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Witchcraft, Shame and Intellectual Disability

Help-seeking for children with intellectual disabilities in
Kampala, Uganda: a mixed methods study

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Abstract

This study aims to explore the influence that stigma and beliefs have on the disability-related help-seeking for children with intellectual disabilities in Kampala, Uganda. These children are regarded as one of the most neglected groups in developing countries, where access to rehabilitation services frequently is restricted starkly, and beliefs and stigma are believed to interfere in the process of seeking help. Implementing a concurrent embedded mixed methods approach using qualitative interviews and a survey questionnaire, caregivers and staff members of the Mukisa Foundation, a rehabilitation facility for children with intellectual disabilities, participated in the data collection. Findings were analysed using the *Integrated Behavioral Model* and a help-seeking process model.

Results show that traditional beliefs, shame and harassment influence attitudes, social norms and self-efficacy with regards to help-seeking, which in turn affect the process of attending support services in a complex interplay with other factors. The influence of stigma and beliefs develops dynamically over the course of help-seeking pathways, fuelled by personal development and disappointing experiences in help-seeking. In sum, stigma and beliefs show the potential to prevent or delay effective help-seeking, which negatively affects life chances of children with intellectual disabilities and their families' socio-economic status in society.

Keywords: Stigma, intellectual disability, special needs, learning disabilities, help-seeking, Integrated Behavioral Model, explanatory (belief) models, rehabilitation, Kampala, Uganda.

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Contents

1. Introductory Chapter

1.1 Introduction

The Convention on the Rights of the Child (CRC) postulates among others the right of each child to live and develop healthy and the right to develop his/her full potential (Art. 6 & 29). The governmental duties to guarantee these basic rights (Art. 4) are, particularly concerning developing countries, under intense scrutiny, and increasingly addressed using large scale programs to guarantee (basic) schooling for children (Unterhalter, 2014:181). However, the equally incorporated right of children with disabilities to special care and support (Art. 23.2), that adds to the more detailed Convention on the Rights of Persons with Disabilities (CRPD), is arguably not sufficiently addressed in resource-poor environments (Dawson et al., 2003:153; Emerson et al., 2012:96). Especially children with intellectual disability[1] (ID) are neglected, and the scarce research on the topic that is available, leads to the overall conclusion that their access to basic education and services is frequently restricted starkly in low and middle-income countries (Emerson et al., 2012:96).

Publications on ID hence explicitly call for additional efforts of disability research in developing countries, and identify, among others, the importance of research on service utilization, beliefs, attitudes and perceptions of stigma (Maulik & Darmstadt, 2007:22; Stone-MacDonald & Butera, 2006:73; WHO, 2011:267). This is necessary as ID needs to be seen as embedded in culture and society, and beliefs and stigma, which are immensely context sensitive, have shown the potential to starkly influence the process of seeking help (Johnson et al., 2009:276,277; McKenzie et al., 2013:1751; Parmenter, 2008:125). Knowledge on this topic gained in one setting, for instance western countries, hence needs to be adapted to the respective circumstances (Evans et al., 2012:1105; Johnson et al., 2009:276; Rubel & Garro, 1992:632-634; WHO, 2011:77). Understanding the influence these themes have on the help-seeking for children with ID thus has the potential to support the development of culturally sensitive interventions to reach those intellectually disabled children not profiting from any current programs or services (Stone-MacDonald & Butera, 2006:73)

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[1] In order to provide for a more convenient reading of this thesis, intellectual disability will interchangeably be used with the term “special needs”.

1.2 Purpose and research question

The given work aims to shed a light on the influence of beliefs and stigmatization on the help-seeking of caregivers for intellectually disabled children in Kampala, Uganda. The study aims to add to the small body of research on the topic by analysing primary and secondary data and giving impetus to further research. Using a mixed methods approach, the study has an exploratory character.

The following research question will be addressed in this thesis:

How do beliefs about intellectual disabilities and related stigma influence the help-seeking process of caregivers of children with intellectual disability in Kampala, Uganda?

To grasp the reach of influences of stigma and beliefs identified in the data analysis, this study also incorporates quantitative means of analysis.

1.3 Outline

Section two introduces concepts that are fundamental to this thesis, discussing intellectual disability, help-seeking, stigma and beliefs. Section three, the literature review, locates the study in given research, and debates its impetus given for this thesis. Background information regarding IDs in Africa and the importance of early intervention will be given in section four. The analytical frameworks will be presented in section five, followed by the presentation of the methodological background of this study in section six. The analysis follows in section seven, arranged according to the analytical frameworks. Discussion and conclusion constitute the final section.

2. Key concepts

In the following, key concepts used in this study will be presented to provide the reader with the conceptual background of this thesis.

2.1 The concept of disability

For this study the "bio-psycho-social model", an integrated conceptualization of disability used by the WHO in its *World Report on Disability* will be used:

> *"Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors* (…)*"* (WHO, 2011:4).

“Intellectual disability” as a sub-category of disability “ (…) *is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.*” (Schalock et al., 2007:118). These difficulties can be caused by, or accompany, a variety of conditions and impairments such as Down Syndrome (Bonnier, 2008:854) and cerebral palsy (Jameel et al., 2014). Conditions and impairments in turn may be caused in various ways, including genetic causes, infectious disease and malnutrition (e.g. Guralnick, 2005; Maulick & Darmstadt, 2007).

2.2 Help-seeking

Help- (or treatment-)seeking behaviour is the process of initiating and engaging with care, for instance therapy services (Clement et al., 2015:12). Influences on help-seeking are manifold, and include demographic factors, issues regarding the appraisal of the problem noticed, and psychological factors such as fear and stigma (Broadhurst, 2003). Factors that are related to the culture for instance include an individual’s perception of the cause of a condition (Kendall-Taylor, 2006:108). Following this notion, a person with disability (or the person responsible for the decision) seeks treatment that corresponds to the perceived cause. For instance, in case an evil spirit is considered as causing impairment, the corresponding treatment might rather be a witchdoctor than a “western” medical institution (Ibid. 108, 109).

2.3 Stigma

Stigma can be described as “(…) *attribute that is deeply discrediting* (…)”, which reduces the bearer “(…) *from a whole and usual person to a tainted, discounted one* (…)” (Goffman, 1963:3). It has hence two basic constituents, the recognition of difference and devaluation (Bos et al., 2013:1). As stigma occurs in social interactions, it does not reside in a person, but rather in the social context (idem), and consists of and follows out of negative, stigmatizing, attitudes and stereotypes leading to prejudice and discrimination (Ditchman et al., 2013:207; Werner et al., 2012:749). Depending on the attitudes prevalent in a population, stigma varies across communities and societies (Pryor & Reeder, 2011:790). It can manifest in various ways, such as avoidance and dehumanization, and has the potential to affect all levels of life (Ilic et al., 2013; Werner et al., 2012). Stigma manifestations relevant for this thesis are: *Public stigma*, *self-stigma*, and *stigma by association*.

Public Stigma consists of perceptions, attitudes and discriminative behaviour people show towards a person with a certain condition (Bos et al., 2013:2; Pryor & Reeder, 2011:791). It is frequently rooted in a cognitive connection of a condition with social norm violation (e.g. HIV infection due to drug addiction) (Bos et al., 2013:2,3).

Deriving out of public stigma, *self-stigma* describes the impact of public stigma on the stigmatized individual. This includes the experiences of being discriminated against (*enacted stigma*) and the anticipation or awareness of public stigma (*perceived stigma*) (Pryor & Reeder, 2011:792).

Stigma by association is present if a person that has some kind of connection to a stigmatized person is devalued, similar to the person with the stigmatized condition itself (e.g. the caregiver of a child with ID) (Bos et al., 2013:4; cf. Hinshaw, 2005:722).

2.4 Beliefs: Explanatory belief model

Varying beliefs about the cause and characteristics of a condition are largely captured as *explanatory belief model* of that person (EM) (Hwang & Myers, 2013:57). They comprise of individual beliefs as well as of those of the persons of the closer and wider social and cultural environment (Johnson et al., 2009:276). EMs as concepts are related to stigmatizing attitudes, since both are based on attitudes and beliefs about a certain "mark", with EMs being general beliefs about illness and impairment, while stigma particularly comprises of negative attitudes, which in turn can be based on beliefs. EMs are believed to influence the help-seeking process in different ways, including the question on if, where and how long care services are made use of (Hwang & Myers, 2013:58; Kendall-Taylor, 2006).

3. Literature Review: Stigma, intellectual disability and help-seeking

Persons (including children) with ID are generally regarded as one of the most stigmatized groups of people (Ditchman et al., 2013:206,207). Public reactions to persons with ID can be summarized, in a sharp way, as "(…) *an uneasy combination of pity, discomfort, and fear from the public* (…)" (Ditchman et al., 2013:208). The stigma on ID is suspected to negatively affect the participation of members of this group in society in general, and to impair adequate service provision for persons with ID (Werner et al., 2012:749).

However, studies investigating stigma of persons with ID and the effects on their lives in-depth are rare, and in terms of children with ID basically absent (Ditchman et al., 2013:207). Literature on attitudes towards persons with ID is abundant, though, but largely limited to western countries. In sum, research concerning attitudes towards ID highlights widespread negative attitudes (e.g. Ditchman et al., 2013:208; Rillotta & Nettelbeck, 2007) as well as stereotypical characterizations of persons with ID, such as a perceived lack of potential to improve their condition (McCaughey & Strohmer, 2005:94). Morin et al. (2013) investigated attitudes in a quantitative study in Canada, referring to a model of attitudes similar to the stigma conceptualization of stereotypes, prejudice and discrimination. Results display positive and negative attitudes differing over various groups. The behavioural factor, similar to the notion of discrimination in stigma concepts however was only based on questions and reactions towards hypothetical situations. What studies focussing on attitudes including Morin et al. (2013) fail to grasp is the impact of attitudes on the life of persons with ID, the previously mentioned discriminating aspect of stigma (Ditchman et al., 2013:207).

Due to the lack of stigma research referring to ID, various academic writers point to mental illness (MI) research as a possible source of information, since both conditions regularly show to be the least socially accepted disability groups (Ditchman et al., 2013:206; Werner et al., 2012). Corrigan et al. (2003:173) for instance show that the refusal to help and negative treatment towards persons with MI is significantly stronger when the cause of mental illness is perceived under the ill person’s control. Furthermore, research in various cultural settings yielded the result that individuals or persons responsible for help-seeking (e.g. parents) might avoid or delay seeking help as they sometimes fear to be subject to outcomes of stigma when being labelled “mentally ill”, a phenomenon called *label avoidance* (Henderson et al., 2013:1; Eapen & Ghubash, 2004; Schierenbeck et al., 2013:115). In general, a person seeking help for a stigmatized condition faces a dilemma as attending a health service often is a public act, opening up the possibility for others to realize that a person has a certain condition (Kendall-Taylor, 2006:113). To what degree the presented findings can be transferred to ID research remains to be revealed.

Research on beliefs and stigma regarding ID in Sub-Saharan Africa is rare as well (Ditchman et al., 2013; McKenzie et al., 2013:1751). Stone-MacDonald & Butera (2006:66) classify beliefs about the causes of disability in three categories, of which several can be held at the same time: Traditional beliefs referring for instance to witchcraft, Christian beliefs considering disabilities as an act of God’s will, and medical beliefs accepting explanations of modern medicine. Especially beliefs of supernatural causations of ID are persistent in many countries, potentially triggering negative attitudes and severely affecting the life chances of persons with ID, as they are, for instance, hidden at home out of shame (McKenzie et al., 2013:1751). For the context of East Africa, Stone-MacDonald & Butera (2006:66,67) state that these supernatural causation assumptions often conceptualize ID as punishments for the violation of social norms by family members, which in turn gives a responsibility to them. Ntswane & van Rhyne (2007) showed in their qualitative study in Namibia, that caretakers of children with ID frequently suffered from social isolation, including rejection of the child. Connecting the presented findings to the impact of stigma on help-seeking in MI research, one could assume that (1) persons with ID, and possible caregivers, might be subject to negative treatment, particularly due to a perceived responsibility for the ID, and (2) could in turn be reluctant to seek help in order to not become subject of further stigmatization.

As the situation of persons with ID in Africa is largely left in the dark (Emerson et al. 2008), little information is available to guide intervention practices. Research or best practices relevant for high-income countries of the global north cannot easily be transferred to settings in other countries, as differing cultural and social settings can strongly influence the conditions for successful interventions (Evans et al., 2012:1105; Parmenter, 2008:130). Services that are available might lack accessibility, often reported for instance for persons with low socioeconomic status (Mercier et al., 2008:85).

4. Background

4.1 The importance of early interventions

Interventions to support persons with intellectual disability (rehabilitation) aiming for "*optimal functioning in interaction with the environment* (…)" (Escorpizo et al., 2011:128; cf. 2.1), such as physical and occupational therapy, introduced at a young age of the person with ID are seen as especially important (Bonnier, 2008; Guralnick, 2005:314; Simeonsson, 1991). Applying as a general rule, a therapy measure is the more effective, the earlier in life is sets in (Bonnier, 2008; Lai et al., 2014:170,6). Positive implications of early interventions include among others language proficiency and general cognitive capabilities (Bonnier, 2008; Lai et al., 2014:170; Rogers et al., 2014:2991,2992). The importance of early intervention creates the necessity in help-seeking research to not only investigate *if* a support service has been visited, but also to consider questions of *when*, for instance referring to delays in help-seeking.

4.2 The picture of sub-Saharan Africa and Uganda

The group of intellectually disabled persons probably forms the largest impairment group on the African continent (McKenzie et al., 2013). The actual number or an approximate share of the population is difficult to give, as official government statistics frequently lack accuracy, if this data is collected at all (Grantham-McGregor et al., 2007:60).

Nonetheless, as the impacts of poor socio-economic environments tend to increase the number of children with intellectual disabilities, for example through infectious disease, the incidence of intellectual disability is estimated to be significantly higher in low-income countries compared to the global north (Durkin, 2002; Emerson et al., 2008:79). Grantham-McGregor et al. (2007) estimated the number of children under 5 years that do not reach their full cognitive potential because of environmental factors such as poverty and malnutrition at 70.9 million in sub-Saharan Africa, Uganda being among the "top ten" countries among all developing countries. However, this data does not directly refer to persons with ID as such, since data on deficits in adaptive behaviour have not been included (Grantham-McGregor 2007:65).[2]

Despite the potentially high incidence rate of ID in children in sub-Saharan Africa, rehabilitation and education services for this group are strongly underdeveloped, and there is no indication that Uganda is an exception in this field (Dawson et al., 2003:153; Emerson et al., 2012:96; McKenzie et al., 2013:1750). With the prioritization of the fight against high mortality rates among children in the past decades, the rehabilitation sector has for a long time been neglected even in relatively prosperous South Africa (Adnams, 2010:439; McKenzie et al., 2013:1752). Many persons with ID can thus not profit from rehabilitation services to help to support participation in their societies.

4.3 ID in the development context: Impacts on (poor) families

The impact of missing or inaccessible rehabilitation and education services for children with ID disproportionately affects economically poor families, and shows traits of a vicious cycle (Msall & Hogan, 2007:182). This is due to the fact that IDs are impacted by environmental factors, such as the socio-economic situation of a family (Parmenter, 2008:126).

Members of economically poor families more often face malnutrition, environmental pollution and infectious disease, especially in low-income countries (Walker et al., 2007).

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[2] The reference however states that most of these children will have difficulties to follow in school.

Cases of ID thus most probably cluster in socio-economically poor milieus (Ibid.). Furthermore, literature suggests that in situations of economic poverty, resources might be directed to “productive” family members rather than to a person with ID who might be unable to contribute to the survival of the family (McKenzie et al., 2013:1752). This factor has the potential to exacerbate the difficulties arising due to an existing impairment (Msall & Hogan, 2007:182).

In the absence or inaccessibility of adequate services this situation can diminish family resources as, depending on the need for assistance of the persons with ID, one or more (usually female) family members might not be able to work as much as would be possible (McKenzie et al., 2013:1752). Diminishing family resources in turn can, as shown above, cause or impede ID, leading to “(…) *intergenerational transmission of poverty and compromised developmental potential.*” (Msall & Hogan, 2007:182).

5. Analytical Framework

In order to fully grasp how stigma and EMs play a role in help-seeking for children with special needs, two frameworks will be used in this study, the *Integrated Behavioral Model* (IBM) (Yzer, 2012; Montaño & Kasprzyk, 2008), and a help-seeking process model based on Srebnik et al. (1996). This way, the in-depth analysis of intention building using the IBM can fruitfully be related to a model that specifically addresses help-seeking processes.

5.1 The Integrated Behavioral Model

The framework used to analyse the impact of stigma on behaviour is the *Integrated Behavioral Model*. It specifically aims at explaining how intentions to pursue an action are constructed, and if these intentions are put into action (Montaño & Kasprzyk, 2008). The main emphasize of this thesis will lie on the intention building aspect.

As visible below in figure 1, the *intention* to behaviour is constructed by three constituents, *social norm*, *attitude* and *self-efficacy*. All of these constituents have several sub-constituents, of which the most relevant for this study will be explained. Other influences on intention building, such as socio-economic variables, information and knowledge, but also public stigma in certain forms are considered as *background variables* which influence intention indirectly through their influence on the three mentioned constituents (Yzer, 2012:23,25,26)

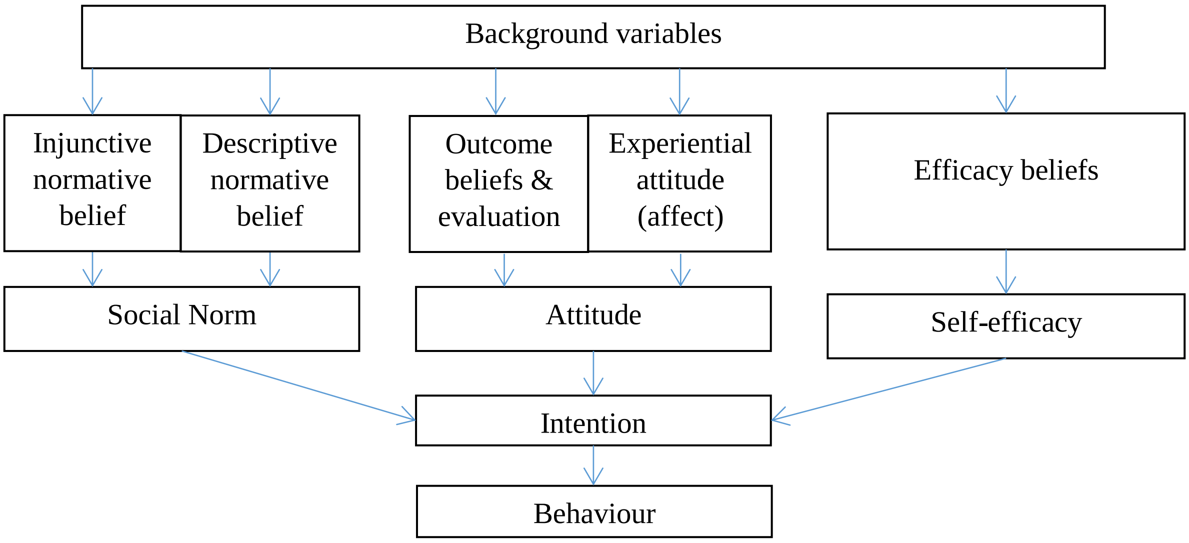

Figure 1: The Integrated Behavioral Model (adapted from Yzer, 2012:23)

Social norm describes the social pressure a person perceives with regards to certain behaviour (Montaño & Kasprzyk, 2008:71; Yzer, 2012). The *social norm* is based on two *normative beliefs*. An injunctive normative belief is the degree members of the social setting of the respective person are expected to (dis-)approve of a certain behaviour, while the descriptive normative belief is the belief whether or to what degree members of that environment conduct the behaviour themselves (Montaño & Kasprzyk, 2008:74; Yzer, 2012:24). The pressure through these normative beliefs is moderated by the individual *motivation to comply* with these norms. As an example, a person suffering from mental illness might feel that his/her family strongly approves of seeking help at a medical institution, which manifests as an injunctive normative belief supporting the intention-building towards seeking help. If persons in the social surrounding are believed to receive treatment at medical institutions for mental illness, the descriptive normative belief is in favour of seeking help as well. Thus, the *social norm* in this case tends to support intention-building towards visiting medical services, though moderated by the *motivation to comply* with these norms.

The *attitude* consists of two parts. On the one hand an evaluative component of attitude towards a certain behaviour, which is a function of three parts: the outcomes a person expects a behaviour to lead to, the *outcome expectations*, the person's evaluation of these, and the expected probability of those outcomes to happen (Montaño & Kasprzyk, 2008:74,75; Yzer, 2012:24). It can furthermore include an affective component, *experiential attitude*, which are the positive or negative feelings associated with a considered behaviour

(Montaño & Kasprzyk, 2008:74). Continuing the example given above, the person suffering from mental illness might expect to be relieved from symptoms of the illness when seeking help, which is a positive *outcome expectation*. However, the person might link negative emotional responses to seeking help, for instance if s/he does not like to interact with doctors. The *experiential attitude* hence does not favour seeking help. The overall *attitude* would be a mixture of these and other *outcome expectations* and feelings associated with seeking help.

The third main point constituting the intention of performing an action is *self-efficacy*. This is a person's perceived capability to conduct a behaviour regarding its own skills, resources, and expected environmental barriers (Ajzen 1991:182[3]; Yzer, 2012:24). In the given example, the *self-efficacy* could for instance be negatively affected by expected expenses that might exceed the ill person's resources.

A weakness of the application of the IBM for help-seeking is the fact that it aims to explain intention-building towards a specific behaviour at a certain point in time (Montaño & Kasprzyk, 2008). In contrast to that, help-seeking is generally seen as a process that includes several subsequent intentions and decisions before the concrete intention to pursue certain behaviour is developed, which the IBM as such does not grasp. Here is where a help-seeking process model as a complementary concept comes into the play.

5.2 The help-seeking process

Help-seeking behaviour, is the process of initiating and engaging with care, for instance therapy services (Clement et al., 2015:12). Due to varying circumstances, people take different considerations into account to decide if, where and how they seek help. A three stage model of help-seeking processes is, in various conceptualizations, generally accepted as accurate depiction of this process (Cornally & McCarthy, 2011; Eisenberg et al., 2009). For this study, the conceptualization of Srebnik et al. (1996), which heavily draws on the model developed by Goldsmith et al. (1988), will be the main foundation of the help-seeking model. Although it has been developed to analyse mental illness help-seeking, it holds the advantage of explicitly including help-seeking processes that depend on the parents of a child that is in need of help (Srebnik et al., 1996:210). Srebnik et al.'s (1996)

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[3] The work of Ajzen (1991) refers to the *Theory of Planned Behaviour*, which is integrated in the IBM as the main foundation (Montaño & Kasprzyk, 2008)

conceptualization furthermore resembles other models of help-seeking which have been developed for general health behaviour (e.g. Murray, 2005:481,482).[4]

The help-seeking model is depicted in Figure 2 below, and incorporates the stages of *problem recognition*, *decision to seek help*, and *service selection* (Srebnik et al., 1996).

Problem recognition is the first stage in the model. It describes the initial need of recognizing a condition or impairment as a problem, which starts the help-seeking process (Goldsmith et al., 1988; Srebnik et al., 1996).

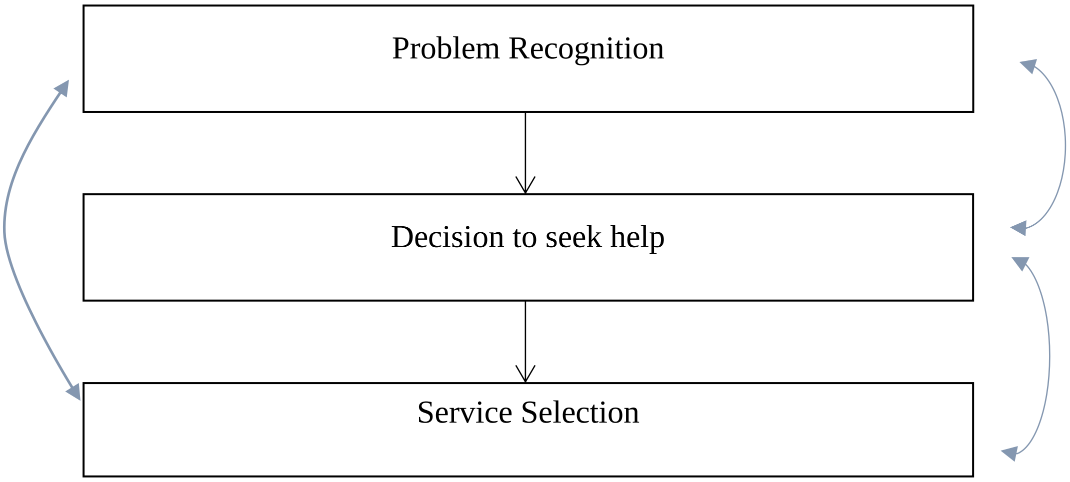

Figure 2: The three-stage help-seeking model (adapted from Cauce et al., 202:46)

The subsequent steps are the general *decision to seek help*, which is the principal decision to visit a help service for a condition, and subsequently the *service selection*, the latter referring to the more particular decision to visit a certain service (Cauce et al., 2002). The term *service* is defined openly and includes informal as well as formal services, such as official medical centres and traditional healers (Goldsmith et al., 1988).

In the course of seeking help, movement through these stages can be less straightforward as the model in an idealistic way might suggest. A help seeker might skip a stage or move back and forth between the stages, for instance looking for different sources of help (See blue arrows Figure 2) (Cauce et al., 2002:46). For this thesis, one pathway from problem recognition to the service selection will be called a “help-seeking episode”, whereas the entireness of help-seeking choices, including various movements through the steps in both “directions” will be termed “help-seeking career”.

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[4] Additionally, one of the major fundaments of Srebnik et al.s (1996) model, the model developed by Goldsmith et al. (1988), includes references to non-mental health issues.

Two weaknesses of the help-seeking process model need to be dealt with. Firstly, although the model acknowledges that steps can be repeated or skipped, the complexity of these dynamics is not modelled. The division into separat, (ideally) subsequent steps pervades all analyses based on this model, limiting the flexibility of the model towards complex, dynamic patterns (Pescosolido et al., 2013:454). Secondly, it does not give guidance on how and why external factors influence the process, though it does acknowledge evaluative decision relating to each stage (Broadhurst, 2003:346; Pescosolido et al., 2013:454).

However, the aim of this study is to understand the influence of stigma and EMs on help-seeking; not to grasp help-seeking processes in their nuanced entirety. Models always are a simplification of reality, and with regards to the exploratory aims of this thesis a simplified, straightforward approach has the opportunity to efficiently classify and evaluate influences on help-seeking rather than getting "lost in complexity". The second point of critique will be addressed using the IBM as a complementary framework, which will be described next.

5.3 The interplay of the models in this study: Weaknesses and complementary strengths

The study does not aim at creating a fully comprehensive inclusive model by integrating the two models into one, but rather uses the complementing characteristics of each. The intention is to grasp as much of the complex impact of stigma and beliefs as possible, not to fully explain the help-seeking process and behaviours of caretakers of children with ID. Thus, it is feasible to "pick" insights given by the various models, rather than doing a full analysis using one of the models, which would require to include various further aspects which impact the complex decision patterns in help-seeking. Relevant aspects of the models will, hence, serve as analytical tools guided by the themes identified in the findings and analysis section.

The IBM and the three stage model complement each other well in order to grasp the influence of stigma and EMs on help-seeking. Where the IBM lacks adjustment to the help-seeking as a process, the three stage model can stand in to better understand where stigma and beliefs intervene in the process. In turn, the weakness of the three stage model, the absence of concrete guidance on how the stages are influenced, clearly is the area of strength of the IBM as it aims at explaining intentions to conduct behaviour in detail. Using detailed evaluation models in the analysis of help-seeking processes is valuable to gain insight into how stigma and beliefs impact the help-seeking (cf. Broadhurst, 2003:346)[5].

Yet, the complementing strengths of the models require some considerations. The IBM aims at explaining behaviour at a certain point in time, from intention-building to the conduct of an action, whereas the three-stage model explains processes where, at the second step, decisions are linked to behaviour only in the final stage. Interestingly though, as Goldsmith et al. (1988:62) point out, each stage in the stage model consists of "(…) *processes,* (…) *that take an individual from considering an action to expecting to perform that action.*". Expecting to perform that action is no different to the *intention* to pursue behaviour as used in the IBM, with the distinction that at the second stage of the process model the link of the expectation to the actual behaviour is moderated by the stage of selecting a particular source of help. Thus, the intention building aspect of the IBM, including *social norm*, *attitudes* and *self-efficacy*, will be used to investigate the *decision to seek help* in the process model, leaving out a direct link to behaviour, as exemplified by the black arrows in figure 3.

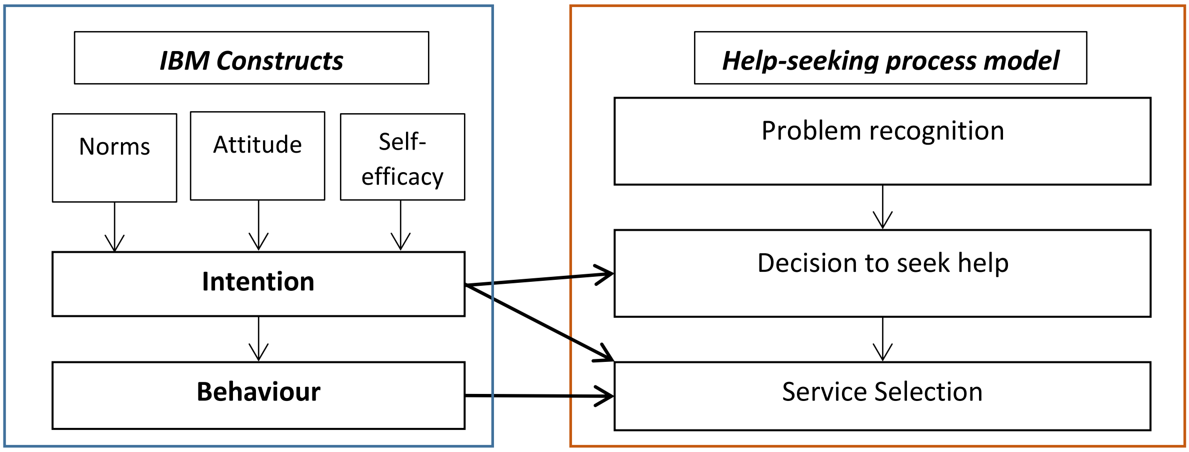

Figure 3: The interplay of the models in this study (simplified)

The IBM does not exclude that decisions can be based on previous decisions, for instance that a person initially only decides to seek help without selecting/deciding on a specific service, it just does not grasp it. Furthermore, in a real setting the help-seeking process is not just a process of two decisions (*decision to seek help*, and *service selection*), but rather consists of various decisions within the respective steps, that might furthermore be linked to behaviour (Srebnik et al., 1996:212). For instance, a general decision to seek help might induce behaviours such as the collection of information to find out about treatment options

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[5] Broadhurst (2003) refers to the Health Belief Model as a valuable means to support the help-seeking model, which belongs to the same family of models (*Expectancy-Value theories)* as the IBM (Montaño & Kasprzyk, 2008)

(Goldsmith et al., 1988:50). The IBM can thus fruitfully interact with the three stage model of help-seeking, giving hints towards the behaviours and behaviour expectations at the second stage.

For the third and final stage of the process-model, these difficulties do not occur. The *service selection* in the conceptualization of this study includes the decision (intention) to seek help as well as the actual behaviour, which mirrors *intention* and actual behaviour from the IBM (Eisenberg et al., 2009:2; see figure 2, 3).

6. Methodology

6.1 Worldview

The study adopts a pragmatic worldview, incorporating a critical realist influence. Pragmatism does not exclude the thinking in certain worldviews, but it aims to take another approach leading away from debates about the existence of realities and knowledge towards the means to collect data in order to support the understanding of a matter of interest as much as possible. The emphasis hence lies on the "what *and* how" (Creswell, 2009:11) to research and all means of data collection, if qualitative or quantitative, can be used and mixed if deemed beneficial.

Critical Realism as described in Zachariadis et al. (2013) acknowledges the existence of the "real", actual social structures. However, the process of knowledge production is potentially incomplete, where a researcher might be unable to fully grasp the objectively existing reality. Interpretative understanding of context dependent social phenomena is, hence, acknowledged in a similar manner to interpretivism. In critical realism, though, this does not exclude real existing social structures that form certain mechanism and influence the behaviour of persons (Zachariadis et al., 2013:857,858). Undoubtedly, issues of stigma and the devaluation of certain persons and groups of persons are such a social structure.

6.2 Case Study Approach

Following Stake's (2000, in Silverman & Marvasti, 2008:164) labelling of case studies, this thesis is labelled an *instrumental case study*, since the study investigates an illustrative case in depth, to explore how stigma and beliefs and influence the help-seeking of caregivers of children with special needs.

For this study, the caregivers of the Mukisa Foundation, a therapy and education facility based in Kampala, Uganda, serve as the case. The Mukisa Foundation is one of few facilities for children with ID in Kampala, it is free of charge and mainly targets caregivers with a low socio-economic background. The caregivers are hence a body of persons of rather low socio-economic status. They live in the bigger Kampala area, and have starkly differing ethnical backgrounds. The Mukisa Foundation has been chosen as a gatekeeping body in order to gain access to caregivers of children with special needs, who might otherwise be difficult to identify. Staff working for the Mukisa Foundation was furthermore considered to possess valuable information.

6.3 Mixed Methods Approach

Various reasons supported the choice to follow a mixed methods research approach. The interconnections of stigma, EMs, and help-seeking are likely to be complex and include different social contexts as well as individual perceptions and reactions to the behaviour of other persons. Using a mixed methods design has the potential to dig deeper into these complex relationships (Morse & Niehaus, 2009:13, 15).

Researching how stigma and EMs influence the help-seeking behaviour does on the one hand bring interest towards *how* the influence works. It is furthermore interesting to investigate the question of *how much*, relating to measurements of how much stigma and respective influences are perceived as well as how many of the caregivers were influenced. Information sought with respect to the latter two points can valuably be supported using quantitative measures. The quantitative means hence aim to give hints into the reach of the problem, whereas the qualitative inquiries serve as the means to grasp its depths (Chin, 2014:12). Since the study is exploratory in a largely under researched field, the mixing of both approaches moreover aims to grasp as broad information as possible (cf. Morse & Niehaus, 2009:13-15).

Following a concurrent embedded approach (Creswell, 2009:214), data was collected in one data collection phase. The emphasis of data collection and the analysis to follow lay on the qualitative section, using the quantitative data as supplementary information. Aiming to grasp the reach of the phenomena discovered in the qualitative inquiry, the quantitative data will not be interpreted on its own, but be considered with regards to the qualitative findings.

6.4 Data construction methods

Qualitative Interviews were conducted as semi-structured interviews with an interpreter for the local language (Luganda) present, using open ended questions followed by deeper investigations during the interviews referring to the information given by the participants. A preparation meeting with the interpreter has been held before the data collection started. Questions entailed in the qualitative interviews were derived from literature and personal observations as well as of observation from staff members of the Mukisa Foundation. The structure of the interviews evolved during the fieldwork period as seemed appropriate given the experience of the preceding interviews.

A quantitative questionnaire has been developed for this study as well, comprising of 31 questions and implementing a cross-sectional survey design (Creswell, 2009:146; cf. Appendix I). Questions include demographic data such as sex and household state as well as questions more directly aiming to measure the strengths of certain phenomena as perceived by the caretakers. For the latter ones, respondents were asked to express their answers in scores reaching from one to five. As an example, respondents were asked "*Thinking back, did you hesitate to join Mukisa because of the fear of the reaction of other people?*" and then to indicate the degree of fear on a scale from one to five, where one indicated "Not at all" and five "Yes, a lot", with the numbers two, three and four left without a label. The choice of questions was informed by the literature, and questions on stigma perception directly taken from established measures.

The first measure was taken from Baxter (1989), measuring the degree of distress of the caregiver about certain behaviour to the child and the caregiver due to the ID of the child. Baxter's (1989) scale has been transformed, and instead of referring to certain behaviour and measuring the distress caused by these, it was rather referred to "special behaviour" by others resulting out of the child's disability in general, and the distress caused by of this. Two further questions referring to stigma were taken from Chou et al. (2009), measuring how ashamed the family/caregiver him-/herself was about having a child with ID in the family. The questions were however put in the past tense referring to the time before the caregiver went to Mukisa, in order to be able to grasp if the attendance at Mukisa lowered this perceived shame.

Quantitative data directly referring to help-seeking often relates to the point of entry at Mukisa. The reason for this is to refer to a fixed point in time aiming to get information that is comparable between various caregivers. It would otherwise not be clear to which point in time the interviewees refer, as help-seeking is a process that evolves over time.

The quantitative questionnaires have been used in English as well as in a translation in the local language (Luganda), due to the multi-language environment of Kampala and Uganda. The translation has been done by the interpreter and was approved by Mukisa therapists who acted as research assistants to conduct the quantitative interviews.[6]

6.5 Sampling and Fieldwork

Sampling for the 24 qualitative questionnaires was initially done using a convenience approach. After interviews showed that visible impairments of the child yielded a higher impact of stigma, caregivers with children that have a visible ID were singled out following a purposive sampling approach (Creswell, 2009:178).[7]

The qualitative, semi-structured interviews were conducted at the homes of the interviewees in various parts of Kampala between January 12th and February 14th 2015 using an interview protocol (cf. Appendix II, III), and had a length of 45 to 90 minutes. Participants were mainly females from differing ethnic background with the age varying between 22 and 49 years. Additionally, two caregivers of children with ID that know about Mukisa but do not attend services there were interviewed with the intention of gaining information on why these persons refuse to seek help. The contact was established via caregivers of the Mukisa Foundation. A further two interviews with the director of the Mukisa Foundation and the social worker as “expert” interviews were done, aiming to get an “insightful outsider view”, and for triangulation purposes.

The quantitative data collection was conducted with the help of 6 therapists of the Mukisa Foundation. Caregivers participating in qualitative interviews participated in the quantitative data collection as well. A preparation meeting was held with the interpreter and the therapists in order to guarantee a feasible data collection. A total of 80 caregivers answered the quantitative survey, of which three were male and 77 female, with the age varying between twenty and forty-nine years (cf. Appendix IV). The sample was a convenience

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[6] Questions regarding the degree of shame were always posed in Luganda, due to the fact that the English word used (“ashamed”) might be considered inappropriate, while the Luganda translation of the word is culturally considered appropriate, according to the therapists/research assistants. It was not reported that the question posed in Luganda was not understandable for caregivers that do not use Luganda as their main language.

[7] The sampling has been done with the help of the social worker and the child care worker of the Mukisa Foundation, two employees that have a good insight into the living situation of the caregivers.

rather than a random sample. The reason for that is mainly that no up-to-date list of caregivers attending the Mukisa Foundation was accessible at that point, so that no meaningful parent population could be identified. Since 80 caregivers are a substantial part of the approximately 200 caregivers attending the Mukisa Foundation, findings do bear a substantial value at least with regards to the Mukisa Foundation.

6.6 Data analysis

All but one of the qualitative interviews were recorded, and notes taken during all of these. In one case a caregiver declined to be recorded. Notes were taken in this case and discussed after the interview with the interpreter to guarantee reliability. The records were transcribed in the aftermath of the fieldwork, coded and analysed following the three steps as described in Creswell (2009:185,186) using the software NVivo 10. The three steps with respective to this study refer to (1) organizing and preparing data for analysis by transcribing interviews, (2) reading through all data to get a general sense of the information, and (3) conducting detailed analysis using a coding process. Nine major themes were identified and subsequently analysed using the analytical frameworks.

Quantitative data analysis was conducted with regards to the procedure recommended in Creswell (2009:Chapter 8). Data was entered into SPSS 19, scanned for errors, and if found these were corrected. Analyses using SPSS 19 have mainly based on Mayers (2013). The quantitative data obtained will mainly be used in a descriptive way. Measures investigating the relationship between different variables will not be the focus, but used when relevant results could be found. Statistical means used for that are Kendall’s Tau-b and the Mann-Whitney U test (cf. Mayer, 2013; cf. Appendix V[8]).

In interpreting the data, this study uses already established research as described in the literature review in an interplay with data collected in an open, exploratory way that is not limited by the boundaries of an already established theory. It hence constitutes and abductive analytical approach (Meyer & Lunnay, 2013).

6.7 Validity and Reliability

Validity and reliability have been subject of discussion regarding mixed methods designs (Morse & Niehaus, 2009:20). For this thesis, reliability and validity in the mixed methods

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[8] Appendix V contains detailed explanations on the path followed to calculate the statistical data

design will be approached following Creswell (2009: Chapter 8-10), who uses the concepts for qualitative, quantitative and mixed methods.

To guarantee reliability in the qualitative data, detailed documentation of all steps in the qualitative research process was done (Creswell, 2009:190-192.), including the taking of notes and audio recordings. Using the software NVivo 10 for the qualitative analysis, detailed coding in combination with the use of memos aimed to prevent a gradual shifting of the meaning of codes (Creswell, 2009). Validity strategies followed included the triangulation of data by incorporating "expert" interviews as well as quantitative data, complemented by "thick description" (Creswell, 2009:191). The analysis, including qualitative and quantitative data analysis, furthermore incorporated discussions of complex findings and the presentation of data that might contradict the themes identified (Creswell, 2009).

The quantitative data mainly supports the qualitative data. The quantitative approach mainly aimed to yield descriptive data. Reliability measures included pilot testing of the questionnaire (Creswell, 2009:150). In mathematical terms reliability can demonstrated for the stigma scale used by Chou et al. (2009). It shows good reliability and good construct validity (Werner et al., 2012:760). It is important to state that the scale was in this thesis not used as a *scale* as such to give an overall stigma measurement, but rather the questions singled out to grasp the dimension the respective question referred to. Validity is guaranteed by means of triangulation with literature and qualitative data.

6.8 Ethical considerations

To reach up to ethical standards, measures to guarantee the participants' dignity, privacy and safety were taken, based on the checklist presented in Mikkelsen (2005:342), which was imperative for this study since it investigates a sensitive topic (cf. Scheyvens et al., 2003:140). One of the main points was to approach participants in a humble way, making sure they would at all times feel comfortable and not coerced to participate. This was necessary especially since I am a male white person visiting the participants at their private homes. This has moreover been important as participants might have considered me to visit them on behalf of the Mukisa Foundation, which would have put me in a position of power relative to the caregivers.

An informed consent form was read out for all of the frequently illiterate caregivers, making sure these were aware of the reason of my visit and the voluntary participation in the interviews and audio recordings (cf. Appendix VI). Anonymity was guaranteed and no data given to the Mukisa Foundation. Participants will be referred to using a number code in this thesis, to reach up to the guaranteed anonymity. To keep the source of information anonymous, names contained in the quotes will replaced by a placeholder, except for the director and the social worker of Mukisa who agreed on being mentioned as such in this thesis.

6.9 Limitations

The main limitations arise due to the sampling of the participants, and the case study approach. A non-random sample for the collection of the quantitative data does not allow generalising the findings statistically to a wider population (Creswell, 2009: Chapter 8). Furthermore, the fact that with the exemption of two participants the caregivers belong to a group that did seek help at the Mukisa Foundation, they are likely to form a special group. The perception of stigma as influencing the help-seeking behaviour might be different in this group compared to persons that did not seek help. It is hence important to be careful generalizing from the data collected. Many questions, in quantitative and qualitative data collection furthermore referred to the past, relying on memory that can be distorted.

Due to the concurrent embedded approach, quantitative data could not be collected based on the findings of the qualitative data, that it was designed to support. Questions asked do thus often not grasp exactly the same themes as have been identified from the qualitative data. Questions from the quantitative questionnaire related to themes identified can thus give hints towards the quantitative distribution of the identified themes in the sample, but often do not catch exactly the same information.

7. Analysis

The analysis section of this thesis contains six parts. It starts showing that children with ID and their caregivers actually experience stigma, which is a basic precondition to analyse the influence of stigma. Furthermore, the character of findings will be explained which is necessary in order to understand the results of the analysis. After that, the analysis of themes identified in the data starts, order by the constituents of the IBM: *Background variables, social norms, attitudes and self-efficacy.*

7.1 The precondition: Stigmatization of persons with ID

Although the degree of stigma itself is not the focus of this study, it is necessary to mention that stigmatizing attitudes and respective behaviour against persons with ID and their caregivers are widespread. The following statement summarizes the stigma experience of many caretakers in a sharp way, as translated by the interpreter:

> "(…) *they could accuse us, mother and child, and I could cry on and on. (...) some could even tell me: '"why doesn't* [child] *pass away and at least get rid of her?!'"* (Interview 1.1)

This statement is a rather drastic one, though no exemption. Caregivers frequently reported negative behaviour towards them (associated stigma) and their children (enacted stigma) based on fears of contagiousness and traditional beliefs about the causation of intellectual disabilities. The finding is supported by the quantitative data as shown in figures 4 and 5.

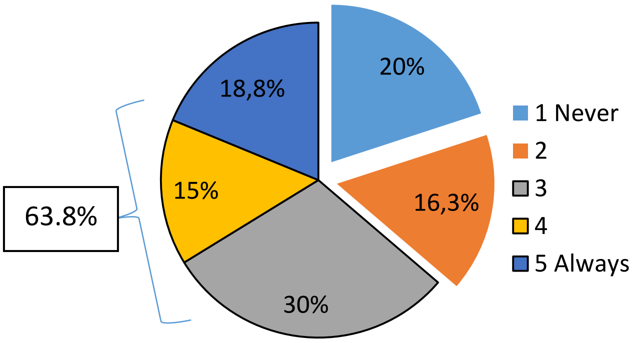

Figure 4: Caregivers' perceived frequency of being treated differently due to their child with ID (cf. Appendix I C.1. (questionnaire), VII.1)

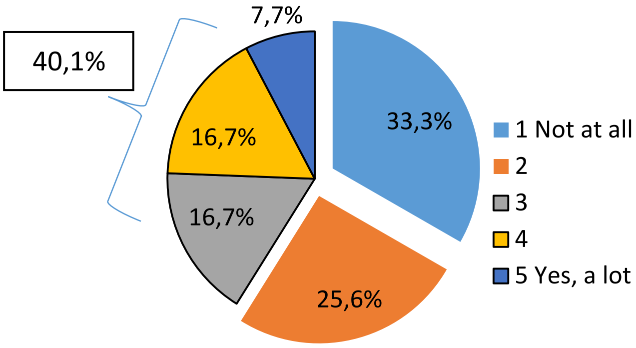

Figure 5: Caregiver's distress about being treated differently (cf. Appendix I C.1.a., VII.1)

63.8% of caregivers in this study reported to be treated differently due to their child with special needs on a moderate (score 3) to high (score 5) frequency. Additionally, 40.1% of the caregivers reported a moderate (3) to high (5) distress due to this treatment. They hence frequently perceived negative, distressing behaviour towards them due to their child's impairment, showing a discriminating aspect as entailed in the stigma concept[9], manifesting in this case as *associated stigma* towards the caregivers. Similar findings can be seen regarding the perceived stigmatization of the respective child (cf. Appendix VIII).

For the upcoming analysis it is furthermore important to show the stigmatizing character of traditional beliefs. These are beliefs that attribute the cause of ID to violations against

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[9] As discussed in 2.3.

traditional norms or the use of witchcraft (cf. McKenzie et al., 2013). A norm violation can for instance be having sex outside of marriage.

In one exemplary case, several persons in the social environment of the mother of a child with intellectual disability, including the father of the child, avoided mother and child and refused to give any support due to beliefs in traditional causes:

> "*They thought I did something wrong to somebody who cursed me, or maybe I did an abortion before. But, after realizing it's a medical problem, some came back and started helping.* (Interview 05.3)

Traditional beliefs thus not only show the attitude of seeing children with IDs as a negative deviance from the "normal", being the "spawn" of a violation of norms, or witchcraft. Following the quote and statements of other caregivers and the director of the Mukisa Foundation, these beliefs are the root causes of offending, discriminatory behaviour towards caregivers and children with intellectual disability.

7.2 The character of findings presented in this thesis

All findings described in this thesis are factors that work in an interplay with corresponding and counteracting factors, which vary between individuals. As an example, the urgent desire to find help can affect the help-seeking careers[10] and could counter other factors speaking against seeking help, as in the following example:

> Question: "*Why would they come to Mukisa if they think the cause is witchcraft, knowing that Mukisa does not treat that?*"
>
> Caregiver: **"***Looking for solution*! *Like, you can know 'this is the reason for why my child is like that, but is there something I can do to make things better?!' But some of them will come and then they will think 'Mukisa is not even addressing the curse issue that I wanted', then they stop coming. So it all depends on the parents.*" (Interview with the director of the Mukisa Foundation)

Quantitative data supports this, showing that help-seekers decided to visit the Mukisa Foundation despite the fact that they hesitated for various reasons such as the belief that the Mukisa Foundation might not be able to help the child (cf. Figure 8)[11]. Factors presented in the analysis to come might hence influence intention-building, but do not necessarily result in avoidance of help-seeking, or actually visiting a service.

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[10] The various pathways of seeking help (cf. 5.2)

[11] This will be discussed in more detail in section 7.5.2.

7.3 Background variable: Public stigma and lack of knowledge

Public stigma can have forms that the IBM grasps as *background variables* regarding the intention-building towards help-seeking. This effect will be discussed more detailed in the sections on the three constituents of intention-building. Moreover, another important stigma and belief related *background variable* influencing intention-building is recognizable in the data:

> "*I had never seen a child with special needs until I was 19 when I joined medical school. You do not see these children unless you have them in your family. People hide them so far away that you never know.*" (Director of the Mukisa Foundation)

> "*They don't reveal easily to you 'I have such and such a child, I went to such place'. They tend to keep those problems to themselves, not telling anyone.*" (Interview 09.1)

Persons with ID are virtually invisible in the public sphere, neither seen nor talked about. As we can see in the quotes, knowledge on intellectual disability in the Ugandan society is scarce. Many persons do not know that persons with ID exist, and if they happen to learn about it because there is a case in the family, it is often not talked about. Assuming caregivers who are ashamed of having a child with special needs are reluctant to talk about it, the quantitative data supports this point. The variables derived from the family stigma scale of Chou et al. (2009) demonstrate that a substantial part of caregivers of the sample, 22.6%, were ashamed of having a child with intellectual disabilities to a moderate (score 3) to high (score 5) degree, prior to visiting the Mukisa Foundation (Figures 6). 37.5% reported feelings of shame within their families due to this reason (Figure 7).

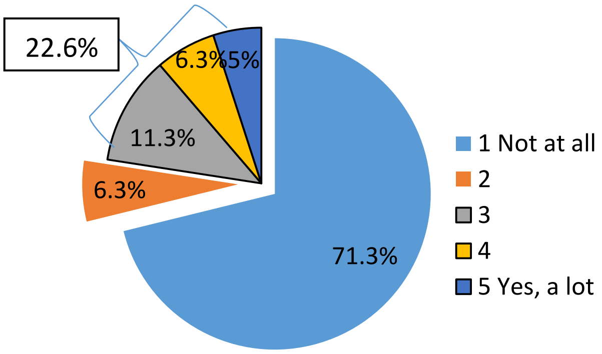

Figure 6: Caregivers' shame of child with ID before joining the Mukisa Foundation (cf. Appendix I C.4., VII.2)

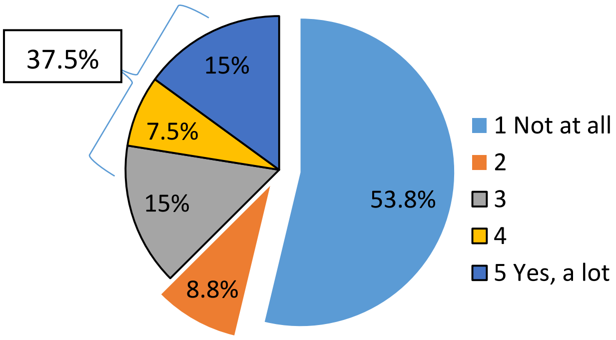

Figure 7: Families' shame about child with ID before joining the Mukisa Foundation (as perceived by the caregiver; cf. Appendix I C.3., VII.2)

The lack of knowledge about the mere existence of intellectual disability plays a role in misperceptions of intellectual disabilities (such as certain beliefs and resulting stigma), and avoiding talking about it clearly shows to hinder the flow of information of treatment options:

> Question: "*What was your first thought when you heard that the size of the child's head is unusual?*"
> Answer: "*I thought the child was bewitched.* (…) [Because] *I had never seen them before."* (Interview 05.2)
>
> "[I]*t is always good to give yourself to people, if you don't... (…) That's why you end up not knowing/getting the information from outsiders*" (Interview 02.1).

If intellectual disability is a topic that frequently is avoided, it is difficult for caregivers to find out what the difficulties of the child are, and if and where they can find help. The latter is the case even if a caregiver was open about the special needs of the child, since persons in the social environment are not likely to know what to do. Stigma and false beliefs are hence a result and a prerequisite of misinformation, as they prevent caregivers (to some degree) from talking about intellectual disabilities, leading to nescience in public, which in turn reinforces misperceptions and stigma, with consequences for help-seeking.

The absence of public knowledge manifests as a *background factor* as described in the IBM, as it influences stigma and beliefs, which in turn influence intention building through *social norms, attitudes* and *attitudes*, which will be discussed in more detail in the following chapters. Additionally, the absence of knowledge about support services prevents the process of intention building from the outset, since visiting certain support services might not even be considered due to a lack of knowledge of their existence.

7.4 Social norm: Stigma manifestation

In the following two sub-sections, the influence of the discriminating (stigmatizing) attitudes that manifest as social norms towards certain caregivers will be discussed.

7.4.1 Help-seeking discouragement

Several caregivers reported other persons to discourage them to seek help:

> *Caregiver: "Where I work, they tell me words of discouragement. It's like: They tell me 'you're just wasting your time', the baby is already lame, so you just don't need to put in any effort."* (Interview 03.1)
>
> Caregiver:" *They think the child cannot get better and I'm just wasting my money on the child."*
> Question**:** "*So, do they see this child has less value than the other children?"*
> Caregiver: "*That is how they think.*"(Interview 05.2)

This discouragement is based on disbelief in the potential of the child with ID to improve. In addition to that, financial cost-benefit assumptions impact the process, which is likely to be intensified by the poor socio-economic conditions of most of the caretakers.

Arguing against seeking help for a child with ID referring to a perceived lack of potential for development of the child and its lower value is a form of discrimination and manifests as *public stigma* (Bos et al. 2013). In terms of the IBM an influence on *attitudes* as well as the manifestation as a *social norm* must be considered. On the one hand, caregivers might fear negative reactions towards them when seeking help as others disapprove of them, which can be seen as negative *outcome expectations*, corresponding to *attitudes* in the IBM. On the other hand however, the qualitative data, such as the latter quote, indicates that caregivers did in this case not fear a certain reaction such as harassment, but simply were aware of disapproval of others prior to (and during) seeking help. Others' opinions as social pressure play a role here rather than concrete expected actions of others in case the behaviour is performed (cf. Montaño & Kasprzyk, 2008:71,78,79). The *public stigma*, acted out as a discriminative discouragement to seek help for the child in this case manifests as a *social norm* towards certain caregivers, rather than as a background variable influencing the *attitudes*. As these caregivers perceive the environment to disapprove of seeking help, it is an injunctive normative belief negatively affecting intention building with regards to seeking help.

Interestingly and importantly, the disapproval of seeking help for the child with ID by others can be subject to change. Caregivers perceived more appreciation of their help-seeking by their environment when improvements in the children were visible. The following dialogue with the parents of one child illustrates this[12]:

> Question: "*So, does that mean you would say for many people it's important to see* [child] *is getting better; they become less critical?*"[13]
>
> Answer: "*Yes*. (…) *I have a step brother who one time asked us why we spend all that money on the child. But recently he passed by and saw a change in the child, and he was really interested in it"* (Interview 07.2)

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[12] It is important to know that in this interview the parents described high expenditures for treatment for the child with ID. The "money" that talked about refers to these expenditures.

[13] The question refers to what the caregiver expressed earlier in the interview. It is hence more a question for clarification and thus not a leading question as one might assume when reading it in an isolated form.

The described evolution in other persons' attitudes is likely to reduce the impairing effect of the perceived social norm on intention-building over time, since the disapproval of others weakened over time for several caregivers interviewed.

Relating this *social norm* to the help-seeking process, it is clear that the discouragement of seeking help influences the second level of the process, the *decision to seek help*, since some persons interpret the act of seeking help as being disapproved by others. Having in mind that help-seeking is a process that is repeated in the career of help-seeking, possible observable improvements in the child's condition might reduce the perception of this norm in later stages of the help-seeking career. This social norm perception could hence become more favourable for intention building in further help-seeking episodes.

Due to the fact that the caregivers eventually did come to Mukisa, this social norm obviously did not prevent the interviewed caregivers from seeking help, and data does not show if help-seeking has been delayed due to this norm. *Attitude*, other possible *social norms* or a *low motivation to comply* might have outweighed this norm.

7.4.2 Pushing for traditional help

While some caregivers are, or have been, discouraged to seek help for their children with ID, others have been pushed to seek specific help. Caregivers were frequently influenced by their social surrounding to seek help at traditional healers treating illness as caused by supernatural events such as witchcraft.

This might happen with the good intention of improving the condition of the child. Yet, the background of this intention is according to the interviews the stigmatizing traditional belief:

> Question: "*You said people were pushing you to seek traditional help. Did you think that these people would not find it good that you go to Mukisa?"*
>
> Answer: "*Even up to today, people ask why I really went to Mukisa.*"
>
> Question: "*These people want you to go to a traditional healer because they think it's witchcraft or demons...?*"
>
> Answer: "*Yes*" (Interview 02.1)

Several caregivers expressed to have felt coerced to visit a traditional healer. Others have left the decision of where to seek help to others in order to avoid confrontation, for instance to elders in the village, showing an observable impact on the decision making. In sum, 33 out of the 80 caregivers (41.3%) contributing to the quantitative data had visited traditional healers (Appendix IX), showing these visits to be a quite common choice in help-seeking.

How many of those felt coerced by their social environment to pursue this path was not recorded, though.

Similar to the previous point, this influence on the help-seeking shows an *injunctive social norm* perceived by some caretakers, which is in favour of visiting traditional healers but disapproves of other types of help[14]. Additionally it is likely that visiting a traditional healer constitutes a *descriptive norm* as well , since this is a common way of addressing intellectual impairments as shown in the quantitative data. However, for constituting a *descriptive norm* caregivers must have some kind of awareness of how others caregivers deal with the disability of the child, which conflicts with the frequent reluctance to discuss intellectual disability outside of the family. Hence, only persons that are in touch with caregivers of children with special needs who visit traditional healers are likely to perceive this *descriptive norm*.

The impact this has on the help-seeking process is relatively clear. The influence does not prevent help-seeking in general, but rather influences intention building regarding the *service selection* towards traditional healers, corresponding to the third stage in the help-seeking process.

7.5 Attitudes towards help-seeking: the influence of stigma and beliefs

7.5.1 Influences of causation beliefs

The three different causation beliefs (Christian beliefs, traditional beliefs, medical beliefs; cf. 3. Literature review) were present among the interviewed caregivers, and show an influence of explanatory models (EMs). As shown in section 7.3, the lack of knowledge is likely to influence these beliefs as a *background variable.* Data shows that the beliefs could be mixed, hence, having a certain belief did not necessarily exclude the other beliefs. Especially religious beliefs of causation did usually not stand alone, but were tied to medical ones, and more of an abstract nature, while the direct causes in these cases were still often attributed to medical factors. In general, the differing belief systems led to a variety of treatment choices, ranging from traditional healers, to religious authorities, to "western-style" medicine.

A connection between the causation beliefs and the selection of services attended was found:

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[14] An influence an influence of this phenomenon on *attitudes* will be discussed in the *attitude* section.

> Question: “*Did you ever have this idea of traditional causation? Things like witchcraft or curses?*”
>
> Caregiver: “*At times* (…). *We have thought about that. We even went for some treatment somewhere* [referring to traditional healers]” (Interview 09.1)

> Caregiver: “*I think the fever that attacked* [child] *caused the disability.* (…) *So I first went to Mulago* [Hospital].” (Interview 02.1)

> Question “*Why didn’t you try out the traditional healer?*
> Caregiver: “*I never went there, because I never believed in that. And I knew where the problem came from.”* (Interview 02.2; referring to medical diagnosis)

In terms of intention building as described in the IBM, the different beliefs people held influenced their *attitude*. Persons believing in supernatural causations expected to achieve better outcomes visiting traditional healers since these address supernatural influences, while persons assuming a medical cause had higher *outcome expectations of* visiting “western” medical support services than other services. The different beliefs thus influenced the *attitude* in a way that favoured intention building towards a treatment choice that addresses the respective believed cause. Beliefs in this case are manifested as *background variables*, which affected *attitudes* through *outcome expectations*.

Importantly, the explanatory models were subject to change. Some caregivers noted that the push for traditional healers as described in 7.4.2 made them doubt beliefs in a medical causation of the impairment of the child, influencing the help-seeking behaviour, as described among others in the following quote:

> “*They told me someone might have bewitched the child.* (…) *I do not belief in that. But when the friends told me about that, I went to church to pray for my child.*” (Interview 08.1)

Medical diagnosis had a similar effect, and showed to permanently exclude traditional pathways from help-seeking:

> Caregiver: “*I finally realized that it was not witchcraft.*”
>
> Question: “*How did you realize that?*”
>
> Caregiver: “*I went to the CT scanner*[15]*, I realized that the brain of the child had a problem*” (Interview 07.1)

These findings indicate the possibility of changes in beliefs through stigmatizing attitudes and explanatory models of the social surrounding, or medical personnel. In this case they are

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[15] It is important to be aware at this point that the CT scan was done because the child was suffering from cerebral Malaria, not to investigate the child’s developmental delays.

indirectly influencing intention building as *background variables* through their impact on *outcome expectations* regarding differing treatment choices, which in turn influence the *attitude* factor.

Disappointing results of one school of medicine influenced beliefs and subsequent choices as well.

> Question: “(…) *but you went to the traditional healer then?*”
>
> Answer: “*Yes”*
>
> Question: “*Do you still believe in these* [supernatural causation] *beliefs you had at that point?*”
>
> Answer: “*I believe I never had such issue connected to it*”
>
> Question: “*What made you change this belief?*”
>
> Answer: “*I never got what exactly I wanted from them. I went there, I went to church, and I also left church because I never got where I wanted. Now I’m only strictly on the hospital.* (Interview 03.1)

After unsuccessfully trying out one type of service, caregivers often lost their faith in this kind of help. The *outcome expectations* related to traditional healers were hence lowered, negatively affecting the *attitude* towards visiting respective services. Caregivers then often turned to other kinds of help, sometimes with a delay of several months or years.

Regarding the latter quote, disappointing results of a service could directly affect the causation beliefs and subsequently the *outcome expectations,* as the caregiver lost the belief into supernatural causations. This finding can be interpreted as an exclusion procedure: caregivers seek help corresponding to their belief, and if that certain kind of help does not work, they lose faith in it, and to some degree in the corresponding belief. They might then turn to other kinds of help. Data however was indifferent if the reduced belief in the former cause, for example in traditional healers, after unsuccessful treatment did also lead into stronger belief into other causations, for example in Western medicine. The expected outcomes of other types of help might in the light of the desperate need to find help also simply be more attractive relative to the now more negative attitudes towards the previous source of help, rather than that a new causation belief was adopted.

As *outcome expectations* and subsequent treatment choices were tied to beliefs, which in turn were subject to change, help-seeking careers were fragmented into various different episodes. A caregiver either visited a medical service or a traditional healer for a certain period of time corresponding to the respective belief held, but not during the same period of time. None of the caregivers interviewed for this study visited traditional healers for their children while visiting the Mukisa Foundation, but 41.3% of caregivers in the quantitative sample did do that at some point (cf. 7.4.2; Appendix IX), showing a considerable importance of traditional beliefs and related treatment. Seeking the help of religious authorities to pray for a child with ID however was frequently pursued alongside seeking western medical help, corresponding to the links between religious and medical causation beliefs as described at the beginning of this section. Both findings are mirrored in the following quote:

> Question: "*Did you do these both, the traditional things and the church related to the child, did you do that before you came to Mukisa, or at the same time?*"
>
> Answer: "*The traditional healing stuff was before, and the church was after I had joined Mukisa.*" (Interview 03.1)

Following these findings, the impact of varying causation beliefs manifests on the third stage of the help-seeking process model, the *selection of a specific service*, after a decision to seek help has already been made. When the results of that service were disappointing, the *service selection,* the third stage of the help-seeking model, has often been repeated influenced by the reported changes in *outcome expectations*, sometimes with the mentioned delay, though. Depending on the individual, the delay has sometimes also been caused by letting go of the idea of seeking help in general. In that case, when restarting to seek for help, caregivers first re-decided to seek help, the second stage of the help-seeking model. Assuming that witchdoctors are evaluated as an ineffective help service, the described phenomenon is likely to delay visits to potentially effective help services.

7.5.2 Beliefs about the potential of the child

EMs and stigmatizing attitudes did furthermore play a role in the help-seeking career connected to beliefs in possible improvements of the respective child. Some caregivers expressed to have had a lack of belief that their child would ever improve even before seeking professional help for their child, similar to the social environments which sometimes discouraged seeking help as discussed above. This disbelief was often based on or mixed with the assumption that there were no services that can support children with developmental delays, or the belief in uniqueness of the condition, showing the influence of the previously described *background variable* of lack of knowledge:

> Question: "*Before you went there* [the hospital], *were you afraid of something?*
>
> Answer: "*I thought I was the only one like that. I had lost hope. I thought* [child]

> *would never sit, or do anything*." (Interview 05.1)

Closely related to the discussion on different causation beliefs under point 7.5.1, the described disbelief in positive development could also develop over time. The following conversation took place with the grandmother of a child with ID (the principal caregiver), regarding the biological parents:

> Caregiver: "(…) [T]*hey used to take her to the hospital. When* [child] *came to two years, they took her to this local traditional stuff. And they realized it was not working. So, that's why they decided to let go of the child. They lost the morale*" (Interview 02.1)

After trying out different kinds of help, caregivers could at some point simply lose belief there would be any way the child could improve, similar to the exclusion procedure as described for the connection between causation beliefs and help-seeking.

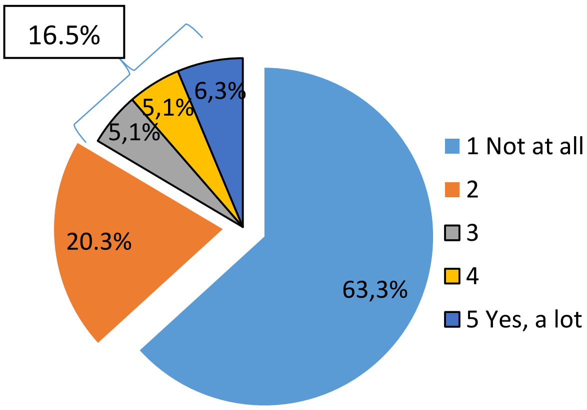

Figure 8: Hesitation to visit the Mukisa Foundation because of belief they would not be able to help (cf. Appendix I E.6., VII.3)

Interestingly, one of the two interviewed caregivers who refuse to seek help justified the refusal with the disbelief in the child's improvement after several unsuccessful therapies[16].

Hesitation out of disbelief in help is also captured in figure 8. 16.5% of the caregivers interviewed, a minority but still a substantial share of the sample, hesitated to a moderate (score 3) to high (score 5) degree to visit the Mukisa Foundation due to the belief it might not be able to help. The data however does not grasp the exact reason for that belief, for instance if it was related to disappointing experiences with other services. Still, qualitative and quantitative data indicate that the disbelief in effective treatment tended to spur reluctance to seek or continue visiting support services (cf. Goldsmith et al., 1988:55).

The wrong conceptualizations of the intellectual disabilities could furthermore outlast contact with medical personnel, showing repercussions of the culture of the health system and prolonging the effect of misinformation:

> "*The children are not diagnosed and even if they are, the doctors do not explain.* (…) *And so the parents have no idea what the condition of their child is.*" (Director of the Mukisa Foundation)

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[16] This caregiver however refused to be recorded, so a direct quote is not accessible.

Lack of belief in improvement of children with ID could be described as an *explanatory model*, since it is a belief about the characteristics of the condition of the child. These beliefs can furthermore be seen as stigma against persons with ID. In cases where timely treatment for a child has not been pursued due to this belief, it is a prejudice that led to discriminating behaviour (the refusal to seek help) and manifests towards the child as *enacted stigma*. Yet, data does not contain information if the disbelief in improvements in these cases has been directed against persons with ID as a group, which is one of the constituents of the stigma concept.

In terms of the IBM these beliefs prevented positive *outcome expectations*, since caregivers did not expect an improvement in the child’s condition regardless of service. Rather than being a *background variable*, the beliefs in this case directly constitute *outcome expectations. Attitudes* were hence negatively influenced with regards to visiting services making the *decision to seek help*, the second stage in the three-stage model, less likely to occur. When the belief of the child’s inability to improve developed over time, the positive *outcome expectations* were gradually lowered. Thus, the further the help-seeking career progressed, the more negative the *attitude* towards help-seeking became, affecting further help-seeking episodes and decisions.

7.5.3 Misconceptualization of the permanent character of intellectual disabilities

Misconceptualizations of the permanent character of intellectual disabilities and a devaluation of (slow) progress in the child’s capabilities affected help-seeking as well. According to the director of Mukisa, evaluations of certain services are frequently related to unrealistic expectations regarding the improvement of the child:

> “*So most people that come to us will be looking for cure: ‘if I come to Mukisa maybe my child will get fine’, you know. And then because of their understanding of disability they don’t understand that this is something that is permanent. So they come and try the therapy, and then they realize it’s not working as fast as they would like, then they stop coming. So the attitudes and the belief-system are always very important.*”

Many interviews supported the point of disproportionately high expectations of services, since caregivers were frequently hunting for a “cure”. The *background variable* “lack of knowledge” prolonged by unclear diagnoses as discussed above (cf. 7.5.2), is likely to play a role in this as well.

The finding shows that false conceptualizations of the impairment of the child (the explanatory models) constitute unrealistic *outcome expectations* regarding the effect of support services. If these expectations are not fulfilled, the *outcome expectations* (at least) for the service that is visited at the respective point in time are perceived more negatively to what the caregiver originally thought could be possible. The *attitude* towards the service visited at this point in time becomes less favourable, which can trigger caregivers' decisions to drop out of care. This finding is interrelated with caregivers giving up on certain kinds of treatment after unsatisfactory visits, as discussed under 7.5.2, since negative evaluations of the improvement of the child during therapy are sometimes based on unrealistic *outcome expectations*. Relative to those, therapy must always be considered ineffective by the caregivers, which in turn can lead caregivers to turn away from services. The phenomenon influences treatment compliance (as in the latter quote), which is difficult to grasp with the help-seeking model, since this only reaches up to decision to select a service. However, interpreting the continued visit at a support service as a repeated selection of it, the decision to not visit this particular service anymore corresponds to the *service selection* stage. In addition, it affects further help-seeking episodes as well through its potential to spur frustration about help seeking.

7.5.4 Fear, shame and harassment

The fact that seeking help entails to disclose the child's ID in public can further influence the help-seeking intention (cf. Kendall-Taylor, 2006:113). Caregivers who keep the ID of the child secret (at least to certain parts of their social surrounding) might be afraid of disclosing the ID of the child simply by going out in public to attend a service. One interviewed person for instance claimed:

> Caregiver: "*Most of the help we got when* [child] *was younger from people who could come and could see the child, because we used to keep her indoors*"
> Question: "*Why didn't you want to take her outside?*"
> Caregiver: "*We at times had that fear people might see her"* (Interview 09.1)

Additionally, when asked about if and why they think other people with children with ID might not seek help for their child, several interviewees expressed their belief, and sometimes experience, that many caregivers were too ashamed to disclose the disability of their child in public.

In a similar way, visiting a special centre reveals the condition of the child to others, which can be seen as a problem by caregivers. This can implicitly be seen in the following quote of the caregiver who has been reluctant to disclose the disability of the child:

> Question: "*Did you fear the reaction of other people when you go to Mukisa because it's an institution for special needs'?"*
>
> Answer: "*No because at times they don't ask. Some are illiterates, they can't read the batch* [on the Mukisa uniform for older children], *and they don't go there. They can't recognize easily* [child] *has special needs.*" (Interview 09.1)

The quote furthermore includes a reference to the geographical location of the Mukisa Foundation. The location has in this and other cases shown to be a subjective advantage for certain caregivers as it is less likely that their social settings become aware of their children's disabilities by visiting services for children with special needs if these are located in an area that does not belong to the caregiver's neighbourhood.

Quantitative data does not grasp the reluctance to disclose the ID of the child as such, but it does show that many caregivers and their family were ashamed to a substantial degree[17], as described before in figures 6 and 7, showing stigma within the family (Chou et al., 2009). Assuming that families and/or persons that are ashamed of their child with ID are wary of disclosing the ID by seeking help, this reluctance might have affected a substantial part of the caretakers of the Mukisa Foundation during the various help-seeking episodes. Additionally, the perceived shame has been subject to change over time. Table 1 shows that 71.3% of the caregivers felt less ashamed since they started visiting the Mukisa Foundation. This shows the potential that the impact of shame on help-seeking decreases over time. Why the level of shame decreased is not captured in the data, though. One factor might be the "western" medical diagnosis that caregivers receive regarding their child at Mukisa, which counters stigmatizing traditional beliefs (cf. 7.5.1).

		Frequency	Valid Percent
Valid	less ashamed	57	71,3
	No change	22	27,5
	More ashamed	1	1,3
	Total	80	100,0

Table 1: Change of perceived shame of caregivers since visiting the Mukisa Foundation (cf. Appendix I C.6.)

Moreover, caregivers expressed more concrete fear related to the previously discussed harassment that they might become subject of (cf. 7.1). Caregivers have been wary to decide to visit a service with the child as this act has the potential to lead to harassment, even if the ID is not hidden in everyday life:

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[17] 22.6% indicating a score of 3-5 for the respective variable.

> Question: "*Do you fear that people might react negatively if you go to Mukisa?*"
> Answer: "(…) *Sometimes those taxis from Kosovo* [area where the Mukisa Foundation is situated] *could have women that could really talk ill about our children.*" (Interview 10.1)

Similar to the decrease of shame over time, caregivers reported to "get used" to harassment, thus potentially lowering its effect over time:

> "*They could accuse us, mother and child, and I could cry on and on. But now I'm content, I'm used to it. I don't cry anymore.*" (Interview 1.1)

Quantitative findings illustrate the fears of help-seeking specifically for visiting the Mukisa Foundation. Figure 9 shows that more than 20% of the caregivers had moderate (score 3) to high (score 5) fear of receiving increasing negative reactions from others when visiting the Mukisa Foundation, though the variable does not itemize the concrete reason for this fear. Hence the fear of disclosure of the ID as well as the fear of harassment might be incorporated here. While this shows that a majority of caregivers did not have this fear, a substantial minority did have it. The level of hesitation (figure 10) because of the fear of other people's reactions is lower, though. Around 11%, still more than every tenth persons doing the quantitative questionnaire hesitated to a moderate (score 3) to high (score 5) degree to visit the Mukisa Foundation due to fears of the reaction of other people.

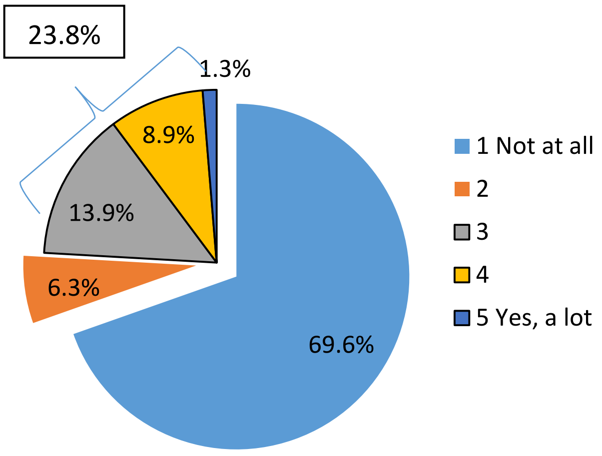

Figure 9: Perceived fear of increasing negative reaction of other people when visiting the Mukisa Foundation (before the first visit; cf. Appendix I E. 1., VII.4)

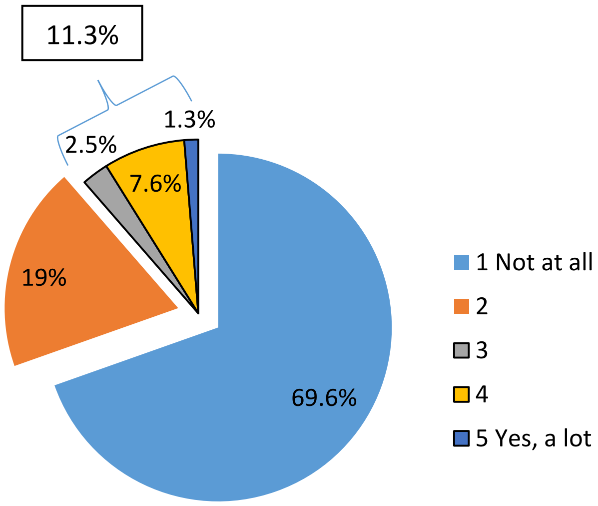

Figure 10: Caregivers' hesitation to visit the Mukisa Foundation because of fears of other people's reactions? (Before the first visit; cf. Appendix I E.3., VII.4)

Fearing the reaction of others does hence not necessarily lead to similar levels of hesitation. This is supported by correlation measures between the variable of fears of increasing negative reactions when visiting the Mukisa Foundation and hesitations to visit the Mukisa

Foundation due to that. A Tau-b value of 0.403 indicates a medium effect size (Mayers, 2013: 121; Pallant, 2013:139; cf. Appendix V.2).[18] This shows on the one hand that higher levels of fear tend to lead to higher levels of hesitation, but the relationship clearly is moderated by other factors. Various factors, such as the desperate need to find help might interfere in this relation. In addition, coping behaviours that are put in place due to the fear of negative reactions could have played a moderating role.

> *"Initially people could laugh at me and the baby, because of the baby's head. So now what I could do, I could cover the baby's head.*" (Interview 01.2; referring to attending the Mukisa Foundation)

As shown in the latter quote, the caregiver was afraid of certain of negative reactions, and used the coping behaviour to counter hesitation out of fear and support help-seeking.

Following this, seeking help at public services and services specifically for persons with ID can be linked to a negative *outcome expectation* as conceptualized in the IBM: The disclosure of the disability of the child to the public, and potential harassment. Results presented show that these negative *outcome expectations* were either triggered by fear of becoming subject to discriminating behaviour by other persons (anticipated stigma), or by the mentioned stigma within the family against the child, who might not want to be associated to a child with such a condition. Public stigma and stigma with the family and caregivers (shame) hence manifest as *background variables* influencing the *outcome expectations* and subsequently the *attitudes*.

Fear can furthermore be linked to the affective part of the *attitude* construct in the IBM. Being afraid of visiting a service out of shame possible harassment is likely to trigger a negative emotional response when considering seeking help, which renders the *experiential attitude* towards seeking help rather negative. Again, stigma in this case manifests as a *background variable*.

The coping behaviours aimed to lower negative expectations or emotions against seeking help. Certain anticipated negative outcomes are less likely to occur in this case, which in turn lowers the negative impact of the described fears on the *attitude* factor.

The *attitude* in the IBM, influenced by the described *outcome expectations* and emotional responses tended to be more negative towards the intention-building on the second stage of

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[18] Significance levels are not reported since a non-random sample violates one of the assumptions for these (Garson, 2012:21).

the help-seeking model, the *decision to seek help*. Negative *outcome expectations* related to shame as well negative influences of harassment could however be reduced gradually after seeking treatment, as found in the quantitative and qualitative data which is likely to support treatment compliance and visiting services in further help-seeking episodes during the help-seeking career.

Additionally, the importance of the geographical location of the Mukisa Foundation showed that the fear of public disclosure of the child's disability has the potential to influence the third stage of the help-seeking process model, the *service selection*, towards services such as home based services or special services located outside of the neighbourhood of the respective caregiver.[19]

7.5.5 "Special" services and the acknowledgment of intellectual disability

Another factor influencing the help-seeking behaviour is related to the use of "special" services for children with ID. By attending a service that is especially for children with ID, caregivers also acknowledge to themselves that their child has special needs.

The director of the Mukisa Foundation expressed it in the interview as follows:

> "*So, most people would say: 'I don't want my child in a special centre, because that means you're confirming to yourself that my child is special'. So, most people will try as much as possible to take them to mainstream school rather than to special centres. Even when they know nothing is happening in the school, they still go, other than going to a special centre, to feel better about themselves.*"

Since the caregivers of the sample visit a special institution, or are aware of their child's disability, this phenomenon could only indirectly be grasped. Interviewees reported this pattern for parts of their family or social network.

Withholding certain potentially effective services in order to avoid acknowledgement of an ID and "*feel better about*" oneself in converse shows that acknowledging to have a child with ID would make the respective person feel bad. Although it might be a natural human behaviour to deny acknowledging a difficult situation, it does show that the ID is seen as a negative deviance from what this person wished for, and the child might not be accepted regarding its special needs. High scores on shame about the children (figures 6 and 7) illustrate the latter point.

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[19] The quote referring to harassment in the taxis in Kosovo seems to be linked to the geographical location as well.

The analytical models offer two possibilities on how the refusal of attending services to not acknowledge the ID of the child has effects on the decision-making in the help-seeking process. This is furthermore likely to depend on each individual. Firstly, following the IBM, the absence of intention building towards help-seeking at special centres could be explained with the experiential attitude (Montaño & Kasprzyk 2008:78). This is the affective component of the attitude factor, and one might assume that a person refusing to accept the ID of the respective child has a negative emotional response to visiting special services, since this is somewhat equivalent to accepting the child's ID. The second possibility however appears clearer, and better grounded in data. This second possibility is to grasp this issue as part of the first stage of the help-seeking model, the *problem recognition*. Reflecting the latter quote, a caregiver might not define the child's developmental delays as a problem that needs a special treatment. As long as this is the case the *decision to seek help* from a special institution will not be made.

However, if one assumes the absence of *problem recognition*, interpreting the phenomenon using the IBM does not appear feasible, since it does only refer to intention-building for behaviour that has actually been considered. If an action is not considered, a person does not evaluate the outcomes of this action, and hence does not build up any kind of attitudes. This exposes the limits of the application of the IBM in conjunction with the help-seeking process model.

7.5.6 Summary

Due to the high number of influences on the attitudes towards help-seeking presented above, a short sum-up of this section will be presented here. Three main factors can be singled out: First, beliefs about the nature of intellectual disabilities. These include differing causation beliefs and misperceptions regarding the permanent character of intellectual disabilities (7.5.1, 7.5.3). As a second factor, stigmatizing attitudes internal to the caregivers were presented, which included beliefs that the child does not have potential to improve (7.5.2), the reluctance to disclose the disability of the child out of shame (7.5.4), and the absence of acknowledging the child's ID as a problem that necessitates special treatment (7.5.5). As a third factor, *public stigma* showed to influence the help-seeking behaviour as it created fears of becoming subject to discriminating behaviour in the case of help-seeking at special services (7.5.4).

7.6 Stigma and self-efficacy

As described before, many caregivers experienced a lack of support from their social environment due to negative attitudes regarding persons with ID. Salient is especially that many of the caregivers are singles, mainly single females, as partners often left the family and refused to take care of the child with ID. See this case of a single mother:

> Caregiver : “*The husband does not accept the child.*”
>
> Interviewer: “*What is the problem that the father of the child has with the child?*”
>
> Caregiver: “*The father feels like the child is a shame to him. So he does not want to associate with it.*” (Interview 10.1)

In a society where gender roles tend to assign the role of the breadwinner to male persons, this situation is likely to lead to a deteriorating financial situation of female caregivers (Warrington, 2013).The director of the Mukisa Foundation confirmed this:

> “*There is always a poor mother, with three children and no food, and no skill, and no job.”* (Director of the Mukisa Foundation, deliberately exaggerating)

Single parenthood and financial difficulties can furthermore be reproduced in the quantitative data with regards to help-seeking. 32 out of the 80 persons answering the quantitative questionnaires were singles, of which 30 were single females (cf. Appendix V.1). Interestingly, the Mann-Whitney U test and a subsequently calculated approximate effect size value “r” of 0.229 showed that singles tended to hesitate to a higher degree to visit the Mukisa Foundation due to fears of expenses, though the “r”-value is considered to show a (higher) small effect size (Appendix V.1; cf. Pallant, 2013:235-238).[20] Other factors hence moderate the relation between these variables, which might for instance be financial support through other parts of the family. Quantitative data however does not grasp how many of the singles have been left by their partner due to the child’s disability, though qualitative questionnaires suggest that this happened to a considerable degree.

In intention-building, the impact of the refusal of many fathers to care (a form of stigma) can only indirectly be grasped using the models, and manifests as a *background variable*, which influences another *background variable*, the financial situation (Yzer, 2012:25). The financial situation influences intention building in the sample for this thesis mainly through its influence on *self-efficacy* in intention building, the perceived capability to perform an

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[20] It is likely that financial difficulties have a comparably high impact on the sample of this study compared to samples from other organizations, since the Mukisa Foundation is a service facility that is mainly directed at persons of low socio-economic status.

action. If a person has lower financial resources it is likely to perceive the actual possibility to seek help as lower (cf. Ajzen, 1991:196). The finding described hence shows to mainly influence the third stage of the help-seeking process model, the *selection of a specific service*, as the interviewees had generally decided to seek help, but were looking for affordable services.

8. Discussion, conclusion, and impetus for further research

Referring to the research question, the main findings are that various forms of *public stigma*, stigmatizing attitudes within the family, and beliefs about the causation and the capability for improvement of the child had the potential to affect help-seeking (cf. figure 11, 12). These could prevent, or lead to delays in, visiting support services, guide caregivers towards certain kinds of help, and generally play a role in intention-building, though they might be outweighed by other factors, such as the urgent desire to find help. Assumptions derived from the mental illness research in the literature review were hence mirrored in the data. However, the influence of stigma and beliefs reached further, and had various other effects on help-seeking, from a general lack of knowledge about intellectual disability to the refusal to acknowledge the child's disability.

As presented in figures 11 and 12, all constituents of the IBM (*background variables*, *social norms*, *attitudes*, and *self-efficacy*) are affected, and influence the help-seeking process in terms of the *decision to seek help* and the *service selection*. In addition, the refusal to visit special services in order to not acknowledge the children's ID is better to grasp with the help-seeking model on its own, and affected the *problem recognition* aspect (cf. figure 11, 12). Quantitative data supported the findings, showing that considerable shares of the sample were affected by stigma and beliefs.

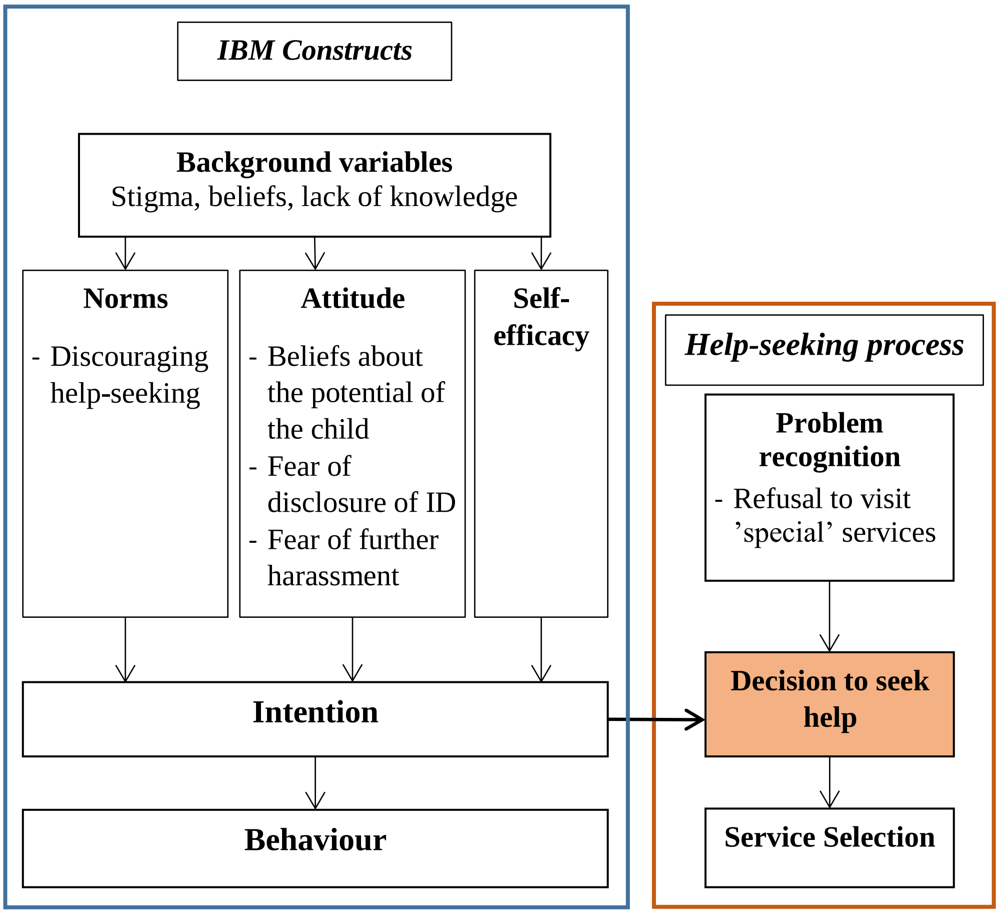

Figure 11: Identified themes that (mainly) affect the decision to seek help categorized after the IBM constituent they influence (simplified)

When aiming to explain how stigma and beliefs influence help-seeking, it is furthermore important to mention that opposing trends identified render the help-seeking process rather complex during the help-seeking career. While treatment that is perceived unsuccessful tends to yield more negative *attitudes* towards treatment options (cf. 7.5.1, 7.5.3) over time, an improvement in the child's condition (cf. 7.4.1) could weaken *social norms* discouraging help-seeking over the course of the help-seeking career. While this shows that improvement in the child's development is a crucial factor supporting treatment compliance and further help-seeking, the matter is complicated by caregivers looking to find cures for the child's developmental delays and subsequent devaluation of improvements falling short of this. Additionally, shame about the child's disability decreased over time as well (cf. 7.3, 7.5.4), and caregivers showed to build resilience against harassment (cf. 7.5.4) which might over the course of the help-seeking career reduce the negative impact of stigma with regards to help-seeking. To which degree which phenomenon takes place and might tend to outweigh the other ones could not fully be grasped in this thesis.

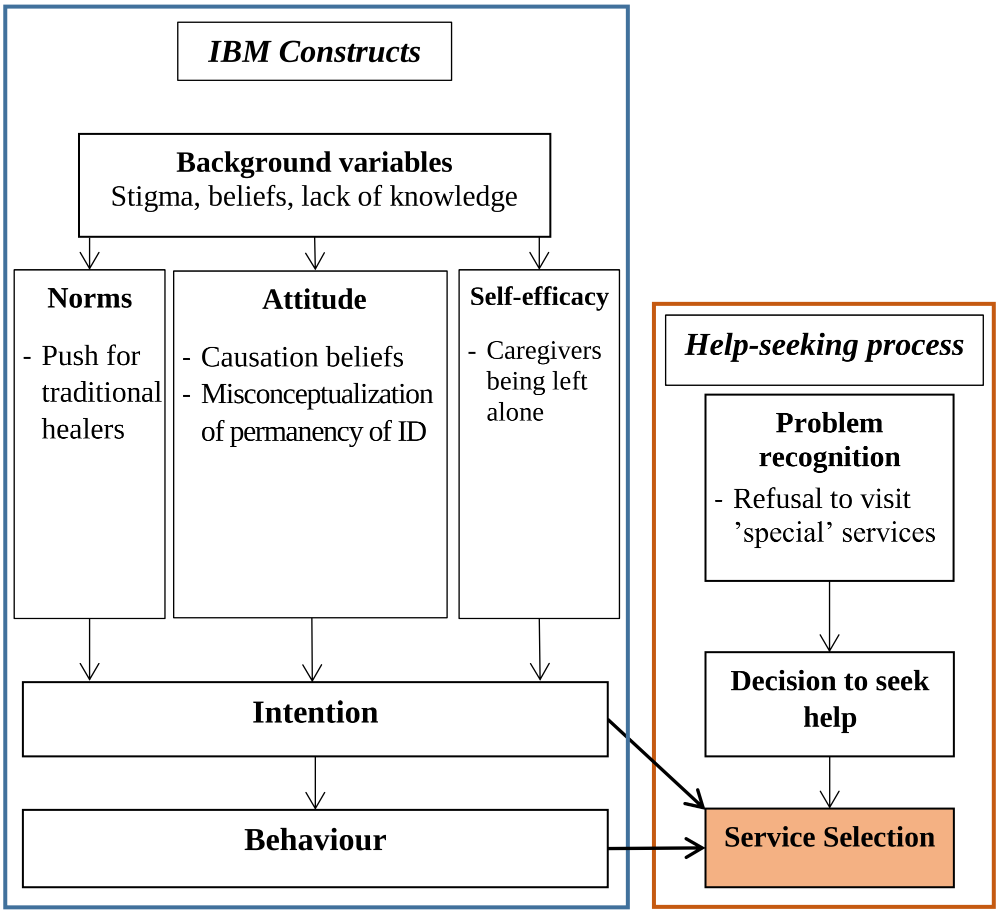

Figure 12: Identified themes that (mainly) affect the service selection categorized after the IBM constituent they influence (simplified)

The analytical frameworks used in a complementary fashion showed to be able to yield valuable insight into the topic of this thesis, following the exploratory aim. The IBM could explain in-depth various factors influencing intention-building processes that affect the help-seeking process. It furthermore showed to be able to present factors influencing the stages of the process model which could not necessarily be observed when focusing only on the actual decisions made as the process model focusses on. This is important since factors supporting help-seeking could outweigh the presented influences that worked against seeking help, yielding decisions to visit services despite opposing trends (cf. 7.2). Especially within a sample of caregivers that did eventually seek help it is crucial to grasp factors that might have been outweighed by other factors, but still play a role in decision making, as the mere observation of decisions taken would not grasp these.

Nonetheless, using the analytical framework for this thesis also presented challenges. On the one hand, separating *background variables* from *attitudes* could be tricky, as beliefs affecting attitudes undeniably have more direct relationships to *attitudes* than for instance the general lack of public discussion. A more nuanced conceptualization of *background* *variables* can be a possible solution for future work on this matter. Additionally, neither the IBM nor the process model can lighten up the process of *problem recognition* (cf. 7.5.5).

The critique against the help-seeking process model mentioning a lack of in-depth modelling of help-seeking careers beyond single help-seeking episodes has shown to come true to some degree. Both, the IBM and the help-seeking model have difficulties in explaining long-term processes, for help-seeking in general as well as more detailed in terms of changes of attitudes.

The study gives two main impulses for further research. First, it is necessary to better understand processes that evolve over time, which are difficult to grasp using the frameworks of this thesis. Changes in beliefs, *attitudes,* and *social norms* within the larger process of a help-seeking career influence help-seeking starkly, and factors influencing these should be investigated in more detail. Second, collecting data from caregivers that do not attend services with their children with ID or visit traditional healers is crucial in order to further explore how beliefs and stigma affect the help-seeking process in these cases. Despite interviewing two persons who do not seek help at during the data collection period, results from this thesis are likely to be distorted with regards to the wider population of caregivers of children with special needs. The question remains as to what degree factors identified in this study are valid among caregivers that do not seek “western” medical help.

Understanding the influence of stigma and beliefs has shown to be crucial in order to understand and support caregivers to seek help. To effectively guarantee the right of children with disabilities to special care and support (CRC Art. 23.2), providing for the mere existence of services does not seem to be enough, since various other barriers internal and external to the caregiver influence help-seeking. These barriers can withhold effective support from children with ID. Bigger societal structures that reproduce stigma and certain beliefs are to be addressed, to allow each child with special needs to develop its full potential.

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Appendix

I: The quantitative questionnaire

A. About the caretaker

1. What is your sex? ☐ Male ☐ Female

2. What is your age?

3. How are you related to the child that receives services from Mukisa?

____

4. Are you married or in some other kind of long-term relationship? ☐ Yes ☐ No

5. Is your partner living in the same household as you? [IF NOT IN A RELATIONSHIP TICK “NO”] ☐ Yes ☐ No

6. Level of education:

B. About the child [THE QUESTIONS ONLY REFER TO CHILDREN THAT RECEIVE THERAPY/EDUCATION FROM MUKISA]

1. Can strangers on the street immediately see that your child has a disability, without getting in close contact? [IN CASE SEVERAL CHILDREN ARE PART OF MUKISA, TICK "YES" IF THIS APPLIES FOR AT LEAST ONE OF THEM] ☐ Yes ☐ No

2. What kind of service does your child receive at Mukisa?

☐ Therapy at Mukisa's compound ☐ Home therapy ☐ Education (classes)

☐ Autism class

C. Caregiver's experiences

1. People treat me different because I take care of a child with special needs

1	2	3	4	5
(never)				(always)

a. This behaviour makes me feel distressed (referring to C. 1)

1	2	3	4	5
(not at all)				(Yes, a lot)

2. People react to my child in a special way:

1	2	3	4	5
(never)				(always)

a. The reaction of other people to my child makes me feel distressed (referring to C.2)

1	2	3	4	5
(not at all)				(Yes, a lot)

3. Thinking back: Before I joined Mukisa, having a child with special needs made my family feel ashamed:

1	2	3	4	5
(Not at all)				(Yes, a lot)

4. Thinking back: Before I joined Mukisa, having a child with special needs made me feel ashamed:

1	2	3	4	5
(Not at all)				(Yes, a lot)

5. Since I joined Mukisa, my family is distressed ☐ More ☐ Less ☐ No change

6. Since I joined Mukisa, I am distressed: ☐ More ☐ Less ☐ No change

D. **Causation beliefs** [QUESTIONS ARE REFERRING TO CHILDREN THAT RECEIVE THERAPY/EDUCATION FROM MUKISA]

1. Did you <u>ever</u> seek the help of a (traditional healer/witchdoctor) for your child?

☐ Yes ☐ No

2. Did you <u>ever</u> seek the help of a religious authority for your child? ☐ Yes ☐ No

E. Barriers

1. We talked before about the reactions of other people towards you and your child. Recalling the time before you went to Mukisa, did you fear that coming to Mukisa would worsen these reactions of other people?

1 2 3 4 5
(Not at all) (Yes, a lot)

2. Recalling the time you went to Mukisa, were you afraid of what people would say about your child if (he/she) was getting help for (his/her) special needs?

1 2 3 4 5
(Not at all) (Yes, a lot)

3. Thinking back, did you hesitate to join Mukisa because of the fear of the reaction of other people ?

1 2 3 4 5
(Not at all) (Yes, a lot)

4. Thinking back, did you hesitate to come to Mukisa because of the fear of certain expenses (e.g. transport) ?

1 2 3 4 5
(Not at all) (Yes, a lot)

5. Thinking back, did you hesitate to come to Mukisa because of the need to invest time to come to Mukisa ?

1 2 3 4 5
(Not at all) (Yes, a lot)

6. Thinking back, did you hesitate to come to Mukisa because you did not believe they could help you?

1 2 3 4 5
(Not at all) (Yes, a lot)

7. Thinking back, which was the most important reason that made you hesitate to come to Mukisa?

☐ Fear of other people's reactions (stigma) ☐ Distance from home to Mukisa

☐ Transport costs ☐ Belief Mukisa might not be able to help my child

☐ Other (specify)____________________________

☐ I did not hesitate

8. Thinking back, did the fact that Mukisa, apart from offering help for the children, supports families influence your decision to come to Mukisa?

1 2 3 4 5
(Not at all) (Yes, a lot)

9. Besides seeking help for your child, what were other reasons for you to come to Mukisa? [SEVERAL ANSWERS POSSIBLE]

☐ No other reasons ☐ Income generating activities

☐ Meeting other caregivers that have children with disabilities

☐ other ____________________________________

10. Thinking back, did the possibility of meeting other caregivers of children with special needs make you support your decision to come to Mukisa?

1 2 3 4 5
(Not at all) (Yes, a lot)

11. Thinking back, did the possibility of taking part in income generating activities support your decision to come to Mukisa?

1 2 3 4 5
(Not at all) (Yes, a lot)

12. What do you like most about Mukisa, besides the help for the children?

☐ Income generating activities ☐ Food received

☐ Meeting other caregivers that have children with disabilities

☐ Other ____

II: Qualitative Interview Protocol

[Note: The protocols used in the interviews contained more space in between the questions in order to take notes; the interview protocol furthermore evolved during the data collection period]

Example: Qualitative Interview Protocol

Respondent:

Date:

Start:

End:

Get informed consent.

Question 1:
When did you find out that your child has special needs, and how?

Question 2:
What were your initial thoughts? What did you think made the child be disabled?

Question 3:
How did your friends and family react when they were told?

Question 4: How did people behave over time? Were they supportive, offered you help?

Question 5: [Remind: Possibility to refuse to answer]
Would you say that, in general, people treat you in a different way because you have a child with special needs?

Question 6: Did you ever experience any negative reactions towards you from people that know you have a child with special needs? What did people do?

Question 7:
How do people react to your child when they find out/see it has a disability?

Question 8: Where did you first go to seek help? Why? Were there other places you knew about where you could have gone?

Question 9: What did your friends/family/neighbour recommend you to do?

Question 10: Did you at that point hesitated to go there? Was there anything you feared? [Ask about transport money etc.] How come you still went to get help?

Question 11: Where else did you go to seek help? Why did you go to other places?

Question 12: Did you ever seek the help of a traditional healer? Why, why not? Have you been satisfied

Question 13: How did you learn about Mukisa?

Question 14: Did you go to Mukisa immediately after you heard about it? [Why didn't you go immediately?]

Question 15: Have you been sure that Mukisa might be able to help? Did you hesitate to go to Mukisa because of that?

Question 16: Were there any problems you saw when going to Mukisa? [If person doesn't really know give examples: e.g. transport etc.]

Question 17:
Specific question: Did you fear other people might react negatively if you go to Mukisa? It is an institutional for children with special needs after all, you acknowledge your child has an issue if you go there

Question 18: *If person went to traditional healer or pastor, or didn't believe in help at Mukisa*
Why did you still go to Mukisa if you think it was some witchcraft-related thing? Or a thing that god did?

Question 19: Do you think there are people that refuse to seek (proper) help for their children with special needs? Why? [do you know anyone?]

Question 20: Is there anything else you would like to say?

Thanks a lot for the interview!

Space for additional comments:

III: List of participants and date of interview

Participant (number code)	Date of interview
01.1	January 12th, 2015
01.2	January 12th, 2015
01.3	January 12th, 2015
02.1	January 14th, 2015
02.2	January 14th, 2015
03.1	January 16th, 2015
03.2	January 16th, 2015
04.1	January 19th, 2015
04.2	January 19th, 2015
05.1	January 21st, 2015
05.2	January 21st, 2015
05.3	January 21st, 2015
06.1	January 23rd, 2015
06.2	January 23rd, 2015
07.1	January 26th, 2015
07.2	January 26th, 2015
08.1	January 29th, 2015
09.1	February 2nd, 2015
09.2	February 2nd, 2015
10.1	February 5th, 2015
10.2 (person that does not seek help at Mukisa)	February 5th, 2015
11.1	February 6th, 2015
11.2 (person that does not seek help at Mukisa)	February 6th, 2015
Interview with the director of Mukisa	February 10th, 2015
Interview with the social worker of Mukisa	February 14th, 2015

IV: Demographic data of survey participants

Sex

		Frequency	Valid Percent
Valid	Male	3	3,8
	Female	77	96,3
	Total	80	100,0

Age

N	Valid	80
	Missing	0
Range		29
Minimum		20
Maximum		49

V: Calculations for statistical measures

In the following, the procedure for obtaining the quantitative measures will be explained.

V.1: The difference of singles and non-singles on hesitation due to fears of expenses

In order to investigate differences in scores on the hesitation to visit the Mukisa Foundation due to fears of certain expenses between singles and non-singles, a Mann-Whitney U test has been conducted using SPSS (Mayers, 2013:464-473). The variables chosen for this test are the variable asking if a partner is living in the same household (table 1 in this section; cf. Appendix I A.5), and the variable asking for hesitation of visiting the Mukisa Foundation due to fears of certain expenses (cf. Appendix I, E.4.). The reason for choosing the variable asking on the status of the household has been chosen over the variable asking on long-term relationships, since interviewees often expressed to be in a long-term relationship when they were still officially married, even though the partner has left the family already.

The Mann-Whitney U test has been chosen as a non-parametric test since the independent variable (household status) is a dichotomous variable, and the dependent variable (hesitation due to expenses) consists of ordinal scores, which showed during data analysis to be non-normally distributed (Mayer, 2013:464). Furthermore, the assumption that two distinct groups are compared is fulfilled, since no individual can appear in both groups.

Following the procedure as pointed out in Pallant (2013:236), the following results were given.

table 1: Partner living in the same Household

		Frequency	Valid Percent
Valid	Yes	48	60,0
	No	32	40,0
	Total	80	100,0

table 2: Hesitate to come Mukisa because of the fear of expenses

		Frequency	Valid Percent
Valid	Not at all	25	32,1
	2	9	11,5
	3	11	14,1
	4	14	17,9
	Yes a lot	19	24,4
	Total	78	100,0
Missing	System	2	
Total		80	

table 3: Test Statistics[a]

	Hesitate to come Muk bec fear expense
Mann-Whitney U	543,000
Wilcoxon W	1624,000
Z	-2,019
Asymp. Sig. (2-tailed)	,043

a. Grouping Variable: partner living in same household

table 4: Report

Hesitate to come to Mukis because of fear of expenses

partner living in same household	N	Median
Yes	46	2,50
No	32	4,00
Total	78	3,00

The "Z" value in table one in conjunction with the "Asymp.Sig." value of 0.043 in table 3 in this section shows a significant difference in scores on the hesitation value between the two groups (Pallant 2013:237). The median sores in table 4 in this section (which are relevant rather than the mean scores since data was not normally distributed; Mayers, 2013:470) clearly indicates that singles tended to score higher on the hesitation due to fears of expenses.[21] An effect size value "r" can be calculated with the "Z" value (leaving out the *minus* sign) using the following calculation (derived from Mayers, 2013:470):

$$\frac{Z}{\sqrt{N}} = \frac{2.019}{\sqrt{78}} = 0.229$$

Following Cohen's (1988 in Pallant, 2013:238) categorization, the "r" value of 0.229 shows a (higher) small effect size.

V.2: Correlation between fears of other peoples reaction and hesitation

Investigating the relationship between the variable measuring the fear of reactions of other people (table 5; cf. Appendix I E.1.) and the hesitation to visit the Mukisa Foundation out of fears of other person's reaction (table 6; cf. Appendix I E.3.) has been assessed using Kendall's Tau-b (Mayers, 2013:121; Pallant, 2013:136). The measure is appropriate considering that the scores of both variables are ordinal, but non-normally distributed within the sample, and was preferred over Spearman's rank order correlation as too many ties have been observed in the data (Mayers, 2013:118-121) As table 7 shows, a positive relationship ("Correlation Coefficient") has been found, indicating that the more fear persons perceived when visiting Mukisa, the more they hesitated. A value of 0.403 indicates medium correlation strength.[22]

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[21] The "Z" value in table one in conjunction with the "Asymp.Sig." value of 0.043 in table 2 shows a significant difference in scores on the hesitation value between the two groups at the 5% level, however due to the non-randomness of the sample significance tests are not applicable in this study (Garson, 2012:21).

[22] Again, statistical significance is not reported due to the non-randomness of the sample.

table 5: Fear of other peoples reaction when visiting Mukisa

		Frequency	Valid Percent
Valid	Not at all	55	69,6
	2	5	6,3
	3	11	13,9
	4	7	8,9
	Yes a lot	1	1,3
	Total	79	100,0
Missing	System	1	
Total		80	

table 6: Hesitation to visit Mukisa because of fear of reaction of other people

		Frequency	Valid Percent
Valid	Not at all	55	69,6
	2	15	19,0
	3	2	2,5
	4	6	7,6
	Yes a lot	1	1,3
	Total	79	100,0
Missing	System	1	
Total		80	

table 7: Correlations

			Fear of ppls react when go to Mukisa	Hesitate come Muk bcs fear of reaction ppls
Kendall's tau_b	Fear of ppls react when go to Mukisa	Correlation Coefficient	1,000	,403
		N	79	78
	Hesitate come Muk bcs fear of reaction ppls	Correlation Coefficient	,403	1,000
		N	78	79

VI: The informed consent form

The interview will be done as a part of the research for my master's study. The topic of the interview will be the experiences and choices of caregivers of children who are currently part of the Mukisa Foundation in Kampala, Uganda. Various caregivers that work with the Mukisa Foundation will be interviewed.

The Mukisa Foundation itself is not part of the research team, and it did not give order to do this research. All information obtained during this interview will be treated with confidentiality, which means that neither the Mukisa Foundation nor anyone else, except for the people present in this room will gain knowledge about what you as an individual said during the interview. The thesis will be public when it is finished, but it will not contain any names or other information that could allow the reader to find out what the participants of the interviews said.

It is important to be aware of the fact that the participation is on absolute free terms. You can at any time stop the interview or refuse to answer certain questions. The claims about confidentiality are valid, no matter if you cooperate or not.

No document or recording of what you say today will have your name written on it. I will only use a short code to be able to link it to the recording.

Do you agree to take part in the interview under these terms?

Date, signature:

VII: Tables corresponding to figures 4 - 10

VII.1: Tables corresponding to figures 4 & 5

Caregivers' perceived frequency of being treated differently due to child with ID

		Frequency	Valid Percent
Valid	1 Never	16	20,0
	2	13	16,3
	3	24	30,0
	4	12	15,0
	5 Always	15	18,8
	Total	80	100,0

Caregivers' distress about being treated differently

		Frequency	Valid Percent
Valid	1 Not at all	26	33,3
	2	20	25,6
	3	13	16,7
	4	13	16,7
	5 Yes a lot	6	7,7
	Total	78	100,0
Missing	System	2	
Total		80	

VII.2: Tables corresponding to figures 6 & 7

Level of shame of caregivers before joining Mukisa

		Frequency	Valid Percent
Valid	1 Not at all	57	71,3
	2	5	6,3
	3	9	11,3
	4	5	6,3
	5 Yes a lot	4	5,0
	Total	80	100,0

Families' level of shame about child w. ID before joining Mukisa as perceived by the caregiver

		Frequency	Valid Percent
Valid	1 Not at all	43	53,8
	2	7	8,8
	3	12	15,0
	4	6	7,5
	5 Yes a lot	12	15,0
	Total	80	100,0

VII.3: Table corresponding to figure 8

Table 5: Hesitation to visit the Mukisa Foundation because of the belief they might not be able to help

		Frequency	Valid Percent
Valid	1 Not at all	50	63,3
	2	16	20,3
	3	4	5,1
	4	4	5,1
	5 Yes a lot	5	6,3
	Total	79	100,0
Missing	System	1	
Total		80	

VII. 4: Tables corresponding to figures 9 & 10

Degree of caregivers' perceived fear of other peoples' reaction when visiting the Mukisa Foundation (before the first visit)

		Frequency	Valid Percent
Valid	1 Not at all	55	69,6
	2	5	6,3
	3	11	13,9
	4	7	8,9
	5 1Yes a lot	1	1,3
	Total	79	100,0
Missing	System	1	
Total		80	

Caregivers' hesitation to visit the Mukisa Foundation because of fear of other peoples' reaction (before the first visit)

		Frequency	Valid Percent
Valid	1 Not at all	55	69,6
	2	15	19,0
	3	2	2,5
	4	6	7,6
	5 Yes a lot	1	1,3
	Total	79	100,0
Missing	System	1	
Total		80	

VIII: Other persons' behaviour towards the children with ID

People react to child in a special way as perceived by the caregiver

		Frequency	Valid Percent
Valid	1 Never	15	18,8
	2	10	12,5
	3	25	31,3
	4	11	13,8
	5 Always	19	23,8
	Total	80	100,0

Caregivers distress about "special" behavior towards child with ID

		Frequency	Valid Percent
Valid	1 Not at all	32	40,0
	2	17	21,3
	3	13	16,3
	4	6	7,5
	5 Yes a lot	12	15,0
	Total	80	100,0

IX: Table indicating visits to traditional healers[23]

Did you ever seek the help of a traditional healer for your child?

		Frequency	Valid Percent
Valid	yes	33	41,3
	No	47	58,8
	Total	80	100,0

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[23] Cf. section 7.4.2.