

## **Self-regulation among Young Women with Disabilities in Jordan from Their Perspectives**

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### **Abstract**

This study investigates the perspectives of young women with disabilities in Jordan, focusing on their self-regulation. 16 young women, aged 18–22, with visual (VI), hearing (HI) impairments and physical disability (PD), were recruited using a snowballing technique. Data were collected using semi-structured interviews, which were analysed thematically. Two main themes emerged where findings show that disability affects self-regulation where there was an overlap between local cultural perspectives in understanding disability of young women, disability and gender in understanding self-regulation of women with disabilities. Disability and gender also influence women with disabilities self-regulation with respect to self-learning, setting goals, self-evaluation, self-monitoring, making decisions and self-reinforcement. Findings will add to the current debate and efforts to understand disabilities in women and lay the groundwork for initiating a campaign in Jordan concentrating on the importance of self-regulation in young women with disabilities.

*Keywords: self-regulation, young women, disability, Jordan, cultural perspectives*

### **Introduction**

Self-regulation (SR) indicates the ability of individuals to manage their behaviour in order to achieve their own goals (Bandura, 1986). SR is defined as the *‘process whereby students activate and sustain cognitions, behaviours, and affects, which are*

*systematically oriented toward attainment of their goals'* (Schunk & Zimmerman, 1994: p. 309). For women with disabilities, the aim of SR is to demonstrate their demands and assert their rights, including the rights related to setting their own goals, access to vocational training to improve their employment opportunities, opportunities to work, promotion at work and equal pay, as well as their right to improvement in the quality of life guaranteed by the state (Abu-Habib, 1997).

In Jordan, the prevalence of disability is around 11% for those aged five and above (Department of Statistics, 2016), with no significant difference between males (10.89%) and females (10.30%). According to the 2015 census, PD's prevalence among females was 4.2%. VI's was 5.4% while HI's was 3%.

As women with disabilities in Jordan have no privacy of marriage, shift work, and limited independence in housing and living (Al-Zboon, 2013), they are more likely to be fully dependent on their families (Abu-Habib, 1997). Because their disability puts extra costs on them in terms of supplies or medication and/or treatments, the need for providing steady incomes for women with disabilities, including working to provide help and assistance to ensure a decent standard of living becomes urgent (Beleza, 2003). Such needs can be satisfied through self-regulation strategies that can assist them in achieving their independence.

As there is a growing interest in research on women who have disabilities across the world, there has been little research into the SR of women with disabilities in the Middle East (Al-Zboon and Smadi, 2015). There is limited data on strategies that women use to gain greater independence and more autonomy (Wehmeyer et al., 2003) and this lack of research is more noticeable in countries such as Jordan, where there is an apparent overlap between local traditions, religious beliefs and local cultural perspectives on disability, where having a child with disability is a source of shame and in some cases children with disabilities are hidden away or excluded from public life (Turmusani, 1999). As a result, women with disabilities respond using several strategies to increase their involvement in life and education (McConnell, 1999) and SR is considered an important factor for success in several domains of life (McCullough & Willoughby, 2009; Chambers et al., 2007).

Women with disabilities use various techniques to respond to difficulties and barriers that they face, the most important of these barriers are stigma, social exclusion and local cultural factors. Goffman (1963) argued that the stigma of disability may extend to those around a person with disability. As a result of disability, people with disabilities become more reluctant to socialise with others and develop their own ways of socialising where their parents may act as 'gate-keepers' to avoid the negative reactions of others. Thus, the aim of this study was to investigate the perspectives of young women with disabilities on SR in Jordan

and reveal the factors affecting the employment of SR strategies in everyday life in Jordan from the perspectives of young women. In this study, the term SR is used to refer to the self-directive processes and self-beliefs that enable women to transform their cognitive abilities into performance skills; e.g., goal setting, self-learning, self-evaluation, decision making, self-reinforcement, selecting and deploying strategies and self-monitoring. These self-regulatory skills help them to adapt to living with their disability in their society.

## **Theoretical Framework**

Mithaug's SR theory (1993) explains how to improve the adaptation of individuals in order to increase the likelihood of their access to resources in their environments. This theory describes the relationship between the individual and their adaptation to changes in their environment. It goes beyond them as to the mechanisms of solving problems and the performance of the solution, leading to adaptation and target maximum. Disability can be seen by others as a barrier to achieving goals or being accepted by society, and in some cases this results in people with disabilities being victims of violence (Goffman, 1963). The parents of women with disabilities face constant queries from outsiders about their daughter's disability and the kinds of support and services they provided. However, parents' fear of 'courtesy stigma', where people who work or have stigmatised children are more likely to bear a courtesy stigma (Goffman, 1963), explains why some parents act as gatekeepers for their daughters and interfere in their choice of goals.

## **Methodology**

This study was designed as a qualitative study. Sixteen young women, aged 18–22, with three types of disabilities (VI (4), HI (5) and PD (7)), were recruited using a snowballing technique.

### **Ethics**

Using a consent form, the participants were fully informed about the study's aims, their rights including the right to withdraw at any time, and an assurance of confidentiality. No real names were used in reporting the findings. Moreover, the research received ethical approval by the Institutional Review Board at the Hashemite University.

### Data Collection and Analysis

Semi-structured interviews were used to collect the data, where interviews lasted 30–45 minutes.

The interview data were subjected to thematic analysis using the approach presented by Braun and Clarke (2006).

## Results

### How Disability Affects the SR of Women with Disabilities

PD appeared to have less impact than visual and hearing disabilities. The participants attempted to learn by themselves, evaluate, monitor and reinforce themselves, and make their own decisions. They perceived that their disability constrained their choice of subjects to study and influenced their goals, how they evaluated themselves and how they were seen by others. They had the impression that their disability influenced their self-reinforcement and their ability to make their own decisions:

- *‘I choose what to do all the time’.*
- *‘Does anyone help you out with that?’*
- *‘I ask for help when I need it’.*
- *‘Do your parents choose for you or tell you what to do?’*
- *‘Yes, they do’.*

She explained the contradiction: *‘Do not forget that I am a disabled woman and I need help’* (L, PD). Although young women with disabilities want to organise their own lives, they must do so in the context of their disability and cultural attitudes to disability. Some participants realised that their disability set limits on their ambitions and adjusted their goals accordingly. When M (VI) was asked about setting goals taking into consideration her impairment, she replied: *‘I cannot forget that I am a blind person’.*

Disability was one of the top factors that they had to take into consideration when setting their goals. Setting goals, as in the case of learning computer skills, was critical for them where disability was not seen as an obstacle.

*‘I evaluate my progress towards my goals, but remember that we live in Jordan and I have to accept that I am a woman. When I set myself a goal, I have to bear in mind that I am visually impaired and it is difficult to get the proper machine to use. So*

*I am slow. I heard some people asking 'do you need these skills?' That was shocking and offensive.'* (M, VI)

Disability and gender had partial effects on their self-monitoring and self-reinforcement. The participants used self-monitoring skills to help them set and achieve goals, but they felt they had to reinforce themselves constantly in order to achieve their goals. Seeing their disability as motivation led to increasing their self-monitoring and self-reinforcement respectively:

*I do monitor myself all the time but I am limited by what I can do. I mean, I have impairment and I cannot see everything, so I have to be careful and in some cases depend on what others say.'* (M2, HI)

Decisions were influenced by the views of family members and their positions as women with disabilities. The participants reported that although they took other people's opinions into account, they made their own decisions and based them on these goals, although they did not ignore the role of their social network.

*I set my own goals and I take decisions for myself. I cannot simply ignore the role of others like my mother and father. They help me and I sometimes ask for their assistance. I cannot say that they do not help me but I try to take my own decisions.'* (M2, HI)

Women with physical disabilities appeared to have a stronger voice in the making of decisions, which affected them more than those with visual or hearing disabilities. Thus, it is not surprising that mothers and elder sisters were the main influences on the participants' decisions. In the local culture, mothers and sisters play a central role in the life of sisters: *'My mother and sister always help me and choose what is better for me'*.

### **Obstacles Facing SR of Young Women with Disabilities**

The participants reported that their society, their disability and their social network hindered their attempts to establish SR. They indicated that they were not seen by their society as productive individuals and that they believed their disability prevented them from organising themselves. The tendency to underestimate the abilities of young women with disabilities was common to several actors and levels:

*'I do not feel I am popular and no one supports me. Sometimes I feel that when I want to do something, everything is against me. I know I am disabled but that does not mean that I do not deserve chances like others. They see my impairment rather than my abilities but that is not going to stop me from organising and planning my life'* (R, VI)

The participants reported that society underestimates their capability, as well as placing barriers in the way of their self-development and regulation. They reported that they were seen as women with a disability rather than as humans.

The participants felt that they did not have the same opportunities as women without disabilities and most indicated that this had a direct impact on their SR. They pointed out that the discrimination prevented them from self-learning and setting personal goals. The participants agreed that they wanted to set their own goals rather than having them decided by any other party:

*'I have to set goals for myself. I know that my society and other people around me will not be interested in my goals or help in any way as they see disability as a bad thing. But I insist on setting goals for myself because it is my life'*. (S, PD)

The participants reported that society's attitude to disability was the main barrier to them achieving their personal goals. In many cases the participants reported that attitudes to disability did not prevent them from setting goals, but did stop them from achieving their goals despite constant frustration:

*'There is constant frustration and that comes from society itself. I struggle all the time to be seen by colleagues and other people as a normal young woman. I am a normal young woman and I have a life and goals I want to achieve, so why do you stop me?'* (M, VI)

Disability was seen as a barrier to SR where it had prevented the participants from setting and achieving goals. Among the sample, it appeared that PD had less impact on SR than other disabilities. The women with a PD appeared to be able to set their own goals, monitor themselves, learn by themselves, evaluate themselves, make their own decisions and reinforce themselves.

Disability hindered the participants from taking control of their lives and achieving goals. As Kh. (PD) said: *Yes, I set myself goals but I do not know how to implement or achieve them. I mean, in my case how can I play sports or swim?'* The participants with a HI seemed to feel that their impairment had less impact on their life than the participants with a VI; the group on whom disability had the greatest impact consisted of the individuals with a PD.

Those with a VI had set themselves the goal of memorising the Qur'an, the Muslim holy book, but their impairment hindered them from achieving this goal. The participants did not consider their disability as a hindrance to setting goals but they reported that it was a barrier to achieving them. Having a disability had an impact on the other components of SR, especially self-evaluation and self-reinforcement.

The participants pointed out that their social network, including family members, was a source of difficulty; the participants felt that there was no trust in their capabilities and it was a source of stress: *'Not everyone believes in me and my abilities, I mean, in many circumstances I feel that I am alone and they do not understand me'* (D, VI).

The participants emphasised that they felt they were constantly under pressure from their social network: *'I sometimes feel that I am watched all the time'*. The participants linked the negative social attitude to disability with the lack of appropriate available support. They reported that they received poor support and were often not assisted in achieving goals. This was attributed by the participants to the providers of support, who tended to underestimate their abilities and as a result sought to define goals for them: *'my family and friends support me but I cannot see that their support is sufficient'* (T, HI).

The participants felt that their social network responded to them with sympathy rather than believing in them and their abilities. This had a direct influence on the participants as they were seen as women with disabilities rather than human beings:

*'Yes, I need their help but do not want them to organise my life. I mean, they see my impairment not my abilities and start deciding and sorting things out for me. This is the last thing I want. I want their psychological support not their pity.'* (J, HI)

## **Discussion**

Understanding the local cultural contexts in which the women with disabilities in the current sample operate is critical to interpreting these findings (Trimble & Fisher, 2006; Groce & Zola, 1993). The findings indicate that disability is seen from different local cultural perspectives, especially when disability disrupts an individual's social life (Shiu, 2001) and leads to stress and low self-esteem (Shiu, 2001; Varni et al., 1996). The local cultural context, including religion, was a critical

influence on the extent to which they were able to self-regulate and this observation reflects findings by Watterson & Giesler (2012). Support can be understood from two perspectives: first, support was identified by the participants as necessary (Hasnain et al., 2008), something they sometimes ask for; then the 'support' represented parents who take full responsibility for their daughter's behaviour and future.

The findings suggest that the women with disabilities had less opportunity for SR and experience more family interference than their non-disabled peers as a result of cultural attitudes to disability, although a few participants claimed to have more control (Kim-Spoon et al., 2013). The interference experienced by people with a disability varies according to the nature of the disability (Groce, 1999), age and gender (Hasnain et al., 2008). Using local cultural perspectives to understand and respond to disability becomes apparent when the person with the disability is female and where their parents tend to play the role of gatekeepers, and when their disability requires constant assistance from family members (Al-Zyoud, 2012; Groce, 1999).

No evidence was found that the young women with disabilities suffered from high social expectations (Muller & Louw, 2004; Groce, 1999); on the contrary, they suffered as a consequence of the low expectations within their society and social networks. Expectations varied according to the type of the disability (Groce, 1999) and gender. It is worth noting that the socio-economic status of the participants was not considered and this should be investigated in future research. It can be concluded that disability in Jordan is still understood in terms of a charitable or medical model, in which disability is seen in terms of the individual deserving pity or suffering from a 'problem' in need of treating, respectively, rather than focusing on providing women with disabilities with opportunities to develop and use their capabilities and function independently (Villach & Llanos, 2007).

The opportunities for women with disabilities to self-regulate were directly affected by their disability and their gender. These constraints influenced their self-learning, self-evaluation, self-reinforcement, goal setting, decision making and performance monitoring and limited their ability to take decisions for themselves and set their own goals. Although the majority of the participants reported that they were able to self-regulate, a deep analysis of their responses indicated that they had only limited control over their own lives and this limitation was attributed to their gender as female and the role of protection that had to be played by family members based on local cultural perspectives (Hasnain et al., 2008). It appears that families often act as gatekeepers for daughters with disabilities and this position reflects a social view that women with disabilities should be protected by their



families. This protection extends to interference with women with disabilities' SR and autonomy, raising again the urgent need for a better understanding of traditional beliefs, attitudes and practices towards disability (Groce, 1999).

Investigating factors that affect the SR of young women with disabilities represents a promising means to encourage them to have SR and enhance their participation in social life in order to achieve their independence and take their role in their society. It also provides women with disabilities with the responsibility to self-regulate and decides about their future where it rightfully belongs to the learners.

## **Limitations and Future Research**

Although this study is a rare example of research into the situation of women with disabilities in Arab countries, some limitations should be taken into account. Firstly, there is a need to confirm the current findings in a larger sample. Secondly, data were only collected from young women with disabilities and this study does not represent the voices of the parties that were perceived to interfere with or play a role in regulating the lives of young women with disabilities, especially parents. Thirdly, the snowballing recruitment method used in this research is a potential source of bias where participants are more likely to recommend their friends or acquaintances and should be avoided in future research. Finally, there is an urgent need to explore the SR of women with disabilities in the light of the increasingly rapid flow of information, the social change taking place in Jordan and the waves of Syrian refugees who have entered the country in the last five years and to analyse the influence of socio-cultural factors.

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