



Parent Action: enabling, advocacy, empowering

Project team: Orla Watt, Sally McCabe, Sara Velasquez, and Parent Action

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Project background

A UK-wide family support organisation found that 70% of families raising children with disabilities in Northern Ireland felt they were socially isolated and that a lack of support from statutory services added to the social isolation of the child/young person and their family. *'These families have to fight to get support, and often the support available is insufficient and/or inappropriate.'* Parent Action (based in Northern Ireland) is a not-for-profit, charitable organisation that seeks to empower the parents of children and young people with disabilities/ serious long-term health conditions and/or continuing care needs to advocate effectively for all their family members' needs. Parent Action members believe the empowerment of parent advocates is a journey, a process with three elements: enablement, advocacy and empowerment. These elements constitute the 'Parent Action model'.

Aims and objectives

The aim was to enable parents to become more self- and critically aware of their family's situation, values, beliefs, priorities and thus be able to advocate more effectively for their children and families.

To achieve this aim, the objectives identified were to:

- Gather together actual and potential members of Parent Action into a community-based parent support and discussion group
- Explore, with parents, using person-centred facilitation methods, their values and beliefs around family-centred care for their children and young people
- Explore, with parents, the design of a shared vision for the group
- Facilitate parents to design meaningful and time-specific action plans
- Evaluate continuously throughout the project

Implications for practice

- Working with parents' hopes, fears and expectations helped the group to develop effective ways of working
- The values-clarification exercise was an effective way to help the group develop collaborative values statements about advocating on behalf of their children
- Working collaboratively with parents enabled them to become more confident. It also enabled the co-production of the guiding principles for Parent Action

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Online

Further information about the project can be accessed from: fons.org/library/report-details?nstd=73212

Key activities and outcomes

• Overview

Parent members of Parent Action, a pre-existing parent advocacy group, reported an absence of mechanisms for communicating with the public services they used and needed for their child. Spurred by this, the project lead brought a group of five parents together to work collaboratively on this project.

• Exploring parents' hopes, fears and expectations, priorities and preferences

Meetings involving the parents were held over a two-month period. A hopes, fears and expectations exercise was used to enable people to make contributions to the group. With skilled facilitation these were translated into the group's 'ground rules'.

• Exploring with parents the design of a shared vision for the group

The project lead introduced a values-clarification activity to help parent members think about what was important to them. The activity was conducted over a series of meetings, and facilitated discussion enabled the group to summarise and agree the most important statements. This resulted in the design of three mandalas explaining the group's collaborative values in relation to the purpose of the group and how it could be achieved.

• Facilitating parents to design meaningful action plans

To help the parent members identify what was important to them, the project lead introduced a reflective process and activity. Each parent presented an issue that was important to them, which was then used by the group as a basis for a group reflection. After a number of presentations over a number of weeks, three themes were identified by the group:

- Discrimination against people with disabilities/learning difficulties
- Me time (carer/parent support)
- Transition planning (between schools and into adult services)

Action plans and success criteria were developed for each theme.

• Collaboration with parents to develop a 'good enough' evaluation of their work

In order for the project to be effective in achieving its aim, parents and the project lead worked together to evaluate and reflect on the following:

- Parents' wellbeing and engagement at each meeting
- Parents' wellbeing and empowerment at three timepoints during the project

• Verbal feedback from the parent members:

'At the start, my main fear was sounding stupid ... now they can't shut me up!'

'With this group, now all supportive of each other, I feel that I can make a difference ...'

'Parent Action makes my brain work!'

'I need to come here and clear my head ... then I can fly my kite for my son's rights...'

'Feeling the creativity now in sharing ... seeing the beauty'