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A personal family narrative: Being part of civil society through a Cerebral Palsy association

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Background: Civil society is the aggregate of non-governmental organizations and institutions that manifest interests and will of citizens, representing a collective voice for a certain group, including the family and the private sphere. It is a relief center for the represented group and an identity, and meeting place for people undergoing similar life challenges.

Method: A personal narrative of a family's perception of the benefits and support experienced through being a member of a Norwegian Cerebral Palsy association.

Narrative and theoretical reflections:

The Cerebral Palsy association has been a pillar of strength for our family, may be even more being an immigrant family. In the early years when many things were new and our son with cerebral palsy was young, the future was very unknown, day-to-day life was challenging and we felt alone with our trials. The organization functioned as an empowering collective voice for us. Meeting other parents going through similar situations was always a big relief, with exchange of ideas on our challenges and even much freeing laughter. The yearly Christmas parties were really a moment for our whole family, amazingly even for our younger kids who got to meet other children with siblings like theirs. For us these parties were a never-miss for many years. When we were in such gatherings it felt like we were in a world we belonged to, totally another world, just because of the easiness and relief it felt meeting others who are walking on same path as ourselves.

Civil society can represent a collective voice, a relief center as well as a meeting place. It is difficult for one person or a family to voice needs on its own; as group the voice comes out much stronger, and has helped in influencing government's policies. Such organizations function as a relief center, especially if they represent a group that has different needs compared to the majority. As a minority, it feels relieving to meet others with similar experiences. This facilitates exchange of ideas without fear or with less exhausting effort to cope with "normality" and "abnormality". Such organizations also provide a genuine social gathering with peer-families, and an arena of togetherness.

Key words: Civil society, narrative experiences, empowerment, relief, togetherness