



School of Nursing and Midwifery  
*Trinity College Dublin*

# **Towards a full life: an evaluation of family support programmes for people with a disability in Ireland**



**TRINITY COLLEGE DUBLIN**  
COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH

THE  
UNIVERSITY  
OF DUBLIN



Cover design by Lisa Fitzgerald of the School of Nursing and Midwifery Trinity College Dublin.



## ACKNOWLEDGEMENTS

The authors would like to thank all of the participants in this study who took the time to share their experiences in the interviews and surveys. The information they provided and stories they shared are critical in making recommendations for changes within these family initiatives.

We would also like to acknowledge the assistance of the project managers and facilitators who participated in the interviews and acted as gatekeepers for the data collection.

Thank you to artist Lorraine Keating for the art depiction of family used in the survey.

Finally, we would like to extend our gratitude to GENIO for funding this evaluation.

## ABOUT THE AUTHORS

Prof. Agnes Higgins is a Professor of mental health nursing at the School of Nursing and Midwifery, Trinity College Dublin.

Dr. Fintan Sheerin is Acting Director of the National Institute for Intellectual Disability at Trinity College Dublin.

Dr. Louise Daly is an Assistant Professor in nursing at the School of Nursing and Midwifery, Trinity College Dublin.

Danika Sharek is a researcher at the School of Nursing and Midwifery, Trinity College Dublin.

Dr. Colin Griffiths is an Assistant Professor of Intellectual Disability Nursing at the School of Nursing and Midwifery, Trinity College Dublin.

Dr. Jan de Vries is an Assistant Professor of psychology at the School of Nursing and Midwifery, Trinity College Dublin.

Pádraig McBennett is a clinical tutor at the School of Nursing and Midwifery, Trinity College Dublin.

This report may be cited as: Higgins A., Sheerin F., Daly L., Sharek D., Griffiths C., de Vries J., and McBennett P. Evaluation Report of Four Family-Focus Initiatives Funded by GENIO.

Dublin: Trinity College Dublin School of Nursing and Midwifery.

Copyright © Agnes Higgins, Fintan Sheerin, Louise Daly, Danika Sharek, Colin Griffiths, Jan de Vries, and Pádraig McBennett; 2013. Published by Trinity College Dublin School of Nursing and Midwifery.

## **GLOSSARY OF ABBREVIATIONS**

AIG –Autism Initiative Group

BOC –Brothers of Charity

LEAP – Leading, Education, Advocating and Planning for full citizenship for people with intellectual disabilities and autism.

DESSA –Disability Equality Specialist Support Agency

FI – Family initiative

PF –Project facilitator or manager of one of the family-initiatives.

Int –Interview response

FM – Family member

## TABLE OF CONTENTS

Executive summary .....	1
Limitations.....	4
Recommendations .....	5
Section 1: Background to the evaluation.....	9
Overview of each project.....	10
Section 2: Current state of evidence on family support initiatives .....	13
Introduction .....	13
Factors that impact on families’ coping.....	13
Family-centered support .....	14
Family support models.....	15
Family focused projects identified within the literature .....	17
Organisational outcomes.....	23
Summary and conclusion.....	25
Section 3: Overview of fieldwork.....	30
Introduction .....	30
Study aim and objectives .....	30
Research design .....	30
Data collection .....	31
Recruitment procedures.....	32
Response rates.....	32
Profile of participants from survey .....	33
Profile of participants from interviews.....	35
Data analysis .....	37
Ethical considerations .....	38
Project facilitators’ expectations for the family focused initiatives.....	39
Summary .....	40
Section 4: Findings – Impact of the family initiative on the family and family member with a disability.....	41
Introduction .....	41
Participants overall view on the usefulness of initiatives .....	41
Increased knowledge and confidence of family member participant.....	43
Changing attitudes towards family member with a disability.....	44
Enhanced skills in supporting family member with disability .....	45
Increased confidence, self-awareness and help seeking behaviour of family member participants .....	48
Impact of the initiative on the person with disability .....	50
Impact of the initiative on the family unit.....	55
Impact of networking with other families .....	57
Section 5: Findings – Family members’ perspectives on content, processes structures, and sustainability .....	61

Introduction .....	61
Family participants’ views on the theoretical content of the initiative .....	61
Family participants’ views on the facilitation process.....	62
Family participants’ views on structural issues .....	65
Family participants’ views on sustaining circles of support and networks .....	68
Inferential statistics: Statistical analysis of the differences between the four initiatives... 70	
Inferential statistics: Family information and perceived helpfulness of the initiatives .....	71
Inferential statistics: Predicting perceived helpfulness of the initiatives from other statements and questions in the survey.....	71
Summary .....	72
Section 6: Strengthening capacity – Project facilitators’ perspectives on organisational impact and benefits .....	74
Introduction .....	74
Intra-organisational learning: Awareness raising among staff.....	74
Intra-organisational learning: Changing working practices.....	75
Inter-organisational capacity building: Making connections and building communities ...	76
Looking to the future: Building sustainability.....	78
Summary .....	81
Section 7: Discussion, limitations and recommendations.....	82
Discussion.....	82
Limitations.....	86
Recommendations .....	86
References .....	90
Appendices.....	95
Appendix I: Content of training workshops.....	95
Appendix II: Interview schedule for family participants.....	98
Appendix III: Interview schedule for project managers and facilitators .....	100
Appendix IV: Survey instrument .....	102
Appendix IV: Survey instrument .....	114
Appendix VI: Inferential statistics .....	115

## LIST OF TABLES

Table 1. Criteria for assignment of programs according to fiscal model.....	16
Table 2. Criteria for Assignment of Programs to Family-Oriented Models.....	17
Table 3. Descriptive studies reviewed .....	26
Table 4. Experimental and pre-post test design studies reviewed .....	28
Table 5. Participatory action studies reviewed .....	29
Table 6. Family member survey response rate for each project site .....	32
Table 7. Interview response rate for each project site.....	33
Table 8. Relationship to family member with a disability .....	33
Table 9. Other conditions of family member with a disability .....	34
Table 10. Level of disability-related support required and level of communication .....	35
Table 11. Relationship to person with disability, gender and nature of the person’s disability .....	36
Table 12. Additional conditions of family members with a disability .....	36
Table 13. Level of disability-related support required and level of communication .....	37
Table 14. Role of project managers/facilitators interviewed.....	37
Table 15. Overall, how helpful was the family initiative for you and your family?.....	41
Table 16. Level of agreement about the impact and practicality of the family initiative .....	42
Table 17. Impact of family initiative on knowledge in supporting family member with a disability.....	43
Table 18. Impact of family initiative on participant attitude towards family member with a disability.....	45
Table 19. Impact of family initiative on skills in supporting family member with a disability	46
Table 20. Level of agreement about the impact of the family initiative on advocacy skills ...	46
Table 21. Level of agreement about the impact of the initiative on seeking support .....	50
Table 22. Level of agreement about the impact of the initiative on community involvement and care.....	54
Table 23. Impact of family initiative on family as a unit.....	57
Table 24. Level of agreement about the impact of the initiative on social support .....	59
Table 25. Level of agreement about the initiative design .....	64
Table 26. Level of agreement of survey sample on sustainability of learning from initiative	68
Table 27. Comparison of the four different programmes for overall helpfulness of the programme and Analysis of Variance .....	70
Table 28. Comparison of the four different programmes for enabling factors, practical learning, application, collaboration, and perceived sustainability and Analysis of Variance	115
Table 29. Comparison of the four different programmes for Impact of the Initiatives and Analysis of Variance .....	116
Table 30. Comparison of the four different programmes for Self-advocacy and Analysis of Variance .....	116
Table 31. Comparison of the four different programmes for Social Support and Analysis of Variance .....	117



Table 32. Crosstabulation of Family Information and Age with perceived Helpfulness of the initiatives.....	118
Table 33. Pearson Correlations with ‘helpfulness’ variable .....	119

## LIST OF FIGURES

Figure 1. Reviewed projects categorised according to degree of family-focus, fiscal model, power model and family-centred benefits .....	24
Figure 2. Mapping of the four initiative in relation to family-centredness, fiscal model and power model.....	25
Figure 3. Mapping of each initiative in relation to 13 key indicators.....	83

## EXECUTIVE SUMMARY

### Introduction

For the past five decades, there has been an increasing awareness of the need for service and societal responses to people with disabilities to be addressed through a person-centred approach, which takes account not only of the person with disability, but also the family. Studies into family focused models of support suggest that they have the potential to led to positive change in the lives of people with disabilities, including enhanced partnerships, respect for autonomy, and the development of problem-solving, decision-making, and advocacy skills.

### Background to current evaluation

The emergence of family-focused support projects and a movement away from service-led to family-led models of support is a recent phenomenon in Ireland. In 2010, Genio grant-aided four family-focused initiatives with a focus on building capacity to promote and support the inclusion of people with disabilities. The four initiatives are:

- Brothers of Charity Clare
- Autism Initiative Group
- Leading Education, Advocacy and Planning for full citizenship for people with intellectual disabilities and autism.
- Disability Equality Specialist Support Agency

The focus of each initiative was on training and capacity building with families of people with disabilities, including people with very severe and complex disabilities. The overarching aim of all of the initiatives was to enable families of children with disability to envision a positive realistic future, and build better lives for themselves and their children, within the context of their local communities. Two strategies were advocated as the means to achieve this desired outcome. Firstly, the initiatives placed a particular emphasis on strengthening participants' and their children's links with local communities through the creation of circles of support. Linked to this was the building of participants' knowledge and skills in order to enhance natural supports within the community, as opposed to having an over-reliance on professional and service models of planning and support. Each initiative set out to encompass an ethos of: person and family-centeredness; the enablement of citizenship; and the strengthening of participants' capabilities to advocate and support their family member with a disability.

In 2012, Genio commissioned a team of researchers, from Trinity College Dublin, to conduct an evaluation of the four grant-aided initiatives from the perspectives of families of people with disabilities and services/organisations.

## Methodology

- The study employed a multi-method approach using qualitative and quantitative methods to provide a comprehensive evaluation. Data was collected using individual interviews, surveys and documentary analysis.
- The final number of surveys included for analysis was 38 representing a 22% response rate.
- Nine interviews were conducted with project managers/facilitators and 19 interviews were conducted with 21 family members.
- All qualitative data was thematically coded and quantitative data were statistically analysed.
- Ethical approval was granted from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin.

## Summary: Impact of the family initiative on the family and family member with a disability

- Overall, findings from survey and interviews indicate that the initiative had, for the majority of participants, a positive impact on the person attending, their family member and the family unit.
- Participants were of the view that the initiative enhanced their knowledge and skills, and what they learned was relevant and practical.
- Several participants described how the initiative challenged and changed their thinking about disability, and increased their awareness that their family member had rights to participate in a full and meaningful life and had the right to have autonomy over their own life.
- Interview and survey data clearly indicated that the initiative positively affected the participants' ability to advocate for the rights of their child and engage with services on a more equal footing.
- Some participants reported greater involvement and social connections of their family with community. This appeared to come about as a result of parental mindsets changing, circles of support being established, and parents requesting that their son/daughter be involved in activities.
- Participants reported improved quality of life, self-esteem and confidence for their family member as a result of their increased autonomy, independence and involvement in decision making.

- Participants described how the initiative had positive effects on the family unit and related: an improved family understanding of the family member with a disability; an increase in dialogue and communication within the family; and an increase in the involvement of other family members in the life of the person with a disability.
- Many participants described the importance of the networking aspects of the initiatives in: overcoming feelings of isolation; helping them to share knowledge and learn from each other; allowing them to feel less isolated and alone; and supporting them in establishing friendships.

### **Summary: Family members' perspectives on content, processes, structures, and sustainability**

- Overall, participants were of the view that the initiatives were well organised and facilitated, and indicated that information presented was empowering, enlightening, relevant and applicable. All participants referred to the importance of learning strategies to enable them to advocate, navigate, and communicate with services and service personnel.
- Participants valued the facilitators' knowledge and interpersonal skills, as well as the interactive nature of the facilitation/teaching strategies used. The opportunity to ask questions and discuss issues in a supportive respectful space was appreciated, as was the small group work which enabled more individual attention to be offered.
- Participants advocated for the continued inclusion of facilitators with experience of having a family member with a disability or the inclusion of a parent as a co-facilitator in future initiatives.
- Initiatives which included weekend or a residential component were positively appraised, as was the respite support offered to families. However, in a few situations there were mixed opinions on whether funding overnight accommodation for family members could more effectively be used to enhance other aspects of the initiatives.
- While some family members formed support networks with the participating families, others noted that their attempts to establish networks had faltered due to the competing demands of everyday life and lack of formal mechanisms to do so.
- Family participants made a number of suggestions for improvement in future initiatives including: improving follow-up; support to help sustain the 'circles of support' and networks; enhanced recruitment strategies to include fathers, siblings and grandparents; attendance of professionals from services; and offering initiatives to family members at a much earlier stage.

- Analysis of the survey responses indicated that participants' overall appreciation of the initiatives was high, and similarly high in all four programmes. Differences in outcomes between the four initiatives were minimal, and differences in outcomes for different kinds of participants (based on family information) were also minimal. Significant correlations between helpfulness and all other statements and questions suggest coherence in the survey. Moreover, the perceived impact of the programmes at present and the sustainable impact in the future seem to be the most significant factors in predicting the overall rating of the helpfulness of the programme.

### **Summary: Strengthening capacity: Project facilitators' perspectives on organisational impact and benefits**

- The initiatives appeared to have a number of impacts on the organisations including: enhanced awareness and understanding among staff of the needs of families; and changing staffs attitudes to, and ways of working with, families and persons with disabilities.
- The initiatives also appeared to help strengthen inter-organisational working through links with other disability organisations and opportunities for sharing expertise and learning. A number of the project facilitators also referred to how the visibility of their organisations had been enhanced among families with disability, professionals and other disability organisations because of the initiatives.
- All of the facilitators described a number of measures to enhance the project organisations' capacity to continue running the initiatives. They emphasised the need to view the initiatives as dynamic and subject to ongoing refinement and continuous quality improvement, also to involve past participants in future initiatives and develop new roles within the organisation and source other funding.

### **Limitations**

Overall, the results of the evaluation of the initiatives are quite positive; however, they need to be interpreted in light of the following limitations:

- The sample under-represents certain groups, including fathers, siblings and grandparents.
- The socio economic status of the participants (survey and interviews) was not clear, consequently, it cannot be assumed that they represent a broad cross section of society from a socio-economic viewpoint.
- A relatively low response rate of 22% was achieved from the family participants. Although this is not an unusual response rate for survey research, it did limit the array of statistical tests that could be performed.
- The low response rate (both survey and interview) from the family participants in the AIG initiative makes generalisation of any of the findings to this initiative impossible.

- An objective comparative measurement of the impact on the initiative on participants' knowledge, attitude and skills, impact on the family member with disability or impact on the family unit was not possible as a baseline measurement of variables for any of these groups prior to attendance at the initiative was not captured.

## Recommendations

In light of the findings, the following recommendations are proposed for: funding; structure, content and format of future initiatives; enhancing capacity building and sustainability; and further research and evaluation.

### Funding future initiatives

- In view of the overwhelmingly positive evaluation, the overall recommendation from this is that funding for these and similar initiatives should be continued.
- Due to the variability of the structure and format of the different initiatives organisations should have flexibility in how best to use funding to support the initiatives.
- Funding of paid support to allow participants to attend the initiatives is crucial and needs to be continued.
- Individualised funding should be obtained from the block grant as envisaged in the Report of the Review of HSE Day Services and Implementation Plan 2012 - 2016: Personal Support Services for Adults with Disabilities (HSE 2012).
- Organisations may need to explore the potential of attendees part contributing but this should be carefully considered, in order to minimise the risk of this requirement prohibiting participation.

### Structure, content and format of future initiatives

- In view of the equally positive response to the four different programmes, it is not possible to recommend one particular delivery format. However, it is recommended that the format needs to fit the particular goals of individual initiatives.
- The participants' experiences and recommendations suggest that organisations planning future initiatives need to give consideration to the following:
  - follow-up support strategies to assist participants to sustain the family focus 'circles of support' and other learning should be an integral part of the initiative. Such supports should be flexible and take into account participants' evolving needs and issues. Untimely removal of support endangers capacity building and sustainability;

- developing a formal participant-led strategy as a core component of the infrastructure of future initiatives to increase and sustain networking among family participants, as this is a fundamental aspect of the family support approach;
  - exploring the most appropriate timing of the workshops with family members to maximise attendance from the group being targeted. For example, initiatives that are designed to involve the whole family, including the person with disability might be better delivered over a weekend. Initiatives that are designed to build skills in family members over time might be best suited to day long or evening sessions spaced out over time;
  - developing a strategy to actively recruit fathers, siblings and grandparents, and given the correlation between disability and disadvantage (WHO 2011) family members from all social classes need to be actively recruited for future initiatives;
  - continually modifying content in collaboration with family members, to ensure initiatives are: flexible; responsive; practically and culturally relevant; and fit for purpose;
  - reviewing initiative recruitment literature to ensure that the aims and objectives of each initiative are clear to potential participants;
  - reviewing recruitment/marketing strategies with a view to improving and widening access to the initiatives.
- In view of the positive appraisal by participants of content and process, it is recommended that facilitators continue to:
    - create an atmosphere of honesty, openness and inclusiveness;
    - involve facilitators/family members who have lived experiences of caring for persons with a disability in the initiative component;
    - continue to use interactive facilitation approaches, including small group teaching and opportunities for question and answer sessions;
    - continue to recruit a broad mix of families at different life stages, so families with young children have an opportunity to meet family members with older children, and family members who have supported their children to achieve various levels of independent living.

#### Enhancing capacity building and sustainability

- To strengthen capacity building and the potential for sustainability, in their ongoing developments the organisations involved in this evaluation should give consideration to:
  - exploring the potential of involving past participants as co-facilitators of workshops or as supports for other family members;

- exploring the possibility of creating a family facilitator or intermediary role to engage with and support participants to enact their plan and develop/maintain circles of support;
  - exploring the potential of using online media and delivery to reduce travel costs of experts from overseas who deliver lectures on the initiatives;
  - exploring the possibility of recording family stories as exemplars of positive changes that occurred following participation in the initiatives. These could be used in future educational initiatives;
  - recruiting professionals onto the initiatives as a means of building capacity and changing the philosophy and way of working within professionally led services. This has the potential to reduce the risk of family members returning to organisations that are not receptive to their new found confidence and assertiveness;
  - exploring strategies for dissemination of learning regarding the family focused or centred philosophy among organisations that are not family led.
- As capacity building is a key feature of the work of GENIO, it is recommended that GENIO give consideration to:
    - developing mechanisms to enable the sharing of project learning between and among funders and organisations. Doing so would avoid the potential for silo effects, in which learning remains at a localised level. Addressing this point may also enhance potential for partnership working at the inter-organisational working level, including the sharing of resources and funding opportunities;
    - developing case studies or exemplars illustrating the key learning points from completed projects to assist other organisations or future grantees in their capacity building and sustainability work;
    - developing an education package on the meaning and processes involved in such work would be of benefit to future grantees and those involved in this and other sectors. This could take the form of an e-learning package accessed through the GENIO website or a face to face facilitated programme.

#### Further research and evaluation

- GENIO should give consideration to the development of an overarching framework for the evaluation of capacity building initiatives, into which applicants can outline specific, realistic, measurable and time framed evaluation indices matched to their specified capacity building strategies, at the point of funding application. Such a framework should allow for the collection of core data but needs to be adaptable to capture the individuality of capacity building work within and between different organisations. This would streamline the collection of data and create a dynamic



database of knowledge that could build an evidence-based resource to inform future capacity building work;

- To overcome the limitations of the present evaluation future initiatives should be evaluated with the use of longitudinal pre-post study designs, and follow-up of the long-term benefits of the initiatives;
- The facilitator data in the present evaluation suggests a degree of transformation within the organisations, however, there is a need to evaluate the degree to which such transformation has occurred and if it is sustained over time.

## SECTION 1: BACKGROUND TO THE EVALUATION

### Setting the context

For the past five decades, there has been an increasing awareness of the need for service and societal responses to people with disabilities to be addressed through a person-centred approach. A person-centred approach is one which seeks to put the person first (National Disability Authority and Department of Health and Children 2004). Such an approach is grounded in, amongst others, the work of Nirje (1969), Wolfensberger (1972) and O'Brien and Tyne (1981) and has involved a movement away from congregated settings, institutional services and professional control (Lord and Hutchinson 2003). The principle of person-centeredness, which is identified as one of the four key principles underpinning Irish health policy (Government of Ireland 2001), is based in the belief that in order to meet the desires and needs of an individual, their “unique identity...particular gifts and wounds...right to choose, and...capacity to develop, participate and contribute” must be maintained centre stage (O'Brien *et al.* 2010: 15). Furthermore, it is recognised that person-centred approaches must take account, not only of the person with disability, but also of the family, as their role may be key in ensuring that true person-centeredness is achieved (O'Brien and Lovett 1992; State of California 2001). This is particularly relevant to the establishment and maintenance of the person's circle of support beyond professional services (Everson and Zhang 2000; Walker 2010). Thus, whereas person-centeredness is rightly focused on the person, there is a need for service providers to also have a family-centred focus, which is aimed at supporting family to support their family member who has a disability.

In 2010, Genio grant aided four family focused initiatives with a focus on building capacity in a variety of stakeholders in order to promote and support the inclusion of people with disabilities. The initiatives involved training and capacity building with families of people with disability, including people with severe and complex disabilities. The general aim of the initiatives was to increase family members' knowledge and skills and enable them to plan better lives for their family member and to advocate on their behalf.

In 2012, Genio commissioned a team of researchers, from Trinity College Dublin, to conduct an evaluation of the four grant-aided family-focused initiatives from the perspectives of families of people with disabilities and services/organisations. The evaluation employed a multi-method approach using qualitative and quantitative methods to provide a comprehensive evaluation. Data was collected using individual interviews, surveys and documentary analysis.

The four initiatives which are the subject of the evaluation are as follows:

- Brothers of Charity Services Clare (BOC)
- Autism Initiative Group (AIG)
- Leading Education, Advocacy and Planning for full citizenship for people with intellectual disabilities and autism (LEAP)
- Disability Equality Specialist Support Agency (DESSA)

### Overview of each project

#### Brothers of Charity Services Clare (BOC) with the Muiriosa Foundation and Cheshire Ireland

The Brothers of Charity provide professional led services to adults and children with intellectual disability. In recent years, the service has undergone significant transformation involving a process of deinstitutionalisation, and a move away from congregated settings to a more individualised, person centered model of service delivery, which is grounded in the concepts of community inclusion and integration.

The family-focused initiative under evaluation is a pilot project aimed at broadening the services provided to encompass a family-centred approach. The initiative is modelled on an Australian Family Leadership programme run by Mamre Association in Brisbane and was led by a member of staff from within the Brothers of Charity Service ([www.mamre.org.au](http://www.mamre.org.au)).

As part of the initiative, five weekend residential workshops were provided to 15 families (from the BOC service along with some families from the Muiriosa service and the Cheshire Ireland service) (see Appendix I for content of workshops). The workshops were aimed at enabling the family members realise the enormous potential of being able to envision, design and direct the support service that their family member with a disability required. Key elements of the initiative were the envisioning of a meaningful and integrated future for the person with disability; and the formation of a circle of support - whereby a group of key people in the life of the person with disability meet on a regular basis, in a spirit of friendship, to support the person to achieve their goals in all domains of life and support the person to forge natural connections in the community. In addition, the concept of 'succession planning' was explored with families, as a means of building sustainable supports for the person and safeguarding their onward journey into the future. The workshops were facilitated by people from within the organisation.

The grant from GENIO was utilised to fund a project leader and the costs of running the workshops, as well as direct support hours for the family member with a disability so that families could attend the programme. It was also used to fund accomodation for families who were living at a distance from the venue where the workshops were taking place. There was a mix of attendees, including: parents; siblings; and some family members with disability.

### Autism Initiative Group (AIG)

Autism Initiative is a parent led group set-up in 2004/2005 that exists to support families of individuals with Autism Spectrum Disorders (ASD) and Aspergers Syndrome. It offers a combination of advocacy, information, education, training and supports for families and provides a number of services including residential and day services, an outreach service, and respite service.

The family focused initiative under evaluation is based on the 'Partners in Policymaking' developed in Minnesota, USA, (<http://www.partnersinpolicymaking.com/>) aimed at building and strengthening the knowledge, skills and capacity of families of children with autism, so that they could help secure a life for their son or daughter that is independent, safe and secure. As part of the initiative, a series of one and two day information and networking focused workshops were run for families. The workshops focused on understanding the person with autism, navigating the system; person centred planning, transition/life planning, and advocacy for inclusion (see Appendix I). The workshops were facilitated by a combination of people from within the organisation and external international experts in the field. There was a mix of attendees, including parents, siblings; special needs assistants, teachers, psychologists, and speech and language therapists.

The funding from Genio was used to finance the delivery of the programme, including funding the international experts, notably Kevin Baskerville (Leicestershire outreach) and Peter Vermeullen (Belgium). Kevin Baskerville is an expert on managing anxiety/understanding the diagnosis. Peter Vermeullen is an expert on 'contextual blindness'. There was a mix of attendees, including: parents; siblings; special needs assistants; teachers; psychologists; and speech and language therapists.

### Leading Education, Advocacy and Planning for full citizenship for people with intellectual disabilities and autism (LEAP)

Leap is a parent lead organisation established in 2009 to support people with Intellectual Disabilities and people with Autism to be active citizens by strengthening their knowledge and their role and influence in partnership with their families and professional allies (people who work in services who can support LEAP's mission and values). LEAP endeavours to achieve this through providing leadership, mentoring and training solutions to families who have a child with a disability and who wish to take control of their own support needs. The group of parents and professionals who came together as LEAP did so as a coalition to bring individual programmes together as a suite of training. This group has since disbanded and two of the original members have stayed with the ethos and brand of LEAP and developed it into a social enterprise as of January 2012 ([www.leapireland.com](http://www.leapireland.com)).

The family focused initiative under evaluation consisted of a number of components including: half day information sessions and workshops; a family leadership weekend; and two longer programmes run over the course of a number of spaced days (see Appendix I). The different components of the initiative were aimed at empowering and up skilling families experiencing disability to lead lives of self-determination and active citizenship. The workshops were facilitated by people from within LEAP and national and international experts co-facilitated some aspects of the programmes (for example Pathways to Possibilities and Communication and Supporting Skills). The family leadership weekend was run in conjunction with Clan Beo, an organisation in the West of Ireland.

The funding from Genio was used to finance facilitation costs and the costs associated with delivering the various initiative components including hiring of venues, accommodation etc. The workshops were attended by parents of children with intellectual disability and autism, and some professional allies also participated in the Pathways to Possibilities programme.

#### Disability Equality Specialist Support Agency (DESSA)

DESSA is a national community development organisation that was set up in 2001. The goal of DESSA is to promote social inclusion by means of policy development and conscientising the disability communities, through the development and delivery of social inclusion initiatives to people with disabilities and their families. The family focused initiative under evaluation, called the ‘Empowering Parents Programme’ was part of an overall “Supporting Families Social Inclusion Strategy”. The aim of the empowering parent programme was to support parents of children with disabilities to become advocates for their children in their local communities and in their search for appropriate services. The programme consisted of series of education workshops that were run in three different locations (see Appendix I). The facilitators for the programme were a diverse group of people drawn from within DESSA, community development workers and independent facilitators who had completed a programme to train the trainers on facilitating the empowering parents programme.

The funding from GENIO was used to fund the delivery of the programme, including hiring venues. The workshops were attended by family members of people with a disability. Having provided a background to the current evaluation and the organisations who participated in the evaluation, the next section will review literature on family support initiatives.

## SECTION 2: CURRENT STATE OF EVIDENCE ON FAMILY SUPPORT INITIATIVES

### Introduction

Family support is defined by Wang and Brown (2009: 149-150) as referring to “a variety of support including cash assistance; professionally provided services; in-kind support from other individuals or entities; goods or products; or any combination of services that are provided to families who have minor or adult members with disabilities living in the family’s home”. This section will review family support initiatives in other jurisdictions that have been highlighted in the professional literature in order to identify the characteristics of initiatives that have a positive impact on families and others<sup>1</sup>. In addition, the section will map the four initiatives (BOC, LEAP, AIG, DESSA) under evaluation using the family support models identified from the literature.

### Factors that impact on families’ coping

“Families...are exposed to stressors from internal sources within the family and from external sources when advocating for health and social services and educational services for the child” (Twyo *et al.* 2007: 252). It is within this context that family-centred supports have their value, as while many families show great resilience and develop coping skills which allow them to undertake supporting roles others may not (Peralta and Arellano 2010). A number of variables have been suggested to be important in relation to resilience. Studies have demonstrated a correlation between type/degree of disability and stress/wellbeing of families (Baxter *et al.* 2000). Socioeconomic status is also important as income may affect the family’s ability to access resources and may impact on choice of service (Knestrict and Kuchey 2009). Maintenance of family rhythm, in terms of roles and routines, has been suggested as a support to coping because it creates predictability and structure in times of stress (*ibid*).

---

<sup>1</sup> An extensive search of the literature was carried out, which sought to identify evaluated family-focused support projects. The review focused on literature published during the period 2006 to 2012 although some frequently-cited papers which predated 2006 were also examined. A search was carried out in CINAHL, Psycho Info, Psych Lit, Social Sciences Index and Google Scholar. Additionally, a manual search of relevant websites was undertaken in order to identify family support initiatives. The following keywords were employed: family, support, disability, autism, intellectual disability, family support programmes, family-centred practice. A total of 90 papers/reports were identified of which only 14 evaluated family support projects similar to those that were funded by Genio. Whilst this section has reviewed only published literature pertaining to evaluations of family-focused projects, it should be noted that many other projects were identified during an internet search which did not have published evaluations. Examples of these include: Life without Barriers (<http://www.lwb.org.au/Services/Disability/Pages/disability-family-support.aspx>); Oxfordshire Family Support Network (<http://www.oxfsn.org.uk/>); Partners in Policymaking (<http://www.partnersinpolicymaking.com/>); Mamre Family Support (<http://www.mamre.org.au/service/family-support.php>); Family Centered Transition Project ([http://www.iod.unh.edu/Projects/fctp/project\\_description.aspx](http://www.iod.unh.edu/Projects/fctp/project_description.aspx));

Other factors, such as family connectedness and cohesiveness, similarly provide support in times of distress (Fiese *et al.* 2002), while having a spiritual belief system may provide a context within which perceptions about the person with disability may be grounded or framed (Bayat 2007). Finally, Peralta and Arellano (2010) note that the availability of a variety of resources in the community and partnership with professionals that care for their children is significant in meeting families' support needs. This is supported by Greer *et al.*'s (2006) Irish study which explored coping in Irish mothers of children with intellectual disabilities in the context of community living. Many studies, however, have demonstrated that people with disabilities and their families have had to cope against a backdrop of disempowerment, fragmented service provision and inadequate access to what services are available. This is a recurrent theme in the literature and spans geographical and cultural boundaries (Powers *et al.* 2006; Ruble and McGrew 2007). Again, resilience has emerged among families who have developed their own circles of support through the recruitment of family members and friends, as well as becoming the *de facto* coordinators of their family member's service provision (Čagran *et al.* 2011; Ajuwon and Brown 2012; Hu and Wang 2012; Rillotta *et al.* 2012). The development of such support circles or networks and of empowering partnerships between families and services is seen to be crucial to the ongoing evolution of person and family-centeredness (Schippers and van Boheemen 2009) and is the basis for many of the family support projects that have emerged in recent years.

### Family-centered support

Many models of family-centered support are reported in the literature. There is little consistency though in terms of ideal structure, with varying approaches employed to achieve positive outcomes for families and individuals with a disability. The emergence of these family-centered models mirror somewhat the development of services for people with disabilities as these tended to be based on a medical model which pathologised both the persons with the disability and their families (Samuel *et al.* 2012), and which offered professional expertise as its answer. The development of alternative family-driven models occurred in many parts in the 1950s and 1960s, often through parents coming together to support each other and to drive alternative models for the education, care and inclusion of their children in mainstream society. Such movements led to the establishment of the National Association of Parents of Backward Children in 1946 (now called MENCAP) in the United Kingdom and of the National Association for the Mentally Handicapped in Ireland in 1961 (now called Inclusion Ireland). These fora have been crucial to the voicing of family views on service provision and configuration, family support and inclusion.

For the past two decades, family voices have increasingly populated research reports in the social work and disability literature as practitioners have sought to identify and collaboratively address the service needs of individuals *and* their families.

The *family-centred approaches* that continue to be developed tend to be grounded in a set of core principles (Dempsey and Keen 2008):

- that the family is the constant in the person's life;
- that the family is best positioned to support the person in determining their needs and desires;
- that the person is best supported through his/her family and community being supported; and
- that the family must be respected, empowered and affirmed.

Espe-Sherwindt (2008: 141) notes that in achieving adherence to such principles, it is necessary for service personnel to move from being 'expert managers' to becoming 'flawless consultants'. She also notes that this may be such a radical change from the traditional model of professional-led service that it may be difficult to achieve in a timely manner. However, such a transition has been identified by families themselves as being crucial to the success of family-centred approaches (Dempsey and Keen 2008). Weiss et al. (2008), in a survey 640 parents of children with autism regarding the Ontario Policy/Program Memorandum 140, reported that respondents wanted greater collaboration between parents and professionals with the target of effective engagement in planning. Similarly, Hiebert-Murphy et al. (2011) carried out a qualitative study with 39 mothers and 22 fathers on a community-based childhood disability program, which focused on enhancing family centeredness. They identified the importance of skilled service coordinators but noted that some professionals maintain their aforementioned role, acting as 'gatekeepers' to services, often not maintaining contact with the family, failing to initiate interaction, not listening, and even judging parents.

It is clear that families have an expectation of excellence from services (Burton-Smith *et al.* 2009) but they also expect that focused support will come from service staff and from the service system (Burton-Smith *et al.* 2009; Samuel *et al.* 2012). However, there is no real consensus on the scope of such support. Singer et al. (2009: 98) refer to "...formal and informal resources designed to promote the benefits and reduce the various social costs of family caregiving for individuals with physical and cognitive impairments".

### Family support models

Having considered the main components of family support, it is necessary to explore the various models of such support that have been reported in the literature. One aspect of support which is raised repeatedly by families is the need for more information about services that are available (Dempsey and Keen 2008; Hiebert-Murphy *et al.* 2011; Samuel *et al.* 2012). Information is, however, of limited value if one cannot navigate the service system, and it is here that the importance of collaboration and partnership re-emerges, as



many families have, to date, had to initiate their own formal and informal supports/services (Weiss *et al.* 2008; Hiebert-Murphy *et al.* 2011; Samuel *et al.* 2012). The outcome of this should be increased empowerment, enablement and independence of families (Espe-Sherwindt 2008; Schippers and van Boheemen 2009; Peralta and Arellano 2010), with the goal of enhancing the quality of life of the care giving family and of the care recipient (Wang and Brown 2009). Espe-Sherwindt (2008: 236) sums up these central components of the family-centred approach: “(i) an emphasis on strengths, not deficits; (ii) promoting family choice and control over desired resources; and (iii) the development of a collaborative relationship between parents and professionals”.

Whilst the literature contains reports on many and varied approaches to family support, there is limited evidence on which approaches offer the best outcomes for both persons with disabilities and their families. Singer *et al.* (2009) notes that approaches may be totally controlled and formulated by the service agency, configurable by the family or anything in between. Drawing on Flanagan and Green (1997), Powers *et al.* (2006) propose an interesting categorisation for examining approaches to family support, grounded in locus of decision-making and control of funding (Table 1).

**Table 1. Criteria for assignment of programs according to fiscal model (Powers *et al.* 2006:68)**

<b>Model</b>	<b>Criteria</b>
<b>Recipient/family-led</b>	Cash is paid directly to the person with disability or their family carers along with advice for those who will be configuring service.
<b>Fiscal intermediary</b>	The family manages the money and engages service providers. The intermediary manages accounts, employment and administrative tasks.
<b>Supportive intermediary</b>	The intermediary acts as the interface between family and supports/providers.
<b>Self-directed care management</b>	The family actively takes part in decision-making but funds/services are controlled by the agency.

This categorisation, however, is somewhat limited in that it does not clearly address the issues of empowerment and collaboration that are inherent in family-centred approaches (Dempsey and Keen 2008). Furthermore, as it focuses to a greater degree on policy and organisational issues, it does not easily allow for classification of small, localised projects such as programmes of training and support (Barlow *et al.* 2006), family support and guiding (Nahom *et al.* 2000), positive parenting (Turner and Sanders 2006), residential support (Stainton 2011) and family link-ups (Butera-Prinzi *et al.* 2010). Such projects resonate with those that are the focus of this current evaluation report.

Dunst et al. (1991), in their discussion of early intervention programmes, offer an alternative framework, which centres on the family-oriented characteristics of such programmes. They identify four types of programmes based on family-orientation: professional-centred; family-allied; family-focused; and family-centred. These are summarised in Table 2.

**Table 2. Criteria for Assignment of Programs to Family-Oriented Models (Dunst et al. 2002:223)**

<b>Model</b>	<b>Criteria</b>
<b>Professionally centred</b>	Families are seen mostly as deficient and incapable of healthy functioning without professional interventions. Professionals see themselves as experts who determine family needs. Families' views and opinions are given little or no credence. Interventions are implemented by professionals with families being passive participants in the intervention process.
<b>Family allied</b>	Families are seen as minimally capable of independently effecting changes in their lives. Families are viewed as agents of professionals for carrying out professionally prescribed recommendations and courses of action. Professionals enlist families to implement intervention under the guidance and tutelage of the professionals.
<b>Family focused</b>	Families are seen as capable of making choices among options professionals deem important for healthy functioning. Professionals provide advice and encouragement to families on the basis of their choices and decisions. Interventions focus on monitoring family use of professionally valued services.
<b>Family centred</b>	Families are viewed as fully capable of making informed choices and acting on their choices. Professionals view themselves as agents of families who strengthen existing and promote acquisition of new skills. Interventions emphasise capacity building and resource and support mobilisation by families.

Person and family-centred approaches have the capacity to be hugely transformative, as they involve a significant change in how power is managed (Wills 1997). Thus, the third model, is based on the family's relationship with agencies, which can be based on service (power over), partnership (power with) or personal power (power within) (Lovett cited by Wills (1997). Whilst collaboration between service providers and families has led to change in the lives of people with disabilities and their families, Wills (1997) proposes that the traditional roles of provider and consumer will not change sufficiently for real empowerment of families to take place, and a transfer of knowledge, problem-solving ability and communication, organisational and advocacy skills must take place. These skills are arguably the basis of family-centeredness and support families to lead and be truly empowered.

### **Family focused projects identified within the literature**

This review identified eight family focused projects which sought to address family support using differing fiscal, family-orientation and power models. All of the projects resulted in positive outcomes for participants, although to varying extents. The next section of the review will discuss how the eight projects use the three family support models (fiscal, family-centeredness and power) discussed in the preceding sections. The main characteristics of

the eight projects, together with evaluation methodologies used are highlighted in Table 3, Table 4 and Table 5 (see pages 26-29).

### The Home Based Support Services Program (Illinois, USA)

The fiscal intermediary approach to care giver support is well represented in the literature pertaining to U.S. models both before and after the introduction of the National Family Caregiver Support Programme, which was the first attempt to address all family care-givers' needs through federal funding (Feinberg and Newman 2004; Whittier *et al.* 2005). An example of such a programme in which funding is made available to families through an intermediary agency is the Home Based Support Services Program (HBSSP) in Illinois, which was set up in 1990. This programme sought to increase the quality of life and autonomy of people with disabilities. This consumer-directed support programme involved the development of an individually-determined package of services which were identified by the person with the disability and his/her family, with the assistance of a service facilitator. The money can be used to purchase, for example, "workshop and supported employment expenses, respite care, therapy costs, rehabilitation aide fees, dental fees, transportation costs, and recreational activities" (Heller *et al.* 1999: 420). Heller *et al.* (1999) explored the impact of this programme on family carers and the persons with the disabilities using a pre-test post-test design with comparison group over a four year period. The variables they explored included caregiver self-efficacy, service satisfaction, met and unmet service need, caregiver burden and community integration. The study found that those families participating in the HBSSP had fewer unmet needs and greater self-efficacy than the comparison group. Whilst they were more satisfied with the service provided, there was no significant difference in caregiver burden. Heller *et al.* (1999) note, however, that the variation in family support programmes makes it difficult to generalise findings from a study such as this.

Caldwell and Heller (2003) further explored the HBSSP, focusing on the outcomes of respite/personal assistance purchased by families. Using a cross-sectional design with multiple regression analyses, the researchers surveyed a sample of 91 families on the above variables, as well as care giving satisfaction, employment of mothers, control of respite/personal assistance services and variables relating to the person with intellectual disability. The findings suggest that when families take more control for decisions related to such services, they report greater satisfaction and engage more community resources, leading to improved community involvement for the person with the disability. Heller *et al.* (2007) continued their evaluation of this programme, exploring its impact on out-of-home placement over an eight year period. They compared placement rates among families on the programme and those on the waiting list for the programme, discovering that those individuals with disabilities on the programme were less likely to experience an out-of-home placement than those on the waiting list. Further work by Caldwell and Taylor (2006),

suggests that consumer-directed supports led to improved economic, health and social outcomes for families. The effectiveness of the HBSSP has also been examined longitudinally over a nine year period in respect of met/unmet service needs, community participation of individuals with intellectual disability, satisfaction with service and caregiver burden (Caldwell *et al.* 2007). The earlier findings relating to met/unmet need and service satisfaction were reaffirmed, whilst no significant differences were noted in caregiver burden or community participation.

#### The Intensive Family Support Strategy (Australia)

An Australian example of a fiscal intermediary programme was reported in a review of the Disability Services Commission's *Intensive Family Support (IFS) Strategy*. The review involved review of IFS data, consultations with stakeholders/service providers and telephone interviews with 28 IFS recipients and unsuccessful applicants. The IFS was instigated in 2001 in the context of a shortage in residential accommodation places. The strategy sought to help families to support their family member with a disability at home. It was based on the provision of personal funding that would be used to access services for the person with a disability with the aims of supporting "primary carers at times of critical need" (Barbara Gatter and Associates 2007: 5), improving a family's well-being and capacity to provide support, and so providing for positive outcomes for the person with the disability. It sought to achieve this through provision of funding to access respite opportunities, thus affording families with a break. Whereas the strategy was found to be effective in supporting families in crisis who wanted respite opportunities, it is noted that it is "not effective for families who have support needs in areas other than respite" (Barbara Gatter and Associates 2007: v).

#### The Arc of Howard County (Maryland, USA)

A further approach to providing support to families through the intermediation of a fund-holding agency is the *Arc of Howard County* in Maryland. The Arc is a service for people with intellectual disabilities which was set up by parents in 1961. It has committed itself to a person-centred approach focused on achievement of personal outcomes, dreams and desires (Walker 2010). This strategic decision carried with it a requirement for organisational change. One of the core areas for change was "creating additional means of communicating with and connecting with families" (Walker 2010: 7). Walker's (2010) case study of this organisation found that staff had recognised the necessity for collaboration with families through family fora aimed at achieving individualised support and control.

#### Passion and Entrepreneurship in Almere (Almere, The Netherlands)

Whereas many of the fiscal intermediary programmes reported in the literature tend to be large scale projects with central or local governmental involvement, it is acknowledged that

there are many smaller scale projects reported, which involve the development of partnerships between families and service providers. Schippers and van Boheemen (2009) citing the Beach Center on Disability (2006), suggest there to be four main types of partnership: i) families and service provider partnerships; ii) intra-service agency partnerships; iii) intra-system (e.g. health or educational) partnerships; and iv) inter-system partnerships. They report on a project in The Netherlands, following the introduction of the Community Support Act, which set out plans for 'support in and by the community' (2009: 19). The Act led to development of sustainable partnerships between family and friends of people with intellectual disabilities, generic social services and intellectual disability service providers, aimed at the realisation of individuals' personal future plans. The paper examines the effectiveness of a project, *Passie en Ondernemerschap in Almere* (Van Boheemen 2006), which was based in developing partnerships between families and service providers and within health and community services. The partnerships were facilitated through the employment of a professional intermediary (*intercedent*) who worked as 'an extra social worker' in the families' homes to support young adults and their families with making choices and planning. The intermediary's role was developed out of her interaction with the nine participating families. This was an action research project employing interviews with multiple stakeholders and a quality of life questionnaire. Upon examination, the intermediary's role was found to be multi-faceted with supportive, consultative, informative, liaising, lobbying, coaching and innovating aspects. This role echoes that of the *community guide* which was described by Nahom *et al.* (2000) in Washington State, although community guides appear to be more tightly defined by the family support programme than by the recipient families. The families and young people with disabilities in Van Boheemen's (2006) study reported that the intermediary's role led them and their support networks to becoming more self-supporting. It was also found that the presence of an effective intermediary improved interaction and collaboration between families and professionals. A positive family-professional relationship is crucial to family-centred approaches but is often a source of difficulty (Murray 2000). The project also led to families and young people taking increasing control of their own lives, thus improving their quality of life. Schippers and van Boheemen (2009) raise a question though regarding the intermediary's employment: who employs this person – service agency or family – and to whom is s/he responsible? This is an important concern in the rollout of such an initiative and returns the focus onto who controls the funds.

### The Training and Support Programme (England)

There are a number of examples of quite specific skill-teaching approaches reported in the literature, aimed at developing parental self-efficacy. For example, Turner's and Sanders' (2006) study of behavioural family intervention and Munford *et al.*'s (2007) work on preschool education activities. Barlow *et al.* (2006) trained 188 parents in the use of a massage technique that could be used with their children at home. This was part of a larger

training and support programme and demonstrated the usefulness of developing approaches to support parents to care at home. The findings demonstrated improved self-efficacy among parents. However, it is notable that anxiety and stress levels of parents following this study were higher than in comparable cohorts. In contrast, in their previous study of this technique, they reported reduced stress levels (Barlow *et al.* 2006), suggesting that further work is required to validate this approach.

### The Family Support Project (Northern Ireland)

A responsive, individualised, approach embarked on in Northern Ireland is reported by Truesdale-Kennedy *et al.* (2006) and Black *et al.* (2008; 2010). Instigated by *Positive Futures*, the Family Support Project employed a number of key aspects: i) a designated support worker for each family; ii) person-centred planning; iii) community development strategies; iv) sibling support; and v) parental involvement in support and education. The support workers visited each family at least once per month but the project was supplemented by the employment of a large number of community volunteers. In a mixed methods evaluation of the project, undertaken by Truesdale-Kennedy *et al.* (2006), 19 families with a member who had an intellectual disability were interviewed and completed rating scales examining family functioning, resources and stress, general health and social support. Two comparison groups, not engaged in the Family Support Project, were similarly interviewed and evaluated. In this study, engagement in the project was found to be associated with improved family functioning and experience of a wider range of support services. As with Barlow *et al.* (2006), however, families did not show a significant reduction in stress levels. The benefits of the Family Support Project were further confirmed during the qualitative component of the study in which families spoke of the improvements that they had witnessed in their family members with intellectual disability both in terms of functioning and socialisation. Parents were generally positive in their experience of person-centred planning, with some reporting that they felt it to have moved the focus from 'disabled person' to just 'person'. Some, however, found the person-centred journey to be overtly emotional for them to engage in, even when structured person-centred approaches, such as *Promoting Alternative Tomorrows with Hope* (PATH) or *Making Action Plans* (MAPS), were used (O'Brien *et al.* 2010). The second reported evaluation of the project, by Black *et al.* (2008), notes that the volunteer aspect was further developed, involving an increased number of individuals from the community and greater integration between community and service. This allowed for other support structures, such as individually tailored programmes, and support groups, for example, siblings, carers and dads, to be set up. In this evaluation, 48 family carers were interviewed regarding their experience of being involved in the project. The principal benefits which emerged related to: i) availability of respite; ii) having staff who could be both trusted and relied upon; iii) increased activities for the children with disabilities; iv) improvements in the children's behaviours; v) person-centeredness; and vi) family support. Carers highlighted the cost-savings that the project approach represented

when compared to other, programmatic, approaches and expressed high rates of satisfaction. The family members with intellectual disabilities and their non-disabled siblings also reported satisfaction with the project. Similar responses were elicited from volunteers and community workers but social workers did not appear to understand the overall project and expressed concerns about confidentiality and duplication of work. Difficulties in engaging with social workers were noted by service managers.

#### **Intensive Family Support Program (New South Wales, Australia)**

New South Wales' *Intensive Family Support Program* was set up to support families of children and young people where there were particular challenges which were impacting on the possibility of the children remaining at home (Breckenridge and Huppert 2010). It is centred on provision of support, information and meaningful support links to families (Family and Community Services 2011). The outcomes are largely defined in terms of out-of-home placement and maltreatment prevalence. The mixed method review incorporating documentary analysis, service data analysis, interviews, a workshop and a client survey described a model of support that is achieving positive outcomes for children and young people with disability and their families. Families reported feeling better supported and resourced with most reporting that they were more able to care for their child. Despite this, some reported that they felt unconnected to family, friends or community.

#### **Family-Family Link Up Program (Melbourne, Australia)**

Butera-Prinzi et al. (2010) describe a *Family-to-Family Link Up Program* (f2f Link Up) in Australia which was developed to support families who had a family member with acquired brain injury. The model is grounded in the concept of peer mentoring, with peers supporting peers, and its development employed a co-operative inquiry approach. The research report describes the implementation and evaluation of the programme. Link Ups were enabled through the employment of facilitators from existing agencies whose roles shared some of the characteristics of the *intercedents* in Schippers and van Boheemen's (2009) study, but who took an active role in recruitment and matching of families. Forty-six families took part in the programme and reported high satisfaction with information and support provided by the facilitators. More than half of the families expressed an interest in continuing with the programme. The rationale for this was made clear in their reflections where they identified that the programme gave them an opportunity to share common experiences. The support that this represented led to a greater sense of empowerment and recognition that there was potential for the sharing of resources (information, experiences and coping strategies) between families. This set the basis for building community with capacity being built within the families themselves. An example of this was the development of support materials by children for children.

No family support programmes were identified which met the criteria for Powers et al.'s (2006) remaining two categories: Recipient/Family-Led Projects and Spectrum Programmes

## Organisational outcomes

Whereas it has been seen that family-focused initiatives have important outcomes for family members and for the person with a disability, there is also evidence of beneficial outcomes for organisations and services. This is most clearly seen in the *Arc of Howard County* (Walker 2010), which sought to incorporate person-centred approaches within an extant service. Significant organisational changes resulted which led to creativity in staff training and development of innovative relationships with families and mainstream community agencies, a finding also reported by Butera-Prinzi et al. (2010). Such creativity and innovation is highlighted by Wright et al. (2010) as a pre-requisite for successful implementation of family-centred projects. Furthermore, Black et al. (2010) note the positive outcomes of such innovative collaboration for services, with new forms of family engagement with non-specialist resources leading to changes in how the disability organisations address service provision and staff resourcing. It appears that such approaches have the potential to unfreeze organisational models and liberate staff to engage with families and people with a disability in innovative ways that are often beyond the boundaries of more traditional, professional-led models. They have also led to the expansion of family-linked services in a direction hitherto undeveloped (Butera-Prinzi et al. 2010).

## Mapping family focused projects using the family support models from the literature

While it is clear that all eight projects reviewed were associated with benefits for family for people with disabilities and services, what is not clear, is whether or not it is possible to extrapolate a preferred model of family-centred support. In the absence of data sets that can be co-related, Figure 1 attempts to present the characteristics and outcomes of the reviewed projects in a quasi-empirical way by identifying their locations on the power, fiscal and family-centeredness scales and seeks to identify key beneficial outcomes that have been associated with such programs (empowerment, decision-making skills, choice, increased information, improved quality of life and greater satisfaction).

Similarly, whilst any attempt to map the four initiatives under evaluation, against the models identified within the literature, remains quite subjective, mapping them does provide a perspective for comparison purposes (see Figure 2). Although all four initiatives, evaluated in this report, were of different duration and had different content, the focus of all four was clearly on empowering family members of people with disabilities to become advocates for both themselves and their family member and envisioning a better or different future for their family member. In terms of their family orientation, all four were somewhere between family focused and family centred, and working from a philosophy of power with. However in relation to the fiscal model, in all cases family members did not have any control of the budget.



Figure 1. Reviewed projects categorised according to degree of family-focus, fiscal model, power model and family-centred benefits

Authors	Family-Centeredness				Fiscal Model				Power Model			Family-Centred Benefits					
	Professionally-Centred	Family Allied	Family Focused	Family centred	Self-Directed Case Management	Supportive Intermediary	Fiscal Intermediary	Recipient/Family-Led	Power Over	Power With	Power Within	Empowerment	Decision-making	Choice	Information	Quality of Life	Satisfaction with Life
<b>Home Based Support Services Program</b> Heller <i>et al.</i> (1999), Caldwell and Heller (2003), Heller and Caldwell (2005), Caldwell (2006), Caldwell and Heller (2007)	▶				▶				▶			NR*	Yes	Yes	NR	NR	Yes
<b>Intensive Family Support Strategy</b> Disability Services Commission (2007)	▶				▶				▶			NR	some	some	NR	NR	NR
<b>Arc of Howard County</b> Walker (2010)	▶				▶				▶			NR	NR	NR	NR	NR	NR
<b>Passie en ondernemerschap in Almere</b> Schippers and van Boheemen (2009)	▶				▶				▶			NR	Yes	Yes	Yes	NR	Yes
<b>Training and Support Program</b> Barlow <i>et al.</i> (2006), Barlow <i>et al.</i> (2008)	▶				▶				▶			NR	NR	NR	NR	NR	Yes
<b>Family Support Project</b> Truesdale-Kennedy <i>et al.</i> (2006), Black <i>et al.</i> (2008, 2010)	▶				▶				▶			NR	NR	NR	NR	NR	Yes
<b>Intensive Family Support Program</b> Breckenridge and Huppert (2010)	▶				▶				▶			NR	NR	NR	Yes	NR	NR
<b>Family-to-Family Link Up Program</b> Butera-Prinzi <i>et al.</i> (2010)	▶				▶				▶			Yes	Yes	Yes	Yes	NR	Yes

(\*NR=not reported)

**Figure 2. Mapping of the four initiative in relation to family-centredness, fiscal model and power model**

Name of Project	Family-Centeredness				Fiscal Model				Power Model		
	Professionally-Centred	Family Allied	Family Focused	Family centred	Self-Directed Case Management	Supportive Intermediary	Fiscal Intermediary	Recipient/Family-Led	Power Over	Power With	Power Within
Brothers of Charity	▶				▶				▶		
DESSA	▶				▶				▶		
Autism Initiative Group	▶				▶				▶		
LEAP	▶				▶				▶		

### Summary and conclusion

This review has examined a number of family-focused support projects which were grounded in the principles of person-centeredness and empowerment. Whilst the key components of these projects have been identified, it is noted that the outcomes evaluated are not uniform across them. This may relate to the variety of methodologies that have been employed as well as the population foci of the projects. In addition, due to variety in project content, structure and orientation, it has not been possible to make direct comparisons between each. However, collectively, the studies provide evidence of both the feasibility and efficacy of family support programmes. It is clear that all projects were associated with benefits for family and for people with disabilities. Findings demonstrated that models which have flexibility in funding and family-directed facilitation achieve outcomes that are highly valued by families. More importantly, families who were empowered to make informed decisions regarding the choices that were available within the wider community used these to form networks of support which supported other people too. This, in itself, speaks to the potential for capacity-building through such approaches as it leads to the location of leadership within families and communities with sharing of resources. The literature also indicated that family-focused initiatives may also have important outcomes for organisations and services. These developments are timely from an Irish perspective in the context of the recent HSE report, *Time to Move on From Congregated Settings: A Strategy for Community Inclusion* (Health Service Executive 2011), which is a potential platform for the growth of initiatives similar to those Genio grant-aided initiatives that are the subject of this evaluation.

**Table 3. Descriptive studies reviewed**

Name/Country	Sample	Intervention	Description of Intervention	Evaluation Methodology	Outcome Measures Used	Benefits/Findings
<b>HBSSP (USA)</b> Caldwell and Heller (2003)	97 families	Existing	Receipt of services	Survey	1. Caregiver burden 2. Caregiver satisfaction 3. Caregiver self-efficacy 4. Community integration 5. Service Satisfaction 6. Community involvement of person with disability 7. Employment of mothers 8. Staff turnover 9. Control in management of service 10. Unmet service need 11. Maladaptive behaviour of person with disability 12. Health status of person with disability	<ul style="list-style-type: none"> <li>• Families have more control over service</li> <li>• Higher levels of satisfaction with service</li> <li>• Greater community involvement of person with disability</li> </ul>
Heller and Caldwell (2005)	1136 families	Existing	Receipt of services	Comparative	1. Placement data	<ul style="list-style-type: none"> <li>• Less likelihood for person with disability to be in out-of-home placement</li> </ul>
Caldwell (2006)	294 families	Existing	Receipt of services	Survey	1. Household income 2. Out-of-pocket disability expenses 3. Caregiver employment 4. Health outcomes 5. Health care access 6. Social outcomes 7. Leisure satisfaction	<ul style="list-style-type: none"> <li>• Reduced out-of-pocket disability expenses</li> <li>• Greater access to health care</li> <li>• Greater social engagement</li> <li>• Improved mental health and health care access for low income families</li> <li>• Improved leisure satisfaction</li> <li>• Greater use of respite and personal assistant services</li> </ul>

<b>Intensive Family Support Strategy (Australia)</b> Disability Services Commission (2007)	28 IFS recipients and unsuccessful applicants 24 service providers and other stakeholders 13 families	Existing	Receipt of services	Exploratory descriptive with mixed methods	1. Service satisfaction 2. Support level of IFS 3. Responsiveness of IFS 4. Service access	<ul style="list-style-type: none"> <li>• Improved outcomes for those persons accessing respite</li> <li>• Improved quality of life</li> <li>• Enabled families to care for person with disability at home</li> </ul>
<b>Passie en Ondernemerschap in Almere (The Netherlands)</b> Schippers and van Boheemen (2009) Van Boheemen (2006)	9 young adults with intellectual disability and families	New	Introduction of an intermediary	Case studies with mixed methods	1. Quality of life 2. Family support 3. Family development 4. Community-based support 5. Role of intermediary	<ul style="list-style-type: none"> <li>• Improved quality of life</li> <li>• Empowerment</li> <li>• Intermediary was very positively evaluated</li> <li>• Improved family relationships</li> <li>• Increased involvement of person with disability in community</li> <li>• Improved perception of person with disability by the local community</li> </ul>
<b>Family Support Project (Northern Ireland)</b> Black <i>et al.</i> (2008.2010)	48 parents 19 young people 4 community workers 8 service staff 7 volunteers 14 social service staff	Existing	Receipt of services	Comparative with mixed methods	1. Social opportunities 2. Family Functioning Questionnaire 3. Parenting Stress Index 4. Parent satisfaction 5. General Health Questionnaire 6. Vineland Adaptive Behaviour Scales 7. Aberrant Behaviour Checklist	<ul style="list-style-type: none"> <li>• Improved parental health</li> <li>• Improved parenting satisfaction</li> <li>• Child's behaviour improved</li> </ul>
Truesdale-Kennedy <i>et al.</i> (2006)	19 families (sample) 50 families (comparison)	Existing	Receipt of services	Comparative with mixed methods	1. Family functioning 2. Resource and stress 3. General Health Questionnaire 4. Social Support Questionnaire	<ul style="list-style-type: none"> <li>• Improved family functioning</li> <li>• Increased number of supports available</li> </ul>

**Table 4. Experimental and pre-post test design studies reviewed**

Name/country	Sample	Intervention	Description of intervention	Evaluation methodology	Outcome measures used	Benefits/Findings
<b>HBSSP (USA)</b> Heller <i>et al.</i> (1999)	78 Caregivers	Existing	Receipt of services	a. Pre-post survey b. Post-test survey	1. Service use and unmet service needs 2. Service satisfaction 3. Care-giving self-efficacy 4. Care-giver burden 5. Out-of-home placement plans 6. Community integration 7. Monthly wage of adults with disability	<ul style="list-style-type: none"> <li>• Increased satisfaction with service. Improved self-Efficacy</li> <li>• Less likelihood of person with disability having out-of-home placement</li> <li>• Increased community functioning of person with disability</li> <li>• Increased monthly wage of adults with disability</li> </ul>
Caldwell and Heller (2007)	38 Families (study sample) 49 Families (comparison)	Existing	Receipt of services	Longitudinal Survey	1. Unmet service needs 2. Service satisfaction 3. Community participation of person with disability 4. Care-giving burden	<ul style="list-style-type: none"> <li>• Decreased unmet service need</li> <li>• Increased satisfaction with service</li> <li>• Decreased care-giving burden</li> </ul>
<b>Training and Support Programme (England)</b> Barlow (2006)	49 Parents (intervention group) 46 Parents (control group)	New	Teaching of a massage skill	Pre-post survey	1. Parent self-efficacy 2. Parent's psychological well-being	<ul style="list-style-type: none"> <li>• Reduced parental stress</li> <li>• Improved self-efficacy</li> </ul>
Barlow (2008)	95 Parents (intervention group) 93 Parents (control group)	New	Teaching of a massage skill	Pre-post survey	1. Parent self-efficacy 2. Parent's psychological well-being 3. Life satisfaction 4. Perceived health status 5. Parental perception of child well-being	<ul style="list-style-type: none"> <li>• Improved self-efficacy</li> </ul>
<b>Intensive Family Support Program (Australia)</b> Breckenridge and Huppert (2010)	55 parents/carers 21 staff	Existing	Receipt of services	Pre-post survey with mixed methods	1. Child Abuse Potential Inventory 2. McMaster Family Assessment Device 3. Outcome Questionnaire 4. State Hope Scale 5. Happiness Measure 6. Working Alliance Inventory	<ul style="list-style-type: none"> <li>• Increased happiness</li> <li>• Increased hope</li> <li>• Improved family functioning</li> </ul>

**Table 5. Participatory action studies reviewed**

Name/Country	Sample	Intervention	Description of Intervention	Evaluation Methodology	Outcome Measures Used	Benefits/Findings
<b>Family To Family Link Up (Australia)</b> <i>Butera-Prinzi et al. (2010)</i>	46 families	New	Facilitated family linking	Co-operative inquiry	1. Family satisfaction 2. Facilitator satisfaction	<ul style="list-style-type: none"> <li>• Sharing of experiences increased support</li> <li>• Increased empowerment</li> <li>• Increased hope</li> <li>• Greater resources available</li> <li>• Greater compassion for self and member with a disability</li> <li>• Increased sense of community</li> <li>• Improved motivation to support others</li> </ul>

## SECTION 3: OVERVIEW OF FIELDWORK

### Introduction

This section of the report sets out the aims and objectives of the evaluation together with a description of the mixed methods approach used to complete the evaluation of the initiatives. In addition, a detailed profile of the people who participated in the surveys and interviews is included. To enable the reader to get an understanding of the project facilitators' expectations of the initiative a brief descriptive overview of their expectations is given at the end of the section.

### Study aim and objectives

The aim of this evaluation was to evaluate four Genio grant-aided family-focused initiatives from the perspectives of families of people with disabilities and services/organisations. The evaluation had seven specific objectives, which were to:

- establish and identify the general and specific benefits derived by families and others through participating in each project;
- evaluate the extent to which participating families formed informal support networks or other forms of informal support;
- identify what families found most helpful about the specific project they were a part of and what they thought could have been done differently;
- establish and identify the impact/benefits to each organisation as a result of running this initiative and learning at the organisational level;
- identify what organisations thought could be done differently;
- explore issues which arose from the projects and which need to be addressed at a policy or systemic level; and
- explore and make recommendations on ways in which family support initiatives should be funded and sustained on an on-going basis.

### Research design

The evaluation employed a multi-method approach using qualitative and quantitative methods to provide a comprehensive evaluation. Data was collected using individual interviews, surveys and documentary analysis.

## Data collection

### Individual interviews

Semi-structured individual interviews were conducted with family members and project facilitators. The interviews conducted with family members examined their experiences of the initiative, benefits to the individual participant and family unit, as well as the challenges encountered, and suggestions for improvement of future initiatives and sustainability. The interviews with project facilitators aimed to explore their experiences and perspectives of the impact and benefits of each initiative to participants and the organisation, as well as their views on sustainability. Two separate interview schedules were developed by the research team to reflect the objectives of the study (see Appendices II and III). Although the interviews were semi-structured, meaning that the interview schedules served as a guide, participants were encouraged to add any new information they felt was relevant to the evaluation.

### Surveys

A 28 item survey was designed to capture quantitative and qualitative data from all of the family participants (Appendix IV), and consisted of Likert-type scale statements and questions (5=Strongly Agree; 4=Agree; 3=Neither agree nor disagree; 2= Disagree; 1=Strongly disagree), plus open questions which provided participants with the opportunity to give more elaborate responses. The survey included sections on perceived impact of the programme on participants' knowledge, self-advocacy; social support; as well as their views on application of learning, collaboration, and sustainability. Some of the questions were adapted from 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), while others were developed by the research team. To optimise the response rate, the survey was designed to be completed either through an online link in SurveyMonkey (SurveyMonkey.com LLC. 2012) or hard copy, and the questions were constructed in such a way that response time did not exceed 15 minutes.

### Documentary analysis

The research team received a number of documents from GENIO about each initiative, including the initial application made, and interim and final reports submitted to GENIO. In addition, if other documentation or evidence was available (booklets, video, programme outlines), this was also reviewed by the researchers.



## Recruitment procedures

### Survey

To protect participants' personal information, family members were recruited by staff within each site. Family members were sent either an email with a link to an electronic survey or a postal survey inviting them to participate. Each hard copy survey had a stamped addressed envelope that the participants could return to the research team free of charge. To enhance the response rate two follow up reminders were sent approximately three weeks apart.

### Interviews

Similarly, family member interview participants were recruited by a staff member at each site, who gave them an invitation letter and information sheet about the purpose of the interviews. In the vast majority of situations the project manager agreed with the family member the time and location for the interview and communicated this to the research team. On some occasions, potential participant details were given, with permission, to the research team. In these situations, a member of the research team followed-up the person with a phone call, answered any questions, and arranged the interview at a time and location that suited the participant. Typically, these locations were around or at the project site, within a participant's home or in a room within a hotel rented for the purpose of the interview. Each interview lasted between 40 and 80 minutes and was digitally audio-recorded.

Interviews were also undertaken with project managers at each project site, who were recruited by the project team through direct telephone contact.

### Response rates

The number of participants contacted and the number of surveys returned is shown in Table 6. In total, 41 family member surveys were returned; however, three were removed as they were incomplete and did not provide any information regarding the aims of the survey. Thus, the final number of surveys included for analysis was 38 representing a 22% response rate. The response rates for each initiative are presented below in Table 7.

**Table 6. Family member survey response rate for each project site**

Project site	Surveys distributed	Surveys returned	Response rate
Brothers of Charity	33	9	27%
DESSA	47	15	32%
Autism Initiative Group	60	3	8%
LEAP	37	11	29%
TOTAL	177	38	22%

In total, 9 interviews were conducted with project facilitators, across all four projects and 21 family members. 9 family members were interviewed from the Brothers of Charity site, 6 from DESSA, and 5 at LEAP. Despite repeated attempts to recruit family participants within the Autism Initiative Group, only one family member was successfully recruited and interviewed.

**Table 7. Interview response rate for each project site**

Project site	Number of family member interviews conducted	Number of family members interviewed	Number of project managers/ facilitators interviewed
Brothers of Charity	7	9	2
DESSA	6	6	3
Autism Initiative Group	1	1	2
LEAP	5	5	2
<b>TOTAL</b>	<b>19</b>	<b>21</b>	<b>9</b>

### Profile of participants from survey

Of the 37 participants who completed the survey, more than 90% of participants (92%; n=34) participated in all the activities offered by initiative. For the 8% (n = 3) who did not participate in full, reasons given were: “not relevant”, “did not realise it was a 4 part thing and I attended one part (Saturday)”, and “I was unable to attend all the information sessions as I have young children and my husband was working, but at least 1 family member did attend all the sessions”.

The majority of family member respondents to the survey were parents of the family member with disability (n = 30). Most participants (71%; n = 27) were mothers, and three other identified as parent (one as foster parent) without indicating whether they were a father or mother. In addition, 16% identified themselves as a sibling (sister n = 5, brother n = 1), one as a grandmother and one an aunt (see Table 8).

**Table 8. Relationship to family member with a disability**

	n (%)
Parent	30 (78%)
Sibling	6 (16%)
Aunt	1 (3%)
Grandmother	1 (3%)
<b>Total</b>	<b>38 (100%)</b>

The majority of participants (69%; n = 25) identified themselves as the primary source of support for their family member with a disability. The gender of the person with disability was evenly split between males (51%; n = 19) and females (49%; n = 18). The mean age for family members with a disability was 16.5 years of age (SD = 12.274), with a range between 2 years and 54 years of age. More than half of the family members had an intellectual disability (53%; n = 20), with one-quarter (24%; n = 9) having a physical disability and one-quarter (24%; n = 9) with Autism. The majority (81%; n = 29) of family members with a disability lived at home with parent/s. A small percentage (14%; n = 5) lived with other family members (siblings) or alternated between living at home with parent and living with siblings. Only two people (6%) were described as living independently.

The family member being supported had a range of disabilities. The most frequently reported difficulties were speech or language, behavioural challenges, mental and physical health problems, mobility challenges, sensory integration impairment, and feeding or eating difficulties (see Table 9).

**Table 9. Other conditions of family member with a disability**

<b>Other condition</b>	<b>n</b>
Speech and or language difficulties	19
Behavioural challenges	17
Physical health problems	17
Mobility challenges	16
Sensory integration impairment	13
Feeding or eating difficulties (feed tubes, major allergies, sensitivities, etc.)	10
Seizures	8
Other	8
Mental health problems	6
Major vision impairment or Major hearing impairment	6
Alzheimer disease or other types of dementia	0

Within the qualitative comments section, respondents reported a range of physical disabilities including epilepsy, congenital heart disease, impaired motor ability, and sensory disabilities such as auditory and visual problems. In addition, concomitant physical diseases included: coeliac disease; hypothyroidism; strokes; constipation; gastric reflux; renal problems; and asthma. Several respondents mentioned depression as a feature of the person's condition. Emotional difficulties, behavioural difficulties and violent outbursts were also reported. Some of these behavioural problems were attributed to lack of control in the person's life or to communication difficulties. Poor social skills, sensory processing difficulties and mobility problems were also reported.

All respondents who offered written comments noted some form of developmental delay as being present in their children or sibling. Speech and language delay was common but varied from a mild impairment to very little meaningful communication (11%; n =4). In terms of the level of disability-related support required for their family member, results were quite varied, with responses spread over the spectrum of requirement from no disability-support required (8%; n = 3) to support required for almost all aspects of life (24%; n = 9). The full results are presented in Table 10.

**Table 10. Level of disability-related support required and level of communication**

	n (%)
<b>Level of communication of family member ( n = 37)</b>	
Able to communicate about a wide variety of topics in a meaningful way	6 (16%)
Able to communicate within a limited range of topics in a meaningful way	10 (27%)
Able to communicate needs, wants, and some ideas in a meaningful way	8 (22%)
Able to communicate basic needs and wants	9 (24%)
Very little meaningful communication	4 (11%)
<b>Level of disability-related support required (n = 37)</b>	
Does not require disability related support	3 (8%)
Requires disability related support for only a few aspects of life	5 (14%)
Requires disability related support for some aspects of life	13 (35%)
Requires disability related support for most, but not all, aspects of life	7 (19%)
Requires disability related support for almost all aspects of life	9 (24%)

Respondents who made comments in the survey noted that the support they provided was multifaceted; for many, this involved 24 hour care of children who required constant and on-going support. Carers reported undertaking roles that included elements of occupational therapy, physiotherapy, nursing, and psychological support, as well as help with activities of daily living. Specifically, parents and siblings would help the person to dress and undress, eat and undertake personal hygiene. Some respondents reported giving their child medicines and one reported feeding their child using a Percutaneous Endoscopic Gastrostomy (PEG) feeding tube. Family members also noted they acted as: advocates; as chauffeurs to get them to school and to other activities; as interpreters so that they could engage with the world; as teachers; cooks; and providers of emotional support. In short, family members reported that they supplemented the efforts of professionals, paid supporters and friends, and that they were the final back-up who could always be relied upon.

### Profile of participants from interviews

In total, 19 women and 2 men participated in the family interviews (18 mothers, 1 sister and 2 fathers). Table 10 provides and more detailed breakdown per site). They were caring for a total of 20 children/adults with disability/autism (F=12; M=8). The age of the person with disability ranged from 3 years to 34 years old, with a mean age 16.5 years. There were 6

people between 3 and 10 years, 6 people between 11 and 20 years, 7 people between 21 and 30 years, and 1 person 31 years or over. One family had two children with disability. In the vast majority of situations, the person with the disability was living full time with his/her parent, with the exception of 1 person within the Brothers of Charity who was living independently.

The children’s disabilities ranged from intellectual disability (n = 11), autism (n = 4), physical disability (n = 2) or a combination of both physical and intellectual disability (n = 3) (see Table 11).

**Table 11. Relationship to person with disability, gender and nature of the person’s disability**

Project site	Brothers of Charity	DESSA	Autism Initiative Group	LEAP
Relationship of interviewee to person with disability	7 Mothers, 1 Father and 1 Sister	6 Mothers	1 Mother	4 Mothers and 1 Father
Gender of person with disability	F=5; M=2	F=3; M=4	M=1	F= 4; M=1
Nature of persons disability	4 intellectual disability; 1 autism; 2 both intellectual and physical disability	2 intellectual disability; 2 autism; 2 physical disability; 1 both intellectual and physical disability	1 autism	5 intellectual disability

As a result the person being cared for had significant and multiple sensory, motor, mental physical and communication challenges, and required a range of disability-related supports (Table 12 and Table 13 provide a more detailed breakdown of persons’ disabilities and needs).

**Table 12. Additional conditions of family members with a disability**

Other condition	n
Speech and or language difficulties	13
Behavioural challenges	10
Physical health problems	5
Mobility challenges	6
Sensory integration impairment	10
Feeding or eating difficulties (feed tubes, major allergies, sensitivities, etc.)	5
Seizures	4
Mental health problems	4

**Table 13. Level of disability-related support required and level of communication**

	<b>n</b>
<b>Level of disability-related support required</b>	
No support required	3
Support required for few aspects of life	5
Support required for some aspects of life	4
Support required for most, but not all, aspects of life	4
Support required for almost all aspects of life	4
<b>Level of communication</b>	
Able to communicate about a wide variety of topics in a meaningful way	5
Able to communicate within a limited range of topics in a meaningful way	7
Able to communicate needs, wants, and some ideas	3
Able to communicate basic needs and wants	4
Very little meaningful communication	1

Of the nine project facilitators who were interviewed, six worked for the organisation and three worked for other organisations in various capacities (see Table 14).

**Table 14. Role of project managers/facilitators interviewed**

<b>Project site</b>	<b>Number of participants interviewed</b>	<b>Role</b>
Brothers of Charity	2	2 working for the organisation
DESSA	3	1 worked within the organisation and 2 worked outside in local family resource centre
Autism Initiative Group	2	2 working for the organisation
LEAP	2	1 worked within the organisation and 1 worked outside

### **Data analysis**

All interviews were transcribed by an independent transcriber and subsequently entered into the software package NVivo Version 8 for analysis (QSR International 2009). To assist in the analysis, an initial coding framework was developed by the team based on the literature and some preliminary analysis of the early transcripts. This was then used to guide the coding of the remaining transcripts, but was sufficiently flexible to allow new emergent codes to be incorporated into the framework. Once all data had been coded, each code was examined and overlapping codes were collapsed to form larger more inclusive categories. In addition, data was analysed to identify similarities and differences within and across initiatives.

Participants' responses to the survey were entered into the PASW Statistics 18.0 (IBM Corporation 2009). Frequency distributions and descriptive statistics were calculated, as were measures of central tendency, range and standard deviations. Participants' scores on each measure were determined to establish the extent to which key objectives of the project have been achieved. Inferential statistics (ANOVA and Multiple Regression) were used to relate participants' responses to satisfaction rates, demographic variables, initiative the person took part in, and other relevant variables, in order to establish which factors contribute to experiences of the initiative. In addition, quantitative data were explored to compare outcomes between each of the initiatives. The open-ended questions were analysed thematically, using the framework developed for the interviews. Similarly, the documents collected were read, reread and analysed in a manner to assist the team to triangulate any evaluation data within the documents with data gathered during this evaluation.

### **Ethical considerations**

Ethical approval was granted from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin. The rights and dignity of participants were respected throughout by adherence to models of good practice related to recruitment, voluntary inclusion, informed consent, privacy, confidentiality and withdrawal without prejudice. The rights of the participants and their well-being were given precedence over data collection. The voluntary nature of participation was emphasised throughout the data collection process and participants were free to withdraw from the study at any time without fear of penalty.

Return of the survey was taken as evidence of implied consent. Both written and verbal consent was obtained before the individual interviews. The survey data was anonymous and no identifying information was requested; however, when this did occur, identifying information was removed prior to analysis. Similarly, all identifying information was removed from the qualitative data. Each facilitator or family participant was given a sequential number within the initiative. The code 'PF' is used to represent a quote from a project facilitator and the code 'FM' is used to represent a quote from a family member. As the number of project facilitators was so few and they could easily be linked to their initiative, the anonymising codes 'Int 1', 'Int 2', 'Int 3' and 'Int 4' are used to represent the four initiative sites in no particular order. The family member participant quotes are linked to the initiative they participated in by the following initiative codes: BOC, LEAP, DESSA, and AIG. Textual data from the survey are represented by the initiative code and the word 'survey'. As only one participant volunteered to be interviewed from the AIG initiative, to protect their confidentiality direct quotes from this person is not included within the report. However, this person's data was coded and used to inform the findings.

## Project facilitators' expectations for the family focused initiatives

To enable the reader to get an understanding of the project facilitators' expectations of the initiative, and set the findings of the evaluation in context, a brief descriptive overview of their expectations is now given.

During the interviews with the facilitators, it was clear, from the outset, that they and their organisation had very specific expectations and hoped-for outcomes from each initiative. Throughout the interviews the facilitators spoke of developing an initiative that encompassed a visible ethos of: person and family-centeredness; the enablement of citizenship; and the strengthening of participants' capabilities to self-care, advocate and support their family member with a disability. In the absence of similar initiatives within an Irish context, all the facilitators considered their initiative innovative because in their view they filled an existing void within Irish service. In the words of one facilitator:

*"...parents of children with disabilities...get nothing [referring to educational and skills input]." (Int 3, PF interview 1)*

The overarching expectation of each facilitator was that the initiative would enable families of children with disability to envision a positive realistic future plan and build better lives for themselves and their children, within the context of their local communities. Two strategies were used to achieve this desired outcome. Firstly, the initiatives placed a particular emphasis on strengthening participants' and their children's links with local communities, through the creation of circles of support. Linked to this was the building of participants' knowledge and skills in order to enhance natural supports within the community, as opposed to having an over-reliance on professional and service models of planning and support. In the facilitators view, the initiatives were:

*"...more about an asset based community development approach. We're more about looking at natural supports from family, friends, neighbourhood and community first and only then bringing in paid support, professional support when needed."  
(Int 3, PF interview 1)*

*"...not service led at all...the families that we traditionally engage with...are people who are service dependent, who believe that service providers have all the answers. So we're not engaged with people who would think anything like circles of support... if you can imagine we're a service provider now trying to promote an approach which is [not service led]....." (Int 2, PF interview 2)*



*“...about looking at that person and particularly working around their interests. Like for instance [reference to a person with a disability] is interested in sport so, and he’s interested in football, so, and he’s interested in [name of football club], so it would be connecting him with somebody who is also interested...circles of support is about looking at the person, what their interests are and getting people [without disability], you know, into their lives, because it’s not all about connecting them in with people” (Int 4, PF interview 1)*

Secondly, facilitators emphasised the goal of helping participants to build their capacity to initiate and make changes in their and their children’s lives by becoming skilled advocates, on behalf of themselves and the person with a disability:

*“...there was a need for somebody to look at how to help parents be better advocates and also be part of the programme development or service development for their sons and daughters.” (Int 4, PF interview 1)*

To these ends, there was recognition that to realise these expectations, *“...a massive mind shift was needed...if it [expectations] was to totally succeed”* (Int 2, PF interview 2). The means to accomplish this shift in thinking was through the creation of space (provided by the initiatives), which would be centred on enabling participant empowerment; providing time for knowledge and information sharing; assisting with skills acquisition; enabling family members to meet others in similar situations; and the provision of support. From the facilitators’ perspectives, these principles were built in to the components of the different family initiatives.

## Summary

- The aim of this study was to evaluate the four family-focused initiatives from the perspectives of families of people with disabilities and services/organisations.
- The study employed a multi-method approach using qualitative and quantitative methods to provide a comprehensive evaluation. Data was collected using individual interviews, surveys and documentary analysis.
- The final number of surveys included for analysis was 38 representing a 22% response rate.
- Nine interviews were conducted with project managers/facilitators, and 19 interviews were conducted with 21 family members.
- All qualitative data was thematically coded and quantitative data were statistically analysed.
- Ethical approval was granted from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin.

## SECTION 4: FINDINGS – IMPACT OF THE FAMILY INITIATIVE ON THE FAMILY AND FAMILY MEMBER WITH A DISABILITY

### Introduction

Family-centred initiatives that involve a significant change in the power balance between professional and family member have the potential to be hugely transformative for the family participants, the person with disability and the family as a whole. Previous studies suggest that initiatives that are based on a partnership approach, and focus on respect for autonomy, capacity building, sharing of knowledge and development of problem-solving, decision-making, and advocacy skills, as well as the visioning of a life for the person with a disability that is centred on citizenship has led to change in the lives of people with disabilities and their families (Schippers and van Boheemen 2009; Butera-Prinzi *et al.* 2010). Some of the key objectives of this evaluation were to identify the general and specific benefits derived by families and others through participating in each initiative. This section reports on findings related to the impact and benefits of the family initiatives on the participants, their family member with a disability and the family unit as a whole. Where appropriate, findings from the survey and family interviews are integrated together.

### Participants overall view on the usefulness of initiatives

Overall, participants agreed or strongly agreed with most of the statements within the survey, thus indicating an overwhelming positive response to their experience. The extent of disagreement with any statements was low and only a few statements yielded significant 'Neither agree nor disagree' responses. Almost 90% (89%; n = 32) of participants found the family initiative they participated in to be useful or very useful, with only a small percentage reporting it not very useful (3%; n = 1) or not at all useful (3%; n = 1) (see Table 15).

**Table 15. Overall, how helpful was the family initiative for you and your family?**

	n (%)
Very useful	22 (61%)
Useful	10 (28%)
Neutral	2 (6%)
Not very useful	1 (3%)
Not at all useful	1 (3%)
<b>Total</b>	<b>36 (100%)</b>

Similarly, 92% (n = 33) of participants felt that the initiative had a positive impact on their lives. Positively, 89% (n = 32) of survey participants felt that what they learned from the family initiative was practical (see Table 16). Qualitative comment by participants supported these positive survey responses:

*“Overall I have to say it was very worthwhile going to.” (BOC, FM interview 4)*

*“I was very glad of it...because there is very little out there.” (LEAP, FM interview 2)*

*“Overall very positive. It helped us through a rough time.” (BOC, survey)*

Only a very small percentage 9% (n = 3) disagreed with the statements that what they learned ‘had a positive impact on their lives’ (see Table 16). An analysis of the written survey comments suggests that for one person their dissatisfaction related to an expectation that the initiative would offer them ‘*personal support*’, which it did not. Another participant described how the initiative left them with a feeling of frustration:

*“To be honest, it has led to a lot of frustration, while the theory is great, building a support network outside of immediate family and disability services proved very difficult. While [the] extended families were enthusiastic, in principle, this did not translate into practical assistance. It takes a forceful and persistent person to drive change and not everybody has the personality or time necessary.” (LEAP, survey)*

**Table 16. Level of agreement about the impact and practicality of the family initiative**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree nor disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
What we learned from the family initiative has had a positive impact on our lives (n = 36)	15 (42%)	18 (50%)	0 (0%)	2 (6%)	1 (3%) <sup>2</sup>
What we learned from the family initiative was practical (n = 36)	13 (36%)	19 (53%)	3 (8%)	0 (0%)	1 (3%) <sup>2</sup>

<sup>2</sup> The one participant who disagreed strongly with both statements was under the impression that she would be attending a support group as opposed to an information day and as a consequence was disappointed with the lack of support she received.

## Increased knowledge and confidence of family member participant

One of the core strategies in family capacity building is the sharing of knowledge in order to improve family members' capabilities to mobilise desired resources and supports for their family member with disability (Dunst *et al.* 2002). While no survey participants indicated that the family initiative greatly improved their knowledge in supporting their family member with a disability, 70% (n = 26) felt it moderately improved their knowledge in this regard, with a further 16% (n = 6) feeling it slightly improved their knowledge (see Table 17). A significant minority (14%; n = 5) felt their knowledge stayed the same.

**Table 17. Impact of family initiative on knowledge in supporting family member with a disability**

	<b>Stayed the same</b>	<b>Slightly improved</b>	<b>Moderately improved</b>	<b>Greatly improved</b>
Knowledge (n = 37)	5 (14%)	6 (16%)	26 (70%)	0 (0%)

Interview and survey participants frequently described 'knowledge as power' and mentioned a number of areas where their knowledge increased, including: understanding the behaviour of the family members with disability; strategies for interacting with the family member with a disability; problem solving within the family (BOC, DESSA, LEAP); developing circles of support (BOC and LEAP); personal funding (LEAP); homeshare or respite care (BOC); entitlements and the legal framework surrounding disability (DESSA); and the financing of disability services (LEAP). A number of participants also commented on developing a knowledge base on how to navigate the systems of the Health Service Executive (HSE), service provider agencies and government agencies, as well as how to interact with staff on a day to day basis about care. Several interview participants also noted how they learned to keep detailed records of their interactions with services and the HSE so that they would be better prepared to engage with people that controlled access to services (DESSA). Participants commented:

*"[I was advised,] if I was on a telephone [to a service provider], to ask somebody their name, to have a notebook, it was all practicality ...on the course I learned how to do my research, how to be informed, how to take another person to an interview or a meeting."* (DESSA, FM interview 6)

*"They really told us write everything down...if you're on the phone to someone, write down the name, write down the date and follow up on it."* (DESSA, FM interview 4)

*“...we don’t, we give out about what they have and we get cross and we’re known as bolshie parents or ‘God, she’s a troublemaker’ or all this sort of stuff, but I actually made a plan and I went to the services and they were thrilled and I was able to change.” (Int 3, PF interview 2)*

### **Changing attitudes towards family member with a disability**

In addition to enhancing the participants’ knowledge, the initiatives appeared to have the effect of challenging their thinking about disability. Participants spoke of the initiative as helping to *“open our mind to the idea that independent living was a possibility not just a notion”* (BOC, FM interview 1) and develop *“a more normal outlook”* (BOC, FM interview 3). One of the participants encapsulated the shift in attitude and thinking by summing up the social model of disability as:

*“It’s society’s problem that disabled people aren’t integrated rather than the disability stopping them from being integrated.” (DESSA, FM interview 4)*

Several participants described how the initiative affected their “approach to life” and their approach to their child. In the context of shifting attitudes, participants described how they learned to be open-minded about their child’s potential and possibilities and challenge their own thinking, for example:

*“The main thing I would have learned is to be open-minded to possibilities that might seem ludicrous when you hear them first, because a lot of them were ludicrous when you hear them first. A lot of the possibilities that [names son] could move out, [names son] could be a home owner. They [project facilitators] brought in different people, over different weekends different people were brought in that had achieved an awful lot in their lives having come from group home living to independent living.” (BOC, FM interview 1)*

This change in approach appeared to have come with the realisation that their family member had rights to participate in a full and meaningful life:

*“[He is entitled to] a full life, no different to anybody else’s...” (DESSA, FM interview 1)*

*“She deserves to have a full life, no different to anybody else’s life” (LEAP, FM interview 1)*

*“Programme reinforced my right to advocate for my child and insist on his acceptance into the community as an active and functioning person.” (DESSA, survey)*

Participants in all of the initiatives also spoke of, or wrote about, moving to a place where they were now more focused on the people’s strengths and abilities, rather than their disability and coming to a realisation that their child was not necessarily so dependent that he or she could not make a contribution, as shown here:

*“What she [daughter] had to offer, what she could do...what she had to offer her friends, her family, the wider community in terms of the social valued role.” (LEAP FM interview 5)*

*“It has made me look at the importance of my daughter’s contribution to the community and society at large...” (BOC, survey)*

*“It has given us a more positive outlook for [names son]'s life.” (DESSA, survey)*

The positive shift in attitude toward the family member was also reflected in the survey responses with 31% (n = 11) reporting their attitudes greatly changed, with a further one-third (33%, n = 12) reporting a slight to moderate change in attitudes (see Table 18).

**Table 18. Impact of family initiative on participant attitude towards family member with a disability**

	n (%)
Stayed the same	13 (36%)
Slightly changed	3 (8%)
Moderately changed	9 (25%)
Greatly changed	11 (31%)
<b>Total</b>	<b>36 (100%)</b>

### **Enhanced skills in supporting family member with disability**

An important outcome of the family initiatives for many participants was an increase in their skill level in supporting their family member with disability. Participants commented that the initiatives were *“more than just information...[but was also] about giving people the skills and strategies to problem solve”*. Although no survey participants indicated that the family initiative greatly improved their skills in supporting their family member with a disability, 68% (n = 25) felt it moderately improved their skill in this regard, with a further 19% (n = 7) feeling it slightly improved their skill.

A significant minority (14%; n = 5) felt their skill stayed the same. Table 19 provides further details. The findings on the impact of the initiative on skill levels were almost identical to the findings on knowledge, perhaps indicating a very close relationship between those two aspects.

**Table 19. Impact of family initiative on skills in supporting family member with a disability**

	<b>Stayed the same</b>	<b>Slightly improved</b>	<b>Moderately improved</b>	<b>Greatly improved</b>
Skills (n = 37)	5 (14%)	7 (19%)	25 (68%)	0 (0%)

Survey participants were also asked more specific questions on the impact of the initiatives on their advocacy skills (see Table 20). While there were a minority of neutral responses for each statement, overall the findings were positive. Between 74% and 89% of participants agreeing or strongly agreeing that the initiative positively affected their ability to: make suggestions (83%, n= 29); ask questions (83%, n= 29); seek information from health care personnel/agencies/organisations (74%, n= 26); and advocate more effectively for their family member (89%, n=32).

**Table 20. Level of agreement about the impact of the family initiative on advocacy skills**

<b>Since participating in the family initiative...</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>N/A</b>
My family member with a disability and I are more assertive about making suggestions to healthcare personnel/services/ organisations about his/her needs (n = 35)	<b>20 (57%)</b>	9 (26%)	5 (14%)	1 (3%)	0 (0%)	0 (0%)
My family member with a disability and I are more willing to ask questions of healthcare personnel, services and organisations (n = 35)	<b>20 (57%)</b>	9 (26%)	5 (14%)	1 (3%)	0 (0%)	0 (0%)
My family member with a disability and I are more likely to seek out information on his/her needs (n = 35)	<b>15 (43%)</b>	11 (31%)	5 (14%)	3 (9%)	0 (0%)	1 (3%)
Participating in the family initiative has enabled me to advocate more effectively for my family member with a disability (n = 36)	<b>17 (47%)</b>	15 (42%)	1 (3%)	1 (3%)	2 (6%)	0 (0%)

Although the interview participants did not speak in the language of ‘increased advocacy skills’, they did talk of acquiring an increased sense of empowerment and assertiveness. This enhanced empowerment and assertiveness appeared to be closely linked to their new found knowledge and confidence, as well as a realisation that their rights and the rights of their child were indivisible. As one participant wrote:

*“...we [family] have a can do attitude that we didn’t have for a number of years. It has helped us to be firmer in our belief in our right to question what is on offer.”*  
(BOC, survey)

Consequently, family members no longer viewed themselves as asking for services or assistance for themselves but as advocating for the rights and entitlements of their family member. Participants described how they felt better prepared, more determined, less fearful and more skilled and confident in dealing with systems such as the HSE and services when asserting their and their family members’ rights and opinions:

*“I can just remain calm and be...and ask a person to feed back to me what they’ve said so I’ve got the right picture, whereas before, I might get emotionally distressed.”*  
(DESSA, FM interview 6)

*“When you are going into service providers, there is no two ways about it, there is a ‘them’ and ‘us’ and I would have felt quite vulnerable...If they had said no, you can’t have this, I would have said, ‘Okay that’s no problem, I’ll leave now.’ Whereas now, I am not accepting that. I know I don’t have to get into an argument with them, it can all be done in a very assertive way...Since then loads of things have happened for [name of child] that I was unhappy with and there’s been changes that I have, have implemented with professionals and it’s been a win-win situation”.*  
(LEAP, FM interview 4)

*“I realise I do not have to apologise when I ring up about services for my son as if I am a nuisance. I now know as my sons advocate, he is entitled to services and resources...I have the confidence to ring and ring if they are not met.”* (DESSA, survey)

In addition to advocating for services, participants reported feeling better able to work with service providers on more equal terms. One family member who attended the BOC initiative felt that her family were more empowered to visit with their relative spontaneously and felt freer to bring her home from the residential setting more frequently.



Others reported being better able to negotiate for Person Centre Programmes [PCP] and for a school placement in an integrated setting, with one mother making the point that:

*“I am a lot more confident I think to fight for [my son’s] rights and to fight for a school place or whatever...whereas before I would see it a bit as charity, you know what we get from the Health Board.” (DESSA, FM interview 4)*

While one parent expressed strong feelings of being under constant stress that damaged the family dynamic and inhibited the development of assertiveness skills, the majority of other interviewees did comment on the positive outcomes of enhanced assertiveness. There was a sense that participants’ increased assertiveness not only offered the possibility of obtaining improved services for their child, but it resulted in participants feeling greater satisfaction with their engagement with services, which in turn enhanced their self-esteem. However, there was also a realisation amongst some family members that this increase in assertiveness did not automatically translate into better services and that some service providers were not as open to the family members’ change of approach. One parent explained that no matter how assertive one might be:

*“At the heel of the hunt if...what you’re looking for isn’t given to you, what can you do?” (BOC, FM interview 3)*

### **Increased confidence, self-awareness and help seeking behaviour of family member participants**

In addition to enhanced knowledge, change in attitudes and increase in assertiveness and advocacy skills, some participants described an increased sense of personal awareness, confidence and self-esteem as an outcome of participating in the initiatives. Participants spoke of the initiative:

*“boosting my self esteem, my confidence” (LEAP, FM interview 4)*

and of:

*“feeling much more positive [about myself]” (LEAP, FM interview 5)*

*“more confident...stronger person...” (DESSA, FM interview 1)*

In many situations, this sense of enhanced confidence came about with the realisation that they had the right to advocate for their child, and the right to have and express an opinion:

*“It’s given me more confidence in myself and not to be afraid to express my opinion even if it is not the right one for other people, you need to be able to stand up for yourself and them in a nice way without offending others.” (DESSA, survey)*

*“It has given me more confidence to bring my son out in public places and ignore the glances and stares if he has a meltdown.” (BOC, survey)*

The importance of caring for oneself was mentioned by some participants as being something they learned. Some mentioned treating themselves to massage and pampering sessions as a means of recognising their own worth. There was also a sense that participants were less reluctant to ask for help from professionals and their friends since participating in the initiative. Some participants commented that as they acquired knowledge and confidence, they recognised that they were entitled as of right to the statutory supports they received. Others came to a place where they realised they could not bear the whole burden of supporting their child alone, and were learning to ‘let go’ and ask for help from family and friends (DESSA, AIG). One family member described her developing self-knowledge as enabling her in:

*“...looking, admitting, admitting to talents and faults, I guess there’s a good and a bad in it, and the impetus it gave me to involve my family.” (LEAP, FM interview 2)*

In addition, one participant spoke of developing the capacity to find one’s way through the system, while developing the resilience to keep their own wellbeing intact. This was described as:

*“A way of navigating without...having to get totally drained yourself.”  
(LEAP, FM interview 3)*

The survey responses support the qualitative findings with 77% (n=27) of participants agreeing that since participating in the initiative they would seek informal support for themselves (e.g. talking to a friend) and 67% (n=14) agreeing that they would seek professional support (e.g. going to see GP). Further findings are shown in Table 21.

**Table 21. Level of agreement about the impact of the initiative on seeking support**

Since participating in the family initiative...	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A
I am more likely to seek informal support for myself (e.g. talking to a friend) (n = 35)	11 (31%)	<b>16</b> <b>(46%)</b>	5 (14%)	3 (9%)	0 (0%)	0 (0%)
I am more likely to seek professional support for myself (e.g. going to see my GP) (n = 36)	9 (25%)	<b>15</b> <b>(42%)</b>	10 (28%)	1 (3%)	1 (3%)	0 (0%)

### Impact of the initiative on the person with disability

The change in attitudes of the participants about their family member with a disability had practical effects on the life of the person with disability, with 84% (n = 30) of survey participants agreeing that participation in the family initiative had enabled them to be more effective in the direct support of their family member (see Table 22). For many family members, the shift in attitude towards a rights and ability based approach was accompanied by a realisation that their family member had a need for: autonomy; voice; involvement; and independence. Some participants described how they changed their own behaviour and had started ‘listening’ to the person and giving them a ‘say’ in decision making. Participants spoke of, and wrote about, coming to a place where:

*“I respect her as an equal and her ability to make decisions.” (BOC, survey)*

*“I realise how I am limiting his life...” (LEAP, survey)*

*“I am more willing to allow him to experience life.” (BOC, survey)*

*“I’m letting her be more independent.” (LEAP, survey)*

Most importantly, the courses impacted on the way parents thought of the potential of their children and the lives that they might lead. Within the interviews participants gave

numerous examples of their changed approach to their family member. One participant explaining that her daughter suggested she would move out of the family home to live independently and that as a result of doing the course she (the parent) could cope and understand this:

*“If I hadn’t done the course I would be totally shocked by what my daughter had come out with...Like she was brushing her hair and she stopped and said, ‘Mum I think I will move out’...‘into an apartment with my friends’. Now if I hadn’t done the programme I would have thought, ‘Oh my God what are they saying to her, she is not prepared to move out...that is just a dream, how do I tell her that it is a dream?’ and I would have been totally shocked if I hadn’t done the programme.”*  
(LEAP, FM interview 5)

Another parent noted that she and her husband had established a circle of support consisting of ten friends and family who came together to support their eighteen year old son who now was starting part time work locally. This mother also explained that the nature of her changed outlook consisted of her pulling back and enabling her son do things himself. The mother perceptively concluded by noting that the changed mind-set of her husband and herself resulted in an improvement in her son’s quality of life. In giving an example of how his life changed, the mother (BOC, FM interview 2) asserted that *“his social life would have improved and I suppose because our attitude would have changed”*. She also offered another instance of her son’s change because he’s *“reading at mass, as well now, that’s a thing he’d never, ever have done either”*.

These changing parental attitudes were also manifested in terms of parents’ approach to the education of their children. Some parents decided that they preferred their child to attend a mainstream school and not the special school that they had been offered (DESSA), while others sought successfully to have their child attend third level college (LEAP).

There was a sense of parents being freed up in their thinking to plan ahead and, consequently, change their reactions. For example this mother spoke of learning to plan ahead so she could continue to do things socially with her child and maintain his connection with the community:

*“I’m trying to get strategies together and thinking a little bit ahead all the time...so you can continue on bringing him out and bringing him to the playground, the beach which he loves, and if he does play up, how to get around it.”* (DESSA, FM interview 1)

This move to enhancing the person with a disability's decision making and connection with community was also echoed in the survey responses, as shown here:

*"We look at her more as a grown up now, rather than a baby way. We choose clothes, etcetera for her age and ask her opinion on what she wants to wear, even though she doesn't care much. We got her some bling [sparkly jewellery] and got rid of the dribbler she hates." (BOC, survey)*

*"The course helped me reflect on the fact I should be assisting him with his decisions, rather than making decisions for him. Having encouraged and cajoled him to try to participate in all mainstream sport like football and basketball, whereas now I encourage and support him in participating in any sport he enjoys doing which tend to be self-oriented like cycling, swimming and judo." (DESSA, survey)*

Many interview participants described how their family member was more involved in social activities at community level and how their life had become more varied as a result of their parents or siblings attending the courses. One participant who attended the Brothers of Charity course explained how her child had gone away for the first time ever with the aid of her support worker, and other participants described how their family members with disability now went to gymnastics, swimming, piano lessons, read at church, attended the cinema and concerts. Another mother emphasised that doing the course had freed her from the house and she now would visit the local community (shops, restaurants) with her son irrespective of how he might behave (DESSA). She referred to her son attending at horse riding stables near her home, *"he goes on a horse and the farm and stuff around the farm and he loves it, for 20 minutes...once a week...the next step will be swimming..."*. The mother noted that previously her attitude had been to keep her son at home, *"if he kicks up now at least he is at home. Whereas now you've got that bit of confidence...it gives you that bit of confidence to go forward"* (DESSA, FM interview 1). Similarly, a survey participant gave the following example of enhanced community involvement:

*"We have asked our community for help in regards to social inclusion and they have supported us. The result being that we are slowly bringing our son out into the community more. There were members of our community who would never have seen our son." (LEAP, survey)*

The opportunity for their son or daughter to start work and the consequent financial independence was named by several parents as a beneficial consequence of them participating in the initiative. One parent commented:

*“And working and that people would be pleased with her, which was, it’s a bonus too, you know. In actual fact, she’s getting some pay from one or two of her jobs.”*  
(BOC, FM interview 6)

As an outcome of the enhanced autonomy, voice and independence, several participants described an improvement in the confidence, personal growth and quality of life for the person with a disability, one parent describing when her daughter first went to the local college said:

*“So when the day came, when she walked out that door with her satchel on her back like all the other students, because we live near [the university], that was one of the happiest days of my...and hers, I could see it in her back as she went out. She was so proud of herself.”* (LEAP, FM interview 5)

Another parent describing her sons return from a two week camp:

*“He grew so much in the two weeks, the independence beaming from him. He was absolutely thrilled with himself.”* (BOC, FM interview 1)

The enhanced confidence and independence of the family member with disability a result of enhanced autonomy and self-sufficiency was also noted in the survey responses:

*“[Family initiative] has made him more self-sufficient. He makes more of his own decisions, which has increased his confidence as he feels he has more control. He no longer sees himself as a list of disabilities and focuses less on the things he has trouble doing.”* (DESSA, survey)

*“She has become much more independent and gained confidence.”* (BOC, survey)

*“He [family member with a disability] is happier, less bored, has taken a better interest with his surroundings.”* (DESSA, survey)

It must be acknowledged that some families had circles of support and had their children connected into the community prior to the initiative. However, for others the implicit engagement with the community that circles of support involve was not reported within the interviews or surveys. Just 47% (n = 16) of survey participants agreeing that the initiative enabled their family member to be more involved in the community and 27% (n=9) disagreed or strongly disagreed (see Table 22). The reasons for the disagreement were multifaceted: children were very young; level of community involvement was high before the initiative; difficulty maintaining momentum after the initiative finished; and other circumstances. For example, one interview participant noted that because her child’s school was in another town her daughter made friends with her school mates in that town and not in her home town with the result that she did not make links to or engage with her local geographical community.

Direct changes to the person with disability’s ability to care for themselves were not reported within the interviews. Only a minority of survey participants (22%; n = 8) agreed with the statement ‘that participation in the initiative enabled their family member to care more effectively for himself or herself’, with 31% (n =11) disagreeing (see Table 22). However, in some cases material benefits did accrue from family members attending the course which had an impact on the life of the person with disability. For example, parents of a child who had communication difficulties reported during interview that as a result of attending the (BOC) initiative, they obtained a consultation from a communications expert who assisted them to communicate with their daughter. One family member reported that the 100 hours of paid support, which was associated with one (but not all) of the initiatives, was empowering because it offered an opportunity for the families to test new ways of doing things.

**Table 22. Level of agreement about the impact of the initiative on community involvement and care**

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Participating in the family initiative has enabled me to be more effective in the direct support of my family member with a disability (n = 36)	11 (31%)	<b>19 (53%)</b>	3 (8%)	0 (0%)	3 (8%)
Participating in the family initiative has enabled my family member with a disability to be more involved in the community (n = 34)	2 (6%)	<b>14 (41%)</b>	9 (27%)	6 (18%)	3 (9%)
Participating in the family initiative has enabled my family member with a disability to care more effectively for himself/herself (n = 35)	4 (11%)	4 (11%)	<b>16 (46%)</b>	7 (20%)	4 (11%)

## Impact of the initiative on the family unit

Overall, participants within the survey and interviews described how the initiative had positive effects on the family unit. For many, this specifically related to an improved understanding of their family member with a disability, an increase in dialogue and communication within the family, and an increase in the involvement of other family members in the life of the person with a disability.

Many participants described how as a family they had come to understand more fully the life of their family member with a disability and the problems people with disability face, while others were of the view that as a family they had a better understanding of what 'independent living' meant and how it might be applied to the life of their family member. In some situations, participants were of the view that this changed perspective was translated into an increased respect and pride for their family member:

*"She has different little jobs and she's getting on very well, I suppose we'd have never foreseen that she would actually be able to have jobs." (BOC, FM interview 6)*

Several participants described improved communication between family members and a greater willingness to discuss issues that concerned the life of the family member with a disability. Issues which had previously been dealt with by one family member were now discussed within the whole family unit:

*"We discussed our sister as a family which we never did before and we all know now what has to be done for her and taking it all as a family not just things being left to one or two members." (BOC, survey)*

*"I think communication is the biggest thing for me, for anything to happen for change to happen communication is key." (LEAP, FM interview 4)*

The initiative appeared to have the effect of increasing the involvement of other family members, especially siblings, in the life of the person with disability. Participants spoke of "work[ing] more as a team" (DESSA) and "taking a more positive outlook as a family" (LEAP). This in turn was perceived by the primary carer as not just a means of sharing the care, but served to increase engagement of the person with a disability with a wider circle of people:

*"It sort of gave everybody [in the family] a vision of what kind of, of what we've been talking about or what we thought we were talking about and what we want to do." (LEAP, FM interview 1)*



*“It has definitely opened up [names person with disability] and her world to everybody [in the family].” (BOC, FM interview 6)*

*“Amongst her family group, she now has twelve people willing to pick up the pieces and they, all their spouses have, each one, is willing to take her on. Now that means she could live her life between six homes or one home or whatever so...”  
(LEAP, FM interview 2)*

Some interview participants described how the role of fathers was expanded as a result of the family initiative. The changed family dynamics appeared to come about when a father attended the initiative or as a result of a mother’s changed attitude following her attendance. Irrespective of the reason, fathers were enabled to join the familial conversation, which appeared to have previously been led by mothers who were the primary carers. This participant described the change within her own family:

*“Because my husband was always at work, which was fine, but you end up carrying most of this and when you attend meetings you go home with your version of events at meetings, so you’re conveying your version of events home. Whereas when both people attend these meetings, as with any meeting, you listen to the same information but you’re obviously bringing two different view points from it, so you have a broader view. He [husband], over the number of meetings he had a completely different view of [names son] because as far as he was concerned [names son] went on the bus every day to the workshop and that was it, that was fine.”  
(BOC, FM interview 1)*

Lastly, there was a mention by some participants of grandparents becoming more involved with the person with disability. This appeared to come about as a result of changed and more open attitudes in the family member.

Survey participants were also asked about how the initiative impacted on the family as a unit. Most positively, 70% (n = 25) agreed that the initiative helped them as a family to make important changes in the life of their family member with a disability, while more than 50% (58%; n = 21) of participants felt the initiative helped them to solve important problems (see Table 23). Similarly, 50% (n = 18) of participants felt the initiative helped them to meet their family’s needs. However, it is important to highlight that several survey participants (3 LEAP and 2 DESSA) felt that the family initiative did not impact in any way on the family as a whole.

One person commented:

*“Don’t feel like it helped the life of my family...More me.” (LEAP, survey)*

**Table 23. Impact of family initiative on family as a unit**

Participating in the family initiative has...	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
helped us make changes that were important for our family member with a disability (n = 36)	11 (31%)	<b>14</b> <b>(39%)</b>	7 (19%)	3 (8%)	1 (3%)
helped us solve important problems (n = 36)	7 (19%)	<b>14</b> <b>(39%)</b>	11 (31%)	3 (8%)	1 (3%)
helped us to meet our family’s needs (n = 36)	6 (17%)	<b>12</b> <b>(33%)</b>	13 (36%)	4 (11%)	1 (3%)

### Impact of networking with other families

The literature on family members as carers, frequently refer to family members’ experiences of isolation, loneliness and sense of being on one’s own and the positive impact of having an opportunity to share common experiences with other families (Butera-Prinzi *et al.* 2010). Similarly interview participants in all four initiatives (AIG, BOC, DESSA, LEAP) described how valuable it was to meet other families and share information and network. Hearing from other family members who had ‘walked the walk’ was important for a number of reasons. Firstly, it enabled participants to acquire a knowledge base that in the words of the participants constituted- ‘knowledge you can’t get from books’:

*“That’s [information received from other parents] worth millions because you don’t get that written in a book, that kind of information.” (DESSA, FM interview 5)*

*“Best thing I have done...Met other parents who were a wealth of knowledge and experience and they shared so much.” (LEAP, survey)*

Family members learned from others about how to deal with the HSE, how to manage behaviours that challenge, how to respond to adolescents and about independent living. Less experienced parents welcomed hearing the experiences of those who had managed the system and achieved a degree of confidence in so doing. In addition, family members who had adult children who were living semi-independently shared their experiences with others

who had younger children, and in so doing acted as points of hope and possibility. As one parent said:

*“we kind of got time to sit and spend time over lunch and dinner with people that was a real part of the learning experience and you can’t, you kind of can’t buy that, you know, it was just part of the experience and it was very, very good.” (BOC, FM interview 5)*

On a more emotional level, participants described how networking with other family members reduced feelings of isolation and aloneness. There was a strong sense that the space provided by the initiatives enabled feelings to be shared amongst people, who understood and were empathetic. In particular, participants spoke of sharing feelings that they found difficult to cope with and speak about in other fora, such as inability to cope with their family member and the despair that goes with it. The successive sessions that were a characteristic of many of the initiatives and the length of time involved meant that family members who were more reticent to discuss their feelings had a chance to develop a sense of trust and engage as the initiative progressed:

*Nice to meet with other families, share experiences, see people understood and you were not alone.” (DESSA, survey)*

*“...you laugh and cry together, you come out feeling ‘I’m not alone”  
(LEAP, FM interview 3)*

*“...one parent would have said, well this is the way I approach this group, this is how I got this service for my child...it’s from linking in with the other people on the course that you learn as much.” (Int 1, PF interview 1)*

The open discussion that took place amongst the participants during the workshops frequently led to informal circles of support becoming established and in some instances the formation of friendships. Although not all participants spoke of developing on-going networks, several mentioned maintaining contact through informal meetings over coffee or simply keeping in touch by email, phone, or the use of Facebook. The positive outcome of the initiatives in terms of decreasing family members’ sense of isolation was also clearly evident in the surveys with 75% (n= 27) of participants agreeing or strongly agreeing that they felt less isolated since participating in the initiative. More than three fifths of the

participants agreed or strongly agreed that they feel more supported by their own family/friends (61%, n=22) and by other families (70%, n=25) in meeting their own needs. In addition, a high percentage agreed or strongly agreed that since completing the initiative, they are more supported by their own family/friends (70%, n=25) and by other families (61%, n=22) in meeting their family member with disability needs. Most positively, 86% (n = 31) of participants felt they were more likely to support other families from the initiative. The full results are presented in Table 24.

**Table 24. Level of agreement about the impact of the initiative on social support**

Since participating in the family initiative...	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A
I feel less isolated (n = 36)	12 (33%)	<b>15</b> <b>(42%)</b>	2 (6%)	4 (11%)	3 (8%)	0 (0%)
I feel more supported by other families in relation to my family member's disability (n = 36)	10 (28%)	<b>15</b> <b>(42%)</b>	6 (17%)	4 (11%)	1 (3%)	0 (0%)
I feel more supported by my own family/friends in relation to my family member's disability (n = 36)	10 (28%)	<b>12</b> <b>(33%)</b>	9 (25%)	3 (8%)	2 (6%)	0 (0%)
I feel more supported by other families in meeting my own needs (n = 36)	6 (17%)	<b>16</b> <b>(44%)</b>	8 (22%)	5 (14%)	1 (3%)	0 (0%)
I feel more supported by my own family/friends in meeting my own needs (n = 36)	8 (22%)	<b>12</b> <b>(33%)</b>	11 (31%)	3 (8%)	2 (6%)	0 (0%)
I am more likely to support other families who participate in the family initiative (n = 36)	<b>16</b> <b>(44%)</b>	15 (42%)	4 (11%)	1 (3%)	0 (0%)	0 (0%)

## Summary

- Overall, findings from survey and interviews indicate that the initiative had, for the majority of participants, a positive impact on the person attending, their family member and the family unit.
- Participants were of the view that the initiative enhanced their knowledge and skills, and what they learned was relevant and practical.
- Several participants described how the initiative challenged and changed their thinking about disability, and increased their awareness that their family member had rights to participate in a full and meaningful life and had the right to have autonomy over their own life.
- Interview and survey data clearly indicated that the initiative positively affected the participants' ability to advocate for the rights of their child and engage with services on a more equal footing.
- Some participants reported greater involvement and social connections of their family with community. This appeared to come about as a result of parental mind-sets changing, circles of support being established, and parents requesting that their son/daughter be involved in activities.
- Participants reported improved quality of life, self-esteem and confidence for their family member as a result of their increased autonomy, independence and involvement in decision making.
- Participants described how the initiative had positive effects on the family unit and related an improved family understanding of the family member with a disability, an increase in dialogue and communication within the family, and an increase in the involvement of other family members in the life of the person with a disability.
- Many participants described the importance of the networking aspects of the initiatives in overcoming feelings of isolation, helping them to share knowledge and learn from each other, allowing them to feel less isolated and alone, and supporting them in establishing friendships.

## SECTION 5: FINDINGS – FAMILY MEMBERS’ PERSPECTIVES ON CONTENT, PROCESSES STRUCTURES, AND SUSTAINABILITY

### Introduction

This section of the report explores the views of family member participants on the content, processes, structures, and sustainability of learning within the initiatives. The findings relate to the objective of identifying what families found most helpful and what they thought could have been done differently. Where appropriate, findings from the survey, and family and facilitator interviews are integrated together. This section concludes with a discussion of the outcomes of the statistical analysis conducted to explore differences between initiatives and factors predicting perceived helpfulness of the initiative.

### Family participants’ views on the theoretical content of the initiative

Overall, participants were of the view that the initiatives were “*well organised*” (AIG, FM interview 1), “*very well run and interesting*” (BOC, FM interview 2), “*excellent wealth of information*” (Survey LEAP), with many participants commenting that they would “*recommend it to any other parent...*” (DESSA, FM interview 1). Although the content varied somewhat across the four initiatives, irrespective of the initiative there were many commonalities in participants’ views on the content delivered. Interview participants were of the view that although “*there was a lot of stuff in it [initiative]*” (BOC, FM interview 7), the information presented was empowering, enlightening, relevant and applicable:

*“I suppose information is power really...you always learned something, even though reading down through the timetable you might think a lot of this doesn’t apply to me but sure something applies to everyone.” (BOC, FM interview 1)*

Participants valued the different perspectives and understanding of disability offered, including the person and family-centred philosophies and the positive possibilities offered for the future of their family member with disability. All participants referred to the importance of learning strategies to enable them to advocate, navigate, and communicate with services and service personnel:

*“...I had never attended a course before where the focus was on the young person...and was at the centre in a positive way, you know? Before you would go to courses and listen to general lecture but never before was it so individualised for me and my daughter with and my family and her community. It was quite extraordinary in that way...” (LEAP, FM interview 5)*

Each interviewee also highlighted different aspects of the content depending on the initiative attended. Those attending the BOC initiative spoke of the advice they received from a solicitor on inheritance and wills, as well as ideas, on how to form a family member support group. The emphasis on independence and choice for users of services was mentioned by the LEAP participants and the rights of the child and the legislation underpinning disability services were mentioned by DESSA participants. This view was also supported by the project facilitator data, as in the words of one facilitator:

*“It’s more than just an information setting it’s about giving people the skills and the strategies to problem solve for themselves, you know, it’s a step further.”*

*(Int 4, PF interview 1)*

Participants made a number of recommendations for the inclusion of different topics in future initiatives. Primarily, participants suggested expanding information on: independent living and employment (BOC, LEAP); education opportunities (DESSA); how to implement learning from the initiative (DESSA); how legal rights can be used to improve services (DESSA); and establishing mentoring programmes for people with disability (LEAP). Some participants (BOC) spoke of the need to make the vision building element of the workshops more concise and culturally relevant and focus on the practical elements of enacting the vision much earlier.

### **Family participants’ views on the facilitation process**

Interview participants made a number of comments on the facilitators and speakers. While participants positively appraised their knowledge and use of multimedia tools, they were firmly of the view that their hopeful and positive outlook, approachability, and respect for the participants were key to the overall success of the initiative. Their approach not only enabled participants to envision a brighter future for their family member than previously thought, but it also gave them confidence to act on that vision:

*“... the facilitators as well because they would give you confidence listening to them, I have to say.” (DESSA, FM interview 5)*

The participants also valued the authenticity of experience over theory, and spoke positively of the involvements of service users as speakers and facilitators who had a family member with a disability. In the participants' views, those presenting were living in the real world, thus easier to connect with:

*"You're not just listening to someone else that has watched what they have done, these have done it, they know what they are talking about." (BOC, FM interview 1)*

Not surprisingly, several participants recommended the continued inclusion of facilitators with experience of having a family member with a disability or the inclusion of a parent as a co-facilitator in future initiatives. In addition, some participants within the DESSA initiative recommended the inclusion of more outside speakers to help them gain a better understanding of how to navigate 'the system':

*"More talks from professionals from various sectors, e.g. HSE, CAMHS, Autism services - schools - to enable parents to navigate on how best to secure support for our children - most info is ad hoc and every parent for themselves." (DESSA, survey)*

*"Would have liked to have more outside speakers to give talks on different therapies or how to access help or information as very difficult to find help from government bodies if you do not fall into a set disability." (DESSA, survey)*

In addition to commenting on the facilitators' knowledge and interpersonal skills, a number of participants made reference to the interactive nature of the facilitation/teaching strategies used. These participants valued the opportunity to engage in small group work which enabled more individual attention to be offered. The contribution of small group work was also commented on by facilitators who considered this aspect of the initiative critical in enabling participants develop problem solving skills for themselves:

*"...I was certainly happy with the way the programme went, with the fact that they were small workshops, because you could run bigger ones but then people wouldn't get the, the individual attention that they needed or the hands on that you can do..." (Int 4, PF interview 1)*



Participants also stressed the importance of having a safe space to ask questions, where their questions were respected as legitimate and not dismissed:

*“... just not to be dismissed, not to, you know, just to feel that yes you have a valid [question], you know, that, I suppose all along I felt I was being dismissed you know?” (DESSA, FM interview 2)*

These positive findings from the interview data were supported by the survey responses to questions on facilitators and partnership. Positively, 97% (n = 34) of survey participants felt they got along well with the team members and facilitators in the initiative. While 80% (n = 29) of participants felt that participation in the initiative was a collaborative effort where they were treated as equal partners, 14% (n = 5) felt neutrally about this and 6% (n = 2) disagreed (see Table 25).

**Table 25. Level of agreement about the initiative design**

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
We got along well with the team members/facilitators in the family initiative (n = 35)	<b>23</b> <b>(66%)</b>	11 (31%)	1 (3%)	0 (0%)	0 (0%)
Participating in the family initiative was a collaboration in which we were equal partners (n = 36)	13 (36%)	<b>16</b> <b>(44%)</b>	5 (14%)	1 (3%)	1 (3%)

In addition to facilitation strategies, participants commented on the importance of having had the opportunity to meet likeminded others who were going through similar experiences, while others talked about having had the opportunity to meet parents who had older or adult children with a disability and the importance of having an opportunity to learn from their experiences:

*“Some had younger children, some had older children, some had gone on to independent living, you know, and from that point of view we met, we got to meet people at a different level, you know?” (BOC, FM interview 2)*

However, at least one parent spoke about being disappointed at not having the opportunity to meet peers because their children were much younger or older than those in the group.

Consequently, some participants were of the view that the composition of the participants within the groups needed be considered to ensure that participants had peers in similar situations who could share knowledge and offer practical advice:

*“...It’s very important to always have somebody there who has a child or children similar to you and are going through similar sort of issues who are on your page...”  
(LEAP, FM interview 3)*

The attendance of professionals from services was suggested by some family members within the LEAP initiative who thought that the exchange of understandings would benefit the parents, siblings and the professionals. It was also considered that such a strategy might lead to a more joined up approach to service delivery. This participant explained:

*“I think it’s really important that service providers are coming on board, professionals are coming on board so they can hear from the parents and equally we can hear it from their side and the road blocks that are in their way.” (LEAP, FM interview 4)*

### **Family participants’ views on structural issues**

Throughout the interviews participants made a number of comments on structural issues, such as duration, timing, venues, advertising, funding and workshop materials. The initiatives which included weekend or a residential component (LEAP and BOC) were positively appraised by the majority of interview participants. One participant described the weekend as “nourishing” (LEAP FM3) and another as a “mini-break” (BOC FM2). Others commented that it enabled a relaxed interaction to take place between participants and helped the building of relationships. The combination of the structured day sessions along with the opportunity for social engagement in the evenings was particularly highlighted as both beneficial and enjoyable:

*“...families could stay and that was quite good as well because people met for dinner in the evening and you met the other families on a more social level as opposed to we’ll say the structure of the day, so we kind of got to know each other and you learn from them, because all the families involved would have been at different stages.”  
(BOC, FM interview 2)*

One of the organisations (LEAP) ran a weekend programme that involved the whole family, including the person with disability. The emphasis was on activity and family fun; opportunities to try something new; individualised support for the person with disability

over the weekend; and breakout sessions for parents. This format was particularly commented on by this family member and facilitators:

*“But what we got was just amazing, of meeting other people. There was eight families altogether and everybody had a common bond, and that became apparent from the very beginning that we all shared something which was having disability in our lives .... We were protected and we were enclosed and it was like we were taken out of the world, you were dropped here and you forgot about everything, you were in the moment for the weekend ...” (LEAP, FM interview 3)*

*“[it allowed parents a] time out completely from their caring role...fresh space that they could think and look at new ideas.” (Int 2, PF interview 2)*

However, where initiatives ran over consecutive days and did not include the whole family, the provision of respite for the family member with disability was, often, what made it possible for other family members to attend. Other education initiatives were shorter and were run as single or half day inputs. Morning time appeared to be the favoured time, as children would be in school, thus increasing accessibility. There was a reference to parents on one initiative having asked to have sessions moved to daytime (from evening time) delivery to enable their attendance. In contrast, one participant suggested that having sessions in the evening might increase the possibility of fathers and those who had work commitments during the day attending.

Overall, participants were very happy with comfort and lay out of venues, the room setups and group sizes and with accessibility to venues by public transport. However, participants had varied recommendations about programme, duration, funding, advertising and recruitment. Some participants were of the view that the initiatives were too short (half day) and others feeling they were too long. While there was overwhelming support for the provision of paid support (BOC) to enable family members to attend the initiatives, there were mixed opinions on whether funding overnight accommodation for family members was an effective use of resources. Some participants commented on the need for improved workshop materials and guides, as they could serve as an ongoing and practical support for families upon completion of the initiative.

In addition, participants commented on recruitment strategies, with several recommending that clearer language be used in the recruitment materials, particularly within the DESSA initiative. A few DESSA participants described issues with the advertising, for example:

*“Well, I think advertising it would have been better, advertising the actual course and to put the wording in proper, probably in simple language for people, you know?”  
(DESSA, FM interview 5)*

Participants within all of the initiatives were of the view that recruitment needed to be expanded to include fathers, grandparents and siblings in order to facilitate communication within the family:

*“...maybe to get the fathers on board. Maybe a men’s, a daddy’s one...” (LEAP, FM interview 4)*

*“All family members should attend. My brothers did not and didn't understand all of a sudden why there was discussions, etc.” (BOC, survey)*

*“Family Initiative [should be] made available to all parents/guardians of people with disabilities.” (DESSA, survey)*

Several participants also felt that the initiatives would be very useful if offered to family members with young children with a disability. In that way, the messages, skills, and tools of the initiatives could be put into place right at the start of the young person’s life. This participant described:

*“I feel the communications and support skills where possible could be targeted to everybody...to get in there early would be great ...” (LEAP, FM interview 4)*

## Family participants' views on sustaining circles of support and networks

There was a strong expectation expressed by the facilitators during their interviews that the initiatives would be sustainable as a result of building family participant capacity. The facilitators envisaged that sustainability would occur through: building circles of support; establishing on-going participant networks; and enhancing community involvement. In terms of family participants' views of sustainability, the majority of survey participants (84%, n = 30) were of the view that the family initiative would have a lasting positive impact on them and 83% (n = 30) were of the opinion that they would be able to sustain their learning into the future (see Table 26).

**Table 26. Level of agreement of survey sample on sustainability of learning from initiative**

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Participating in the family initiative will have a lasting positive impact (n = 36)	15 (42%)	15 (42%)	4 (11%)	1 (3%)	1 (3%)
In the future, we will be able to sustain what we learned from the family initiative (n = 36)	13 (36%)	17 (47%)	4 (11%)	1 (3%)	1 (3%)

During the interviews, there was also a palpable sense among the family participants that their future vision for their child had grown and become more optimistic as a result of the initiative. For some family participants, the circle of support was seen as an important strategy in achieving their vision. The circle of support was viewed as a means of ensuring a greater number of people willing to help. It was also regarded as a 'safety net' ensuring continuity in the person's life in the event that the parents died or something happened in the future (BOC, DESSA, LEAP). Many parents expressed the view that progress would happen for their child into the future and speaking of the impact of the course, one family member said:

*"A lot is achievable, it really is...when you can't see a way forward for a child with special needs...there has to be another life possible for them." (BOC, FM interview 1)*

However, several family members noted that their attempts to establish networks with the participating families had faltered due to the competing demands of everyday life. Participants noted: *"there's too much going on at the moment..."* (BOC, FM interview 6); and *"great workshops but fizzled away, momentum fades"* (BOC, survey). Although one initiative did provide a 'catch-up day' for family members to maintain contact after the

initiative finished (LEAP) and many family members formed spontaneous links, others did not. Therefore, not surprisingly participants' were disappointed that there was no structured framework for continued connection and frequently recommended improved follow-up. In their view, follow up support would enable the energy generated during the initiatives to be built on and enable the peer support and learning to continue:

*"We were coming back in the car and we said, 'We have to go back to life now', it felt that special. When we were leaving...what we'd shared in the group and it was amazing...so, yeah, if I can get a piece of that again, absolutely..." (LEAP, FM interview 3)*

More specifically, participants wanted opportunities to check their progress and receive support from project facilitators in setting up and sustaining the 'circles of support' so they could realise the plans made for their family member and themselves:

*"You do need that [catch up day]...[to ask yourself], 'Are we still on path?' Because you can get bogged down with so much that's going on in their lives and, you know, there are problems and obstacles to overcome...so, it does need to [be]continuous." (LEAP, FM interview 5)*

Participants also suggested that short 'maintenance' sessions at three or six month intervals would be helpful:

*"Follow-up half day sessions monthly for a few months in order to support families." (LEAP, survey)*

*"Follow-up after final meeting perhaps 6 months later...Support call centre [and] information you can access anytime." (BOC, survey)*

Finally it was felt that ‘catch up’ days or reunions would allow the participants to check in with each other and allow them a formal way to link back in and re-establish support networks:

*“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.” (BOC, survey)*

*“I think even if it wasn’t the same group, but if there was an annual, almost conference, of anybody who had done it since and that you could get together and there was a few workshops, it would just keep you fresh. It would keep you meeting people in similar situations.” (BOC, FM interview 6)*

### Inferential statistics: Statistical analysis of the differences between the four initiatives

To compare the differences between the four different initiatives, means and standard deviations were computed for each initiative out of the survey responses, and differences between the means were tested for their significance using Analysis of Variance. The size of the effect was also computed (Eta Square). All items with Likert-type scales (24 statements and 5 questions) were included in this procedure. However, caution needs to be maintained with the interpretation of findings as the number of participants representing each programme was low, and extremely low for the AIG (n=3) initiative. See Appendix VI for the full outcomes of the Analysis of Variance.

Overall, in their estimation of how helpful the programme had been for them, participants in the four programmes did not differ to any great extent (see Table 27). While the outcomes for BOC, DESSA and AIG are slightly higher than for LEAP, these differences were not significant ( $F(3,35) = .559, p = .646$ ) and the effect size was very small ( $\text{Eta}^2 = .050$ ).

**Table 27. Comparison of the four different programmes for overall helpfulness of the programme and Analysis of Variance**

Question	Total (mean/sd) (n=36)	Programmes (mean/sd)				ANOVA	
		BOC (n=9)	DESSA (n=14)	AIG (n=3)	LEAP (n=10)	F (p)	Eta <sup>2</sup>
Overall, how helpful was the family initiative for you and your family?	4.42 (.94)	4.44 (1.13)	4.57 (.514)	4.67 (.58)	4.10 (1.29)	.559 (.646)	.050

This finding reflects the results for the other variables which yielded no significant differences between the responses of the participants in the four different programmes (see Appendix VI). Just one exception occurred; the extent to which participants got on with

staff/facilitators in the programmes, while high overall, showed a significant difference ( $F(3,35) = 5.46, p = .004^{**}$ , with  $\text{Eta}^2 = .346$ ). This difference is the result of a lower mean score for the AIG participants. In comparison with the other three programmes, they scored about a whole point lower on average. The  $\text{Eta}^2$  suggests a potentially large effect, but, as mentioned above, the low number of participants in the AIG programme means this finding, while statistically significant, is of little consequence. Moreover, because 28 similar tests were computed, a Bonferroni adjustment for multiple tests (Abdi 2007) should perhaps be taken into account. This adjustment suggests that in this case significance should be accepted only if  $p < .0017$ .

The conclusion from these Analysis of Variance procedures is that the participants in the different programmes did not respond significantly differently to the statements and questions and, therefore, reported similarly good experiences of the initiatives in which they took part.

### **Inferential statistics: Family information and perceived helpfulness of the initiatives**

An important question in the analysis of the outcomes of an evaluation is to what extent the initiatives may have been more helpful for some groups of participants in comparison with others. Chi-Square procedures were performed in which all quantified family information was crossed with the helpfulness variable (see Appendix VI). Results indicated that the factors analysed did not predict how helpful the initiative was perceived to be. One exception, however, was noted; namely, whether participants had participated in full or not had a significant impact. The three people (out of 36) who had not participated in full rated the programme as significantly less helpful (Chi-square  $(4,35) = 22.82, p = .000^{***}$ ). However, the low number of participants who had not participated in full ( $n = 3$ ) calls for caution in drawing further conclusions from this finding. Overall, it is safe to say that how helpful the programme was perceived to be could not be predicted from the information that participants had given about themselves and their family member with a disability.

### **Inferential statistics: Predicting perceived helpfulness of the initiatives from other statements and questions in the survey**

In studies such as this, it is also customary to provide statistics regarding how responses to key statements or questions would predict outcome variables. In this case, the outcome variable was how helpful people found the programmes. In light of the small numbers (36 participants) and the relatively large number of variables (28 statements and questions) that could serve as predictors, advanced procedures such as Multiple Regression Analysis were not suitable (Hill and Lewicki 2007). Nonetheless, a correlation matrix (Pearson Correlations) was produced to provide an overview of linear relationships between the helpfulness variable and all other statements and questions (see Appendix VI).



The high correlations of some of the variables with helpfulness suggest that they may be particularly closely related to how helpful participants found the initiatives. Particularly salient are the high correlations that the statements on impact ('What we learned from the family initiative has had a positive impact on our lives' ( $r = .82, p = .000^{***}$ )) and sustainable impact ('Participating in the family initiative will have a lasting positive impact' ( $r = .83; p = .000^{***}$ )) had with helpfulness. This suggests that participants were probably incorporating impact and sustainable impact in their overall rating of the helpfulness of the programme.

One of the three statements and questions that did not correlate significantly with the overall perceived helpfulness was the question about the amount of work participants do for their family member with a disability (How has the amount of work you do in support of your family member been affected by the family initiative?;  $r = .06, p = .710$ ). To a large extent, this is because the amount of work had not changed for many participants, but in addition, this variable does probably not relate to the helpfulness rating. The two other items not significantly correlating with helpfulness were: 'I am more likely to seek professional support for myself' ( $r = .23; p = .184$ ) and 'We got along well with facilitators' ( $r = .27, p = .125$ ). Low variability in the response to those items is at the basis of this.

## Summary

- Overall, participants were of the view that the initiatives were well organised and facilitated, and indicated that information presented was empowering, enlightening, relevant and applicable. All participants referred to the importance of learning strategies to enable them to advocate, navigate, and communicate with services and service personnel.
- Participants valued the facilitators' knowledge and interpersonal skills, as well as the interactive nature of the facilitation/teaching strategies used. The opportunity to ask questions and discuss issues in a supportive respectful space was appreciated as was the small group work which enabled more individual attention to be offered.
- Participants advocated for the continued inclusion of facilitators with experience of having a family member with a disability or the inclusion of a parent as a co-facilitator in future initiatives.
- Initiatives which included weekend or a residential component were positively appraised, as was the respite support offered to families. However, in a few situations there were mixed opinions on whether funding overnight accommodation for family members could more effectively be used to enhance other aspects of the initiatives.
- While some family members formed support networks with the participating families, others noted that their attempts to establish networks had faltered due to the competing demands of everyday life, and lack of formal mechanisms to do so.

- Family participants made a number of suggestions for improvement in future initiatives including: improving follow-up; support to help sustain the 'circles of support' and networks; enhanced recruitment strategies to include fathers, siblings and grandparents; attendance of professionals from services; and offering initiatives to family members at a much earlier stage.
- Analysis of the survey responses indicated that participants overall appreciation of the initiatives was high, and similarly high in all four programmes. Differences in outcomes between the four initiatives were minimal, and differences in outcomes for different kinds of participants (based on family information) were also minimal. Significant correlations between helpfulness and all other statements and questions suggest coherence in the survey. Moreover, the perceived impact of the programmes at present and the sustainable impact in the future seem to be the most significant factors in predicting the overall rating of the helpfulness of the programme.

## SECTION 6: STRENGTHENING CAPACITY – PROJECT FACILITATORS’ PERSPECTIVES ON ORGANISATIONAL IMPACT AND BENEFITS

### Introduction

The previous two sections of the report focused on capacity building from the perspectives of the participants and discussed the impact of the initiatives on their and others’ lives. This section addresses the project facilitators (n = 9) views on in the impact of the initiatives under the following headings: awareness raising among staff; changing work practices; and building community connections. The facilitators’ perspectives on sustainability and challenges are then discussed. To protect the confidentiality of the facilitators, the initiative they were associate with is not identified.

### Intra-organisational learning: Awareness raising among staff

All the facilitators spoke of the enhanced intra-organisational awareness and understanding of the real needs of families that arose as a result of the initiatives. Not unexpectedly, this was particularly relevant to the organisations that were not parent-led (BOC, DESSA). In their view, while they enabled family participants to create a new vision during the initiatives, the learning was a two way process with the facilitators (parent and professional) gaining an increased understanding of family participants’ lives and the issues that they faced on a daily basis:

*“... it was just a very positive experience for me, it was, like I say it widened my knowledge I suppose and gave me confidence in delivering the programme as well ...”*  
(Int 1, PF interview 3)

*“...the professionals...they actually begin to see what the parents want...and they actually begin to realise that their services actually don’t offer any of this at all.”* (Int 3, PF interview 2)

Findings from the interviews suggested that this increased awareness and understanding was beginning to have an impact on staff members' attitudes to, and ways of working with, families and persons with disabilities:

*"...now what we try to do based on our work with families over the life of this project is we, we would be inclined to sit down more with the family...we would come up with a proposal for the HSE in terms of what the package should look like and how much it should cost. And then after that it's over to the family to advocate for that funding..."* (Int 2, PF interview 1)

*"So I think to actually be in touch with the end user and seeing the effect of this training on the ground, there's been huge learning."* (Int 1, PF interview 2)

### **Intra-organisational learning: Changing working practices**

There were visible indications that the majority of the organisations were intending to or had already adopted new ways of working. For example, there were indicators of changes in the strategic direction and working practices of some of the organisations, particularly in terms of inclusiveness:

*"I think it made us just that little bit more aware of mainstreaming our programmes...for children...even if it is the language that we use, it has made us more aware of the language that we actually use because it is the power of language."* (Int 1, PF interview 1)

*"...I think in the beginning certainly we felt more sort of responsible for families than we do now...there's no point us being yet another disempowering service...we need to empower people...standing back and letting them work out their own solutions at a local level."* (Int 3, PF interview 1)

There was also emergent evidence of enhanced understanding, or in one case clarification, of organisational goals, roles and responsibilities in terms of working with a family-focused philosophy:

*“I suppose from an organisation perspective, we’ve been able to draw on all of the information and knowledge from the external speakers...and that’s been very positive. It’s also fed into this organisation wider, it’s a corporate approach that is not so much changing how we deal with our service users but its setting out a professional model for how we deal with our service users and with the families.”*  
(Int 4, PF interview 2)

*“You’ll have families who will hand everything over...and that might be because they just haven’t got the capacity to take on the responsibility right there and then, they might be burned out from caring...there might be other issues in the family, but where we see that the family have capacity to be more active and more involved, we try to nurture and grow that whereas before the think would be to race in and take over and call the shots.”* (Int 2, PF interview 1)

However, there was an acknowledgment by some facilitators that the transition to a family-focused way of working, while necessary, was challenging especially for professionally led organisations:

*“If we want to remain in business to be crude about it, we need to start thinking and working in this way to really engage with families in an empowering way...and that’s a challenge to, for some...who have been around for a long time who have been very used to being in control of the situation and now have to handover control to a family.”* (Int 2, PF interview 1)

### **Inter-organisational capacity building: Making connections and building communities**

The family focused initiatives also appeared to help strengthen inter-organisational working. For example, some of the organisations established connections with other disability organisations for the purposes of getting their assistance to recruit participants onto the family initiatives. This simple strategy *“...opened channels of communication”* (Int 4, PF interview 2) between organisations, which resulted in facilitators later being in a position to refer parents to some of these organisations, as they were more locally based. As one facilitator said: *“... [it helped] us spread the wealth in terms of the parents...we are getting the parents to the groups that are most local to them”* (Int 4, PF interview 1). However, one

project facilitator expressed the view that the time scale did not lend itself to making connections and building communities:

*“No, I don’t think that happened, I think probably long term it would be envisaged that it would if this was a way of working, but realistically a year, too short a time scale for anything like that to happen.” (Int 2, PF interview 2)*

Project facilitators also referred to the opportunities this engagement with other organisations created for cross fertilisation in terms of sharing expertise and learning accrued from the family focused initiatives:

*“...I suppose we share our information, we share our learning with other organisations, we work well with them, that’s an important part of our, it’s part of what we do.” (Int 1, PF interview 1)*

A number of the project facilitators also referred to how the visibility of their organisations had been enhanced among families with disability, professionals and other disability organisations because of the initiatives. There were references to: *“it promotes our own organisation actually”* (Int 1, PF interview 1) and *“the word being out, getting around”* (Int 3, PF interview 1). The impact of this form of connection had already been experienced by some organisations, with one securing further funding to finance their ongoing work (in part or as a consequence of having run the family focused initiatives) and others receiving invitations to speak about their work. One project facilitator (Int 3, PF 1) explained that her organisation had now been invited to deliver components of their programme to other organisations or speak about their approach and were now doing so both nationally and internationally.

Some work on strategic alliance building among organisations was also demonstrated in terms of the formation of organic partnerships to deliver family focused initiatives or establishing productive relationships with other disability organisations. In some cases, this involved delivering programmes with organisations that had similar aims. There was also some preliminary evidence of the coming together of some project organisations with other organisations to pursue funding for joint ventures. Where this occurred, it appeared to have occurred with clear intent rather than a happenstance occurrence. One facilitator summed this up:

*“We would regularly, we would network. We believe in empowered networking...we try to get our faces around...and meet anyone who is prepared to talk to us...I think that’s invaluable.” (Int 3, PF interview 2)*

## Looking to the future: Building sustainability

All of the facilitators demonstrated a future orientation in terms of the initiatives and described a number of measures to enhance the project organisations capacity to continue running the initiatives. While the majority of the facilitators were of the view that the content of the training was very good, effective and demonstrated an appropriate fit for the intended purpose, they emphasised the need to view the initiatives as dynamic and subject to on-going refinement and continuous quality improvement. Some facilitators spoke of having already changed the format of programmes, or changed a particular delivery format in response to feedback from participants. For example, as a result feedback on the strength of the residential weekend in terms of peer support between parents and easier access for families, one organisation (LEAP) chose to discontinue (for the moment) their single day workshops in favour of the weekend workshops. In contrast, some facilitators (BOC) who were involved in residential weekends were of the opinion, in times of increasing financial constraints, that the sustainability of their initiative may mean organising 'one off' days around visioning, planning and developing 'circles of support'. However, the provision of paid support to allow participants to attend the workshops was seen as crucial and needed to be continued.

In addition, facilitators described the need to continually adapt and refine learning materials; especially those developed for other contexts, and ensure they meet the needs of participants and were culturally appropriate to an Irish audience:

*"...because it [a programme content resource] was modelled so closely...on quite a different culture... I think if you were to do it again or any organisation was to do it again they would have to base it in an Irish culture if possible...but it would certainly have to be something closer to home and in a jurisdiction that is some way governed like our disability services are governed." (Int 2, PF interview 2)*

This same facilitator also spoke of the need to make the vision building element of the workshops more concise in future workshops:

*"The workshops went on too long about the vision and families got frustrated... 'Where is this going to go?' There's a lot of money gone in to it and is my son or daughter going to have a better service because of it,' and they questioned that a lot. So, therefore, the speed of the workshops and the content of them was pushed towards the practical before myself and [names other facilitator] would have liked it ...It was quite clear that the mindset really hadn't changed all that much or sufficient enough anyhow for the families to say, 'Okay, we can manage our own service, or we can do something innovative here.'" (Int 2, PF interview 2)*

Furthermore, in order to enhance sustainability, one project facilitator (Int 1, PF1) referred to the idea of past family participants facilitating future initiatives. In that way they would become self-sustaining with support from the project organisation, if funding for costs of new delivery sites could be addressed. Two facilitators spoke of incorporating a 'train the trainer' type component into the initiative, with an expectation that past participants (staff and family) would be involved in future delivery (Int 3, PF 2 and Int 1, PF 1). This would enhance the longevity and reach of the different programmes, as illustrated by this facilitator who desired that, *"... every parent of a child with a disability should have an opportunity to partake in this programme, because it opened up all sorts of different avenues and different ways of looking at things and different opportunities"* (Int 3, PF interview 2). To this end, LEAP participants who had completed a 'train the trainer' programme were undergoing accreditation as future facilitators.

There was also recognition by the facilitators that some of their expectations in relation to 'circles of support' and networking were only partly realised. Facilitators acknowledged that creating and envisioning a very different life for their family member, to that previously anticipated, was challenging for some parents as they grappled with conflicting emotions. Such parental reactions, where they occurred, were considered to be an initial step in the change process that required empathy and sensitive support, as well as enabling parents to realise the importance of self-care. One facilitator commented:

*"An awful lot of parents had never ever thought even that way [independent living]...it saddens them...this beating up of themselves...[the family focused initiatives] give families kind of the, the space to deal with that grief or deal with the realisation of, 'Oh my God, I mightn't have done everything right here.'" (Int 2, PF interview 2)*

In the facilitators' view, to enable some participants to move to the next step there was a need for sustained support, such as the development of new roles to support families and the development of follow-up days. To this end, one organisation (LEAP), while expanding the number of family focused retreats being run were also developing a new role to subsequently engage in one to one work with individual families in their own homes.



However, one issue worthy of highlight here is a point made by one facilitator of the need not to exceed their existing capacity and resources. This suggests cognisance of the need to balance commitment to family-focused working with parents and family members with inter-organisational working so as not to compromise the effectiveness of the organisation's purpose:

*“But what we have to be very cognisant of is that we don't want to, I suppose over commit, because we're very small...so it's that piece around how much can we actually deliver of this without sort of, you know, exhausting ourselves or any loss in quality and so forth.” (Int 3, PF interview 1)*

Another facilitator highlighted a similar challenge for professionally led services, and mentioned the need to balance organisational flexibility with the needs of staff, if initiatives are to be sustainable:

*“To do the facilitation properly...you're not a nine to five person and if you are going to, if a family are going to engage in the whole process well the very least the service provider should do then is to meet with them at seven or eight o'clock in the evening in their family home. If extended family are going to be good enough to sit around a table then the very least you can do is travel to that home at night time and do it where it facilitates the neighbours, the uncles, the aunts, because that's your best chance of getting them round the table”. (Int 2, PF 2)*

While acknowledging the importance and impact of the GENIO funding in helping build capacity, there was an acknowledgement that the infrastructure and funding mechanisms, such as personalised budgets needed to be truly family-centred. This was not, however, a fully realisable possibility in the Irish system currently, although this type of funding system is recommended in the Value for Money and Policy Review of Disability Services in Ireland (Department of Health 2012). One organisation was asking family member participants to contribute to the cost of running the initiatives (LEAP). One project facilitator also described having being awarded further funding to advance the work began in the current study:

*“We've done an awful lot, we are applying for charitable status...we are just about to sign our first little contract with the [name of national healthcare organisation] ...We've got a lot more funding since, so we are definitely doing a bunch of things well.” (Int 3, PF interview 1)*

Finally, in terms of sustainability, facilitators were also concerned that families may be fearful of attending future initiatives, and emphasised the need to allay family fears that the new model of service provision, is not a 'covert way' of withdrawing supports to the family. This sentiment is evident in the following quote:

*"...families are very, very worried at the moment, regardless of what age their family member is, and with reducing budgets and they're hearing on the television that HSE have no more money...they want their son or daughter looked after, they're not getting any younger and quite a few of the, both mother and father will work, so realistically if we're going to come to a stage where there's a reliance a lot on informal social networks, realistically that will mean that either Mum or Dad gives up their job, to call a spade a spade...I'm not quite sure if families will go down that line if essentially it means that their son or daughter is only going to get two or three hours paid support and that the informal or the circle will provide the rest." (Int 2, PF interview 2)*

## Summary

- Overall, there was a positive perception among the facilitators that in broad terms they had achieved many of the objectives they set out to achieve.
- The initiatives appeared to have a number of impacts on the organisations including enhanced awareness and understanding among staff of the needs of families; and changing staffs attitudes to, and ways of working with, families and persons with disabilities.
- The initiatives also appeared to help strengthen inter-organisational working through links with other disability organisations and opportunities for sharing expertise and learning. A number of the project facilitators also referred to how the visibility of their organisations had been enhanced among families with disability, professionals and other disability organisations because of the initiatives.
- All of the facilitators described a number of measures to enhance the project organisations' capacity to continue running the initiatives. They emphasised the need to view the initiatives as dynamic and subject to on-going refinement and continuous quality improvement, also to involve past participants in future initiatives and develop new roles within the organisation and source other funding.

## SECTION 7: DISCUSSION, LIMITATIONS AND RECOMMENDATIONS

### Discussion

The emergence of family-focused support projects is a recent phenomenon in Ireland, resulting in a shift away from service-led to family-led models, grounded in family and community support (Department of Health 2011, 2012; Health Service Executive 2011). The four Genio-funded initiatives that have been evaluated in this report embody a range of family-oriented characteristics, many of which were encountered in the review of the literature in section 1. Whereas the four initiatives employed different approaches (information sessions; education workshops; networking sessions), they were all grounded in person-centred and family-centred philosophies. The overarching aim of all the initiatives was to enable families of children with disability to envision a positive realistic future plan and build better lives for themselves and their children, within the context of their local communities. Two strategies were advocated as the means to achieve this desired outcome. Firstly, the initiatives placed a particular emphasis on strengthening participants' and their children's links with local communities, through the creation of circles of support. Linked to this was the building of participants' knowledge and skills in order to enhance natural supports within the community, as opposed to having an over-reliance on professional and service models of planning and support. This is consistent with Mansell and Beadle-Brown's (2004: 2) notation that "...families in particular have a stake in the arrangements made to support an individual with intellectual disabilities in a way that service employees do not ... mobilizing the service user's social network is ... intended to broaden and deepen the range of resources available to help them". The mixed methods evaluation reported in this study, which involved both the participants and facilitators, highlights some success with regard to the overarching initiative aim described above, and details a number of benefits to the: participants; person with disability; family unit; and organisations involved as will now be discussed.

It is clear from the findings in this report that the family-focused initiatives were perceived to have had positive outcomes for the families concerned, which in turn impacted on their family member with disability and the family as a whole (see Figure 3).

**Figure 3. Mapping of each initiative in relation to 13 key indicators**

Key: ++ Strong evidence; + Some evidence; -No evidence; NA Not applicable

Impact on	Participants					Person with disability				Family Unit			
	Increased knowledge	Shifted attitudes	Increased advocacy skills	Increased confidence and self esteem	Decreased feeling of isolation	Decision-making	Autonomy/Choice	Circle of support	Community involvement	Enhanced involvement	Understanding of person	Respect for ability	Increased family communication
<b>BOC</b>	++	++	++	++	+	+	++	++	+	++	++	+	++
<b>DESSA</b>	++	++	++	++	++	+	+	++	+	++	+	+	+
<b>LEAP</b>	++	++	++	++	+	+	++	+	+	++	++	+	++
<b>AIG<sup>3</sup></b>													

As with many other such initiatives, participants reported that their knowledge and skills had been increased particularly in relation to: the creation of and in some cases realisation of positive aspirations for their children with disability; assertiveness; and advocating for their family member with a disability. Such skills are identified by families in Butera-Prinzi *et al's.* (2010) study as important capacity-building resources, which empower families to engage more effectively with agencies in seeking services. Family members' responses in the initiatives evaluated herein demonstrated that they felt empowered to: engage with service agencies on a more equal basis; to pursue rights and entitlements; and to draw on a range of practical knowledge and skills learned in the course of the different initiatives to enable negotiation and communication.

Although not discussed to a great extent in the literature, Dunst (1990) cited in Dunst *et al.* (1991) has identified the strengthening of family functioning as being an important family support principle. Breckenridge and Huppert (2011) have also noted that the confidence-building that accompanies skill development can further strengthen family coping resources. This is confirmed in this study by the reported beneficial effects on the family unit as a

<sup>3</sup> In view of the low response rate from participants involved in the AIG initiative, it was not realistic to make a commentary on the outcomes.

whole with increased communication and involvement within the family leading them to work together to solve problems and to make family-directed changes.

While the initiatives had positive outcomes for both the participants and family members, it is also clear that they had benefits for the person with a disability. For example, there were social valorising (Wolfensberger 2000)<sup>4</sup> outcomes which resulted in the person being perceived more positively by family members and others.

The emphasis on a rights and an ability based approach was also accompanied by a realisation that their family member had a need for: autonomy; voice; involvement; and independence. This focus on rights, potentiality and abilities of the person has been seen in other such projects (Schipper and van Boheemen 2009, Butera-Prinzi *et al.* 2010) and is often associated with improved quality of life for and empowerment of the person with a disability (Schipper and van Boheemen 2009). This was true for the initiatives in the current evaluation. Primarily, the impact on the person with disability was the attainment of person-centred outcomes, such as enhanced autonomy, involvement in decision making and increased community involvement and connections. Such outcomes are very much echoed in current Irish reports in the sector, which advocate that people with intellectual disability “should make their own life choices” and should have “the right to direct their own life course” (Health Services Executive 2011: 4, 12). International literature echoes this perspective with writers such as Mansell and Beadle-Brown (2004) going so far as to state that there is no credible alternative but that services must be tailored to the individual’s needs, desires and situation. As such, the findings demonstrate that initiatives such as those evaluated here can contribute to the realisation of the values outlined in policy and literature by enabling families to support and include persons with disability in making life choices. This supports the need for both the continuation and the expansion of future initiatives in this regard.

One of the main objectives of the programmes was the development of circles of support and networks. Some families had developed such circles prior to attendance, and others reported success in setting them up during the programmes. However, some participants highlighted challenges in maintaining momentum after completion, particularly the concern that ‘circles of support’ would become a replacement for formal support services. This fear is also recognised in the international literature. For example, O’Brien (2004), writing in relation to moves toward person-centred planning, highlights the potential risk of circles of support being used to obscure the costs of family caring and other informal supports involved in the lives of people with disability. Furthermore, Mansell and Beadle-Brown (2004) identify the potential for service agencies to redefine the supports within their remit.

---

<sup>4</sup> Wolfensberger (2000:105) describes social role valorisation as ‘a high-level and systematic schema, based on social role theory, for addressing the plight of people who are devalued by others, and especially by major sectors of their society.’

The findings of this report and the literature suggest that the primary goals of circles of support, in assisting with the development and enactment of the personal plan (NDA 2005), should be clear, not only to those who participate in initiatives, but particularly to policy makers and service agencies. It is important that a political impetus be maintained to ensure continuance of entitlements during the implementation of such initiatives (O'Brien 2004).

The background literature presented previously in this report identified how other peer supported education programmes have been positively evaluated by those who participated in them (Heller *et al.* 1999, Caldwell and Heller 2003, Heller and Caldwell 2005, Caldwell 2006, Truesdale-Kennedy *et al.* 2006, Caldwell and Heller 2007, Schipper and van Boheemen 2009, Black *et al.* 2008, 2010, Butera-Prinzi *et al.* 2010). Similarly, participants in this evaluation really valued the opportunity to meet other parents, for learning and emotional support purposes. They greatly valued the sharing of personal stories both from the facilitators and from other participants. While some maintained previously built networks, others spoke of the challenges encountered and were disappointed with the level of follow-up by the initiative leads to enable networks to flourish. Similar to other programmes evaluated (Butera-Prinzi *et al.* 2010, Black *et al.* 2008, 2010), participants were highly satisfied with the content and delivery of the initiatives, with an overwhelming majority agreeing or strongly agreeing that they would recommend the initiative to others.

A significant finding of this study pertains to impact at organisational level. While the nature of the organisations differed, in those organisations that were service-led in particular, there was evidence that the learning gained was beginning to have an effect on, or had expanded on already changing roles and strategic ways of working with families and persons with disability, as well as how disability was viewed. This is noteworthy particularly in light of the *Report of the Disability Policy Review* (Department of Health 2011) and *Value for Money and Policy Review of Disability Services in Ireland* (Department of Health 2012) reports identifying the need to strategically reframe disability service provision towards the enablement of active citizenship and independence using a system of individualised supports. It also raises the question of how the pace and reach of such change can be expedited into the future to ensure harmonious and productive working between persons with disability, their families and service providers. This need was also recognised by family participants and some of the project facilitators interviewed in this study who recommended that professionals participate in future initiatives to build understanding to this end. The importance of such collaboration was similarly highlighted by Black *et al.* (2010) and is considered to be essential to effective family support (Espe-Sherwindt 2008).

Disability service provision in Ireland has historically been provided through a 'wraparound' approach (Department of Health 2011) with all services provided by a single agency. Current policy is focused on a move away from such provision towards individualised support making use of the 'same services as the general population, known as 'universal services'

(Department of Health 2011: 13). The *Report of the Disability Policy Review* acknowledges that, for this to be successful and for capacity to be built, there needs to be increased inter-organisational working (*ibid.*). The findings of this study suggest that the programmes were successful in achieving the connections to support such working with new channels of communication opening between service agencies and local organisations. The result of this was an increased awareness of service agencies and opened up the possibility of collaboration and innovation, something that was also reported by Schippers and van Boheemen (2009) in their Dutch study. It is important to note, however, that participants in the present study highlighted the need for organisational buy-in, at the highest level, a sentiment also shared by participants in Wright *et al.*'s (2010) study.

### Limitations

Overall, the results of the evaluation of the initiatives are quite positive; however, they need to be interpreted in light of the following limitations:

- The participants under-represent certain groups, including fathers, siblings and grandparents.
- The socio economic status of the participants (survey and interviews) was not clear, consequently, it cannot be assumed that they represent a broad cross section of society from a socio-economic viewpoint.
- A relatively low response rate of 22% was achieved from the family participants. Although this is not an unusual response rate for survey research, it did limit the array of statistical tests that could be performed.
- The low response rate (both survey and interview) from the family participants in the AIG initiative makes generalisation of any of the findings to this initiative impossible.
- An objective comparative measurement of the impact on the initiative on participants' knowledge, attitude and skills, impact on the family member with disability or impact on the family unit was not possible as a baseline measurement of variables for any of these groups prior to attendance at the initiative was not captured.

### Recommendations

In light of the findings, the following recommendations are proposed:

#### Funding

- The overwhelmingly positive evaluation suggests that participants benefitted considerably from the family initiatives and that they fulfilled an important need. The overall recommendation from this is that funding for these and similar initiatives should be continued.

- Due to the variability of the structure and format of the different initiatives organisations should have flexibility in how best to use funding to support the initiatives.
- Funding of paid support to allow participants to attend the initiatives is crucial and needs to be continued.
- Individualised funding should be obtained from the block grant as envisaged in the Report of the Review of HSE Day Services and Implementation Plan 2012 - 2016: Personal Support Services for Adults with Disabilities (HSE 2012).
- Organisations may need to explore the potential of attendees part contributing but this should be carefully considered, in order to minimise the risk of this requirement prohibiting participation.

### Structure, content and format of initiatives

- In view of the equally positive response to the different programmes, it is not possible to recommend one particular delivery format. However, it is recommended that the format needs to fit the particular goals of individual initiatives.
- The participants' experiences and recommendations suggest that organisations planning future initiatives need to give consideration to the following:
  - follow-up support strategies to assist participants to sustain the family focus 'circles of support' and other learning should be an integral part of the initiative. Such supports should be flexible and take into account participants' evolving needs and issues. Untimely removal of support endangers capacity building and sustainability;
  - developing a formal participant-led strategy as a core component of the infrastructure of future initiatives to increase and sustain networking among family participants, as this is a fundamental aspect of the family support approach;
  - exploring the most appropriate timing of the workshops with family members to maximise attendance from the group being targeted. For example, initiatives that are designed to involve the whole family, including the person with disability might be better delivered over a weekend. Initiatives that are designed to build skills in family members over time might be best suited to day long or evening sessions spaced out over time;
  - developing a strategy to actively recruit fathers, siblings and grandparents, and given the correlation between disability and disadvantage (WHO 2011) family members from all social classes need to be actively recruited for future initiatives;
  - continually modifying content in collaboration with family members, to ensure initiatives are: flexible; responsive; practically and culturally relevant; and fit for purpose;



- reviewing initiative recruitment literature to ensure that the aims and objectives of each initiative are clear to potential participants;
  - reviewing recruitment/marketing strategies with a view to improving and widening access to the initiatives.
- In view of the positive appraisal by participants of content and process, it is recommended that facilitators continue to:
    - create an atmosphere of honesty, openness and inclusiveness;
    - involve facilitators/family members who have lived experiences of caring for persons with a disability in the initiative component;
    - continue to use interactive facilitation approaches, including small group teaching and opportunities for question and answer sessions;
    - continue to recruit a broad mix of families at different life stages, so families with young children have an opportunity to meet family members with older children, and family members who have supported their children to achieve various levels of independent living.

#### Enhancing capacity building and sustainability

- To strengthen capacity building and the potential for sustainability, in their ongoing developments the organisations involved in this evaluation should give consideration to:
  - exploring the potential of involving past participants as co-facilitators of workshops or as supports for other family members;
  - exploring the possibility of creating a family facilitator or intermediary role to engage with and support participants to enact their plan and develop/maintain circles of support;
  - exploring the potential of using online media and delivery to reduce travel costs of experts from overseas who deliver lectures on the initiatives;
  - exploring the possibility of recording family stories as exemplars of positive changes that occurred following participation in the initiatives. These could be used in future educational initiatives;
  - recruiting professionals onto the initiatives as a means of building capacity and changing the philosophy and way of working within professionally led services. This has the potential to reduce the risk of family members returning to organisations that are not receptive to their new found confidence and assertiveness;
  - exploring strategies for dissemination of learning regarding the family focused or centred philosophy among organisations that are not family led.

- As capacity building is a key feature of the work of GENIO, it is recommended that GENIO give consideration to:
  - developing mechanisms to enable the sharing of project learning between and among funders and organisations. Doing so would avoid the potential for silo effects, in which learning remains at a localised level. Addressing this point may also enhance potential for partnership working at the inter-organisational working level, including the sharing of resources and funding opportunities;
  - developing case studies or exemplars illustrating the key learning points from completed projects to assist other organisations or future grantees in their capacity building and sustainability work;
  - developing an education package on the meaning and processes involved in such work would be of benefit to future grantees and those involved in this and other sectors. This could take the form of an e-learning package accessed through the GENIO website or a face to face facilitated programme.

#### Further research and evaluation

- GENIO should give consideration to the development of an overarching framework for the evaluation of capacity building initiatives, into which applicants can outline specific, realistic, measurable and time framed evaluation indices matched to their specified capacity building strategies, at the point of funding application. Such a framework should allow for the collection of core data but needs to be adaptable to capture the individuality of capacity building work within and between different organisations. This would streamline the collection of data and create a dynamic database of knowledge that could build an evidence-based resource to inform future capacity building work;
- To overcome the limitations of the present evaluation future initiatives should be evaluated with the use of longitudinal pre-post study designs, and follow-up of the long-term benefits of the initiatives;
- The facilitator data in the present evaluation suggests a degree of transformation within the organisations, however, there is a need to evaluate the degree to which such transformation has occurred and if it is sustained over time.

## REFERENCES

- Abdi H. (2007) Bonferroni and Šidák corrections for multiple comparisons. In *Encyclopedia of Measurement and Statistics* (Salkind N.J., ed), Sage, Thousand Oaks, CA.
- Ajuwon P. and Brown I. (2012) Family quality of life in Nigeria. *Journal of Intellectual Disability Research* **26**(1), 61-70.
- Barbara Gatter and Associates (2007) *Evaluation of the Disability Services Commission's Intensive Family Support Strategy*. Disability Services Commission, Australia.
- Barlow J., Powell L., Gilchrist M. and Fotiadou M. (2006) The effectiveness of the Training and Support Program for parents of children with disabilities: A randomized controlled trial. *Journal of Psychosomatic Research* **64**(1), 55-62.
- Baxter C., Cummins R. and Yiolitis L. (2000) Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability* **25**(2), 105-118.
- Bayat M. (2007) Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research* **51**(9), 702-714.
- Black L., McConkey R., Roberts P. and Ferguson P. (2010) Developing a person-centred support service for families caring for children with severe learning disabilities in rural and urban areas. *Journal of Intellectual Disabilities* **14**(2), 111-131.
- 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*. Positive Futures, Bangor.
- Breckenridge J. and Huppert S. (2010) *Intensive Family Support Programs: Keeping Children with a Disability Safely in their Families*. University of New South Wales, Sydney.
- Brown I., Brown R., Baum N., Isaacs B., Myerscough T., Neikrug S., Roth D., Shearer J. and Wand M. (2006) *Family Quality of Life Survey: Main Caregivers of People with Intellectual or Developmental Disabilities*. Surrey Place Centre, Toronto.
- Burton-Smith R., McVilly K., Yazbeck M., Parmenter T. and Tsutsui T. (2009) Service and support needs of Australian carers supporting a family member with disability at home. *Journal of Intellectual and Developmental Disability* **34**(3), 237-247.
- Butera-Prinzi F., Charles N., Heine K., Rutherford B. and Lattin D. (2010) Family-to-Family Link Up Program: a community-based initiative supporting families caring for someone with an acquired brain injury. *Neurological Rehabilitation* **27**(1), 31-47.
- Čagran B., Schmidt M. and Brown I. (2011) Assessment of the quality of life in families with children who have intellectual and developmental disabilities in Slovenia. *Journal of Intellectual Disability Research* **55**(2), 1164-1175.

Caldwell J. and Heller T. (2003) Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research* **47**(4/5), 352-366.

Caldwell J., Heller T. and Taylor S.J. (2007) Longitudinal outcomes of a consumer-directed program supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities* **45**(3), 161-173.

Caldwell J. and Taylor S.J. (2006) Consumer-directed supports: economic, health, and social outcomes for families. *Mental Retardation* **44**(6), 405-417.

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**(1), 67-73.

Dempsey I. and Keen D. (2008) A review of processes and outcomes in family-centred services for children with a disability. *Topics in Early Childhood Special Education* **28**(1), 42-52.

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

Dunst C., Boyd K., Trivette C. and Hamby D. (2002) Family-oriented program models and professional helping practices. *Family Relations* **51**(3), 221-229.

Dunst C., Johanson C. and Trivette C.H., D. (1991) Family-oriented early intervention policies and practices: Family centered or not? . *Exceptional Children* **58**(2), 115-126.

Espe-Sherwindt M. (2008) Family-centred practice: Collaboration, competency and evidence. *Support for Learning* **23**(3), 136-143.

Everson J. and Zhang D. (2000) Person-centred planning: Characteristics, inhibitors, and supports. *Education and Training in Mental Retardation and Developmental Disabilities* **35**(1), 36-43.

Family and Community Services (2011) *Intensive Family Support Program Review*. NSW Government, New South Wales.

Feinberg L. and Newman S. (2004) A study of 10 states since passage of the National Family Caregiver Support Program: Policies, perceptions, and program development. *The Gerontologist* **44**(6), 760-769.

Fiese B., Tomcho T., Douglas M., Josephs K., Poltrock S. and Baker T. (2002) A review of 50 years of research on naturally occurring family routines and rituals: cause for celebration? *Journal of Family Psychology* **16**(4), 381-390.

Flanagan S.A. and Green P.S. (1997) *Consumer-Directed Personal Assistance Services: Key Operational Issues for State CD-PAS Programs Using Intermediary Service Organizations*. U.S. Department of Health and Human Services, Washington D.C.

- FRIENDS (2004) *The Family Support Program Outcomes Survey*. FRIENDS, Chapel Hill.
- Government of Ireland (2001) *Quality and Fairness – A Health System for You*. Government Publications Office, Dublin.
- Greer F., Grey I. and McClean B. (2006) Coping and positive perceptions in Irish mothers of children with intellectual disabilities. *Journal of Intellectual Disabilities* **10**(3), 231-248.
- Health Service Executive (2011) *Time to Move on From Congregated Settings: A Strategy for Community Inclusion*. Health Service Executive, Dublin.
- 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**(4), 419-429.
- Hiebert-Murphy D., Trute B. and Wright A. (2011) Parents' definitions of effective child disability support services: implications for implementing family-centred practice. *Journal of Family Social Work* **14**(2), 144-158.
- Hill T. and Lewicki P. (2007) *STATISTICS: Methods and Applications*. StatSoft, Tulsa, Oklahoma.
- Hu X. and Wang M.F., X. (2012) Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research* **56**(1), 30-44.
- IBM Corporation (2009) *PASW Statistics Version 18.0*. IBM Corporation, Armonk, New York.
- Knestrict T. and Kuchey D. (2009) Welcome to Holland: characteristics of resilient families raising children with severe disabilities. *Journal of Family Studies* **15**(3), 227-244.
- Lord J. and Hutchinson P. (2003) Individualised support and funding: building blocks for capacity building and inclusion. *Disability and Society* **18**(1), 71-86.
- Munford R., Sanders, J., Maden, B., Maden, E. (2007) Blending Whanau/family development, parent support and early childhood education programmes. *Social Policy Journal of New Zealand* **32**, 72-87.
- Murray P. (2000) Disabled children, parents and professionals: partnerships on whose terms? *Disability and Society* **15**(4), 683-698.
- Nahom D., Richardson M., Romer L. and Porter A. (2000) Family support and community guiding. *Families in Society* **81**(6), 629-633.
- National Disability Authority and Department of Health and Children (2004) *National Standards for Disability Services*. National Disability Authority and Department of Health and Children, Dublin.

Nirje B. (1969) The normalisation principle and its human management implications. In *Changing Patterns in Residential Services for the Mentally Retarded* (Kugel R.B. and Wolfensberger W., eds), Presidents Committee on Mental Retardation, Washington D.C., pp. 179-195.

O'Brien J. and Lovett H. (1992) *Finding a Way Toward Everyday Lives: The Contribution of Person Centred Planning*. Pennsylvania Office of Mental Retardation, Harrisburg.

O'Brien J., Pearpoint J. and Kahn L. (2010) *The PATH & MAPS Handbook: Person-Centred Ways to Build Community*. Inclusion Press, Toronto.

O'Brien J. and Tyne A. (1981) *The Principle of Normalisation: A Foundation for Effective Services CMH*. CMH, London.

Peralta F. and Arellano A. (2010) Family and disability: A theoretical perspective on the family-centred approach for promoting self-determination. *Electronic Journal of Research in Educational Psychology* **8**(3), 1339-1362.

Powers L., Sowers J. and Singer G. (2006) A cross-disability analysis of person-directed, long-term service. *Journal of Disability Policy Studies* **17**(2), 66-76.

QSR International (2009) *NVivo Version 8.0*. QSR International, Chesire.

Rillotta F., Kirby N., Shearer J. and Nettelbeck T. (2012) Family quality of life of Australian families with a member with an intellectual/developmental disability. *Journal of Intellectual Disability Research* **56**(1), 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**(4), 360-372.

Samuel P., Hobden K., LeRoy B. and Lacey K. (2012) Analysing family service needs of typically underserved families in the USA. *Journal of Intellectual Disability Research* **56**(1), 111-128.

Schippers A. and van Boheemen M. (2009) Family quality of life empowered by family-oriented support. *Journal of Policy and Practice in Intellectual Disabilities* **6**(1), 19-24.

Singer G., Biegel D. and Ethridge B. (2009) Toward a cross disability view of family support for caregiving families. *Journal of Family Social Work* **12**(2), 97-118.

Stainton B., J., Crawford, C., Hole, R., Charles, G. (2011) Comparison of community residential supports on measures of information & planning; access to & delivery of supports; choice & control; community connections; satisfaction; and, overall perception of outcomes. *Journal of Intellectual Disability Research* **55**(8), 732-745.

State of California (2001) *Person-Centred Planning: Building Partnerships and Supporting Choices*. State of California, Sacramento.

SurveyMonkey.com LLC. (2012) *SurveyMonkey*. SurveyMonkey.com, LLC. Retrieved from [www.surveymonkey.com](http://www.surveymonkey.com).

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

Turner K. and Sanders M. (2006) Dissemination of evidence-based parenting and family support strategies: Learning from the Triple P – Positive Parenting Program system approach. *Aggression and Violent Behaviour* **11**(2), 176-793.

Twoy R., Connolly M. and Novak J. (2007) Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners* **19**(5), 251-260.

Van Boheemen M. (2006) *Passie en Ondernemerschap in Almere*. Stichting Philadelphia Zorg, Nunspeet.

Walker P. (2010) *Arc of Howard County, Maryland: Reclaiming Person-Centred Planning*. Center on Human Policy, Syracuse.

Wang M. and Brown R. (2009) Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work* **12**(2), 144-167.

Weiss J., White S. and Spoelstra M. (2008) *Autism Ontario PPM-140 Parent Survey 2008*. Autism Ontario, Toronto.

Whittier S., Scharlach A. and Dal Santo T. (2005) Availability of caregiver support services: implications for implementation of the National Family Caregiver Support Program. *Journal of Aging and Social Policy* **17**(1), 45-62.

Wills R. (1997) Up against it! Quality of Life and Families. In *Human Services: Towards Partnership and Support* (O'Brien P. and Murray R., eds), Dunmore Press, Palmerston North, pp. 293-304.

Wolfensberger W. (1972) *The Principle of Normalisation in Human Services*. National Institute on Mental Retardation, Toronto.

Wright A., Hiebert-Murphy D. and Trute B. (2010) Professionals' perspectives on organizational factors that support or hinder the successful implementation of family-centred practice. *Journal of Family Social Work* **13**(2), 114-130.

## APPENDICES

### Appendix I: Content of training workshops

#### Brothers of Charity

##### **Residential workshops (2 days duration over 5 weekends)**

Topics addressed at the six workshops included:

- What is Family Leadership and why is it so important.
- How to develop a vision for and with your family member with disability.
- How to sustain the vision.
- How to turn your Vision into Action.
- How and why to develop a circle of support.
- How and why succession planning is necessary in order to safeguard the life of the person into the future.

#### Autism Initiative Group

##### **Information and networking focused workshops (1 and 2 day duration)**

Topics addressed at the six workshops included:

- Understanding the Nature of ASD
- Transitioning from Childhood to Adulthood for Individuals with ASD
- Social Thinking
- Transition for Individuals with ASD
- Teaching Friendship Skills
- Anxiety & Self Esteem Issues
- I am Special
- Enabling Positive Futures
- Discussing Diagnoses and building Self Esteem
- Anxiety & Self- Esteem
- Communication and Autism Issues and Strategies

#### LEAP

##### **Workshops (4 half days)**

- Advocacy for Inclusion
- Person-centred planning
- How to build social networks
- Circles of support



### **Family Leadership Weekend (1 Weekend)**

- Families participated in an adventure weekend break and family members were introduced to a practical leadership programme.
- Each family was assigned a 'Family Pal' as well as activity leaders with experience of working with people with a disability.
- Topics/activities included:
  - Developing a vision of a good life for the family;
  - Finding support with other families;
  - Practical insights about how to support family members to live a fuller, better life.

### **Pathways to Possibilities (6 day programme spread across 4 weeks. Ran twice.)**

- Purpose of the programme is to move parents from resignation to realistic hope.
- Parents paired with a professional ally or friend and had tasks to complete between meetings.
- Topics/activities included:
  - Empowering parents to take control and to think differently;
  - Opening up participants to realistic future possibilities for the child/adult with disability and fulfilling dreams and expectations;
  - Giving participants tools for planning and writing a plan;
  - Skills for working with staff and professionals to achieve the above;
  - Catch up session following the main programme.

### **Communications and Supporting Skills (normally 14 hours spread over 7 weeks)**

- Ran once in order to train the trainers – delivered over a shortened period of time to facilitate attendance at this course only.
- Professionals and Parents participate together.
- Topics/activities included:
  - Giving parents the opportunity talk within a confidential safe environment to share feelings and problems;
  - Listening skills to enable communication both within the family and with staff and professionals;
  - Assertiveness skills;
  - Support for participants from other parents;
  - Catch up session following the main programme.

DESSA: Disability Equality Specialist Support Agency

**Information Workshops (2 hour session once a week for 6-8 weeks depending on location)**

Topics addressed:

- An examination of the social versus the medical model of support for people with disability
- Disability legislation
- Advocacy skills [how to go about meeting and seeking services from Irish bureaucracies such as schools, the HSE and other organisations, how to conduct oneself, keeping a record, asking pertinent questions, how to negotiate]
- Entitlements
- Rights of the child
- Inclusion in education

## Appendix II: Interview schedule for family participants

### **Preamble:**

- Welcome participant and introduce yourself
- Discuss the following:
  - the research aim and purpose – e.g. to understand the family initiative project, how you experienced it and what was learned from the project that can be used to benefit other similar projects
  - independence of the research team
  - project funded by Genio
  - potential outcome, e.g. written report
  - approximate interview length, 30-40 minutes
  - permission to record the interview
- Answer any participant questions.
- Complete participant consent form.

### **Interview:**

**How did you become involved in the project?**

**Describe the project as you experienced it?**

**What did participation in the project offer to you and your family?**

- Examples of benefits.
- What did you learn? Eg. knowledge, skills, empowerment, self-advocacy, connecting in to the wider community, developing community based supports.
- Obtain relevant and useful information?
- Has the way you see yourself changed?

**What do you do differently?**

- Impact on your well-being and quality of life, impact on your family?
- Specific benefits such as :
  - Can you now see what your child/ family member's life might be like and how might you achieve it?
  - Do you now know how to identify resources in the community in order to meet the needs of your family member?

**Can you tell me about any problems that you might have experienced in relation to your participation in the project?**

- Barriers or facilitators to participation

**What was the impact of the project for the person with the disability or autism?**

- Benefits to the person with a disability or autism
- Changes in how you see your child/family member
- Vision for your child /family member changed?
- Organisation of supports around your child /family member rather than around what the service offers – person-centred supports

- Effects on the person's well-being and quality of life
- Achievement of his/her personal outcomes to a greater degree?
- Enhanced integration or engagement in the community?

**Has your experience of the project increased your capacity to be assertive in organising a service for your family member?**

- If so, how?
- Examples of changes in engagement with service providers
- More empowered? How?
- More assertive? How?
- The extent to which you/your family member are better at 'navigating the system'

**Did you have the opportunity to share experiences with other people with similar challenges/situations?**

- Experiences of forming and participating in informal support networks
- Experiences of networking
- Sustainability of networks / relationships

**Are you now more involved with or interact more in your community?**

**Looking to the future, will your participation in the family initiative continue to benefit you?**

**Summary questions:**

- What was good about the project and worked well? (e.g. 2 points)
- What was not so good or didn't work well? (e.g 2 points)
- Suggestions for future improvement
- Review interview purpose and anything else that the participant would like to add

**Conclusion:**

- Answer participant questions, reminder that transcript copy is available if desired, thank participant.
- Fill in participant demographic information sheet.
- Ask participant whether it is okay to contact him/her after the interview if you have any additional questions.
- Check to see if you can obtain contact information to send a thank you.
- Explain that we will also be sending a survey but that it will ask different questions than in the interview.

## Appendix III: Interview schedule for project managers and facilitators

### **Preamble:**

- Welcome participant and introduce yourself
- Discuss the following:
  - the research aim and purpose – e.g. to understand the family initiative project, how you experienced it and what was learned from the project that can be used to benefit other similar projects
  - independence of the research team
  - project funded by Genio
  - potential outcome, e.g. written report
  - approximate interview length, 30-40 minutes
  - permission to record the interview
- Answer any participant questions.
- Complete participant consent form.

### **Interview questions:**

#### **What was your role in relation to the project?**

- Part of the organisation or brought in to facilitate
- If external facilitator, what was the particular expertise brought to the project
- Present from the beginning or joined the project after it was set up
- Number of years in your role/the organisation

#### **Could you tell me about the project?**

- Setting up the project
- Participating in the project
- Was the information/content provided for the participants relevant and useful?

#### **Can you tell me about any problems that were experienced during the project?**

- Barriers/facilitators encountered
- Recruitment / engagement
- Personnel (facilitators availability / expertise)
- Impact of timelines
- Resources

#### **What was the impact of the project on the organisation?**

- Benefits to the organisation
- What does the organisation do differently as a result of this project?
- How are these new ways of working being resourced?
- Changes in the interaction between the organisation and the wider community
- Suggestions for future policy and systems development

#### **Has the learning from this project been disseminated to other organisations?**

- New partnerships or links established

#### **Do you see this project as sustainable?**

- For your organisation, if yes how?

- For participants, if yes how?
- Ways in which to sustain this project (or similar projects) in the future?
- How might the project be run differently in the future?
- Were participants taught to deliver the project to future participants?

**In your opinion, did the project achieve what it set out to do?**

- What was good about the project and worked well?
- What was not so good or didn't work well?
- Suggestions for future improvement

**Summary questions:**

- Review interview purpose
- Any final recommendations?
- Anything else that the participant would like to add?

**Conclusion:**

- Answer participant questions, reminder that transcript copy is available if desired, thank participant



# Evaluation of Family Initiatives



Please read the following instructions carefully.

- This survey will take about 15 minutes to complete. If there are any questions you do not want to answer, you do not have to.
- Please note that most of the questions ask that you **indicate your answer by placing a tick mark (√)** on the appropriate line or in the appropriate box or **circling a response**. Some questions ask that you **write your answer** in the space provided.
- Unless the question states otherwise, please select only one response.
- You cannot be identified by this questionnaire and we do not need your name or address. All of the information you give us will be anonymous and confidential.
- The terms **'family initiative'** and **'project'** will be used to indicate the family initiative that you have participated in.
- The term **'family member with a disability'** is used to indicate your family member with an intellectual or physical disability, or autism.

Please return this survey free of charge in the large brown envelope provided or mail to: License DN6047, Agnes Higgins, Trinity College Dublin, 24 D'Olier Street, Business Reply, Dublin 2. **Please be sure to include the license number.**

**1. All questions in this survey are about your participation in one of the following family initiatives. In which initiative did (or do) you and your family participate?**

- Family Focus: GENIO project
- DESSA – Disability Equality Specialist Support Agency: Empowering Parents Programme
- Autism Initiatives ASDI
- LEAP – Leading Education, Advocacy and Planning for full citizenship for people with intellectual disabilities and autism.

**2. Did you participate in full in all the activities offered to you by the family initiative?** \_\_\_\_\_ Yes \_\_\_\_\_  
No

If 'No' please explain which aspects you did not participate in and why:



## Section 1: Family information

### 3. What is your relationship to your family member with a disability?

*FQOL survey*

(For example: mother, father, brother, sister, spouse/partner)

### 4. Within your family, are you the primary source of support for your family member with a disability?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

### 5. Can you briefly describe the support you provide?

**Please indicate the following details about your family member with a disability:**

**6. Gender:** \_\_\_\_\_ Male      \_\_\_\_\_ Female

*FQOL survey*

**7. Age:** \_\_\_\_\_

*FQOL survey*

**8. Type of disability:**  Physical Disability

Intellectual Disability

Autism *FQOL survey*

**9. Where does your family member with a disability live?**

\_\_\_\_\_ At home with me

\_\_\_\_\_ He/she lives independently

\_\_\_\_\_ Community Residence

\_\_\_\_\_ Campus based Residence

\_\_\_\_\_ Other (please describe).....

**10. Often people with an intellectual or physical disability or autism have other conditions. Please check (✓) any that apply to your family member with a disability.**

*FQOL survey*

- Behavioural challenges
- Mental health problems
- Physical health problems
- Mobility challenges
- Seizures
- Alzheimer disease or other types of dementia
- Major vision impairment or Major hearing impairment
- Sensory integration impairment
- Speech and or language difficulties
- Feeding or eating difficulties (feed tubes, major allergies, sensitivities, etc.)
- Other (please specify) \_\_\_\_\_

**11. Please describe condition(s) checked in #10 above.**

---

---

---

---

**12. Overall, what level of disability-related support is needed for your family member with a disability?**

(Examples of disability-related support are: special needs assistants in school, wheel chair, special transport arrangements, alternative communication systems such as PECS for autism, etc.) (Check ✓ level that applies)

*FQOL survey*

- Does not require disability-related support
- Requires disability-related support for only a few aspects of life
- Requires disability-related support for some aspects of life
- Requires disability-related support for most, but not all, aspects of life
- Requires disability-related support for almost all aspects of life

**13. What level of communication best describes your family member with a disability?** (Check ✓ level that applies)

*FQOL survey*

- Able to communicate about a wide variety of topics in a meaningful way
- Able to communicate within a limited range of topics in a meaningful way
- Able to communicate needs, wants, and some ideas in a meaningful way
- Able to communicate basic needs and wants
- Very little meaningful communication

## Section 2: Enabling, practical learning and application, collaboration, sustainability

14. Please read each of the following statements and indicate the degree to which you agree/disagree with them.

(Check ✓ only one box for each statement)

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Participating in the family initiative has <b>enabled</b> my family member with a disability to care more effectively for himself/herself					
Participating in the family initiative has enabled me to advocate more effectively for my family member with a disability					
Participating in the family initiative has enabled me to be more effective in the direct support of my family member with a disability					
Participating in the family initiative has enabled my family member with a disability to be more involved in the community					
What we <b>learned</b> from the family initiative has had a positive impact on our lives					
Participating in the family initiative has helped us solve important problems					
What we learned from the family initiative was practical					
Participating in the family initiative has helped us make changes that were important for our family member with a disability					
The family initiative we participated in helped us to meet our family's needs					
Participating in the family initiative was a <b>collaboration</b> in which we were equal partners					
We got along well with the team members/facilitators in the family initiative					
In the future we will be able to <b>sustain</b> what we learned from the family initiative					
Participating in the family initiative will have a lasting positive impact					

### Section 3: Impact of the family initiative

15. To what degree has your knowledge of how to support your family member been affected by the family initiative? Please circle one.

1 Stayed the same	2 Slightly improved	3 Moderately improved	4 Greatly improved
----------------------	------------------------	--------------------------	-----------------------

16. To what degree have your skills in supporting your family member been affected by the family initiative? Please circle one.

1 Stayed the same	2 Slightly improved	3 Moderately improved	4 Greatly improved
----------------------	------------------------	--------------------------	-----------------------

17. How has the amount of work you do in support of your family member been affected by the family initiative? Please circle one.

1 Greatly increased	2 Increased	3 Stayed the same	4 Reduced	5 Greatly reduced
------------------------	----------------	----------------------	--------------	----------------------

18. To what degree has participating in the family initiative changed your attitude towards your family member? Please circle one.

1 Stayed the same	2 Slightly changed	3 Moderately changed	4 Greatly changed
----------------------	-----------------------	-------------------------	----------------------

19. If your attitude changed, can you describe in what way? Please give examples.

--

**20. Can you describe how the family initiative has affected the life of your family member with a disability? Please give examples.**

**21. Can you describe how the family initiative has affected your life? Please give examples.**

**22. Can you describe how the family initiative has affected the life of your family as a whole? Please give examples.**

In Sections 4 and 5, please read each of the following statements and indicate the degree to which you agree/disagree with them (Check ✓ only one box for each statement).

#### Section 4: Self-Advocacy

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
<b>23. Since participating in the family initiative...</b>						
My family member with a disability and I are more likely to seek out information on his/her needs						
My family member with a disability and I are more assertive about making suggestions to healthcare personnel/services/organisations about his/her needs						
My family member with a disability and I are more willing to ask questions of healthcare personnel, services and organisations						

#### Section 5: Social Support

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
<b>24. Since participating in the family initiative...</b>						
I feel more supported by other families in relation to my family member's disability						
I feel more supported by my own family/friends in relation to my family member's disability						
I feel more supported by other families in meeting my own needs						
I feel more supported by my own family/friends in meeting my own needs						
I feel less isolated						
I am more likely to seek informal support for myself (e.g. talking to a friend)						
I am more likely to seek professional support for myself (e.g. going to see my GP)						
I am more likely to support other families who participate in the family initiative						



## Section 6: Overall views

25. Overall, how helpful was the family initiative for you and your family? Please circle one.

1 Not at all useful	2 Not very useful	3 Neutral	4 Useful	5 Very useful
------------------------	----------------------	--------------	-------------	------------------

26. What was most helpful about the family initiative?

27. Please list any improvements you would like to see made in the family initiative you have been participating in.

**28. If you have any final comments, please list them here.**

**Thank you for taking the time to complete this survey!**

## Appendix IV: Survey instrument

The following variables were included:

- Did you participate in full in the programme? (yes/no)
- Are you the primary support for family member with disability? (yes/no)
- gender of family member with disability (male / female)
- type of disability (physical / ID / Autism)
- Where does family member with disability live? (at home / independently / community res. / campus residence / other)
- Level of disability related support needed ( 5 levels from minor to major support)
- Level of communication of family member with disability (5 levels from low to high level)
- To examine the relationship between age of family member with disability and how helpful the programme was perceived to be a Pearson Correlation was computed (Chi-Square is less appropriate with so many possible values).

## Appendix VI: Inferential statistics

**Table 28. Comparison of the four different programmes for enabling factors, practical learning, application, collaboration, and perceived sustainability and Analysis of Variance**

Statement	Total mean (sd)	Programmes mean (sd)				ANOVA	
	(n=36)	Family Focus (n=9)	DESSA (n=14)	AIG (n=3)	LEAP (n=10)	F (p)	Eta2
1. Participating in the family initiative has <b>enabled</b> my family member with a disability to care more effectively for himself/herself	2.91 (1.12)	3.44 (1.01)	2.50 (1.16)	3.33 (.58)	2.89 (1.17)	1.52 (.230)	.128
2. Participating in the family initiative has enabled me to advocate more effectively for my family member with a disability	4.22 (1.05)	4.44 (.53)	4.36 (1.15)	3.33 (1.16)	4.10 (1.20)	.98 (.414)	.084
3. Participating in the family initiative has enabled me to be more effective in the direct support of my family member with a disability	3.97 (1.08)	4.11 (.60)	4.00 (1.41)	3.67 (.58)	3.90 (1.10)	.14 (.938)	.013
4. Participating in the family initiative has enabled my family member with a disability to be more involved in the community	3.18 (1.09)	3.86 (.69)	3.00 (1.24)	3.33 (.58)	2.90 (1.10)	1.31 (.289)	.116
5. What we <b>learned</b> from the family initiative has had a positive impact on our lives	4.22 (.93)	4.22 (.97)	4.29 (.83)	4.00 (.00)	4.20 (1.23)	.07 (.973)	.007
6. Participating in the family initiative has helped us solve important problems	3.64 (.99)	3.78 (.97)	3.64 (1.01)	3.33 (.58)	3.60 (1.17)	.15 (.930)	.014
7. What we learned from the family initiative was practical	4.19 (.82)	4.22 (.67)	4.36 (.63)	4.00 (.00)	4.00 (1.25)	.41 (.749)	.037
8. Participating in the family initiative has helped us make changes that were important for our family member with a disability	3.86 (1.05)	4.11 (1.05)	3.64 (1.01)	3.67 (.57)	4.00 (1.25)	.45 (.722)	.040
9. The family initiative we participated in helped us to meet our family's needs	3.50 (1.00)	4.11 (.78)	3.21 (.89)	3.33 (.58)	3.40 (1.27)	1.65 (.198)	.134
10. Participating in the family initiative was a <b>collaboration</b> in which we were equal partners	4.08 (.94)	4.11 (.60)	4.07 (1.00)	4.00 (.00)	4.10 (1.29)	.01 (.998)	.001
11. We got along well with the team members/facilitators in the family initiative	4.63 (.55)	4.63 (.52)	4.86 (.36)	3.67 (.58)	4.60 (.52)	5.46 (.004)*	.346
12. In the future we will be able to <b>sustain</b> what we learned from the family initiative	4.11 (.92)	3.89 (1.05)	4.36 (.63)	4.00 (.00)	4.00 (1.25)	.55 (.651)	.049
13. Participating in the family initiative will have a lasting positive impact	4.17 (.94)	4.00 (1.00)	4.29 (.73)	4.00 (.00)	4.20 (1.32)	.19 (.902)	.018

**Table 29. Comparison of the four different programmes for Impact of the Initiatives and Analysis of Variance**

Statement	Total mean (sd) (n=36)	Programmes mean (sd)				ANOVA (*p < .05; **p < .01; ***p < .001)	
		Family Focus (n=9)	DESSA (n=14)	AIG (n=3)	LEAP (n=10)	F (p)	Eta2
1. To what degree has your <u>knowledge</u> of how to support your family member been affected by the family initiative?	2.57 (.73)	2.89 (.33)	2.40 (.83)	2.67 (.58)	2.50 (.85)	.89 (.457)	.075
2. To what degree have your <u>skills</u> in supporting your family member been affected by the family initiative?	2.54 (.73)	2.56 (.73)	2.40 (.83)	2.67 (.58)	2.70 (.68)	.36 (.786)	.031
3. How has the <u>amount of work you do</u> in support of your family member been affected by the family initiative?	2.96 (.98)	3.00 (1.41)	2.93 (.80)	3.00 (1.00)	2.60 (.84)	.33 (.806)	.029
4. To what degree has participating in the family initiative changed your <u>attitude</u> towards your family member?	2.50 (1.28)	2.63 (1.19)	2.33 (1.29)	1.67 (1.16)	2.90 (1.28)	.85 (.475)	.074

Bonferroni's adjustment: For multiple tests (28 tests) suggests that a significant difference comparable to an alpha of 0.05 is achieved at 0.0017857

**Table 30. Comparison of the four different programmes for Self-advocacy and Analysis of Variance**

Statement	Total mean (sd) (n=36)	Programmes mean (sd)				ANOVA (*p < .05; **p < .01; ***p < .001)	
		Family Focus (n=9)	DESSA (n=14)	AIG (n=3)	LEAP (n=10)	F (p)	Eta2
1. My family member with a disability and I are more likely to seek out information on his/her needs	4.12 (.98)	4.13 (1.13)	4.29 (.73)	3.50 (.71)	4.00 (1.25)	.43 (.734)	.041
2. My family member with a disability and I are more assertive about making suggestions to healthcare personnel/services/organisations about his/her needs	4.37 (.84)	4.75 (.46)	4.14 (.86)	4.00 (1.00)	4.50 (.97)	1.17 (.337)	.102
3. My family member with a disability and I are more willing to ask questions of healthcare personnel, services and organisations	4.37 (.84)	4.75 (.46)	4.29 (.83)	4.00 (1.00)	4.30 (1.06)	.789 (.509)	.071

Bonferroni's adjustment: For multiple tests (28 tests) suggests that a significant difference comparable to an alpha of 0.05 is achieved at 0.0017857.

**Table 31. Comparison of the four different programmes for Social Support and Analysis of Variance**

Statement	Total mean (sd)	Programmes mean (sd)				ANOVA	
	(n=36)	Family Focus (n=9)	DESSA (n=14)	AIG (n=3)	LEAP (n=10)	F (p)	Eta2
1. I feel more supported by other families in relation to my family member's disability	3.81 (1.06)	3.38 (.92)	4.07 (.73)	3.00 (1.00)	4.00 (1.41)	1.48(.238)	.122
2. I feel more supported by my own family/friends in relation to my family member's disability	3.69 (1.14)	3.75 (1.49)	3.79 (.98)	3.00 (.00)	3.73 (1.27)	.39 (.763)	.035
3. I feel more supported by other families in meeting my own needs	3.58 (1.03)	3.25 (.89)	3.86 (.86)	3.00 (1.00)	3.64 (1.29)	.95 (.431)	.081
4. I feel more supported by my own family/friends in meeting my own needs	3.58 (1.11)	3.50 (1.31)	3.64 (.93)	3.00 (.00)	3.73 (1.35)	.35 (.790)	.032
5. I feel less isolated	3.81 (1.26)	3.63 (1.19)	3.64 (1.34)	3.67 (1.53)	4.18 (1.25)	.45 (.720)	.040
6. I am more likely to seek informal support for myself (e.g. talking to a friend)	4.00 (.91)	3.75 (.89)	3.93 (1.07)	3.67 (.58)	4.40 (.70)	1.02 (.399)	.089
7. I am more likely to seek professional support for myself (e.g. going to see my GP)	3.83 (.36)	3.50 (.54)	3.79 (1.19)	3.33 (.58)	4.27 (.79)	1.49 (.237)	.122
8. I am more likely to support other families who participate in the family initiative	4.28 (.78)	4.00 (.76)	4.50 (.65)	3.67 (.58)	4.36 (.92)	1.43 (.252)	.118
Bonferroni's adjustment: For multiple tests (28 tests) suggests that a significant difference comparable to an alpha of 0.05 is achieved at 0.0017857.							

**Table 32. Crosstabulation of Family Information and Age with perceived Helpfulness of the initiatives**

Family Information	Pearson Chi-Square Test (2-tailed) (*p < .05; **p < .01; ***p < .001)		
	df	value	p
9. Did you participate in full in the programme? (yes/no)	4	22.82	.000***
10. Are you the primary support for family member with disability? (yes/no)	3	5.54	.137
11. gender of family member with disability (male / female)	4	3.37	.497
12. type of disability (physical / ID / Autism)	8	5.14	.742
13. Where does family member with disability live? (at home / independently / community res. / campus residence / other)	8	8.56	.381
14. level of disability related support needed ( 5 levels from minor to major support)	16	9.60	.887
15. level of communication of family member with disability (5 levels from low to high level)	16	14.39	.570
	Pearson Correlation (2-tailed)		
	n	r	p
16. Age: To examine the relationship between age of family member with disability and how helpful the programme was perceived to be a Pearson Correlation was computed (Chi-Square is less appropriate with so many possible values).	35	-.08	.647

**Table 33. Pearson Correlations with ‘helpfulness’ variable**

Pearson Correlations (2-tailed) with Helpfulness ‘How Helpful was the family initiative for you and your family’. (*p < .05; **p < .01; ***p < .001)			
Bonferroni's adjustment: For multiple tests (28 tests) suggests that a significant difference comparable to an alpha of 0.05 is achieved at 0.0017857.			
Items (Statement/Questions)	r (p)	Items (Statement/Questions)	r (p)
Participating in the family initiative has <b>enabled</b> my family member with a disability to care more effectively for himself/herself	.451 (.007**)	To what degree have your <u>skills</u> in supporting your family member been affected by the family initiative?	.650 (.000***)
Participating in the family initiative has enabled me to advocate more effectively for my family member with a disability	.509 (.002**)	How has the <u>amount of work you do</u> in support of your family member been affected by the family initiative?	<b>.064</b> <b>(.710)</b>
Participating in the family initiative has enabled me to be more effective in the direct support of my family member with a disability	.569 (.000***)	To what degree has participating in the family initiative changed your <u>attitude</u> towards your family member?	.366 (.031*)
Participating in the family initiative has enabled my family member with a disability to be more involved in the community	.540 (.001**)	My family member with a disability and I are more likely to seek out information on his/her needs	.423 (.016*)
What we <b>learned</b> from the family initiative has had a positive impact on our lives	<b>.819</b> <b>(.000***)</b>	My family member with a disability and I are more assertive about making suggestions to healthcare personnel/services/organisations about his/her needs	.484 (.004**)
Participating in the family initiative has helped us solve important problems	.720 (.000***)	My family member with a disability and I are more willing to ask questions of healthcare personnel, services and organisations	.597 (.000***)
What we learned from the family initiative was practical	.754 (.000***)	I feel more supported by other families in relation to my family member's disability	.598 (.000***)
Participating in the family initiative has helped us make changes that were important for our family member with a disability	.762 (.000***)	I feel more supported by my own family/friends in relation to my family member's disability	.716 (.000***)
The family initiative we participated in helped us to meet our family's needs	.591 (.000***)	I feel more supported by other families in meeting my own needs	.669 (.000***)
Participating in the family initiative was a <b>collaboration</b> in which we were equal partners	.484 (.003**)	I feel more supported by my own family/friends in meeting my own needs	.693 (.000***)
We got along well with the team members/facilitators in the family initiative	<b>.268</b> <b>(.125)</b>	I feel less isolated	.601 (.000***)
In the future we will be able to <b>sustain</b> what we learned from the family initiative	.781 (.000***)	I am more likely to seek informal support for myself (e.g. talking to a friend)	.481 (.004**)
Participating in the family initiative will have a lasting positive impact	<b>.834</b> <b>(.000***)</b>	I am more likely to seek professional support for myself (e.g. going to see my GP)	<b>.233</b> <b>(.184)</b>
To what degree has your <u>knowledge</u> of how to support your family member been affected by the family initiative?	.469 (.004**)	I am more likely to support other families who participate in the family initiative	.613 (.000***)