

Effects of Stigma on the Intellectually Disabled

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In recent years, many people have come forward to share their experiences with stigma. For some groups, stigma is not a large defining factor in their daily life, but for others, stigma plays an important part in shaping their identity. One group that experiences heightened levels of stigma is the intellectually disabled; often marginalized, the stigma they receive can change the way they look at themselves. The four studies in this paper examine the effects of the stigma faced by individuals with intellectual disabilities, and the paper will use these studies to try and reach a conclusion about the relationship between stigma and personal identity.

Developing an identity while also trying to gain independence is examined by Jahoda et al., who studied two individuals with intellectual disabilities and their struggles to develop the identity they want. Jahoda et al., conducted interviews and took photographs and videos of individuals with intellectual disabilities as they try to establish their identities. The authors use theories of social construction and self-perception to discuss the findings (521).

The literature review of several other studies shows the stigma that people with intellectual disabilities face, and their responses. The discrimination against people with intellectual disabilities was often recognized by people with such disabilities. Accounts of discrimination ranged from childhood bullying to abuse or infantiliza-

tion in adulthood (Jahoda et al., 522). In many cases, the intellectually disabled expressed wishes to make their own choices about their life and reject negative stereotypes and stigma (Jahoda et al., 522). Distinguishing oneself from other disabled persons and showing support for the disabled community are also discussed, as are methods of dealing with stigma. Such methods range from comparisons to people without disabilities to promoting a “positive collective identity” (Jahoda et al., 523). The authors used methods similar to those used by Langness and Frank to create “case studies” of an individual’s life (524).

Using a qualitative method of open interviews and recorded material over the span of 6 to 18 months, Jahoda et al., highlight the results from two participants, given pseudonyms of “Gary” and “Sharon,” who were chosen because of their “contrasting experiences in dealing with stigma” (525). They were interviewed over the course of six to eighteen months by themselves or with family or support service workers, and were given a disposable camera, as well as a video-camera, to document their life.

Gary once lived alone but had since moved in with his father at the time of the interview. Gary was a graduate from a school for people with intellectual disabilities; his life seemed promising, but bullying at his workplace and lack of help from support services resulted in his losing his job and flat, and he turned to alcohol and

suicidal behaviors (Jahoda et al., 526). Gary describes his isolation and boredom: "I don't know what I'm going to do today, I'm sick of this," he says on his video diary (Jahoda et al., 527). Gary is also trying to re-invent himself and his identity to become "part of mainstream society," his nurse tells the researchers (Jahoda et al., 527). His experiences with stigma have led him to try to change himself to conform to society's standards.

Sharon's experiences with her limitations have also led her to negotiate an identity that fits within these limitations. An eighteen-year-old girl living with her mother, Sharon goes to school and once had a job caring for older people, but she describes her inability to perform the tasks that normal adults can. Depression, anxiety, and epilepsy have severely limited what she can do and decide; her mother also limits her freedom and Sharon knows "she would not be allowed" to cook or go to college alone (Jahoda et al., 529). Sharon tries to make sense of herself within these limitations: "Feel stupid you cannot do nothing... Okay, I can use the microwave, I can make toast. But failing that I cannot go any further." (Jahoda et al., 530).

Both cases show the attempts of the subjects to create an identity, while also grappling with their limitations. Each subject has experienced stigma, and each has tried to develop a sense of self. Comparing themselves to the rest of society, Gary and Sharon try to reject stereotypes and build an identity that is closer to larger society. Social comparison and stigma are also explored in the second study, examining the relationship between the two and self-esteem.

"Stigma, Social Comparison and Self-Esteem in Adults with an Intellectual Disability" uses a questionnaire to measure levels of self-esteem, stigma, and social comparison in 43 adults with intellectual

disabilities (Paterson et al., 166). The questionnaire uses three scales to gauge stigma, social comparison and self-esteem, with participants asked to select the option that seemed the truest to them. In the comparison scale, they were asked to finish incomplete sentences with answers concerning their similarly disabled peers and people in the larger community (Paterson et al., 169). Statistical analysis was then done to measure the results. The researchers found a positive correlation between stigma and low self-esteem; the higher the perceived stigma, the lower the self-esteem. Individuals with already low self-esteem recalled experiences with stigma, but there was no relationship between individuals with higher self-esteem and lower perception of stigma (Paterson et al., 172).

In contrast, there was no relationship between social comparisons to other disabled people and perceptions of stigma, but there was one between comparisons to the community and stigma, especially in the categories dubbed "social attractiveness" and "achievement and rank" (Paterson et al., 171). Negative social comparisons and low self-esteem were positively correlated; in addition, people who identified more with other disabled people regarded themselves "more able" than others of the same group (Paterson et al., 173). However, no correlations between a feeling of belonging to a particular group and self-esteem were found, suggesting that perhaps "people with an intellectual disability do not need to express an affinity with or sense of belonging to the community to feel good about themselves" (Paterson et al., 173). The perception of stigma and responses to such stigma are also featured in Jahoda and Markova's study of the intellectually disabled as they moved from hospital to assisted housing.

"Coping with Social Stigma: People with Intellectual Disabilities Moving from Institutions and Family Home" is a study

based on the interviews of 28 people with mild intellectual disabilities, who come from two different environments: a hospital and a set of "hostel-type" apartments (Jahoda and Markova, 721). Interviews were carried out with all participants, focused on the topics of their experience, or perception of, stigma, and their responses to said stigma (Jahoda and Markova, 721). The researchers then analyzed the interviews, to find common themes in the way individuals described and responded to stigmatizing experiences (Jahoda and Markova, 722).

The analysis of experiences with stigma revealed several common themes. In the hospital group, participants felt restricted by the staff, and resented the lack of privacy and freedom (Jahoda and Markova, 723). They also recognized the stigma associated with being from the hospital, and how that made it hard for patients to make connections (Jahoda and Markova, 723). The housing group shared many of same concerns, indicating the same wishes to be "called adults instead of children" and worrying that their disabilities prevented them from working jobs "like normal people." (Jahoda and Markova, 724). The expressed views also influenced their self-image and the changes they believed were necessary to prevent the stigma.

The hospital group linked their identities to the institution they lived in, but instead of accepting the label of "patient," they rejected it. The participants wished to stop being "classed as patients," since they consider themselves as ordinary (Jahoda and Markova, 722). Furthermore, upon leaving the hospital, the participants distanced themselves from their past, stating that "if you start telling people, they'll start telling everybody else and all of them will start making a fool of you." (Jahoda and Markova, 725). Many also argued they should have not been there in the first place, placing themselves above other patients by

calling themselves "residents" or "grown men." (Jahoda and Markova, 725). Residents from both groups pointed to their agency as an important part of determining their self-image.

The housing group, although in a freer environment, still had to deal with the restrictions of their parents and significant others. The group would point to examples of self-sufficiency and often expressed frustration that their parents still treated them as children (Jahoda and Markova, 726). They also considered going to the day centers an affront to their capabilities and identities, and many said they were not disabled and did not need to attend them (Jahoda and Markova, 727).

The two groups expressed similar views about their living situations. Both recognized and wished to escape the stigma associated with living there and viewed themselves as mostly normal. However, while they rejected the labels, the groups did not deny their disabilities, and some showed empathy for other disabled persons (Jahoda and Markova, 728).

Another study that compares two groups, albeit two groups of high school-age children, is the study by Cooney et al., which deals once again with social comparison and perceived stigma. "Young People with Intellectual Disabilities Attending Mainstream and Segregated Schooling: Perceived Stigma, Social Comparison and Future Aspirations" is a study that examines children, aged 15 to 17, with mild intellectual disabilities in two different school settings, measuring the differences in three categories (Cooney et al., 432). The groups were selected by the school's teachers, with 28 children from the mainstream school and 32 in segregated schooling, 60 in all (Cooney et al., 432). The study used a set of scales to measure responses. To measure social comparison, the groups were presented with descriptions of two individuals,

one more severely disabled, and one without a disability (Cooney et al., 435). They were then asked to complete incomplete sentences. Stigma was measured with a yes/no questionnaire (Cooney et al., 435). To compare future aspirations, the children were asked to answer a series of questions about their wishes for the future, then rate the perceived difficulty of achieving each wish (Cooney et al., 436).

Between the two groups, the mainstream school children reported more instances of stigmatized treatment, including exclusion by their non-disabled classmates (Cooney et al., 438). There were not many examples of suffering stigma reported by the segregated school group, but both groups experienced stigmatized treatment outside of school, such as name-calling (Cooney et al., 438). Both groups compared themselves favorably to both the more severely disabled and non-disabled examples; there was no difference between the two (Cooney et al., 439). Most of the participants aspired to blue-collar-type jobs; only eight children out of 28 from the mainstream school group chose professional-level jobs (Cooney et al., 439). The two groups showed little difference between the perceived difficulties of achieving their goals, although both acknowledged their intellectual limitations (Cooney et al., 440). Perceived stigma did

not play a role in the groups' future aspirations, and all the children maintained optimistic attitudes (Cooney et al., 440).

These studies contribute to establishing that intellectually disabled people are aware of the stigma they face; in some cases, this stigma affects their self-esteem, as is the case with Paterson et al.'s study of self-esteem, comparison, and stigma (172). However, stigma does not affect social comparisons as strongly as self-esteem; Cooney et al. reports no relationship between stigma and comparisons (439). Using the studies of Jahoda et al. and Jahoda and Markova, the responses of the intellectually disabled to stigma can be seen. Gary's interviews show his wish to become a member of mainstream society and reject his "disabled" label, similar to the people moving out of the hospital in Jahoda and Markova's study (Jahoda et al., 527). These four studies reveal the variety of ways in which stigma impacts the lives, self-images, and aspirations of the intellectually disabled. As evidenced in all four studies, society must change before the intellectually disabled can freely express themselves without experiencing stigma; many of the studies suggest acceptance is crucial and that developing a sense of individualism and agency can protect against the effects of stigma.

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