Disabled people marginalized by paperwork and programs that aim to help them

September 13 2019

Credit: CC0 Public Domain

Disabled people face being marginalized by the very programs that are designed to help them.

Rather than taking their differences and particular preferences into

account, projects and welfare systems established to provide support are normalizing disabled people, and unintentionally contributing to their further marginalization.

Research from Lancaster University Management School (LUMS), published in *Organization Studies*, investigated a program that allocated computers to disabled people. Its aim was to help people improve their sociability through electronic interactions. The research focuses on the part played by an assessment form designed to establish whether or not a person qualified for a computer.

The study found that the scheme's assessors did not apply a strict interpretation of the questions and answers on the form, and sometimes ignored responses or shaped answers to better suit the program's requirements. This allowed some of those involved to receive a computer even though they did not comply with the allocation criteria, but had the unintended effect of glossing over their views and wishes in favor of the preset organizational goals of promoting sociability.

Dr. Yvonne Latham, of the LUMS Department of Organization, Work and Technology, who conducted the research, observed that carers, family members and project staff applied their own views and perceptions of what was important for disabled people, while often ignoring their actual preferences.

"The assumptions of those who organized the project were that disabled people are lacking something that can be 'fixed' so as to make their lives similar to those of the able-bodied," said Dr. Latham. "Forms will often have yes or no answers to questions which demand more complicated responses. Consequently, welfare worked treat issues such as whether individuals are able to wash, dress or use the toilet by themselves—capabilities that are forever changing, often on a daily basis–with limited importance as they try to render impaired bodies more

predictable than is plausible.

"In our case, while the form itself had implications for disabled people, the filling in of the questions and responses, and the results thereof, are also affected by the assumptions of those carrying out the questioning. Everyone has preconceived ideas, and these are evident with how they would violate both the spirit and the letter of the form—often normalizing assumptions of the needs and desires of those people with whom they are speaking."

For example, among the disabled people interviewed was Ron. During his interview, Ron revealed that he did not want to use the computer for which he was being assessed to increase his social connectivity, but rather for activities such as buying and selling shares. He answered: "I don't want to increase my social interactions because I'm miserable, like my brother." He felt that people looking to fill out the form in a certain way were not listening to him.

The interviewer eventually decided that Ron would benefit from using the computer with internet access and would see a boost to his independence as a result, and thus was allocated a computer despite his not fitting the prior organizational criteria of a suitable user.

Other examples included Chloe, a 25-year-old wheelchair user, whose mother was adamant she would not let her use the computer for online shopping (one of the criteria of 'fit' for the program), as she wanted to continue to take her out shopping. Chloe was not seen as socially isolated so much as lacking independence as a result of her mother's control over her life.

Polly, a woman in her 60s with Lupus, Angina and Arthritis, gave the expected responses, thus allowing a straightforward and positive form filling process. As a result of the cost of broadband and the discomfort

she had while trying to sit and use the allocated computer, Polly later returned it because she said it was causing her stress, and because she had not really wanted it in the first place.

Co-author Professor David Knights added: "These examples show how the responses on the form can both be shaped by the interviewer to gain the expected response, but also how the interviewee can give responses they feel are what is expected, even if the result is not what they desire.

"The form and the project were designed to help overcome the marginalization of disabled people through increasing their sociability, but these assumptions and the form's usage were reconfigured by those involved, glossing over the actual discussions that took place during the interviews and, on occasion, leading the interviewees to feel their views were being ignored.

"Imposing norms on disabled people and expecting them to fit in with preconceived ideas can have the unintended consequence of marking them out as being in need of special attention. There is a fine line in welfare between care and patronizing power."

Provided by Lancaster University