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How Stigma Affects Us: The Voice of Self-advocates

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Self-stigma or internalized stigma is shaped profoundly by how one believes one is seen by others (Lucksted and Drapalski 2015). Self-stigma occurs when individuals recognize negative attitudes that surround them and endorse these, believing and accepting that they apply to them (Corrigan and Watson 2002). Some have suggested that many people with intellectual disabilities do not identify with the label of "intellectual disability" ascribed to them (Cunningham et al. 2000; Davies 1998; Davies and Jenkins 1997) and have little awareness of their stigmatized status (Beart et al. 2005; Finlay and Lyons 1998). However, others suggest that people with intellectual disabilities do indeed understand that stigma and oppression are related to the label ascribed to them and therefore try to reject that label in the hope of avoiding the associated stigma (Jahoda and

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Markova 2004). Distancing themselves from others who ascribe the label of intellectual disability has negative implications in terms of sense of belonging and social isolation (Ali et al. 2012; Cunningham and Glenn 2004; Spassiani and Friedman 2014).

A systematic review on self-stigma among people with intellectual disabilities concluded that research should focus on the process by which stigma associated with the intellectual disability label is internalized and on the social and psychological factors associated with stigma (Ali et al. 2012). Accordingly, the study presented in this chapter sets out to investigate stigma and self-stigma as experienced by people with intellectual disabilities, to examine their actions in “dealing” with stigma, and the impact of participating in a self-advocacy group (SAG) on these perceptions of stigma and self-stigma.

Consulting Research Committee

Adopting a partial participatory research approach, our study recognized that people with intellectual disabilities are the experts on their lives while the researchers are the “technicians” in charge of planning, collecting, and analyzing the data and writing up the results. A partial participatory research approach was employed by forming a consulting research committee comprised of three individuals with intellectual disabilities, two professionals who are involved with SAGs, and the three researchers. The primary role of this committee was to oversee the research design and process. The tasks of data analysis and reporting of results were completed by the researchers without intellectual disabilities.

One key issue which was evident in the committee’s discussions was that although people with intellectual disabilities themselves frequently use the terms “stigma”, “negative attitudes”, or “prejudice”, these terms appeared to be unclear to the committee members and caused some confusion. Thus, it was necessary to provide an in-depth explanation in order to make sure that everyone understood these terms before progressing. Further, the discussions elicited many emotions such as frustration, anger, and sadness to the point of one member with an intellectual disability weeping.

The consultants with intellectual disabilities described experiencing ridicule, bullying, exploitation, and violence, which they attributed to being “disabled”. Ahmed (all names used are pseudonyms), a 30-year-old man from the Bedouin Muslim Community in Southern Israel, described his feelings in relation to how others view him: “I feel ashamed to speak in front of people because I’m afraid they will laugh at me. I feel that they are talking behind my back.” Uri, a young Jewish man from Jerusalem, added, “Sometimes I am laughed at, near my home they say to me ‘you are retarded’ and all sort of things. Today that I am already an adult, I understand. They think I am stupid, that I don’t understand.”

The consulting committee recognized that stigma was a very intense, difficult, shameful, and painful subject. Two committee members expressed concern that raising this topic “out of the blue” with other individuals with intellectual disabilities may cause them much distress. As one member said: “It’s difficult, difficult to talk about it, difficult to think about.” In order to avoid causing distress, it was decided only to recruit participants that had either raised the issue of stigma previously and/or were experienced in addressing painful issues. Further, in order to be able to provide ongoing support to participants, in the case that such a need would arise, it was decided to recruit the participants via SAGs.

Focus Group Study

A semi-structured interview guide was developed taking into consideration the issues raised by the consulting research committee. The following questions were included: Why are people afraid of us and reluctant to interact with us? Why do people think we are stupid? Why can’t people accept us as we are? Why can’t people believe in us? Are we really disabled? Why do people feel pity toward us? Why do people think we need charity? Why do our families and others tell us we cannot do things? These questions stemmed from committee members feeling violated by people around them and not understanding why they were treated so poorly. Additional questions were raised spontaneously during the focus group discussions, some by the participants themselves. For example, “How do you ‘really’ feel? What are you ‘really’ worth?”; “How do stigma and bad attitudes affect you?"; "How did self-advocacy change you?" The questions which included the word "really" were asked by individuals with intellectual disabilities and may imply that they perceived that some of the responses provided were perhaps not genuine.

Two groups took part in this study. First, a national Israeli SAG, made up of self-advocate leaders (or "guides" in Israeli SAG language) of seven different SAGs across Israel who have been meeting monthly for several years. The group included 12 guides and 5 "enablers" (SAG cofacilitators without intellectual disabilities). Second, a less well-established Tel-Aviv-based SAG that meets fortnightly took part. This group included one guide, nine self-advocates, and one enabler. In both groups there were a similar proportion of men and women, who ranged in age from 20 to 60 years. The majority of participants were Israeli Jews of different levels of religiosity and three Israeli Arab participants. One two-hour meeting was held with each group. The SAG members were familiar with the researchers, having met them on several previous occasions and felt comfortable in their presence.

The group discussion was opened by the researchers and one of the consulting committee members who outlined the purpose of the meeting. The meetings were audio recorded and transcribed. Further, field notes were taken by one of the researchers. Of note, rarely did focus group participants respond to questions or initiate responses spontaneously—most had to be directly asked and encouraged to participate. Further, participants who had difficulty expressing themselves were provided with support and adaptations necessary to help them participate, for example, rephrasing questions, waiting for a response, and asking questions which can be answered by yes/no responses.

The study was approved by Beit Issie Shapiro's Ethics Committee. All participants provided written consent from their parent or legal guardians as (is still) required by law.

Results

The following five themes represent concerns and responses to stigma raised most frequently by participants in both groups.

Emotional impact of stigma. Participants talked about being afraid of stigma, feeling ridicule, anger, shame, rejection, and pain related to others' reactions toward them. They described how their life experiences of negative societal attitudes had "taught" them to expect to be ridiculed and that people talked about them behind their backs. The statements that follow exemplify this: "they make a circus [make fun] of me"; "I feel exploited, they laugh at me"; "they think bad things of me"; "they laughed at me and said, this one is retarded"; "someone says to you that you are limited, it hurts, it pinched my heart"; "they think we are retarded." These statements clearly provide evidence of the negativity and pain these individuals experience, but it is unclear whether these stigmatic experiences were accepted and internalized by them. Some participants appeared not to internalize stigma but rather perceived it as unjust. They "swallowed" the insult, but did not accept it.

Not understanding why stigma occurs and is directed toward us. Many participants indicated that they did not understand why they were being treated negatively: "I don't know why they laugh at me … we should be treated like everybody else…"; "I left my last job, they said I was too slow, but I worked as fast as possible exactly like the other worker." Another participant said: "I do all the work there is to do, I work harder than all the other workers, but they don't let me be the coordinator of the children in the kindergarten, despite the fact that I do things none of the other caregivers do." Some of the other participants said: "I am regular like everyone else"; "they think we are retarded and not normal"; "she said that I am a person with special needs, so I thought, what, I am retarded? So I asked her, and she said no." These findings can be explained in different ways. Firstly, it is possible that participants do not internalize the stigma associated with intellectual disability. Thus, they did not understand why they were being ridiculed, seen as unable to do what "normal" people do, or treated differently from those around them. This was reflected in answers to the question "why do you think you are treated like that", a question many participants were unable to answer. Instead, they elaborated on *how* they were treated and not *why* they were treated negatively. A second possible explanation is that no one had truly explained to them what it means to have an intellectual disability and its potential impact on them and their lives. It is possible that saying out loud "I have an intellectual disability" is too difficult, as society considers this term as derogatory. Yet, when listening closely to the participants, it was clear that there was a strong dissonance between their expressed denial of being different and their unspoken sense of being different and somehow deficient. This can be seen in statements made by participants when asked more directly: “we are different in our brain level”; “we cannot function alone”; “I work slower.”

Confusion in self-concept and identity. Participants referred to themselves as having many titles and definitions: “special needs”, “handicapped”, “retarded”, and “intellectually disabled”. When asked how they would like their disability to be referred to, they suggested, “limited, this means that our brain is limited”; “intellectually disabled, this sounds nicer than limited or disabled”; “special needs because this will cause less people to laugh at me”; “mild retardation, so they understand that we have limitations in everything”; “a regular person, a person that does not have a problem”.

Most of the participants felt very uncomfortable, especially in the national SAG, to address the issue of their identity related to being a person with an intellectual disability. They appeared more comfortable focusing on additional physical or sensory impairments that affected some of them. For example, in one of the groups there was a lively discussion about one of the participant’s visual impairment, which the group was clearly more comfortable to discuss than intellectual disability.

Ignoring as a default response to stigma. Most participants described attempting to deal with the insults they faced by trying, in their words, “to ignore” them or avoid contact with people who had insulted them. Nevertheless, it seems that their attempts were not always fruitful. The behavioral response of ignoring carried with it an emotional cost. When asked how they responded to situations in which they were exposed to stigma, they said they were silent, looked down, and did not confront the offending person. Many shared situations in which they had chosen not to confront others: “They laughed at me, said I was limited, retarded, that I am a retarded one, ‘that one, she has no brain’. I did not respond, I did not react, and I felt very bad.” “If they laugh at me, I ignore it”; “if we will respond to them, they will burst at us”; “they will not listen to me … ignore … ignore …” “They told me ‘you are from the retarded organization, you are limited’. I don’t answer, I don’t respond." (Researcher asked: "How did you feel?") "I feel sad. I cannot say anything."

Participants appeared hesitant to confront the people who hurt them because they feared they might encounter an even more negative reaction. By ignoring the situation they felt safer at the price of reinforcing negative reactions. Ignoring was a skill they were taught by their environment and those caring for them, who frequently gave them advice such as "ignore it, it is not true". While potentially well meaning, such advice encourages the person neither to stand up for themselves, nor to deal with their intellectual disability, and instead could be seen as being complicit in failing to challenge stigma.

The opportunity provided by self-advocacy. Participating in SAGs clearly provided participants with an alternative, an opportunity to be less fearful, talk, explain, and stand up for their rights, not ignore. The SAGs had an optimistic atmosphere where learning about self-advocacy provided a new and different way of being in the community. They were not focused on erasing or ignoring the disability but rather on increasing group members' understanding that having a disability and being different from others does not justify disrespect or hostility. Taking part in the SAG strengthened their sense of personal control: "I am responsible for myself"; "I am aware of my difficulties, but I am equal"; "I can explain what is difficult for me, but I still deserve fair treatment." Other statements illustrating this theme included: "I will talk to people so that they can listen to how people like us feel"; "SAG does good for me … gives me hope, I can stand on my own … if I see that things are not right I can say something"; "I can say in a nice polite way that they should treat us nicely and equally"; "I feel that I am doing something for myself and not for someone else"; "the group gives me the power, I am not afraid to tell people to treat me with a little more respect. Many times I was scared because I was treated like a child and today I am not afraid to say it"; "to know how to approach normal people … I also have the right to things." Other participants provided additional examples of how membership of a SAG helped them stand up for themselves: "If people in the community do not treat you nicely, argue with them and stand on your own in all cases, because people change their opinions." Or as another SAG member said: "You must stand on your own, if you do not stand on your own, you will not get what you want."

Members of the consulting committee also reported similar experiences related to being members of SAGs: “In the SAG I learned things and skills I succeeded in and it made me change how I think of myself.” “Before the SAG I felt bad, I felt out of place, and then I changed. I did not think I had abilities, just suffer and go on.” “I never heard of self-advocacy, I learned a lot, it changed my life. It gives me strength, it gives me power, and I have changed.” “Our life has changed for the better.”

Discussion and Conclusions

The findings of this study are consistent with previous studies in indicating that some individuals with intellectual disabilities do not identify with having an intellectual disability and prefer to refer to themselves as having other forms of disability. Further, individuals with intellectual disabilities who participated in this study described various difficulties that they faced due to holding a stigmatized status and being treated badly by others (Ali et al. 2012; Cunningham et al. 2000; Davies 1998; Davies and Jenkins 1997; Jahoda and Markova 2004). Accordingly, some individuals with intellectual disabilities feel frustrated about the label of “retardation” or “intellectual disability” ascribed to them (Dagnan and Waring 2004). They may respond by distancing themselves from other individuals with intellectual disabilities and ignoring and avoiding situations which may elicit stigmatic responses toward them, such as negative remarks and insults (Gibbons 1985; Jahoda and Markova 2004).

Self-stigma of individuals with intellectual disabilities is a very complex construct to measure. One question which remained unanswered in the current study is in what ways does self-stigma differ from public stigma? Is self-stigma a product of public stigma, that is, do all or most individuals who are prone to public stigma internalize this? On the one hand, the participants’ descriptions of their behavior reflects that many internalized a sense of themselves as “inferior to others”, along with a strong fear of society, and a tendency to avoid contact with those that impose stigma. On the other hand, participants had great difficulties saying “I have an intellectual disability.” It seems that many participants had a sense that they “do not deserve such treatment", but did not understand why they are treated poorly or what to do about it.

The group discussions made it clear that ignoring, a strategy frequently chosen by participants, ultimately served to reinforce stigma. In contrast, self-advocacy provided a collective sense of strength and injustice. In listening to their voices, ideas, and experiences, it is clear that there is a need to support more self-advocacy, convince others of its importance and benefits, and support the development of different formats of self-advocacy, as regular discussion-based groups may not suit everyone. It is necessary to convince families, service providers, and policy makers of the importance and the necessity of self-advocacy and to encourage diverse forms of self-advocacy from a younger age as a possible method to mitigate the negative impact of stigma. Effort should be directed to examine how to promote the self-esteem of individuals with intellectual disabilities and provide them with skills to help them cope with their realities, alongside informing and educating communities at large to reduce and eliminate stigmatic beliefs.

Key Learning Points

- This chapter presents a study designed to hear the voices and investigate how people with intellectual disabilities experience stigma and self-stigma.
- The study was conducted using elements of the participatory research approach recognizing that people with intellectual disabilities are the experts on their lives.
- The participants were well aware of their stigmatized status within society, but did not understand why stigma is directed toward them. They preferred to ignore situations which raise stigma. Further, self-advocacy was described as an alternative approach to dealing with stigma.
- Efforts should be directed to examine how to promote individuals' self-esteem and provide them with skills to help them cope with their realities, and to inform and educate communities to reduce and eliminate stigmatic beliefs.

Accessible Summary

- We asked people with intellectual disabilities what other people without disabilities think about them.
- People with intellectual disabilities felt that others laugh at them. This made them feel bad about themselves. They didn't understand why others treat them this way. Many preferred to ignore situations in which people made fun of them or hurt them.
- Taking part in SAGs, they learned to speak for themselves and say what they want and feel. In these groups they are able to learn how to talk back and not let others treat them badly.
- People with intellectual disabilities should learn how to speak up for themselves and feel more confident. It is also very important to teach people without disabilities that people with intellectual disabilities are people just like them.

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