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“This is not what I thought life would be like” Participation in the disability movement after a trauma

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This article looks at why people with acquired disabilities – those who become disabled later in life – do or don’t join disability organizations. It focuses on RTP (Personskadeförbundet), a Swedish group that supports people with impairments caused by sudden trauma.

The study asks three main questions:

1. Do you want to participate?
2. Are you able to participate?
3. Has anyone asked you to join?

Joining a disability organization can help people adjust, find support, and build a new identity. But it isn’t always easy. Physical challenges, invisible disabilities, and money problems can make participation harder. At the same time, these struggles can also inspire people to get more involved.

The Disability Movement

The disability movement began as a response to discrimination and inaccessible environments. It rejected the “medical model,” which views disability only as a health problem. Instead, it supports the “social model,” which says society creates barriers that disable people.

The article argues that the social model must be inclusive, making space for different views and experiences – even from people who don’t want to be labelled as disabled.

What the Study Found

The researcher interviewed 27 people (23 women, 4 men) who became disabled, mostly through trauma. Some were active members of RTP, some had been members, and others weren’t sure if they counted as members at all. Membership, it seems, isn’t a simple yes-or-no status.

1. Do You Want to Participate?

Most participants didn’t join RTP because of interest in disability politics. They joined

because they needed help. For them, the better question is: “Do you need to participate?”

2. Are You Able to Participate?

Participation was possible, but often tiring or painful. People had to decide if it was worth the cost. Many joined for specific activities, like thermal baths, but stayed for the community. Being with others who understood them gave a sense of belonging. Ability to participate also changed over time with health, family, and life circumstances. So, the real question is: “Is it worth it?” – and the answer may change.

3. Has Anyone Asked You to Join?

Most had never heard of RTP before their trauma. They usually found it themselves, often through the internet, when they needed information. For them, the question of being “asked” to join didn’t make sense. Membership often happened naturally rather than by invitation.

Conclusions

To sum up, all of the questions the study asked had to be revised to fit this group and to give a better sense of reality.

One of the strongest benefits of joining was feeling part of a “we.” This helped people form an identity beyond being disabled. But identity isn’t always linked to the type of impairment. Some people didn’t want to be defined by disability, some had invisible impairments, and others even had negative views of disability. A truly inclusive movement must make space for all of these perspectives.

Participation isn’t a one-time choice. People may join, leave, and return. Needs also change over time: new members may mainly want information, while long-term members may seek friendship or advocacy. Today, RTP often focuses on recruiting new members through events and competitions. But the study shows that keeping members is just as important. Organizations should also think about what participation really means, not just about numbers.

Thus, the disability movement needs to adapt. It should include diverse experiences and offer flexible ways to engage, including online. Its power comes from collective effort, not rigid rules. To grow stronger, organizations should ask themselves:

- Why do we want more members?
- What do we offer them?
- What is our main purpose?

Answering these questions can help build a movement that is more inclusive and meaningful – one that truly represents the people it serves.

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