The impact of four family support programmes for people with a disability in Ireland

Louise Daly
Trinity College, Ireland

Danika Sharek
Trinity College, Ireland

Jan DeVries
Trinity College, Ireland

Colin Griffiths
Trinity College, Ireland

Fintan Sheerin
Trinity College, Ireland

Padraig McBennett
Trinity College, Ireland

Agnes Higgins
Trinity College, Ireland

Abstract

Background: This article reports on an evaluation of four family support programmes in Ireland for families of people with a physical or an intellectual disability or autism. The focus of the evaluation, which took place within a year of the programmes' completion, was on establishing whether the programmes had an impact on families' capacity to effectively support their family member. **Method:** A mixed-method design was used, which included a survey ($n = 38$) and interviews ($n = 19$) with participating family members. Ethical approval for the study was given by the relevant university ethics committee. **Results:** Findings suggest that participation in the programmes enhanced knowledge, attitudes, and competencies of families and also impacted their ability to advocate for their family member and to connect with the community. **Discussion and conclusions:** Whilst outcomes were overwhelmingly positive, further follow-up would be required to ascertain if sustained capacity building took place.

Corresponding author:
Colin Griffiths, The School of Nursing and Midwifery, Trinity College, 24, D'Olier street, Dublin 2, Ireland.
Email: cgriffi@tcd.ie

Introduction

The importance of environment and family as significant contributors to the quality of life of the person with a disability is well recognized (Brown and Brown, 2004). Families, as opposed to institutions or services, are considered the primary support unit and social resource for a person with intellectual disability (Rillotta et al., 2012). However, to be effective in their supporting role, families, in turn, need support (Resch et al., 2012). Often this support is not forthcoming. Findings of studies in several countries show insufficient support with access to services, fragmented or ineffective service provision and disempowerment of families (Courtin et al., 2014; Powers et al., 2006; Ruble and McGrew, 2007; Taggart et al., 2012). Furthermore, whilst Courtin et al.'s (2014) review of carer support in Europe identifies the importance and availability of carer-specific supports, it appears that financial support, in terms of direct payments or entitlements, is often the approach employed. This may be due to the difficulties in developing individualized supports but is more likely to be related to an unwillingness of carers to access such supports (Courtin et al., 2014). The most urgently needed supports for families have been identified as developing knowledge and self-advocacy skills, building of peer support networks and helping with accessing and navigating services (Etmanski et al., 2011).

Programmes to meet these needs are increasingly recognized as important (Breckenridge and Huppert, 2010; Dunst 1990 cited in Dunst et al., 1991). The evolution of family support initiatives as alternatives to the hegemonic influence of more medical approaches began in the 1950s and 1960s. These were often initiated by parents and advocated for education, care, and community inclusion of the person with a disability. Since then, the perspective of families has increasingly featured in the research literature as the service needs of individuals and their families have been prioritized (Higgins et al., 2013). Dunst et al. (2002) proposed a model to categorize family-oriented supports according to the extent of self-sufficiency and capability assumed. In order of increasing level of family centredness, they identified (a) *professionally centred* supports that generally see families as deficient and incapable without professional interventions, (b) *family-allied* supports in which families are carrying out professionally prescribed interventions, (c) *family-focused* supports that emphasize professionals offering choices to families and monitoring their use of services, and (d) *family-centred* supports that work on the assumption that families are fully capable to make informed choices whilst professionals support this.

Family-centred and family-focused programmes have been shown to be more likely to facilitate choice, involvement, knowledge and skills to augment functioning within families (Dunst et al., 2002, 2007; Truesdale-Kennedy et al., 2006). Activities consistent with family-centred or -focused practice tend to emphasize improving well-being, social support and service satisfaction via increased parental self-efficacy (Department of Human Services and The Department of Education and Early Childhood Development, 2012; Heller et al., 1999). To be successful, it is important that the impact of such programmes is sustainable and incorporates building capacity in participants. The Irish Department of Health (2012a: xi) phrases it as follows: 'Capacity-building is the process of ensuring that an individual or organisation has the skills, competencies, knowledge, structures

and resources to realise their goals effectively'. For family support programmes, capacity building means first and foremost the provision of relevant and practical materials and skills that can be implemented independently by participants. Butera-Prinzi et al. (2010) found that the acquisition of knowledge, envisioning of a positive future and the development of advocacy skills by parents were pivotal capacity-building resources. Other studies also demonstrate the significant benefits of building interconnections and peer networks among families as a form of capacity building in terms of sharing of information and experiences leading to greater empowerment (Black et al., 2008). Findings such as these may suggest that effective programmes should focus on empowering the families in their engagement with policymakers, services and local communities. As such, family support programmes, if successful, may enhance quality of life for people with disability and family members and facilitate them to determine their futures (Taggart et al., 2012).

Knox et al. (2000) highlight the importance of considering 'family' as a component of an ecological structure located within social, economic and political systems that directly affect family. In this context, Chenoweth and Stehlik (2004) argue for innovative supports to create social capital and capacity by working with people with disabilities, families and communities to support social inclusion. This is by no means a given. For example, research has demonstrated that families and people with disability encounter barriers to, or have reduced capacity to become part of, naturally occurring networks in the community through which social capital can be generated (Chenoweth and Stehlik, 2004). Therefore, whilst specific knowledge and advocacy skills may be useful to families, it would seem that without generating an element of community support, the programmes would be found lacking.

This article reports on the impact of four programmes in the family-focused and family-centred spectrum that were designed in Ireland to support families of people with a variety of disabilities. Each of the programmes was developed according to the principles outlined in the previous paragraph offering a mixture of skills training, broadening of participants' knowledge base and establishing support networks. The programmes were funded for a fixed duration of time. This article reports on a subsequent follow-up evaluation commissioned by the funder to establish the impact of the programmes on participating families (Higgins et al., 2013).

Four family support programmes

The family programmes were delivered by four different organizations in the Republic of Ireland (see Table 1 for full detail). Two of the organizations were parent led and two were professional led. One of the professional led services had undergone a transformation to emphasize individualized service delivery focusing on community inclusion and integration. The format of the initiatives varied. Two services offered families full day or residential weekends, whilst others offered shorter information sessions typically 2-h evening sessions that were spread over a period of months. The four initiatives used different activities to achieve their objectives, which included workshops to promote advocacy, develop social networks and develop circles of support with a view to enabling families to connect more meaningfully to their local community. The initiatives also used workshops on person-centred planning, family leadership and interestingly one initiative opened a dialogue with community child care providers on inclusive policy and practices. All the initiatives had taken place during the year prior to the research taking place. The programmes were targeted to enable families to rethink the way in which they and their family member approached their futures. In particular, they facilitated participants to develop their personal skills and also their knowledge of how to advocate for their family member by engaging with services and government agencies.

Table 1. Main features of the four programmes.

Project name	Number of participants.	Type of sessions	Aim of sessions	Times for sessions	Types of participants
A	47	A programme of training to enable parents and families to support their family member effectively in their community, this included a parent advocacy 'Train the Trainers' Programme.	The aims of this initiative were to increase the number of children participating in mainstream activities, inclusive child care and play services. Also to enable parents of children and young people with disabilities to advocate on their behalf.	Evening sessions over autumn and spring. Saturday workshops.	Parents, siblings, children with disabilities. Some individuals from the local community.
B	60	A programme of training to enable families to understand autism and its impact on the person. Skills taught included how to plan for the future, navigate the system and build personal networks.	The programme aimed to give families a clear understanding of the needs of the person with autism, of behaviour management strategies, communication strategies, social skills and life skills that are needed to transition from childhood to adulthood.	Mid-week sessions, weekends and evenings.	People with autism and their families.
C	37	A programme of training to enable parents and families to build resilience, knowledge base, skills and capacity for the person with disability, family members, circle of support members and staff.	The initiative aimed to embed effective family-centred practise by building organizational capacity in relation to family leadership to transform the relationship between people with disabilities, their families and all other stakeholders.	Weekend residential – whole family participation. Midweek courses and evening courses.	People with disability and their whole family.

(continued)

Table I (continued)

Project name	Number of participants.	Type of sessions	Aim of sessions	Times for sessions	Types of participants
D	33	A programme of training to empower and upskill families and individuals with intellectual disability and/or autism to lead self-determined lives.	The aims were to empower and upskill families and individuals with disabilities to lead self-determined lives and be active citizens in their own communities.	Weekend residential and midweek sessions.	Families and individuals with intellectual disabilities and/or autism

Method

Study aim and objectives

The aim of the study was to evaluate four grant-aided family-focused initiatives. Specific objectives were as follows:

   a. to identify the specific impact of the programmes on knowledge, skills, self-advocacy, social support, attitudes, and confidence related to the support of the family member with the disability;
   b. to identify the extent to which the programmes had succeeded in building capacity in the families in their care and support for the person with the disability in their family; and
   c. to evaluate the satisfaction of the participants with the programmes.

Research design

The evaluation employed a mixed-method approach using qualitative and quantitative methodology. Data were collected from family member participants using surveys and interviews. The study received ethical approval from the relevant ethics committee at the authors' university. Consent and treatment of participants was according to the Declaration of Helsinki (World Medical Association, 2013).

Data collection

Survey tool and development. A 28-item survey was devised to gather quantitative and qualitative data from family participants. The survey consisted of Likert scales, statements and closed and open-ended questions. It was structured in sections that addressed the specific objectives of the study. The survey design was informed by the Family Quality of Life scale (Brown et al., 2006), the Enabling Practices scale (Dempsey, 1995) and the Family Support Program Outcomes Survey (Friends, 2004). The survey took 15 min to complete, and the participants had the opportunity to complete the survey either in hard copy or via an online link to an online survey tool (SurveyMonkey.com LLC., 2012). Cronbach's α for all Likert-type survey questions included was 0.96, which indicates a high degree of reliability and consistency within the survey (generally 0.70 is considered acceptable within the social sciences).

Table 2. Participating family members in programmes, surveys and interviews (*n*) and response rate (%).

Programme code	A	B	C	D	Total
Total surveys distributed	47	60	37	33	177
Surveys returned and % of total	15 (32%)	3 (5%)	9 (27%)	11 (29%)	38 (22%)
Interviews	6	1	9	5	21

Survey recruitment and sample size. All participants in the four family-focused programmes were approached either by post or via email to participate in the survey. Two follow-up reminders were sent 3 weeks apart. Of the 177 total participants in the programmes (see Table 2), 38 participants responded to the survey (response rate of 22%). At a confidence interval of 95% this means that the sample had a confidence interval or margin of error of 14.13 (sample error = 11.7%). Of the responses, the majority were from parents (79%; *n* = 30), a further 16% (*n* = 6) identified themselves as siblings, one was a grandmother and one an aunt.

Interview guide

To gain an in-depth perspective on family members' experiences of the initiatives, semi-structured interviews were conducted. The interviews explored perceptions of the initiative, perceived benefits to the participant, family unit and the person with a disability, challenges encountered in participating and applying learning and suggestions for future initiatives.

Interview recruitment and sample size. The survey packages that were sent out contained an opt-in form for people interested to be interviewed. Twenty-five people completed the opt-in form, all of whom were contacted, and 21 interviews could be arranged (18 mothers, 1 sister and 2 fathers). Interviews took place at a time and location that suited each participant and with permission were digitally recorded. Interviews took between 40 and 80 min.

The person with a disability. Just over half of the participating family members attended the programmes because they had a person with an intellectual disability (53%; *n* = 20) in their family (with mostly moderate to severe intellectual disability), with 24% (*n* = 9) with a family member with a physical disability and 24% (*n* = 9) with a family member with autism. The mean age of the person with a disability was 16.5 years (SD = 12.3) ranging from 2 years to 54 years. Gender was distributed evenly. The majority of family members with a disability lived at home with their parents (81%, *n* = 29) or other family members (14%, *n* = 5). Only two lived independently. Various conditions were mentioned as part of the disabilities, such as speech and language difficulties (*n* = 19), behavioural challenges (*n* = 17), physical health problems (*n* = 17), mobility challenges (*n* = 17), feeding or eating problems (*n* = 10), seizures (*n* = 8), major hearing or vision impairments (*n* = 8) and mental health problems (*n* = 6). Many participants mentioned multiple issues. The level of communication was assessed with a 5-point scale, ranging from low to advanced, that is, low (11%), basic (24%), needs based (22%), limited range of topics (27%) and advanced (16%). The level of support required was also assessed with a 5-point scale indicating the extent of aspects of life requiring disability-related support, for example, almost all (24%), most (19%), some (35%), a few (14%) and none (8%). The responses indicated that significant degrees of support were needed for the person with the disability in most of the families involved in the study.

Data analysis

All survey data were entered into SPSS statistics 19.0 (IBM Corporation, 2010). Descriptive statistics were generated, including frequencies, means, range and standard deviations. These statistics provided a measure of the extent to which each objective of the project had been reached. Comparisons of data between initiatives were also computed. Computation of inferential statistics was limited by the small sample size; therefore, few inferential statistics could be reported.

A thematic analysis (Creswell, 1998; Guest, 2012; Thomas, 2006) of the open-ended survey questions was conducted using NVivo. Each interview was transcribed verbatim and then entered into the software package NVivo version 8 for analysis (QSR International, 2009). A preliminary coding framework was developed from the literature and early analysis of the first transcripts. This remained open to facilitate the inclusion of emergent codes to be incorporated as analysis proceeded. On completion of the first level of data analysis, codes were reviewed and overlapping codes were merged into higher level themes. The resultant coding structure was then reviewed by the research team to compare and contrast findings within and across the four projects. The approach to coding was informed by the inductive process detailed by Thomas (2006). Where appropriate, findings from the survey and family interviews are integrated together in the presentation of the findings. Quotes from the interviews are presented using the following conventions: project initiative letter code along with 'FM', meaning family member and the participant number.

Results

The results are presented in four sections in which quantitative and qualitative findings are combined and related to one another. Qualitative findings from the surveys (open questions) and the interviews are addressed in tandem. The first section provides a general overview of the response to the four initiatives in terms of satisfaction and perceived impact. The following three sections each address a specific theme emerging from the qualitative data.

Table 3. Comparison of the four different programmes for overall helpfulness of the programme and ANOVA.

Question: Overall, how helpful was the family initiative for you and your family?	Programmes (mean/SD)					ANOVA	
	Total ($n = 38$)	Project A ($n = 15$)	Project B ($n = 3$)	Project C ($n = 9$)	Project D ($n = 11$)	F (p)	η^2
Response (range 1–5) 5 = *very helpful* (61%) 4 = *helpful* (28%) 3 = *neutral* (6%) 2 = *not very helpful* (3%) 1 = *not at all helpful* (3%)	4.42 (0.94)	4.57 (0.514)	4.67 (0.58)	4.44 (1.13)	4.10 (1.29)	.559 (0.646)	0.050

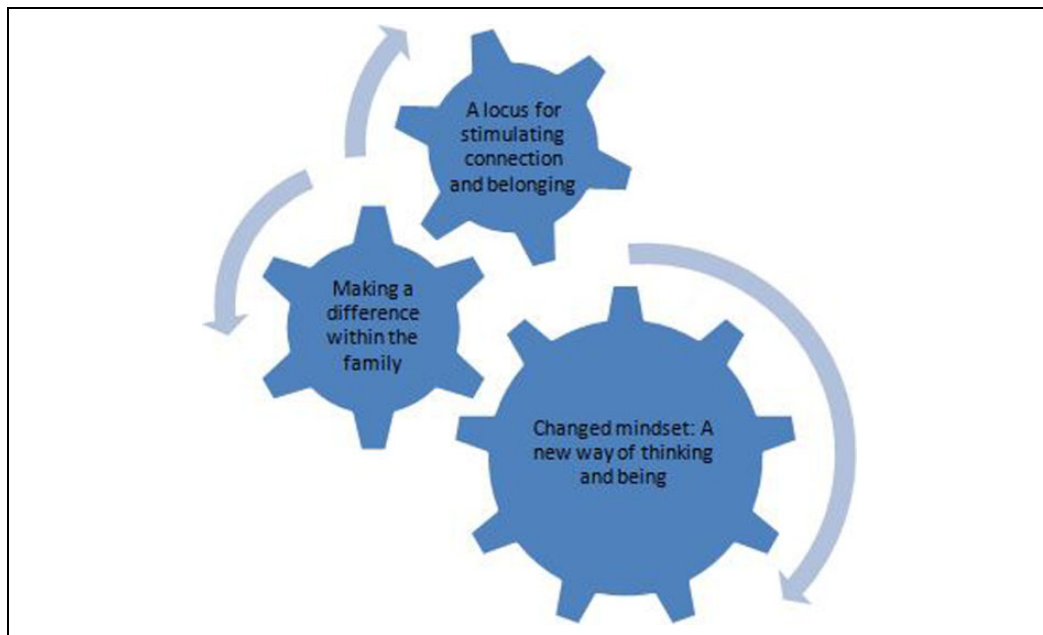*Note:* ANOVA = analysis of variance.

Figure 1. Overview of the thematic findings and their interrelationships.

Overall helpfulness of the initiatives

The question addressing the helpfulness of the initiatives (Table 3) serves as an indication of impact. The overall response shows that a very high percentage found the initiative to be very helpful (61%), whilst an additional 28% found it helpful. Very few participants were neutral or negative on this issue. In terms of mean scores that ranged from 1 to 5, the high overall mean of 4.42 (SD = 0.94) further indicates convincing satisfaction with the helpfulness of the initiatives. All four initiatives scored highly on helpfulness, and an analysis of variance confirmed that the response to the initiatives was not significantly different.

This is also supported by the findings from the qualitative interviews and open survey questions. Detailed analysis of these findings revealed three interrelated themes that described the family member participants' perspectives on the impact and benefits of the family initiatives (Figure 1). Findings from the quantitative data set are incorporated where appropriate.

Theme 1: Changed mindset – A new way of thinking and being

This theme demonstrates the impact of the initiatives on participants' knowledge, skills, confidence and attitudes and explores how participants adopted new ways of thinking and being. Participants described a number of areas where their knowledge and skills increased, including improvement in understanding the actions of their family member with a disability, development of strategies for supporting and living with their family member, increase in problem-solving skills within the family, development of circles of support, enhanced understanding of concepts, such as

Table 4. Impact of family initiative on knowledge, skills and attitude in supporting family member with a disability.

	Stayed the same	Slightly improved	Moderately improved	Greatly improved
Knowledge ($n = 37$)	5 (14%)	6 (16%)	26 (70%)	0 (0%)
Skills ($n = 37$)	5 (14%)	7 (19%)	25 (68%)	0 (0%)
	Stayed the same	Slightly changed	Moderately changed	Greatly changed
Attitude ($n = 36$)	13 (36%)	3 (8%)	9 (25%)	11 (31%)

personal funding, home share, respite care and disability service financing and an improved knowledge of the legal framework related to disability. Acquiring this knowledge was viewed as a source of empowerment, as described by these participants:

> I suppose information is power really. . . . (Project C FM 1)

> The more knowledge you have the more you can do with it. . . . (Project D FM 3)

Supporting this (Table 4), more than two-thirds of the survey participants felt the initiatives moderately improved their knowledge (70%; $n = 26$) and skills (68%; $n = 25$) in supporting their family member. Attitude change was reported by 64%.

Many participants described how the initiatives opened up their minds to future possibilities that their children had in life. Participants described shifting their focus from the way in which their children with disability would survive in society to thinking about how their children could thrive and live a meaningful life. They described acquiring a new belief that their child as a citizen was *entitled* to have a full and meaningful life, not something that could be given or taken away by society as described by this participant:

> She [the trainer] also discussed what inclusion was . . . which I think is very important . . . where children have a right, especially in a pre-school setting, to be able to be involved and to play alongside a non-disabled child . . . and these rights are there and parents are very slow to take them up. They feel that their child should fit into a certain set-up rather than society working around the child and she really emphasized that, do you know? Which I felt was brilliant. (Project A FM 1)

With this shift in attitude, participants demonstrated movement into a more strengths-based mindset, focusing on their child's strengths and abilities rather than solely challenges they might have due to the presence of disability.

Participants also described an increase in their self-confidence to advocate for the rights and entitlements of their family member. For example, participants described acquiring improved skills related to participating in meetings and negotiating with service providers. This increased confidence was related to their enhanced knowledge and skills base, particularly in relation to understanding the legal basis for their requests; the best strategies for managing interactions with service providers; and an enhanced determination to advocate for their family member as demonstrated here:

> I am going to be the best advocate for [my daughter] . . . it [the initiative] has given me the tools for change . . . to change me, which is ultimately going to have an impact on helping [my daughter] to get to

Table 5. The impact of the family initiative on advocacy skills (*n* = 36).

Impact	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Improved assertiveness	20 (57%)	9 (26%)	5 (14%)	1 (3%)	0 (0%)
More willing to ask questions of services	20 (57%)	9 (26%)	5 (14%)	1 (3%)	0 (0%)
More likely to seek out information	15 (43%)	11 (31%)	5 (14%)	3 (9%)	0 (0%)
Advocate more effectively	17 (47%)	15 (42%)	1 (3%)	1 (3%)	2 (6%)

where she needs to be because I . . . don't have to pussyfoot around anybody. I can say, 'These are my daughter's needs. Now, how are we going to meet them?' (Project D FM 4)

Given the challenges posed by both service providers and the Irish health care system, many participants acknowledged there was a need for these advocacy skills.

The survey also found an improvement in advocacy skills in relation to participants' self-reported ability to make suggestions (83%, *n* = 29), ask questions (83%, *n* = 29), seek information from health-care personnel/agencies/organizations (74%, *n* = 26) and advocate more effectively for the family member with the disability (89%, *n* = 32; see Table 5 for further details).

Theme 2: Making a difference within the family

Two overarching changes in family life were identified as occurring in consequence of participation in the initiatives:

- enrichment of the quality of life of the person living with a disability and
- beneficial changes in family dynamics, relationships and understanding.

Enrichment of the quality of life of the person living with a disability. The overall purpose of each of the initiatives was to build participant capacity to promote and support the inclusion and citizenship of people with disabilities and the building of natural supports to make a positive and lasting difference to the life of the person experiencing a disability. The findings provide good evidence to demonstrate success in this regard primarily through the building of participant capacity leading to the enrichment of the quality of life of the family member living with a disability. For example, participants referred to how their enhanced awareness of the right of, and possibilities for, the family member to achieve self-determination, have their voice heard and represented, and experience a meaningful fulfilled life translated into concrete advancements. Increased community involvement, employment, engagement with hobbies and interests, independent living and socializing were some of the linked outcomes identified by a number of participants.

The changed worldviews, knowledge and skills gained through participation in the initiatives provided the mechanisms by which change was effected. Participants spoke of being more visible within their communities, for example, some spoke of arranging social situations in which the family member with a disability could experience enhanced integration in everyday social settings. The data also demonstrated how participants worked to ensure that the family member's plans incorporated their likes and abilities, meaning that the plan was a realistic person-led plan. This finding was a departure for a number of participants in that the changed mindsets outlined in the

Table 6. Impact on the family and the family member with a disability (*n* = 36).

Impact	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Enabling direct support	11 (31%)	19 (53%)	3 (8%)	0 (0%)	3 (8%)
Helped us make important changes	11 (31%)	14 (39%)	7 (19%)	3 (8%)	1 (3%)
Helped us solve important problems	7 (19%)	14 (39%)	11 (31%)	3 (8%)	1 (3%)
Helped us to meet our family's needs	6 (17%)	12 (33%)	13 (36%)	4 (11%)	1 (3%)
Enabled my family member with a disability to care more effectively for himself/herself	4 (11%)	4 (11%)	16 (46%)	7 (20%)	4 (11%)
Enabled my family member with a disability to be more involved in the community	2 (6%)	14 (41%)	9 (27%)	6 (18%)	3 (9%)

previous theme opened up new vistas of possibility for the person with disability as demonstrated here:

> Actually, we've reviewed everything she's doing with a view to the sort of positive things that are happening in her life and about the building of friendships, the building of her social side and . . . we've been supporting that. (Project D FM 1)

Respect for the individuality of the family member with a disability was further evidenced in participants' reports of moving away from paternalistic beneficence, for example, making decisions *for* the family member, to enabling or participating in decision-making *with* the family member. Participants also referred to having the confidence to step back and to support the family member's freedom and participation in new endeavours and activities:

> We had to treat her as an individual . . . she's much more of an individual now, whereas before she had to go with the flow which didn't work for her because she has her own way of thinking and she's just an individual with learning disability. . . . (Project C FM 6)

The data suggest that changes which resulted from participating in an initiative differed from one participant to the next. Some participants and their family member had good pre-existing community connections or well-established circles of support in advance of the initiatives, and for them changes may not have been experienced to the same degree. Survey data support this, with 47% (*n* = 16) of participants agreeing or strongly agreeing that the family member had greater community involvement; however, 27% (*n* = 9) disagreed or strongly disagreed with this statement (Table 6). Reasons for this difference included previous high levels of community involvement, the nature of the person's disability or loss of momentum post the initiative. This important finding reflects the individuality of participants and their family members experiencing disability, illustrating the very unique needs and circumstances of each family unit.

Changes in family dynamics, relationships and understanding. With reference to the wider family, participants reported that the learning from the initiatives led to changes in family dynamics and relationships. Enhanced family communication and understanding was highlighted as central to positive family outcomes. For example, there were reports of other family members gaining a

better understanding of the person with the disability and becoming more involved in the life of the person. This was particularly pertinent to siblings and, in some instances, fathers, as described here:

> He [husband]...had a completely different view of [names son] because as far as he was concerned [names son]...He couldn't achieve or he couldn't go forward or he couldn't, he was limited...Whereas I always hoped there might be more of a possibility, and this [initiative] gave a framework to it. So by him [husband] attending the meetings with me, he was included in the thought process and in the vision going forward and he really took to it. (Project C FM 1)

Some participants outlined examples of greater family communication and cohesiveness as a consequence. For example, one participant described facilitating discussions within the family on issues such as future planning. Others reported family members pulling together, working as a team and taking a more active role in their family member's life. It is important to note that 70% of the survey participants perceived the initiative had assisted the family to make changes in the life of the family member, 50% reported that the initiatives assisted them to meet family needs and 84% agreed or agreed strongly that the programme had made them more effective in supporting the person with the disability in the family (Table 6). In contrast, only 22% thought that the programme had helped the person with the disability directly to care more effectively for themselves. This emphasizes the focus of the programmes on primarily supporting the families, rather than the individual with the disability, or their integration in the community, but it also questions the practical impact of the initiatives on the quality of life of the family members with disabilities.

Theme 3: A locus for stimulating connection and belonging

Whilst the previous themes illustrate the impact of the initiatives on the family as a unit, participation in the family-focused initiatives also provided a locus for participants to make connections with others in similar circumstances. This led to a sense of belonging, shared identity, mutual support and, in some cases, catharsis. For participants who attended initiatives that were delivered over a longer duration (weeks), they generally referred to building bonds and connections incrementally over the course of the initiatives. Likewise, those who participated in shorter initiatives, for instance, over weekends, reported similar experiences. Findings of connection and belonging were of two forms. Firstly, the initiatives provided a locus wherein participants could engage with others in the context of a shared frame of reference with 'likeminded people' (Project D FM 3).

To this end, participants referred to the value of having the opportunity to both seek, and share information, guidance and advice based on their experiences and lessons learned. Connecting with others offered the additional benefit of having access to a real-world knowledge base from those in similar circumstances or those further along in their journey. Participants referred to the credibility, value and sustaining impact of the gains obtained from these connections as inestimable. In addition to the pragmatic benefits, the findings further suggested that experiencing connection and a sense of belonging led to important emotional benefits, such as opportunities to share feelings that those without disability in their lives might not understand, a reduction in feeling alone and an increase, or in some cases new found, sense of hope for the future and its possibilities, as the following demonstrates:

> Well I found a huge benefit was meeting other parents...whilst I know that's not, you know, possibly the initial objective of having a workshop or a meeting I think that's definitely a secondary benefit and

Table 7. Lasting impact, sustained learning and reduced isolation following participation in the programme (*n* = 36).

Statement	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I feel less isolated	12 (33%)	15 (42%)	2 (6%)	4 (11%)	3 (8%)
Participating will have a lasting positive impact	15 (42%)	15 (42%)	4 (11%)	1 (3%)	1 (3%)
In the future, we will be able to sustain what we learned	13 (36%)	17 (47%)	4 (11%)	1 (3%)	1 (3%)

> turns out to be hugely beneficial because . . . you start talking to other people and you get a sense of kind of 'I'm not on my own here', you know, and you can actually make contact with people and you can, if you want, you can meet them from a support point of view or you can meet them from a knowledge-based point of view. (Project B FM 1)

Findings related to the second aspect of this theme demonstrated that some participants established networks with other participants that extended beyond their involvement in the initiatives – 'And then the other huge reward was the friendships' (Project A FM 6). For example, a number of participants described keeping in touch with fellow participants using social media, telephone contact or meeting for coffee. The data also suggested that for some participants, this expanded beyond the context of those encountered in the initiatives to include more community involvement and also development of a greater connection with, and perceived support from, family and friends. These findings suggest that the initiatives had an impact on expanding participants' wider social connectedness. Indeed, 75% (*n* = 27) of the survey participants agreed or strongly agreed that they perceived themselves as less isolated after the initiatives (Table 7).

In summary, the three interrelated themes presented above describe the family member participants' perspectives on the impact and benefits of the family initiatives. An important component of any capacity-building initiative is the sustainability of change and learning following participation. In total, 84% (*n* = 30) of the survey participants anticipated an enduring positive impact, whilst 83% felt that the learning achieved would be sustained moving forward (Table 7).

Where circles of support (themes 1 and 2) were present, some of the interview participants perceived that these would be an important contributor to the realization of the vision for the person with a disability and a way in which to source more people willing to help as well as a means of continuity into the future. However, where such supports were not in place participants expressed a wish for structured follow-up and/or facilitator support to implement circles of support, they suggested:

> Follow-up half-day sessions monthly for a few months in order to support families. (Project D Survey)

In addition, where the forming of networks with other initiative participants had not become established, catch up days with the opportunity to link back in with fellow initiative participants were suggested:

> Maybe to meet up once a year . . . You made a lot of friends during these courses and it is one way to keep in contact. (Project C Survey)

Discussion

The findings suggest that the participants in the study found the programmes helpful and were confident that they would be able to sustain the changes. The capacity-building effect of the programmes was broad and varied, emphasizing a positive impact on mindset around disability, increased confidence and effectiveness in accessing services, beneficial changes in family dynamics and more effective community connections (circles of support). This is in line with Irish health service policy. In Ireland, similar to other jurisdictions, extant policy advocates the strategic reframing of disability and service provision based around individualized supports and values, including person centredness, active citizenship, independence and community inclusion (Department of Health, 2012a; Health Services Executive, 2012). The recent National Carers' Strategy (Department of Health, 2012b) also recognizes the importance of rights, particularly the rights of carers, to work in partnership and to be valued and supported in their role. This recognition of citizenship and rights-based approaches to disability suggests a breakaway from traditional biomedically grounded and professional-led approaches to caring and supporting people with intellectual disability. The study suggests that the family support programmes that were evaluated made a meaningful contribution to this process.

The benefits of supporting families have been widely shown to directly help those living with disability (Bailey et al., 2006). Similarly, in the current study, the programmes were seen to have a positive impact on the person with disability within the families, in particular, through increases in the autonomy, independence and decision-making involvement of the family member with a disability, all of which were reported as being linked to improvements in quality of life. Considering that the initiatives had targeted largely rural populations, it is of particular relevance that the evaluation showed that they had assisted in both reducing a sense of isolation and forging new friendships. Beyond the immediate contacts established in the course of each initiative, a number of participants reported greater community visibility, involvement and, in some cases, the setting up of circles of support, with some participants indicating they intended to do so or would do so but needed more assistance in this regard. Central to these outcomes and similar to other research findings (Department of Human Services and The Department of Education and Early Childhood Development, 2012; Heller et al., 1999,) was the empowering and self-esteem-boosting benefits of the initiatives coupled with the knowledge and skills acquired. Knox et al. (2000) in their research with 68 families with a child with a disability also found that gaining a sense of control strengthened and sustained the family and was crucial to experiencing satisfaction in terms of lifestyle and quality of life. Their analysis revealed three components necessary to a perception of control, namely, positive prospects for the family's future, sharing of decision-making with service personnel and availability of accessible and relevant information, all of which were reported by participants in the family-focused initiatives in this study. The findings suggest the perspective that families may benefit from a variety of supports is a valid one. Furthermore, the findings suggest that family support programmes that aim to offer multiple supports are appreciated by the families and may have a sustained capacity-building impact.

Limitations

When interpreting the findings, it should be noted that participants were those who chose to participate in the family-focused initiatives and more specifically those who subsequently chose to participate in the study. This has the potential to be a source of bias. As with all voluntary post hoc evaluations, it is possible that participants with positive experiences of the programmes would

have been more willing to be included in its evaluation. The low overall response rate to the surveys (22%) leaves the researchers unable to guess what the response of the other 78% would have been. Ethical guidelines prevented the researchers from more 'adamant' reminders. The under-representation from one of the programmes was of particular concern, but the researchers did not want to exclude it from this publication as they wish to present their findings as accurately as possible. Furthermore, whilst the focus of the study was on the impact of the programmes on the families, it could also be seen as a limitation that the perspective of the family member experiencing disability was not included in the study. In defence of the study, it needs to be highlighted that its post hoc character was a given and not by design. Also the almost uniformly positive response of the participants suggests at least that those who chose to be involved in the evaluation were very positively affected by the programme. Finally, it is acknowledged that this was an evaluation study commissioned to assess the impact of initiatives that had already taken place, so it was not possible to establish baseline and post-initiative levels and perspectives, which would have made for a more robust design.

Conclusion

Contemporary research and international practice recognize the interdependence of family members and the implications of this for family support as a way of supporting people with a disability. This, along with increasing knowledge of the lived experience of the family, challenges organizations to create practices that 'respect . . . , empower . . . and strengthen . . . ' families (Knox et al., 2000: 18). Central to the success of any such initiative is the need to ensure lasting beneficial outcomes for people with disability and their families. One way in which to achieve this is to ensure that initiatives incorporate the building of participant capacity as a central aim. As Resch et al. (2012) highlight, parents of children with disability require skills, supports and resources to facilitate the undertaking of the actions inherent in their role. Family-focused/centred initiatives, such as those reported on in this article, aim to meet this challenge, and the findings suggest success in this regard. Specifically, knowledge, relevant skills and social inclusion were successfully enhanced by the initiatives evaluated in this study. The response of the participants to the evaluation suggests that the programmes were successful because they provided relevant knowledge and practical skills for the families. Moreover, the programme facilitators put effort into emphasizing the shared interests of the participants and promoting the creation of new networks of reciprocal peer support. The latter was considered invaluable and perhaps the most lasting impact of the programmes. However, the findings also highlight the potential need for ongoing encouragement for families in order to sustain momentum and to implement changes. This suggests the need for further efforts to explore the nature of ongoing supports to sustain change. It is evident that such research would benefit greatly from a pre/post/follow-up design approach and needs to be incorporated in the development of support programmes.

References

Bailey DB, Bruder MB, Hebbeler K, et al. (2006) Recommended outcomes for families of young children with disability. *Journal of Early Intervention* 28: 227–251.

Black L, Roberts P and McConkey R (2008) *LifeLines: An Evaluation Report of the Impact of the Families Services Delivered by Positive Futures in Rural and Urban Areas of Northern Ireland*. Bangor: Positive Futures.

Breckenridge J and Huppert S (2010) *Intensive Family Support Programs: Keeping Children with a Disability Safely in their Families*. Sydney: University of New South Wales.

Brown I and Brown RI (2004) Family quality of life as an area of study. In: Turnbull AP, Brown I and Turnbull HR (eds) *Families and People with Mental Retardation and Quality of Life: International Perspectives*. Washington: American Association on Mental Retardation, pp. 3–10.

Brown I, Brown R, Baum N, et al. (2006) *Family Quality of Life Survey: Main Caregivers of People with Intellectual or Developmental Disabilities*. Toronto: Surrey Place Centre.

Butera-Prinzi F, Charles N, Heine K, et al. (2010) Family-to-family link up program: a community-based initiative supporting families caring for someone with an acquired brain injury. *Neurological Rehabilitation* 27: 31–47.

Chenoweth L and Stehlik D (2004) Implications of social capital for the inclusion of people with disabilities and families in community life. *International Journal of Inclusive Education* 8: 59–72.

Courtin E, Jemiai N and Mossialos E (2014) Mapping support policies for informal carers across the European Union. *Health Policy* 118: 84–94.

Creswell JW (1998) *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks: Sage.

Dempsey I (1995) The enabling practices scale: the development of an assessment instrument for disability services. *Australia and New Zealand Journal of Developmental Disabilities* 20: 67–73.

Department of Health (2012a) *Value for Money and Policy Review of Disability Services in Ireland*. Dublin: Department of Health.

Department of Health (2012b) *The National Carer's Strategy: Recognised, Supported, Empowered*. Dublin: Department of Health.

Department of Human Services and The Department of Education and Early Childhood Development (2012) *Family-centred, Person-centred: A Guide for Everyday Practice and Organisational Change*. Melbourne: Government of Victoria.

Dunst C, Johanson C, Trivette, et al. (1991) Family-oriented early intervention policies and practices: family centered or not? *Exceptional Children* 58: 115–126.

Dunst CJ, Boyd K, Trivette CM, et al. (2002) Family-oriented program models and professional helpgiving practices. *Family Relations* 51: 221–229.

Dunst CJ, Trivette CM and Hamby D (2007) Meta-analysis of family-centred helpgiving practices research. *Mental Retardation and Developmental Disabilities* 13: 370–378.

Etmanski E, Collins J and Cammack V (2011) *Safe and Secure: Six Steps to Creating a Good Life for People with Disabilities*. Vancouver: Plan Life Advocacy Network (PLAN).

Friends (2004) *The Family Support Program Outcomes Survey*. Chapel Hill: Friends.

Guest G (2012) *Applied Thematic Analysis*. Thousand Oaks: Sage.

Health Services Executive (2012) *New Directions. Review of HSE Day Services and Implementation Plan 2012-2016*. Dublin: Health Services Executive.

Heller T, Miller A and Hsieh K (1999) Impact of a consumer-directed family support program on adults with developmental disabilities and their caregivers. *Family Relations* 48: 419–427.

Higgins A, Sheerin F, Daly L, et al. (2013) *Towards a Full Life: An Evaluation of Family Support Programmes for People with a Disability in Ireland, Dublin*. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

IBM Corporation (2010) *IBM SPSS Statistics for Windows, Version 19.0*. Armonk: IBM Corp.

Knox M, Parmenter TR, Atkinson N, et al. (2000) Family control: the views of families who have a child with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities* 13: 17–28.

Powers L, Sowers J and Singer G (2006) A cross-disability analysis of person-directed, long-term service. *Journal of Disability Policy Studies* 17: 66–76.

QSR International (2009) *NVivo Version 8.0*. Cheshire: QSR International.

Resch JA, Benz MR and Elliott TR (2012) Evaluating a dynamic process model of well-being for parents of children with disabilities: a multi-method analysis. *Rehabilitation Psychology* 57: 61–72.

Rillotta F, Kirby N, Shearer J, et al. (2012). Family quality of life of Australian families with a member with an intellectual/developmental disability. *Journal of Intellectual Disability Research* 56: 71–86.

Ruble L and McGrew J (2007) Community services outcomes for families and children with autism spectrum disorders. *Research in Autism Spectrum Disorders* 1: 360–372.

SurveyMonkey.com LLC (2012) *SurveyMonkey*. SurveyMonkey.com, LLC. Available at: www.survey-monkey.com (accessed 8 August 2012).

Taggart L, Truesdale-Kennedy M, Ryan A, et al. (2012) Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities* 16: 217–234.

Thomas DR (2006) A general analytic approach for analysing qualitative evaluation data. *American Journal of Evaluation* 17(2): 237–246.

Truesdale-Kennedy M, McConkey R, Ferguson P, et al. (2006). An evaluation of a family-centred support service for children with a significant learning disability. *Child Care in Practice* 12(4): 377–390.

World Medical Association (2013). WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. At http://www.wma.net/en/30publications/10policies/b3/ (accessed 19 December 2014).