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The SOPHIE

Special Olympics Programmes Health Impact Evaluation

2013-2015 Study

Executive summary report



Special
Olympics
Ireland



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Executive summary

Background

No previous mixed-methods study has examined the impact of participation in Special Olympics (SO) programmes on the health and well-being of persons with ID and their families and compared them with persons with ID who do not take part in SO programmes. Special Olympics is an international organisation that provides sporting and social outlets for individuals with intellectual disability (ID). In Ireland, SO activities are resourced in part by the Exchequer, via the Irish Sports Council, and in part by voluntary funding. Recently, both sources of financing have been adversely impacted because of fiscal tightening in Ireland and a reduction in the capacity to raise funds. In Ireland, SO is the most popular organisation or club that individuals of any age with ID attend.

Aim

The primary aim of the study was to explore whether people with IDs who take part in SO programmes are healthier and happier than people with IDs who do not take part in SO programmes. For the purposes of this report, these groups shall be referred to as ‘athletes’ and ‘non-athletes’. Barriers to participation in SO were also explored. A secondary aim was to examine if there are any wider impacts on the families of athletes in terms of health and well-being. A third aim was to review the costs of delivering SOI programmes and to explore the value generated.

Method

A mixed-methods approach was employed. Using a cross-sectional study design, we recruited people with ID who take part or who do not take part in SO programmes in Ireland. Every attempt was made to try to ensure that participants were matched by age, sex, level of disability and level of ambulation within their own services, so, in theory, the only difference between them was that one group takes part in SOI while the other group does not. We conducted detailed interviews with athletes and non-athletes consisting of questionnaires and physical measurements. The questionnaires consisted of an EQ-5D-3L (as a measure of quality of life), the SLAN (Survey of Lifestyle, Attitudes and Nutrition) 2007 Survey (as a measure of health status and health-service use) and the International Physical Activity Survey (as a measure of physical activity). This was administered face to

face with participants (assisted by their principal family carer). The physical measurements included accelerometry (as an objective measure of physical activity), resting blood pressure, weight, height and waist-circumference measurements. Physical-fitness levels were assessed using a six-minute walking test. Nutrition intake was assessed using four-day food diaries.

Focus groups were conducted with persons with ID to explore their experiences and thoughts about taking part in SOI programmes as well as to explore barriers for those who do not. Qualitative interviews and focus groups were also conducted with their family carers and care staff.

We also administered the EQ-5D-3L and the SLAN survey to family carers about their own health status, and family carers completed a proxy EQ-5D-3L on behalf of the person with ID.

Financial records of SOI operating costs (2009-13) were analysed to determine the average operating costs over a four-year cycle. Survey questions measured athlete training time, volunteering time and funds raised by community clubs. The value of activities generated by SOI were considered benefits and valued according to the appropriate monetary values dependent on activity. The value of SOI was derived from the ratio of cost to benefits and expressed in terms of the net present value.

We interviewed SOI management staff to examine the strategies employed by the SOI organisation to overcome barriers to participation in SOI.

Main results

Participants

Participants were recruited from urban and rural day and residential care services for persons with ID in the Republic of Ireland. We invited 1,840 participant groups (athletes and non-athletes and their principal family carers) to take part in the research study. A maximum of four contact attempts by telephone were made to each participant group in order to recruit them. Approximately 8,200 phone calls were made in total in attempting to contact potential participants and subsequently in making arrangements to set up the research interview. Two hundred and ninety-two participants took part in this research.

This included 146 primary participants (101 athletes and 45 non-athletes) with an ID and 146 of their principal family carers. Of the recruited primary participants (athletes/non-athletes), 58.2 per cent were male and 41.8 per cent were female, with a mean age of 33.01 ± 11.09 years. Just under half (47.5 per cent) of the population had a mild ID, 46.1 per cent were considered to have moderate ID, and 6.4 per cent had a severe ID. Most of the principal family carers recruited (70 per cent) were female, and most (76 per cent) were parents.

Health-related quality of life

Athletes rated their own health-related quality of life as better than non-athletes, and this was statistically significant ($p = 0.03$). Non-athletes reported higher rates of depression than athletes, also statistically significant ($p = 0.07$).

Physical activity

Athletes self-reported significantly ($p = 0.002$) more mean minutes of moderate to vigorous physical activity (MVPA) daily (28.8 ± 32) than non-athletes (9.7 ± 22). A significantly ($p < 0.000$) greater distance was walked in the six-minute walking test by athletes (541 ± 103) compared to non-athletes (436 ± 100.6). A health profile score calculated by combining scores from body mass index, blood pressure, meeting ≥ 30 minutes MVPA daily and distance walked in the six-minute walking test showed that SOI athletes scored a significantly ($p = 0.013$) higher overall health profile (2.18 ± 0.81) than non-athletes (1.64 ± 0.70).

Nutrition

Seventy-five per cent of the sample were overweight or obese, but there was no statistical difference between athletes and non-athletes in terms of body mass index or waist circumference measurements. Energy contributed from fat, saturated fat and sugar was greater than recommended in the majority of study participants. Few study participants were meeting recommended daily amounts for micronutrients.

Focus groups with participants, family members and care staff

The focus groups show that SO impacts positively on athletes and their families. The benefits of participation for athletes were wide-ranging and included physical and

psychological well-being, increased levels of independence, improved social inclusion and higher levels of self-determination. For families, the benefits included an increased social network and an increased sense of family pride. Families noted the considerable time commitment of being part of SO but acknowledged that the benefits of participation outweighed any potential negatives.

Barriers to SO participation were identified, with particular difficulties articulated relating to transport, volunteer shortages and demands on older parents. For those not involved in SO, it was identified that more accessible information may be an important factor in enhancing the numbers taking up programmes. The current ‘selection process’ (the way in which athletes progress through the four-year cycle to world games) was identified by almost all athletes and families as a source of dissatisfaction and discontent. It was apparent that staff at the care services involved played an important role in supporting athletes to be able to take part in SO.

Focus groups with Special Olympic management

SOI staff identified themselves as a ‘national governing body for sport’ that provides sporting opportunities for people with ID. Access and financial constraints were identified as barriers to participation in SOI in a previous report; however, in this focus group, SOI staff reported that they do not believe these barriers fall within their remit to address. This view appears to be at odds with that of the athletes, who reported that they believe SOI should address these barriers.

Economic analysis

SOI supports in the region of 380 clubs and 9,000 registered athletes. Approximately 25,000 volunteers are registered with SOI, of which about 8,000 are active annually. Our analysis shows that SOI operations cost, on average, €6.04 million per annum over the past four-year cycle. The value of the athlete training provided by SOI was €7.59 million per annum (95 per cent CI: €4.62 million to €10.60 million). The value of volunteers to SOI was €1.58 million per annum (95 per cent CI: €1.23 million to €1.94 million). Funds raised in community clubs were an estimated €1,374,516. The net present value (i.e. expenditure plus monetary value of benefits) was €4,507,233.

Discussion

It is difficult to estimate the net gain from the health and other benefits accrued as a result of SO participation, but this study shows that they may exist. The sample of people with ID who take part in SOI programmes has a higher self-reported health status than those who do not take part in SOI programmes. Self-rated health and quality-of-life measures are increasingly being recognised as a valid indicator of a person's health status. Studies show that self-rated, health-related quality of life consistently predicts health outcomes. The study also shows that those in SOI have higher levels of physical activity, are physically fitter and have a higher health-profile score. Obesity was a feature of both the athlete and non-athlete group and was more prevalent than it is in the general population in Ireland.

For families of those involved in SOI, there appear to be beneficial effects also. These include increased social engagement with other families and enhanced family pride. The barriers to participation in SOI programmes identified in this report could potentially be overcome with local planning, enhanced communication and reallocation of funds to tackle transport shortages and strategic identification of those most in need of this resource at local club level.

The team encountered significant difficulties in recruiting participants to the study, particularly from the non-athlete group. Recruitment of an ID population has been recognised as a difficulty in previous studies and is not unique to this one, but it does limit the generalisability of the findings. Reasons for low uptake included competing priorities, unavailability, inability to make contact, insufficient verbal communication skills, respite stay, illness, no-show at research interview, transport issues and geographical distance from the prearranged sports venue.

Conclusion

It is clear that SOI are fulfilling their mission, as stated on their website: 'to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with an ID, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendships with their families, other SO athletes and the community'.

This study provides unique data which has not previously been probed, showing the benefits and generated value attributable to the work of the voluntary organisation, SOI. Our study provides novel quantitative and qualitative information, giving us a better understanding of the benefits, impacts and experiences of taking part in SOI programmes for athletes and their family carers. It also provides us with useful insights into non-involvement by families of people with ID which could be used to inform strategies to improve participation rates. The results will be valuable to athletes, to their families and to the SO organisation.

Limitations and strengths

This is the first study of its kind to our knowledge. The strengths of the study include a detailed face-to-face survey, physical measurements and qualitative information gathered directly from persons with ID who take part in SOI programmes as well as a comparable group of people with ID who do not. Due to the poor response rates, this study cannot be considered a representative study of people in athletes and non-athletes.

Recommendations

The Irish State should continue to invest in the health and well-being of people with ID through SO. We recommend that funders and policy-makers ensure that sufficient funds are provided to SOI annually to allow continued support of SOI clubs nationally. Future research should be undertaken with sufficient statistical power to detect health gains over multiple time points as a result of SO participation. Those attending SOI programmes should be supported to continue attending, and those not in SOI should be invited, encouraged and supported to attend where possible.

Efforts to reduce barriers to participation in SOI programmes should be undertaken specifically to address difficulties of transport and associated costs of involvement; to increase volunteer numbers and identify and address issues of particular concern to older parents. There needs to be an acknowledgement that current methods of communicating information are not always effective, and SO should consider identifying additional ways of promoting participation. The SO selection process, by which athletes progress through the four-year cycle to the world games, needs to be reviewed by the organisation as there is a general dissatisfaction with the current way in which athletes are chosen for

competitions. This may involve a different communication strategy as well as a review of the current system.

We recommend that SOI clubs record information on athlete training and all volunteer time provided and communicate this data to the central SOI organisation to generate national-level data. In addition, SOI should document the professional qualifications of volunteers so that a true value of the work they do can be more precisely estimated.

Health-care professionals working with people with ID should monitor the issue of overweight and obesity in this population and utilise evidence-based interventions for dealing with these. They should also be made aware of the reported benefits of participation in SOI and be encouraged to facilitate as much participation as possible in its programmes by people with ID in their care.