	
KWN _3	Wie lange wird Ihre Krankheit noch andauern?	Für immer	Noch länger	Nur mehr kurz	Nicht mehr krank	
KWN _4	Können Sie Ihre Krankheit kontrollieren?	Ja vollständig	Etwas	Kaum	Gar Nicht	
KWN _5	Kann Ihnen eine Behandlung helfen?	Ja	Etwas	Kaum	Gar Nicht	
KWN _6	Wie viele Beschwerden haben Sie durch Ihre Krankheit?	Viele	So manche	Wenige	Keine	
KWN _7	Machen Sie sich Sorgen wegen Ihrer Erkrankung?	Viele	So manche	Wenige	Keine	
KWN _8	Wie motiviert sind Sie Ihre Krankheit zu bekämpfen?	Meistens/ Sehr	Häufig/etwas	Selten/Kaum	Nie	
KWN _9	Kennen Sie die Ursachen Ihrer Erkrankung?	Ja, alle	Manche	Wenige	Keine	Warum sind Sie krank? Ursachen..
BHIWN _1	Haben Sie eine Behinderung?	Ja		Nein		Wenn ja, welche?
BHIWN _2	Wie stark beeinträchtigt Sie Ihre Behinderung?	Sehr	Etwas	Wenig	Gar Nicht	
BHIWN _3	Können Sie Ihre Behinderung kontrollieren?	Ja, vollständig	Etwas	Kaum	Gar Nicht	
BHIWN _4	Kann Ihnen eine Behandlung helfen?	Ja	Etwas	Kaum	Gar Nicht	
BHIWN _5	Wie viele Beschwerden haben Sie durch Ihre Behinderung?	Viele	So manche	Wenige	Keine	
BHIWN _6	Machen Sie sich Sorgen wegen Ihrer Behinderung?	Viele	So manche	Wenige	Keine	
BHIWN _7	Wie motiviert sind Sie Ihre Behinderung zu bekämpfen?	Meistens/ Sehr	Häufig/etwas	Selten/Kaum	Nie	

BHIWN _8	Kennen Sie die Ursachen Ihrer Behinderung?	Ja, alle	Manche	Wenige	Keine	Ursachen/ Funktionsweise

TEIL 3: Risikoverhalten bzw. Gesundheitsverhalten

		AF 1	AF 2	AF 3	AF 4	AF 5
FK_SPKF_1	Ich achte auf meine Gesundheit	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_2	Ich tue wenig für mein Aussehen	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_3	Ich achte darauf, ausreichend Schlaf zu bekommen	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_6	Ich achte auf eine gesunde Ernährung	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SPKF_7	Auf meine Zahnpflege lege ich Wert	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
FK_SKEF_8	Ich bewege mich nicht regelmäßig (Sport)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
GV_1	Ich achte kaum darauf meine Haut vor der Sonne zu schützen (Kleidung, Creme)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
GV_2	Ich pflege meinen Körper (waschen, ..)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
SIS_2	Ich vermeide Verletzungen in dem ich mich an Sicherheitsvorschriften halte (z.B. Autogurt, Fahrradhelm)	Sehr ZT	Etwas ZT	Kaum ZT	Nicht ZT	-
SIS_1	Ich nehme meine verschriebene Medikation ein	Immer	Meistens	Selten	Nie	Ich nehme keine Medikamente
SIS_4	Ich schütze mich beim Geschlechtsverkehr vor Krankheiten	Immer	Meistens	Selten	Nie	Ich habe keinen Geschlechts-verkehr
SIS_5	Ich habe Freunde, die mir helfen können, wenn es mir nicht gut geht (Soziales Netzwerk: innerhalb/außerhalb WG)	Immer	Meistens	Selten	Nie	Ich habe keine Freunde
GV_3	Ich tue etwas gegen meinen stressigen Alltag (Stressreduktion/ Therapie/ Massage).	Immer	Meistens	Selten	Nie	Ich habe keinen Stress
GV_4	Ich sollte weniger Alkohol trinken.	Ja	Manchmal	Selten	Nein	Ich trinke keinen Alkohol
GV_5	Ich sollte weniger rauchen.	Ja	Manchmal	Selten	Nein	Ich rauche nicht

TEIL 4: objektive Daten

OD_1	Körpergewicht in kg
OD_2	Körpergröße in cm
OD_3	Zigaretten pro Tag
OD_4	Medikation

Fragbogen für die Allgemeinbevölkerung

Soziodemografische Fragen und Vortest

CODE:				
SD_1	Alter			
SD_2	Geschlecht	Mann	Frau	
SD_3	Bundesland	Wien	Niederösterreich	Steiermark
		Kärnten	Burgenland	Tirol
		Oberösterreich	Salzburg	Vorarlberg
SD_4	Höchster Ausbildungsgrad	Pflichtschule	Lehrabschluss	Matura
		Bachelor	Master/Magister	pHD/Doktor

TEIL 1: Subjektive Definition von Gesundheit, Krankheit und Behinderung

Was fällt Ihnen zu den Begriffen ein?
Gesundheit
Krankheit
Behinderung
Unterschied Krankheit und Behinderung

RATING:
Reihen Sie die genannten Vorstellungen nach ihrer persönlichen Wichtigkeit (1= sehr wichtig, 4 bzw. 5 = nicht so wichtig)?
Jeder Wert 1-4 kann nur einmal UND muss einmal vergeben werden!

DEF_1	Gesundheit …	…beeinflusst mein Verhalten. Ich bin leistungsfähiger, kreativer und ausdauernder	**Rangplatz:**
		…bedeutet das Fehlen von Krankheit, beeinträchtigenden Symptomen,….	**Rangplatz:**
		…bedeutet emotionales Wohlbefinden	**Rangplatz:**
		…wird durch die Umwelt bedingt (z.B. durch die Nahrung, Luft)	**Rangplatz:**
DEF_2	Krankheit …	…beeinflusst mein Verhalten. Ich bin weniger leistungsfähig	**Rangplatz:**
		…bedeutet die Anwesenheit von beeinträchtigenden Symptomen,…	**Rangplatz:**
		…bedeutet emotionales Unwohlsein (z.B. Traurigkeit)	**Rangplatz:**
		…wird durch die Umwelt bedingt (z.B. durch die Nahrung, Luft)	**Rangplatz:**
DEF_3	Behinderung …	…beeinflusst mein Verhalten. Ich bin dauerhaft weniger leistungsfähig	**Rangplatz:**
		…bedeutet die dauerhafte Anwesenheit von beeinträchtigenden Symptomen	**Rangplatz:**
		…bedeutet emotionales Unwohlsein	**Rangplatz:**
		…wird durch die Umwelt bedingt.	**Rangplatz:**
		…beeinflusst die eigenen Emotionen NICHT	**Rangplatz:**

TEIL 2a: Wahrnehmung des eigenen Befindens/Körpers

		Diese Aussage TRIFFT SEHR auf mich zu	Diese Aussage TRIFFT ETWAS auf mich zu	Diese Aussage trifft KAUM auf mich zu	Dieses Aussage trifft GAR NICHT auf mich zu
FBK_1	Ich bin robust und stark				
FBK_15	Meine körperlichen Mängel stören mich				
FBK_18	Manchmal wünsche ich mir, völlig anders auszusehen				
FK_SGKB_1	Meistens fühle ich mich körperlich wohl				
FBK_14	Ich fühle mich topfit				
FK_SGKB_3	Ich bin häufiger krank				
FK_SGKB_4	Ich stoße manchmal an meine körperlichen Grenzen				
FK_SGKB_6	Ich fühle mich gesund				
FK_SSAK_1	Wenn es möglich wäre, würde ich Teile meines Körpers austauschen				
FK_SSAK_2	Ich habe mehr körperliche Mängel als andere				
FK_SSAK_4	Ich bin mit meinem Aussehen zufrieden				
FK_SASE_2	Ich bin mit meinem Körpergewicht zufrieden				
FK_SASE_3	Ich mag meine Haare				
FK_SASE_4	Ich mag meine Gesichtsform				
FK_SASE_5	Meine Stimme passt zu mir				
FK_SASE_6	Ich habe eine gute Figur				
FK_SASE_9	Ich bin mit meiner Körpergröße zufrieden				

TEIL 2b: Wahrnehmung Gesundheit, Krankheit und Behinderung

		AF 1	AF 2	AF 3	AF 4	Freier Kommentar
GHWN_2	Können Sie Ihre Gesundheit kontrollieren?	Ja, vollständig	Etwas	Kaum	Gar nicht	
KWN_1	Haben Sie aktuell eine Erkrankung?	Ja		Nein		Wenn ja, welche? (chronisch, Infektionskrankheit,..)
KWN _2	Wie stark beeinträchtigt Sie Ihre Erkrankung?	Sehr	Etwas	Wenig	Gar Nicht	
KWN _3	Wie lange wird Ihre Krankheit noch andauern?	Für immer	Noch länger	Nur mehr kurz	Nicht mehr krank	
KWN _4	Können Sie Ihre Krankheit kontrollieren?	Ja vollständig	Etwas	Kaum	Gar Nicht	
KWN _5	Kann Ihnen eine Behandlung helfen?	Ja	Etwas	Kaum	Gar Nicht	
KWN _6	Wie viele Beschwerden haben Sie durch Ihre Krankheit?	Viele	So manche	Wenige	Keine	
KWN _7	Machen Sie sich Sorgen wegen Ihrer Erkrankung?	Viele	So manche	Wenige	Keine	
KWN _8	Wie motiviert sind Sie Ihre Krankheit zu bekämpfen?	Meistens/ Sehr	Häufig/etwas	Selten/Kaum	Nie	
KWN _9	Kennen Sie die Ursachen Ihrer Erkrankung?	Ja, alle	Manche	Wenige	Keine	Warum sind Sie krank? Ursachen..
BHIWN _1	Haben Sie eine Behinderung?	Ja		Nein		Wenn ja, welche?
BHIWN _2	Wie stark beeinträchtigt Sie Ihre Behinderung?	Sehr	Etwas	Wenig	Gar Nicht	
BHIWN _3	Können Sie Ihre Behinderung kontrollieren?	Ja, vollständig	Etwas	Kaum	Gar Nicht	
BHIWN _4	Kann Ihnen eine Behandlung helfen?	Ja	Etwas	Kaum	Gar Nicht	
BHIWN _5	Wie viele Beschwerden haben Sie durch Ihre Behinderung?	Viele	So manche	Wenige	Keine	
BHIWN _6	Machen Sie sich Sorgen wegen Ihrer Behinderung?	Viele	So manche	Wenige	Keine	
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TEIL 4: objektive Daten

OD_1	Körpergewicht in kg
OD_2	Körpergröße in cm
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7. ANNEX II: Publication History

Journal	**Impact Factor:**	**ISI Journal Citation Reports © Ranking: 2011:**	**Original submitted**	**Revision submitted**	**Acceptance**
Zeitschrift für Gesundheitspsychologie	0.324	-	01.06.2012	first: 13.08.2012 second: 30.10.2012	14.11.2012
Journal of Policy and Practice in Intellectual Disabilities	0.971	35/67 (Rehabilitation); 45/62 (Health Policy & Services)	23.07.2012	13.11.2012	04.12.2012
Journal of Intellectual Disability Research	1.877	6/37 (Education Special); 11/67 (Rehabilitation)	15.11.2012	first: 18.02.2013 second: 13.03.2013	02.04.2013
Journal of Applied Research in Intellectual Disabilites	1.385	21/67 (Rehabilitation); 21/51 (Psychology Educational)	02.04.2013		

Lebenslauf

Mag.[a] BREHMER-RINDERER Barbara

Klinische- und Gesundheitspsychologin

Erreichbarkeit	Tel.: +43/650/5124458 E-Mail: barbara.brehmer@univie.ac.at
Geburtsdatum	21. Mai 1983

Wichtigste Berufserfahrungen

Jan. 2010 →	**Mitarbeiterin des Initiativkollegs „Empowerment through Human Rights“**
Wichtigste Tätigkeiten und Zuständigkeiten	Arbeit an der eigenen Dissertation zur Wahrnehmung der eigenen Gesundheit und Gesundheitsverhalten von Menschen mit/ohne intellektueller Behinderung
Arbeitgeber	Universität Wien; Initiativkolleg „Empowerment through Human Rights“, Hörlgasse 6, 1090 Wien
Okt. 2009 – Okt. 2011	**Selbstständige Tätigkeit als Trainerin**
Wichtigste Tätigkeiten und Zuständigkeiten	Schulungen von Angehörigen, BetreuerInnen und Gesundheitspersonal von Menschen mit Behinderungen zu den Themen Altern, psychologische Diagnostik, Gesundheitsunterschiede bei Menschen mit intellektueller Behinderung
Arbeitgeber	u.a. Fonds Soziales Wien, Guglgasse 3, 1030 Wien
Juni 2008 - Jan. 2009	**Klinische und Gesundheitspsychologin in Ausbildung**
Wichtigste Tätigkeiten und Zuständigkeiten	Klinisch-psychologische Diagnostik von intellektueller Behinderung, psychischen Erkrankungen und Begutachtung der Arbeitsfähigkeit; Planung von psychologischen und sozialen Interventionen
Arbeitgeber	Fonds Soziales Wien, Guglgasse 3, 1030 Wien
Dez. 2005 →	**Projektmitarbeiterin/-managerin**
Wichtigste Tätigkeiten und Zuständigkeiten	Projektmanagement und Projektmitarbeit in verschiedenen internationalen Projekten zum Thema intellektueller Behinderung und Altern: EU-Projekt AGID (“Developing training modules for staff on ageing and disability issues”) EU-Projekt eDESDE („Coding System for Long Term Care Services“) EU-Projekt CARERS (“Content mAterials to Raise Employability and Reinforce Skills of carers”) EU-Projekt POMONA II (“The health of people with intellectual disability”)
Arbeitgeber	Universität Wien; Liebiggasse 5, 1010 Wien

Listung wissenschaftlicher Erfahrungen

Conference Attendances

- Munich (12 – 13.11.2004): Psychoonkologische Perspektiven (Psychooncological perspectives)
- Klagenfurt (28 – 30.04.2006): 7.Wissenschaftliche Tagung der Österreichischen Gesellschaft für Psychologie (7th Congress of the Austrian Society of Psychology)
- Vienna (8 – 9.05.2006): Sturz – Risikoerfassung und Prävention (Conference on Falls and Prevention)
- Maastricht (2 – 5.08.2006): IASSID European Congress
- Vienna (2 – 3. 06.2007): 2nd International Congress of Gender Medicine
- Barcelona (5-8.3.2009): conference attendance „Bridging Knowledge in Long Term Care and Support" and Partner Meeting eDESDE

International Project Meetings

- Maastricht (2 – 5.08.2006): All Partner Meeting – POMONA II
- Barcelona (20 – 23.09.2007): All Partner Meeting – POMONA II
- Vienna (25.-27.09.2008): Kick Off Meeting eDESDE EU – Project
- Toulouse (4.-7.02.2009): Partner Meeting EU-Project CARERS
- Newcastle (3.2-5.2.2010): Partner Meeting E-Health
- Brussels (February 2012) Partner Meeting EU-Project AGID
- Newcastle (June 2012) Partner Meeting EU-Project AGID

Poster Presentations at Conferences

- Graz (8 – 9.06.2006): Alter und Behinderung *(Conference Age and Disability; Topic: EU-Project POMONA II)*
- Vienna (15.9. – 16.9.2008): Quality of Life Measures – International Conference *(Topic: EU-Project CARERS)*

Key Note Lecture at Conferences

- Linz (21.11.2009): Österreichisches Psychologenforum Jahrestagung *(Title of presentation: „Psychologie und Behinderung: Wissensstrukturen und aktuelle Forschungsergebnisse in Österreich" – „Current Research on intellectual disabilities in Austria")*

Oral Presentations at Conferences

- Vienna (9 – 12.05.2007): 2. Gemeinsamer Österreichisch – Deutscher Geriatriekongress (*Titel of presentation „Einstellungen zu Tod und Sterben im höheren und hohen Erwachsenenalter" – Attitudes toward death and dying in adulthood)*
- Zagreb (10 – 13.10.2007): 6th European Mental Health Congress in Intellectual Disabilities *(Titel of presentation: "Frailty syndrome and mental health issues in an older population with intellectual disability")*
- Linz (23 – 26.04.2008): 8.Wissenschaftliche Tagung der Österreichischen Gesellschaft für Psychologie *(Titel of presentation: „Die Gebrechlichkeit von Menschen mit intellektueller Behinderung und ihr Einfluss auf die Lebensqualität" - "The fraitly of people with intellectual disability and its influence on the perceived quality of life")*
- Cape Town, South Africa (25. – 31.08.2008): IASSID 13th World Congress *(Titel of presentation: "Frailty syndrome and mental health* issues *in an older population with intellectual disability")*
- Vienna (6.-9.05.2009): 4.Gemeinsamer Österreichisch – Deutscher Geriatriekongress *(Titel of presentation: „Gebrechlichkeit, Sturz und andere physische Problematiken bei Menschen mit intellektueller Behinderung" – „Frailty, falls and other physical health problems in people with intellectual disability")*
- Amsterdam (3. – 5.9.2009): 7th European Mental Health Congress in Intellectual Disabilities *(Titel of presentation: "The course of frailty in people with intellectual disability")*
- Brussels (October 2009): Final Conference CARERS Project *(Titel of presentation: Results of Module 4 – Aging of People with intellectual disability)*
- Vienna (11.2009): INIC Conference *(Title of presentation: "Results and implications of the EU-Project CARERS „Content mAterials to Raise Employability and Reinforce Skills of carers")*
- Newcastle (3.-5.2.2010): Partner Meeting e-Health "Health and adults with intellectual disability" *(Title of presentation: "Health Indicators of people with intellectual disability")*
- Bad Hofgastein (March, 2010): 5. Gemeinsamer Österreichisch – Deutscher Geriatriekongress *(Title of presentation: "Der Verlauf von Gebrechlichkeit bei Menschen mit intellektueller Behinderung – the course of frailty")*
- Rome (Oct, 2010) 3rd IASSID-Europe Conference (*Titles of both presentations:* "Creating a health promotion model for people with intellectual disability" and "The course of frailty")
- Salzburg (13.12.2011): ich – du – wir. Kongress der Lebenshilfe Salzburg (*Title of presentation*: „Health of persons with learning disabilities")

Publications

- Brehmer, B., Zeilinger, E. & Weber, G. (2008) Abschlussbericht des POMONA II – Projekts: „Die Gesundheit von erwachsenen Menschen mit intellektueller Behinderung“(„Final report of POMONA II Project: the health of adults with intellectual disability“). *Psychologie in Österreich*, 5, 488-493.
- Brehmer, B. & Weber, G. (2010) Frailty vs. Disability Distinctions in people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7 (1), 49-58. doi: 10.1111/j.1741-1130.2010.00247.x
- Emerson, E., Barron, D.A., Blacher, J., Brehmer, B., Clinch, S., Davidson, P.W., Davies, R., Felce, D., Glidden, L.M., Hassiotis, A., Hastings, R.P., Hatton, C., Heller, T., Holland, T., Janicki, M., Kerr, M., Knefel, M., Llewellyn, G., Murphy, G., Ouellette-Kuntz, H., Reinders, H., Timmons, V., Walsh, P.N., Weber, G. (2012). *Better Health, Better Lives: Research Priorities*. Copenhagen: World Health Organization Regional Office for Europe.
- Zeilinger, E., Nader, I., Brehmer-Rinderer, B., Koller, I. & Weber, G. (2012 Epub) CAPs-IDD: Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders. *Journal of Intellectual Disability Research.* doi: 10.1111/jir.12003
- Brehmer-Rinderer, B., Zigrovic, L., Naue, U., & Weber, G. (2013). Promoting Health of Persons with Intellectual Disabilities using the UN Convention on the Rights of Persons with Disabilities: Early Implementation Assessment in Europe (Spain and Hungary). *Journal of Policy and Practice in Intellectual Disabilities*, 10 (1), 25-36.
- Brehmer-Rinderer, B. & Weber, G. (2013). Gesundheitsförderung von Menschen mit intellektueller Behinderung: Stand der Forschung und aktuelle Problembereiche. *Zeitschrift für Gesundheitspsychologie, 21 (2),*
- Brehmer-Rinderer, B., Zeilinger, E., Radaljevic, A. & Weber, G. (2013). The Vienna Frailty Questionnaire – Revised. *Research in Developmental Disabilities, 34,* 1958-1965.
- Brehmer-Rinderer, B., Zigrovic, L., & Weber, G. (in press). Evaluating a health behaviour model for persons with and without intellectual disabilities. *Journal of Intellectual Disability Research.*

- Brehmer-Rinderer, B., Zigrovic, L., Zeilinger, E., & Weber, G. (submitted). The relation of an individual’s health knowledge and the personal perception of one’s body and disabilities to reported health behaviours in persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities.*