Health literacy for all? Inclusion as a serious challenge for health literacy: The case of disability

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Introduction

The concept of health literacy started its triumphal march from the healthcare sector. In this context, health literacy meant ‘simply’ to be able to read and understand the patient information leaflet of a prescribed drug. Despite ongoing theoretical and conceptual improvement and the growing number of publications (for example, Nutbeam, 2000; Sørensen et al, 2012; WHO, 2013), the link between the personal level of health literacy on the one hand, and the personal literacy and educational performance on the other, continued to be more or less unquestioned. In most of the health literacy concepts and models, to be health-literate means, at least to some extent, to be educated (Nutbeam, 2009). Thus, it is not surprising that statistically there is a high correlation between the formal educational status of a person and the individual rating regarding different health literacy scales. It seems as if education has replaced the economic resources of action regarding the significance of health inequalities.

In the last few years there has been a visible differentiation of the health literacy discourse, regarding first, the theoretical models and concepts (Sørensen et al, 2012; Bröder et al, 2017; Okan et al, 2018; see Chapter 1, this volume), second, some sub-concepts of health literacy such as eHealth literacy or mobile health literacy, and third, specific target groups that should be addressed by health literacy empowerment interventions in order to strengthen their personal health literacy level. In most cases, target groups are senior citizens, children and adolescents or immigrants. Surprisingly, people with disabilities are rarely mentioned in the context of health literacy in particular and health inequalities in general. They are rarely addressed, for instance, as a special target group for health literacy interventions. Even in the recent World Health Organization (WHO) publication Health literacy: The solid facts (2013) there is neither a link to people with disabilities nor to inclusion nor to the International Classification of Functioning, Disability and Health (CF), which was developed by WHO itself in 2001.

In parallel, people with disabilities are the focus of a broad international discourse on inclusion, following the Convention on the Rights of Persons with
Disabilities (CRPD), entered into force in 2008 by the United Nations (UN) and ratified by 174 nation states (UN, 2017). Although the right to health is an important feature of the Convention (Article 25), in the context of inclusion, most of all the right to inclusive education is highlighted in scientific, political and public discourses. The topic of health and health inequalities in general and health literacy in particular is rarely mentioned in the context of inclusion and CRPD (cf Hollenweger, 2006). In this respect, there is a mutual non-perception of the two discourses.

In this chapter we argue that it would be fruitful and insightful if the concept of health literacy would face challenges posed by the concept of inclusion. In its very core, the concept of inclusion means societal participation in each field of agency for all people, independently of the individual resources of action. Applying this principle to the concept of health literacy would mean that health literacy is not centred on individuals’ capacities and skills, but would lead to a health literacy perspective that is closer to the WHO slogan: making the healthier way the easier choice (cf NHS Scotland, 2017). To bring together these two broad discourses, we start to present very briefly some basic understandings of health literacy, focusing on the measurement tools and conceptualisations of health literacy in order to prepare it for an inclusive addition. Next, we also sketch very briefly some basic ideas of the concept of inclusion. We also want to identify some major challenges for the health literacy concepts. We then sketch some consequences for an inclusion-oriented health literacy concept and practice.

Concept and measurements of health literacy and the significance of education

According to the current state of empirical research, there is no doubt that individual health literacy is linked to social determinants. In sum, the WHO stated that:

specific vulnerable groups have much higher proportions of limited health literacy than the general population in Europe, including lower social status (low self-assessed social status, low level of education, low income and problems in paying bills), with worse health status (measured by self-perceived health, long-term illness and limitations in activities because of health problems) or relative old age. (WHO, 2013, p 14)

Nevertheless, in the health literacy research there is a strong tendency to focus on individual education status or educational performance as the most important factor of health literacy. This is particularly true for the measurement practices of health literacy.

As Pleasant et al (2011, p 11) point out: ‘Building a comprehensive approach to measurement of the social construct called health literacy may well be the
most significant and necessary task facing health literacy research and practice.’ Health literacy research is still a work in progress, or in Levin-Zamir et al’ terms (2017, p 133) ‘a dynamic construct’, up to now ‘no gold standard measure for HL [health literacy] has emerged’ (Nguyen et al, 2017, p 190). Thus, at present, more than 150 health literacy measures exist (2017, p 189; see also Chapters 5 and 6, this volume). Depending on the measurement tools, the relation between health literacy and education is measured as a direct (on the basis of objective tests and performances) or indirect (on the basis of self-reported skills) relation (Ormshaw et al, 2013; Kiechle et al, 2015).

The indirect measurement strategy refers to scales on self-reporting attitudes and/or behaviour, for example, the European Health Literacy scale (HLS-EU 47) (cf Sørensen et al, 2012; Pelikan et al, 2013; see also Chapter 8, this volume), the Health Literacy Measure for Adolescents (HELMA) (Ghanbari et al, 2016) or the US-based Health Activity Literacy Scale (HALS) (Rudd, 2007). One of the fundamentals of this strategy is that an overwhelming number of studies prove a stable positive correlation between individuals’ (formal) educational level and the corresponding level of health literacy (for an exception, see Wångdahl et al, 2015). Generally speaking, the higher the education level, the higher the self-reported comprehensive health literacy level. To give just a few examples: the HLS-EU has shown for six of the eight participating countries weak or moderate correlations (even in multivariate analysis, where gender, age, social status and financial deprivation are controlled) between educational status and general health literacy level (with the exceptions of Austria and Ireland) (see Figure 44.1). In a representative Japanese survey from 2006 a research group found that ‘individuals with a low level of educational attainment were also likely to have limited communicative/critical HL’ (Furuya et al, 2013, p 508). In a recent representative

**Figure 44.1: Mean scores of general health literacy by education for countries and total**

Source: HLS-EU Consortium (2012)
Swiss survey, it was shown that people with low education possess less health literacy (Schweizerische Akademie der Medizinischen Wissenschaften, 2015). In a representative German survey from 2013 conducted by the Robert Koch-Institute, which is responsible for official health monitoring in Germany, the low educational status group has nearly a double share of people with inadequate health literacy compared to the high educational status group (Jordan and Hoebel, 2015, p 945).

All these empirical correlations refer to theoretical models that conceptualise the formal educational status as an individual resource of action, which is linked with self-reported health literacy. But theoretically at least, it is possible and sometimes plausible that people with a low educational status and/or those with little competencies in writing and reading have a high level of health literacy, for instance, regarding healthy daily routines or even patient autonomy. In a recently conducted survey in Afghanistan, we found out that even those who are illiterate reported – to a smaller share, of course – adequate health literacy (measured by HLS-EU Q16) (cf Harsch et al, forthcoming). This means that individual educational level correlates very much with the self-reported health literacy level, but it does not determine it. So it is possible that people with low educational status are principally able to live a healthy lifestyle, albeit having limited educational resources.

In the direct measurement strategy, the mostly often used instruments measure skills and performances directly:

The large majority of empirical HL research has used the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA), or some variant of these tools…. The REALM is a word pronunciation test that uses medical words, an extremely narrow lens through…. Alternatively, the full TOFHLA includes reading, numeracy, and document literacy, and the modified cloze procedure to ensure that the TOFHLA tests a person’s understanding. (Nguyen et al, 2017, p 190)

The individual test scores on these instruments differ significantly according to educational background and completed years of school (cf Carthey-Goulart et al, 2009).

Although there is some critique that tests like REALM or TOFHLA are too narrow to catch a more comprehensive understanding of health literacy outside clinical settings (see, for example, Nutbeam, 2009, p 304; O’Neill et al, 2014, p 2), particularly in healthcare and curative settings the use of these tests are still the standard procedure. And there are some good reasons for it, for example, because of relations between literacy level and specific medical knowledge: ‘Low literacy is associated with less diabetes-related knowledge and may be related to other important health outcomes’ (Bailey et al, 2014, p 582). But there are two strong limitations to a direct link between health literacy and education: first, if a high educational level is reached, almost no differences in health outcomes
are found between high educated people with little and high health literacy, measured by a short version of the TOFHLA (Hansen et al, 2015). Second, a measurement strategy that links directly the individual literacy level and health literacy level leads to the result that an illiterate person has, by definition, almost no health literacy, although this is not very convincing. Such a direct test strategy is furthermore challenged by the fact that there are large groups of immigrants and minority ethnic groups in each country of the world who are not able to speak the language of the majority as good as the native speakers. This means that the validity and test fairness of REALM, TOFHLA etc are basically limited. This is true even for the US or Canada, where a lot of empathy regarding minorities could be supposed. For the case of Canada, Omariba and Ng stated (2015, p 390) that, ‘from a health literacy perspective, poor knowledge of English and French means that individuals are not able to communicate, access, and use health information to maintain their health.’ And for the US case, Nguyen et al (2015, p 1503) mentioned that, ‘most existing HL measures were developed and validated in English. Among them, there is a strong bias towards the validation of measures in White and Black populations. Using tools that are not well-validated for a given population can lead to substantive measurement error.’

These insights bring to the fore the very fundamental challenge of diversity of individuals and social groups for the concepts, models and measurements of health literacy. Research on diversity and social determinants in public health discourses normally refers to the three basic structural components of societies: class, gender and race/ethnicity. Another important dimension that is regularly taken into account is age. While the research results are not always clear for the gender dimension, we know that there are (partly strong) correlations between educational status, social (and employment) status, belonging to a minority ethnic group and to an older age group on the one hand, and the average level of health literacy on the other (cf Canadian Council on Learning, 2008; Pelikan et al, 2013; WHO, 2013; Zok, 2014; Omariba and Ng, 2015; Hearian et al, 2017; Levin-Zamir et al, 2017). But little is known about the relationship of health literacy and other important dimensions of diversity. For instance, it is still an open question as to whether sexual orientation is associated with functional, adequate or critical health literacy.

The state of research regarding disability and health literacy is hardly better. The measurement of disability is sometimes reduced to self-reported activity limitations. Omariba and Ng (2015, p 391) describe their (very vague) operationalisation-strategy:

Disability was ascertained from five questions on current disability and activity limitation related to vision, hearing problems, speech, learning, or any other disability or health problem lasting six months or more. Respondents who replied affirmatively to any of the listed conditions were considered as having a disability; all others were defined as disability free.
According to this operationalisation 27 per cent of Canadians older than 16 belong to the group of people with disabilities. The advantage of such a measurement strategy is surely to make clear that people with any kind of disability make up a very large group in every society. However, the group of people with disabilities also includes those with severe and multiple disabilities, or intellectual disabilities, who are not able to fill out a questionnaire.

All of the presented measurements in this chapter are not feasible to measure the health literacy level of a considerable group of people with disabilities. This is a challenge, because the recognised diversity within health literacy will be limited from the beginning if only human beings are taken into consideration who are able to fill out a questionnaire. Furthermore, this has implications for policy strategies to increase the health literacy level particularly of vulnerable groups (WHO, 2013). It is important to note that the standard strategy and policy of increasing the health literacy level as a tool to improve the population’s health in general is challenged very much in case of people with severe and multiple impairments (or of functional illiterates, but this is another discussion). As Don Nutbeam (2009, p 304), one of the pioneers of the health literacy concept, noted, ‘health literacy can be developed by education. Health literacy can be regarded as a measurable outcome to health education in the same way that measures of literacy are used as one way of assessing the success of school education.’ This widely accepted perspective is not only limited to highly industrialised countries, but also to countries of the Global South. A similar statement comes from an Iranian research group: ‘Health Literacy capacity may be affected by individual and social factors that are modifiable using education’ (Haghdoost et al, 2015, p 2).

What might happen if increasing education is hardly possible or impossible to manage? From a traditional health literacy approach, people with disabilities, who are hardly or not able to read and write, have, by definition, no health literacy. If somebody is not able to find, understand, appraise and apply health information, for instance, because of brain damage or traumatic learning blockades, then the health literacy level is near to zero. Consequently, those people belonging to these groups are more objects than subjects in the healthcare sectors and settings, and barely part of any health promotion perspective. This is sensitive because health literacy is called one important strategy of (patient) empowerment and participation (for good practice, for example, see NHS Scotland, 2017; see also Chapter 40, this volume), and such a perspective finally puts people with severe disabilities in a passive status, reduces their autonomy theoretically and neglects their subjectivity to a certain degree. This is hardly compatible with a WHO perspective that claims the best health for all people (WHO, 1986).

But what is an alternative to this perspective? First of all, it could be assumed that every person in the world has some abilities and competencies, independently from educational or cognitive performance. Thus, we are able to assume that even people with severe and multiple impairments have health literacy and are
able to cope with their everyday life as well as possible (Feuser, 1996). So, the perspective should be that if measurement instruments are not able to measure the competencies of specific groups, it should not mean automatically that these groups have no competencies, and in our case, health literacy. Rather, scientific research should find ways to develop concepts and measurement instruments that are able to show the competencies of the groups concerned. If we want to find out what health literacy means as part of the agency in everyday life of, for example, people with disabilities, we need to change the methodological approach. It is necessary to watch people with disabilities closely to explore their potentials, their spectrum of autonomy, and to value them as human beings and people independently from the grade and severity of their impairments. For this change in perspectives the United Nations’ (UN) Convention on the Rights of Persons with Disabilities (CRPD) and the subsequent discourse of inclusion, as well as the International Classification of Functioning, Disability and Health (ICF) from the WHO, are promising starting points.

**CRPD, ICF, inclusion, health and health literacy**

In the development of human rights and in the formulation of human rights declarations and human rights conventions by the UN there is a comparable and analogous process as in the WHO. The latter comes from the broad non-medical definition on health in 1948, progressed to the Declarations of Alma-Ata and Ottawa Charter focusing on health promotion, and continues to the Nairobi Declaration and to the last two WHO Conferences in Helsinki and Shanghai, where health literacy played a crucial role (see Chapter 42, this volume). While the programmatic development by the WHO continues to widen the normative frames regarding health equity, and to concretise the methods and policies to increase health equity, the logic of the progress in human rights – at least according to one common understanding of human rights education (cf Sahrai et al., 2015a, b; Gerdes et al., 2015) – is to emphasise the rights of discriminated groups as the subjects and recipients of human rights. Therefore, it is no coincidence that in the preamble of the CRPD the overarching general significance of human rights are emphasised as well as the ‘universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms’ for people with disabilities. The main aim of the CRPD is to also ensure the full possible amount of human rights for people with disabilities. The preamble of the CRPD (UN, 2017) emphasises in paragraph v the ‘importance of accessibility to the physical, social, economic and cultural environment, to health and education, and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms.’ Even widely unknown in the public health field, this Declaration is, by its very nature, relevant for a comprehensive health perspective because people with disabilities are, from another angle, to a very large degree simply people with chronic diseases. Furthermore, Article 25 of the CRPD addresses health issues directly (see Box 44.1).
Box 44.1: UN Convention on the Rights of Persons with Disabilities, Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people’s own communities, including in rural areas;

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Particularly relevant for the health literacy context is the demand for providing people with disabilities the same range, quality and standard of health programmes in the area of population-based public health programmes (see above CRPD, Article 25[a]). It is urgent to note that this demand is not an add-on for health literacy policies but a human right for each person, including those with any disability!

To bring health literacy models, concepts and policies closer to people with disabilities, the distinction between functionings and disabilities, which was supported by the WHO itself 15 years ago, is of particular value. This differentiation comes from the ICF (WHO, 2002; cf also Hollenweger, 2003). ‘ICF is WHO’s
framework for health and disability. It is the conceptual basis for the definition, measurement and policy formulations for health and disability. It is a universal classification of disability and health for use in health and health-related sectors’ (WHO, 2002, p 2; original emphasis). Although meant as a complementary tool to the ICD-10 classification, this classification is rarely known in health literacy discourses: ‘ICD-10 is mainly used to classify causes of death, but ICF classifies health’ (WHO, 2002, p 3). The basic idea of ICF is to distinguish impairments of a person’s body (regarding physiological/psychological body functions and body structures understood as anatomical parts of the body) from social and environmental factors that hinder people with impairments from activity and participation. In this perspective, disability is always an interaction of individual characteristics and contextual factors. This is illustrated in Figure 44.2.

While a biomedical perspective on disability focuses on a single person and its disease and disability, the social model of disability refers to the social construction of disability. The strength of the ICF is to value each perspective and combine the medical and social approaches to a biopsychosocial model of disability. In this integrated model, education is also addressed as an individual factor (next to gender, age, coping styles etc), but from this perspective low educational status or performance would not have an automatic impact on health literacy, at least at the theoretical and conceptual level. If disability is conceptualised as the ineluctable interplay between personal characteristics and environmental and social conditions, then the health literacy of people with disabilities could not be reduced to a personal resource or skill either, particularly for those individuals with severe impairments. In Table 44.1 some examples are listed for the interplay between personal characteristics and social and environmental influences on different outcomes.

**Figure 44.2: ICF model of functioning, disability and health**

![ICF Model Diagram]

*Source: WHO (2002)*
This means that an increase in individuals’ health literacy could also be triggered by environmental and social factors: ‘Reductions in the incidence and severity of disability in a population can be brought about by enhancing the functional capacity of the person and by improving performance by modifying features of the social and physical environment’ (WHO, 2002, p 5). According to this approach, individuals’ health literacy is socially embedded, it is part of flexible situations and opportunity structures that enable, support or hinder individuals’ resources of action (see Chapter 37, this volume). At this point of the argument the CRPD comes in again, since it refers primarily to the duties of states to ensure the maximum of opportunities for people with disabilities, and to abolish social structures that hold some extra limitations of activity and participation for people with disabilities.

Following the entering into force of the CRPD in 2008, a worldwide discourse on inclusion started emphasising the right to full inclusion for people with disabilities into communities and society. States that have signed the Convention commit themselves to make visible efforts in including people with disabilities and to stop discrimination and social exclusion. The most visible field, especially in Europe, is the field of education, which is also particularly significant for health literacy. In Germany and Switzerland, for instance, for 10 years the hierarchically differentiated school systems has faced more and more problems of legitimisation. In accordance with the critical sociology and pedagogy of education, under the discourse of inclusion, the call to establish an inclusive school system and to liquidate the traditional separated school system for children and adolescents with disabilities (special needs education) has gained new power (cf Pfähl and Powell, 2011; Biermann and Powell, 2016). Although there are different understandings

<table>
<thead>
<tr>
<th>Health condition</th>
<th>Impairment</th>
<th>Activity limitation</th>
<th>Participation restriction</th>
</tr>
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<tbody>
<tr>
<td>Leprosy</td>
<td>Loss of sensation of extremities</td>
<td>Difficulties in grasping objects</td>
<td>Stigma of leprosy leads to unemployment</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>Anxiety</td>
<td>Not capable of going out alone</td>
<td>People’s reactions lead to no social relationships</td>
</tr>
<tr>
<td>Spinal injury</td>
<td>Paralysis</td>
<td>Incapable of using public transportation</td>
<td>Lack of accommodations in public transportation leads to non-participation in religious activities</td>
</tr>
<tr>
<td>Juvenile diabetes</td>
<td>Pancreatic dysfunction</td>
<td>None (impairment controlled by medication)</td>
<td>Does not go to school because of stereotypes about disease</td>
</tr>
<tr>
<td>Vitiligo</td>
<td>Facial disfigurement</td>
<td>None</td>
<td>No participation in social relations owing to fears of contagion</td>
</tr>
</tbody>
</table>

Source: WHO (2002)
of inclusion, it is widely accepted that inclusion is a ‘new paradigm for the analysis of current societal structures and the fundament for comprehensive reform programmes’ (Hollenweger, 2006, p 45). In line with ICF and CRPD, the concept of inclusion refers to a shift in perceiving disabilities. The (still very present) focus on the specific demand of one single subject in terms of special needs education is questioned by an inclusive perspective, and should be replaced by a more participatory-oriented practice. This idea reflects the basic assumption in the concept of inclusion: people with disabilities are conceptualised as just another dimension of the big variety of human beings – analogously to dimensions like (()), race/ethnicity, gender, sexual orientation or age. To close the loop: if health literacy concepts, measurements and policies are meant to reflect the heterogeneity of a population in order to measure adequately, develop tailored policies and to empower people, then people with disabilities have to be taken into consideration. Thus, until now an almost unquestioned link between education and health literacy presented above should be questioned against the background of inclusion. However, this has some consequences for the concept of health literacy itself. In the following we present two different opportunities for health literacy concepts, models and measurements to deal with the topic of inclusion and disabilities.

**Health literacy: inclusive or exclusive**

The motto and general goal of the WHO is to achieve *Health for all* (WHO, 1998). If health literacy is really a significant factor for health outcomes, as shown by many international research studies, then it is not compatible with the WHO main goals to exclude a group of people, for example, with disabilities, arguing that they have too little educational performance to understand, appraise and apply health information. That means that policy programmes that are implemented to increase the health literacy level of the population – for example, community-based programmes – must include programmatically and practically people with disabilities, no matter how severe the degree of disability of a person (Feuser, 1996). From the perspective of the general goal *Health for all* by the WHO, two different strategies are possible in reaching the demands of people with disabilities. The first strategy could be to widen the concept of health literacy substantially; the second one, to keep the concept of health literacy narrow and to widen the WHO programmatic issues since the Nairobi Declaration (WHO, 2009).

Widening the health literacy concept addresses at least two different issues. First, it should have become clear that neither the indirect nor the direct measurement of health literacy is suitable for different minority groups, including minority ethnic groups, due to language differences, senior citizens or people with disabilities. The predominantly cognitivist concept of health literacy needs a turn to look for health literacy in everyday life. This could be realised by ethnographic studies that accompany people, peer groups or families following methodological approaches such as action research or participatory health research. Regarding the
health literacy in the everyday lives of people with disabilities it is paramount to conceptualise health literacy as the interplay between subjects and the social and physical environment. Then the health literacy of people with disabilities comes to the fore, and they are more than a group of underscorers who are always at risk of becoming stigmatised because of their poor test results (Kronzer, 2016). In this case, according to the biopsychosocial model of disabilities, health literacy needs an intersubjective turn (cf Habermas, 1981). From here it is necessary and, in our view, possible to transport the idea and concept of health literacy to organisations, institutions and even societies. For the healthcare sector this demand is clearly formulated by the WHO: ‘Action must take place in many sectors: health professionals urge the education sector to improve the literacy skills of populations, but the health sector itself must take action to remove literacy-related barriers to information, services and care’ (2013, p 26). But there are hardly any concepts or operationalisations for a health-literate society (cf Nielsen-Bohlman et al, 2004).

Another strategy to include people with disabilities in health discourses and programmes comes from a perspective on human rights and the theory of justice. If people with certain severe impairments will never be able to be high scorers on the traditional cognitivistic and education-oriented measurements, the absence of (such an understanding of) health literacy, however, must not have any negative effect on the best possible health status for these people. They should be enabled and empowered to reach the maximum of health under difficult circumstances without having functional, adequate or even critical health literacy skills. To us, it is an open question which of both strategies is more challenging and more promising, but we are sure that people with disabilities should gain greater attention both in health literacy and health research.

References


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