

Participation as a human right – and a health benefit

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This interesting paper casts light not just on rehabilitation for youth with physical disabilities, but also on the *International Classification of Functioning, Disability and Health*. As a result, we are challenged to think about broader concepts in disability – in particular, what participation means and how it affects functioning.

In this study, the authors show that participating in community activities for youth with physical disabilities had benefits to their physical functioning and their mental health. The young people selected their own activities, which included walking, swimming, drawing, computer programming and piano. Over the eight week period in which these activities were regularly practised, the participants both became more proficient in the specific activities themselves, but also experienced a range of improvements at the level of body functioning, both physical and mental. Not all functionings were improved, but each activity brought physical and psychological benefits. A benefit of the paper is the very careful measurement and analysis methodologies which demonstrate that, for an admittedly small sample, genuine health benefits result from participation.

While impressed by the rigour of the methodology, I confess, as a non-clinician, to be bemused by the need to prove this question in the first place. I recognise that research has long explored the relationship between different levels of the ICF (Wright et al 2008). However, while the ICF dominates the rehabilitation field, I worry that our developing understandings of disability have left the ICF model behind (Mitra and Shakespeare 2019).

Did anybody doubt that regular practise of a physical or mental skill would lead to improvement in abilities? People generally become stronger, more coordinated, and dextrous, from engaging in physical activities, and these often have impacts on self-esteem, concentration and relaxation (Martin 2006). Would there be any scientific benefit in testing non-disabled young people to see if engaging in sports and creative pastimes had benefits on their physical and mental health? Educationalists have assumed this for centuries, and few doubt that it would be better for all of us to stop using obesogenic, individualistic screens and revert to traditional participatory sports and arts activities. Why should it be different for children with disabilities? It cannot be that there is still an assumption that sports and arts are for nondisabled children, and not relevant or helpful for disabled children (Johnson 2009).

The other innovation in the study is that the activities which were evaluated were first co-produced. The researchers discussed with the young people what they would like to do, and then set about providing them with opportunities to do that. It is well known that coproduction is a successful strategy (Morris et al 2015). It leads to empowerment, and better outcomes (Friedman and Van Puymbrouck 2019). People are more committed to activities which they have chosen for themselves. Involving children and young people in health services is an established strategy (NHS Confederation 2010). We criticised the lack of person-centeredness in the ICF (Mitra and Shakespeare, and it is good to see ICF-based research taking this co-production approach.

This study is based on the ICF perspective, and talks of activity limitations and impairments at the level of body function and structure. Yet there is a vital third dimension to the ICF. Perhaps what would be of more importance is to talk to these young people about what had previously stopped them from doing these sports and cultural pastimes, from their perspectives. They would be likely to

identify participation restrictions – negative attitudes, inaccessible facilities, lack of services. What require more attention – and action – are these barriers, of both finance and opportunity, which prevent young people with disabilities accessing art, music, sport and other pastimes which could give them such health benefits. From a disability rights perspective – following the 2006 Convention on the Rights of Persons with Disabilities (UN 2006) – barrier-removal has to go hand in hand with individual-based rehabilitation services.

The very best psychological and social benefits are likely from hobbies in which both disabled and non-disabled young people participate equally, perhaps via youth clubs, faith groups, or after-school activities. Real participation happens when young people do not simply access pastimes, but do so as valued and equal members of society, alongside their peers. There are no health reasons why this is impossible, and many health reasons why it is desirable – and will be most attractive to young people with disabilities themselves.

References

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