



Evaluation Report For Family Voice Hub 2020 -2023



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1. Introduction

1.1 Purpose of this report

This report sets out the findings of Autonomie's evaluation of the Family Voice Hub project. The project was funded through National Lottery Community Fund (People & Communities) for a period of 3 years. The report aims to provide:

- An overview of the Services provided by Autonomie.
- A summary of the Family Voice Hub project
- A description of how we conducted the evaluation of the project; and
- A summary of the project's outcomes and the future plans for the project.

The parents and siblings of a child or young person with a disability often feel they are overlooked and feel isolated as they need to fight for everything their child needs – they are often passed from pillar to post and from statutory service to statutory service.

This evaluation will demonstrate how the Family Voice Hub has provided a vital service to these parents, carers and wider families of a child or young person with a physical disability and/or a mild to moderate learning disability. It will show how the Family Voice Hub has made massive difference to the families who have used it via direct feedback from those who use its services.

"Being the parent of a young person with complex needs can be a very lonely place at times. The Family Voice Hub provides me with an opportunity to connect with other people who are in a similar situation and talk through the challenges that we face. It has also been an invaluable source of support and information over the last 3 years."

(Feedback from one of our parents)

The report will also highlight some of the lessons we have learnt on the project over the last 3 years and will make a case for the continuation of the project in a new and improved format.

1.2 Autonomie Services

Autonomie was established to support the inclusion of young people with disabilities into the community by offering support and advice in education, social, and leisure activities and the promotion of independence and transition into adult working life. We strongly believe that there is a real gap in service provision for young people with additional needs and that there is a significant drop off in the level of support available to them after they leave school. This gap in service provision has been made worse by the COVID-19 pandemic and the current 'cost of living crisis' and this is likely to continue for some years.

Autonomie's overall purpose and aims are summarised in the following diagram which sets out our vision statement, mission, and values.

Figure 1 – Vision, Mission & Values

Vision

All young people with disabilities can have lives which are full of fun, friendship and real in opportunities and independence. Just like any other young person's.

Mission

To empower young people living with a disability, their parents, carers and siblings throughout Northern Ireland.

Values

Resilience, Inclusion, Collaboration & Empowerment.

Autonomie currently delivers 3 flagship projects, namely:

- **Family Voice Hub** – a project which provides a support hub for parents and siblings, offering much needed practical and emotional support for living with a child or young person with a disability.
- **Freedom2Choose** – a 'youth club' based project which offers structured opportunities for practical learning, social and recreational activities, and access to what is on offer in the community.
- **SAIL – (Social and Independent Living)** provides practical independent living skills, personal development, and self-awareness as well as mental health and wellbeing.

Prior to the Covid pandemic we also offered the **Independent Living Experience** which offered participants a chance to gain a greater understanding of their strengths and limitations, improve their existing independent living skills and develop new skills both social and life and have the opportunity to experience 'independent living' stay at our headquarters building, Lilac House.



2. The Family Voice Hub Project

2.1 Project Overview

The parents of a child/young person with a disability can feel very alone, marginalised due to attitudes and challenges they find themselves having to address on a daily basis - they are often passed from pillar to post and from statutory bodies. Siblings of a child or young person with a disability often feel they not an important member of the family unit, as all focus is based around their brother/sister who has a disability.

The idea of a Family Voice Hub was planned and developed following a meeting of a group of parents whose common concern was *"How do other parents find out about organisations, agencies and support they need? Wouldn't it be good to have a one stop shop as I have had to search through the internet to find out everything?"*

In addition, several siblings of participants in our other projects had spoken to Autonomie staff saying that they felt 'left out' or 'were not a sister/brother but a carer' and that they did not want to upset their parents by raising their feelings.

The existing Autonomie Parents Forum then raised these points with the Autonomie Management Committee and the concept of the Family Voice Hub was conceived. In April 2020 Autonomie was successful in securing a grant from National Lottery Community Fund (People & Communities) of £198,943 and the Family Voice Hub was formally launched in September 2020.

There are currently 75 families who are registered with the Family Voice Hub, which equates to a total of 315 individuals. The Family Voice Hub has evolved and continually adapted to the ever-changing needs of our families throughout the past 3 years. The needs of families with a child or young person with a disability have become more complex during this period, especially with the ongoing impact of Covid-19 and, more recently, the Cost-of-Living crisis.

2.2 Project Objectives

As stated above, the parents and siblings of a child or young person with a disability often feel overlooked and isolated as they try to support their children. These feelings have been exacerbated as statutory services have been greatly reduced over recent years due the funding crisis within public services in Northern Ireland. The Family Voice Hub has sought to address this situation by providing a 'one stop shop' to support parents, carers, siblings and their wider family circles.

The overall objectives of the Family Voice Hub projects are as follows:

- a) Provide a support hub for parents & siblings on a drop-in basis in a safe, comfortable, and friendly environment.
- b) Provide advice, guidance and information relevant to individual parents and siblings.
- c) Provide workshops, information sessions , specialist speakers highlighting self-care & mental health.
- d) Provide emotional and practical support for parents & siblings.
- e) Provide an outreach service to those families who are unable to travel to the Centre.
- f) Provide one-to-one, family or group counselling.
- g) Deliver age-appropriate activities and programmes for siblings.

- h) Develop communication networks to enable parents & siblings to have contact with others who have shared experiences.
- i) Further develop the Parents Forum to enable to monitoring, evaluation and to identify gaps in services for parents & siblings.

Later in this report how these objectives were achieved/not achieved will be discussed in more detail.

The following diagram highlights the support services which the Family Voice hub has delivered to parents, carers, siblings and wider family members over the last 3 years.

Figure 2 – Family Voice Hub Services



In the remainder of this section we provide examples of the specific activities which have been carried over the last 3 years to meet the objectives which were set for the project.

a) Provide a support hub for parents and siblings on a drop in basis in a safe, comfortable and friendly environment.

The top floor of our headquarter building, Lilac House, has been adapted to suit the needs of the Family Voice Hub – providing a meeting room, kitchen, therapy/sensory room and a fully accessible bathroom. This has provided an ideal setting for both parents and siblings to meet with Family Voice Hub staff, or to have one-to-one or family based services (including holistic therapies) as well as a relaxed meeting area which has been used for meetings with other agencies, parents, extended support networks and siblings. This 'one stop shop' allows families to seek out the information they require in a safe, relaxed, supportive environment.

"What a relief, I was able to call in when it suited me, and I was able to relax with a cuppa, and was not passed from pillar to post. Lovely suite to visit".

(Comment left in Lilac House visitors book)

b) Provide advice, guidance and information relevant to individual parents and siblings.

The types of advice and guidance requested has been much wider than we originally expected, following the pandemic, families experienced issues which had never been presented before. Parents were finding changes in the behaviour of both the child/young person with the disability but also in relation to siblings. Isolation, fear, anxiety and worry about health conditions increased.

With the use of Zoom, the Family Voice Hub was able to maintain contact with families and enabled families to interact with others who were experiencing similar concerns and worries and facing similar challenges. In addition, virtual calls were made to address individual queries, there was a real lack of services as other agencies were working from home or did not have the capacity to provide the range of services required. Following Covid, advice and guidance needs actually increased and being able to provide support 'in person' was essential for families due to the continued reduction in public or statutory services. To date this continues to be the case.

"Thank you to Sharon and Grainne, they have been life savers over the past year, Covid was a dark time for our family."

(Feedback from one of our parents)

Families have been signposted to a range of other agencies for further advice, guidance and information, including:

- Advice NI (Benefits, Completion of Forms etc.).
- PIPS (Suicide Prevention).
- Solas (Special programmes for children/young people with Autism).
- Clever, Fulton, Rankin (Wills & Trusts).
- Various housing associations (Supported accommodation providers).
- Housing Rights (Housing adaptations, suitable housing).
- Autism NI (More specialist support).
- Apheideo Associates (Employer provided welfare support).
- Carers NI (Recognition for their roles as carers).
- SENAC (Special educational needs advice centre).
- Nicolas Quinn Solicitors (A unique legal practice specialising exclusively in all aspects of children's rights law).
- Childrens' Law Centre
- The Law Society
- Kids Together
- Orchardville Society

c) Provide workshops, information sessions and specialist speakers

A large number of workshops, information sessions and specialist speakers have been held within the Family Voice Hub over the past 3 years, including sessions on:

- Good Mental Health & Mindfulness
- Yoga
- Direct Payments
- Wills & Trusts
- Self-Care
- Supported Housing

-
- Looking to the future
 - Saturday Saunters/Teatastic Tuesdays
 - Carers Events
 - Supported Living Information Exhibition Day

The above have been available to all of our parents, siblings and other carers/family members.

d) Provide emotional and practical support for parents and siblings

The range of emotional and practical support needed during the pandemic was massive and continues to present itself on a day-to-day basis for the majority of families. The onset of the Cost of Living crisis is now evident in the practical and emotional support which is being provided provided by the Family Voice Hub. Families concerns have increased in the absence of a functioning Northern Ireland Assembly, with the cuts to statutory services and, in particular, the reduction of the number of social workers having a particularly dramatic negative impact.

Although the original plan was to provide Family Voice Hub to 5 different postcode areas, support was being requested from throughout Northern Ireland. We have found that families are prepared to travel to the FVH Centre from as far apart as Coleraine and Killeel. This trend continues to the present day.

Families are telling us that their stress levels with worries, anxieties and lack of information, support or communications from agencies are vital to their child/young person's health, physical and emotional development. The reduction in face-to-face appointments with GP's, Consultants, health professionals, Educational Psychologists, and the low availability of social workers, is increasing the number of referrals, calls etc. which are coming into the Family Voice Hub, as parent/carers do not know who else to turn to in their hour of need.

"My area currently operates with 2½ social workers for all of those with a learning disability and are only dealing with emergencies and there is no definition of what constitutes an emergency. When I asked for a definition of an emergency, I was asked if I wanted to file a complaint."

(Feedback from one of our parents)

Emotional & Practical support has been provided in the following ways:

- One-to-one appointments.
- Family appointments.
- Bespoke Holistic Therapies.
- Bespoke Holistic Therapy Workshops (for use at home by family).
- One-to-one Counselling (Parents, Siblings & Young People).
- Group Counselling.
- Mental Wellbeing Sessions/Workshops.
- Mums & Dads Evenings.
- Carers Events (parents do not see themselves as carers and need reminding & appreciated).
- Saturday Saunters – walking for mental & physical health with a social aspect.
- Signposting to relevant specialised agencies.
- Advocating for families who do not have the confidence to deal with officialdom – families can be concerned about not getting the right details, information or not fully understanding the processes.
- Sharing of information (all in line with GDPR).

e) Provide an outreach service to those families who are unable to travel to the Centre

The Family Voice Hub started delivering services in September 2020. This was 6 months after the onset of the Covid-19 pandemic and, although our application outlined a clear vision for the services we would provide, it quickly became apparent that there was an even greater need for such services than we originally thought.

Our original idea for an 'outreach service' had to change dramatically due to the pandemic and we found that families needed the support hub more than we had expected. When the project was first planned, it was largely based on delivering a 'face-to-face' service for parents and siblings in their own homes and providing day-to-day advice and guidance for those with a child/young person with a disability who were unable to travel to Belfast.

However, Covid-19 changed this dramatically. Face-to-face appointments were banned, contact with those who had underlying health conditions was limited, and/or families were shielding preventing them from receiving any visitors. Anxiety, stress and poor mental health were at an all time high, and we found that telephone contact was insufficient as it was not able to provide personal support at the high standard that the project expected. Families still needed someone to chat to, to get up-to-date advice/guidance on relevant topics but the pandemic raised more challenges and concerns in relation to their clinically vulnerable children/young people.

Virtual appointments became essential, and by using Zoom we were able to see families, and therefore identify what their body language or expressions were indicating. As well as providing virtual support to families, we introduced a Zoom platform for the families to connect with each other through 'Teatastic Tuesdays', this provided one hour per week where parents could have a cup of coffee/tea along with a friendly topical conversation, while their child/young person was occupied by other Autonomie projects via Zoom.

From June 2021, the Family Voice Hub has resumed operating via direct contact, although we have found that the outreach service is now more accepted via Zoom for initial meetings. Although this allows us to cover a wider area and does not have major budgetary impacts, some families still feel the face-to-face is more conducive to building relationships with the staff and to provide them with confidence to join other families via our Parents Forum and Saturdays Saunters.

"Autonomie has provided an outstanding service right through a very dark time (Covid). They are engaged with our needs and are individualistic in their responses. Autonomie staff are well trained, qualified and as some have personal experience of what we are going through, they have a unique grasp of family's needs and sensitivities of the whole family."
(Parent/member of Parents forum)

f) Provide one-to-one, family or group counselling

Family Voice Hub found that an increasing number of parent/carers, siblings and the children/young people were experiencing high levels of stress and anxiety, the causes ranged from Covid-19 and its impacts, transitioning processes in relation to education, and of course the day to day challenges of having a child/young person with a disability. A high number of the young people were also displaying symptoms of anxiety and depression due to hearing news about parents dying from Covid, and the realisation that they were clinically vulnerable and this led to questions about their health.

The whole family's health and wellbeing was supported by a BACP registered counsellor who provides the service free of charge to Autonomie. Holistic Therapies were introduced as an alternative to talking therapies, especially for those young people with limited speech or who were under 16 and required art/play therapy. Following on from these sessions, training was provided to parents/carers so that they could continue the relaxation, therapy or support at home or advise the education establishment on preventative treatments.

During the last 3 years the Family Voice Hub has delivered:

- 25 client one-to-one counselling sessions.
- 60 clients for holistic therapies (group and/or one-to-one sessions).

As part of 'Mental Health Awareness Week' sessions were provided to the participants of Autonomies SAIL programme, and volunteers. This was aimed at enabling them to have stress management, relaxation and better sleep. All sessions were timed, scheduled and provided to reflect the person's needs.

"It was great having someone to talk to and who listened to me as an equal without judging me. It helped me to cope with my feelings and the dread that sometimes took over me and gave me ways to control it."
(Young Person/Sibling)



g) Deliver age-appropriate activities and programmes for siblings

The original plan for our Siblings programme was to provide brothers and sisters of a child/young person with a disability. The plan was to provide them with a platform to meet with similar people and to chat about their feelings and their experiences. Due to the Covid pandemic, this area of work was delayed as the current group of siblings could not engage with virtual meetings.

Once face-to-face contact returned, we held a Siblings' Day, to find out what type of support or events we could provide for them and what they felt would be useful. In this meeting, the original idea changed – the siblings informed us that at their age (over 20), they felt that this type of support would have been more useful at a younger age (from 5 – 14 years) when they realised/were told that their brother or sister was 'different'.

As they grew up they came to see that all family outings, events focused on the young person with a disability. They told us that at times this caused resentment, and sibling friction, and had the Autonomie programme been around, to have someone to talk to, to air their feelings and be able to meet others who were having similar feelings would have been a benefit to them.

Although the original outcome has not been met, as the group felt that having a sibling with a disability was the norm in their household and although a programme of activities did not develop a number of siblings did make use of the Counsellor, holistic therapies, yoga and Saturday Saunters, and other family events.

"I wish I had been able to get to a sibling programme 10 years ago, when I realised I was not a sister with a younger sister but I had to be a carer for her and instead of playing with her, I needed to help feed her and wash her."

(Sibling)

h) Develop Communication networks to enable parents and siblings to have contact with others who have shared experiences.

Due to the difficulties with the ages of the sibling group, and the increased need for parental/carer support, this activity was not a high priority. The sibling group informed us that they had perfected communication with parents and felt it was more important to offer additional support to the whole family.

As stated in point 2.2 (d) we provide a number of 'family' events both virtually and face to face:

- Family Quiz Nights
- Yoga Sessions
- Saturday Saunters
- Bingo Night
- Annual Celebration Events

During all of the above, parents and siblings were able to share experiences as well as concerns, issues and to develop friendships outside of Autonomie. Parents developed their own WhatsApp chat and were able to communicate with each other when challenges arose or when they knew someone had already dealt with certain issues.

i) Further Develop Parents' Forum to enable monitoring, evaluation and to identify gaps in services for parents and siblings.

The parents' forum met fortnightly (due to the increase in areas of concern caused by Covid and the Cost Living Crisis and other issues relating to having a family member with a disability). This forum is co-ordinated by the Chair of the Autonomie Management Committee who then feeds back to the Management Committee meetings which are held bi-monthly. The membership of the parents' forum has increased from 6 prior to Covid and is now sitting at 14.

2.3 How the project was delivered

Family Voice Hub was staffed by 1 Full Time Coordinator, 1 Part Time support worker, a team of 20 volunteers and a volunteer registered counsellor. This team was augmented by other members of the Autonomie team on an 'as required' basis.

When the concept of the Family Voice Hub was conceived, all of the activities were to be based on parents/carers shared experiences and the need for a 'drop in one stop shop', Covid-19 put a stop on all of this. The project was launched using Zoom, as the country was still in the midst of lockdown, contact was made with existing parents/carers whose child/young person was attending other Autonomie services.

Once things returned to in person service delivery, contact was made with other Family support hubs and networking with these groups became a vital part of the project. Getting the word out to the wider community was important as our established parent group highlighted the challenges, concerns and anxiety about life after lockdown and the difficulties they had experienced through this period. Support and information were provided via telephone for a number of families who were still under isolation guidance from PHA.

Contacts were made with 11 Family Support Hubs within the Belfast area and 4 Family Support Hubs within the Northern Trust area. Family Support Hubs within the South-Eastern Trust and the Southern Trust already had their quota of external agencies.

As reputation of the Family Voice Hub became more well known, other agencies contacted our staff for information and our staff were invited to participate in a range of initiatives, including those organised by:

- Social Work Teams.
- GP's Practices.
- Schools.
- Other Agencies (such as CiNI, CYPSP, Advice NI, Carers NI),.

All of the above means our external networks have increased significantly over the past 3 years and we are playing a growing role (alongside other statutory, voluntary and private agencies) in planning and delivering services for the young people we support.

Throughout the last 3 years we have supported 315 individuals and 75 Families.

The uniqueness of the Family Voice Hub is that when a family feel they have received adequate support/information their file is never closed, and if they find they need more support/information they can return without having to re-apply, re register or 're-refer'. The main reason for this is that as the child/young person grows so do the ever changing challenges.

3. Detailed Evaluation of the Project

3.1 Evaluation methodology

Evaluation information has been collected regularly during the project from September 2020 to the end of August 2023, as well as at key points during the life of the programme. Some of the evaluation tools used in the production of this report included:

- Questionnaires, which were completed by parents and young people on a 3-monthly basis.
- Parents forum meetings, on a fortnightly basis..
- Youth Committee meetings held bi-monthly.
- Informal discussions with parents, carers, and the young people throughout the project.
- Meetings of the Autonomie Management Committee.

The information collected from the above was used to assess how successful the project was in delivering the outcomes which were outlined in the original application for grant support.

3.2 Evaluation of FVH against project objectives

This section of the report sets how the objectives set for the Family Voice Hub were fully met, partially met, or not met. We have tried to provide concrete evidence for each rating by providing samples of feedback received.

a) Provide a support hub for parents and siblings on a drop in basis in a safe, comfortable and friendly environment.

We believe that this objective has been fully met. The top floor of Lilac House was refurbished to provide an ideal setting for both parents and siblings to meet with Autonomie staff, to have one-to-one or family based services as well as providing a relaxed meeting area which has been used for meetings with other agencies, parents, extended support networks and siblings. This 'one stop shop' allows families to seek out the information they require in a safe, relaxed, supportive environment.

"With a newly diagnosed son, I did not know where to find non-medical support or information, finding the Family Voice Hub was a lifeline. I made one phone call and was invited to a very relaxed office, and felt I was visiting a family."

(Parent)



b) Provide advice, guidance and information relevant to individual parents and siblings.

We believe that this objective has been fully met. As outlined above, the types of advice and guidance requested by parents, siblings and other carers/family members was much wider than we first expected. Advice & Guidance has been provided in the following areas:

- SEN Assessments
- Transitions – into adult services
- Wills & Trusts
- Direct Payments
- Benefits
- Signposting to appropriate health practitioners
- Signposting for day services
- Signposting for long term supported living

"Sharon, I would just like to say a massive thank you for all the help and guidance you have given us over the past few months, with forms, getting placements for my brother its taken a lot of pressure of Dad. We really do appreciate the work and time given."

(Sibling)

c) Provide workshops, information sessions and specialist speakers

We believe that this objective has been fully met. A large number of workshops, information sessions and specialist speakers have been held within the Family Voice Hub over the past 3 years, including sessions on:

- Good Mental Health & Mindfulness
- Yoga
- Direct Payments
- Wills & Trusts
- Self-Care
- Supported Housing
- Looking to the future
- Saturday Saunters/Teatastic Tuesdays
- Carers Events

By way of example our recent workshop on Supported Living was attended by c200 people, with 20 organisations presenting to parents, carers, siblings, other family members and our young people.

"An absolutely superb event. Thinking about what will happen to my daughter when we are no longer around is a very difficult thing and causes me lots of emotional distress. The Family Voice Hub brought representatives from all the relevant organisations (Social Workers, the Housing Executive, Service Providers, Lawyers etc). Before the event I didn't know where to start. As a result of the event, I now have a gist of plan to try to provide a better long-term future for my daughter and the rest of the family".

(Feedback from event attendee)

d) Provide emotional and practical support for parents and siblings

We believe that this objective has been fully met. With the ongoing reduction in access to statutory services for health, emotional and practical support we believe (and our feedback supports our view) that we provide badly needed emotional and practical support for parents and siblings. The Family Voice Hub has provided this support via:

- One-to-one appointments.
- Family appointments.
- Bespoke Holistic Therapies.
- Bespoke Holistic Therapy Workshops (for use at home by family).
- One-to-one Counselling (Parents, Siblings & Young People).
- Group Counselling.
- Mental Wellbeing Sessions/Workshops.
- Mums & Dads Evenings.
- Carers Events (parents do not see themselves as carers and need reminding & appreciated).
- Saturday Saunters – walking for mental & physical health with a social aspect.
- Signposting to relevant specialised agencies.
- Advocating for families who do not have the confidence to deal with officialdom – families can be concerned about not getting the right details, information or not fully understanding the processes.
- Sharing of information (all in line with GDPR).

"Thanks Sharon, for your help on Friday when I was having a meltdown re: Covid vaccination booking. Thanks for all your guidance, very impressed as always and am massively grateful."
(Parent)

e) Provide an outreach service to those families who are unable to travel to the Centre

We believe this objective was fully met. However, not in the way we had originally planned. A high percentage of the outreach was carried out in a virtual manor due to the pandemic. We found that because people had to use Zoom, Microsoft Teams or Facetime that they were more comfortable to interact using these mediums.

For the first 18 months of the project families became more confident and at ease using virtual meetings, it also demonstrated that initial meetings could be done over Zoom providing families and the staff with virtual 'face-to-face' contact. Families could also develop the relationship with staff even when meetings were not possible.

This provided us with the opportunity to reach out to more families as travel time was reduced and yet the service was still delivering a full range of services.

"Living outside of Belfast with a 3 year old with complex disabilities is a challenge in itself. When I heard about Family Voice Hub, I was feeling isolated as we had to shield due to Covid. I was told I could meet with Sharon/Grainne virtually I was so delighted as I was spending my time overthinking the problems we currently facing included a confirmed diagnoses and social worker intervention."
(Parent)

f) Provide one-to-one, family or group counselling

We believe this objective was fully met. As previously mentioned, the impact of Covid-19, the cost of living crisis and the day-to-day challenges of living with a family member with a disability, parents, siblings and the young people needed someone outside of the family unit to confide their worries and concerns to and be able to do this with a BACP Registered Counsellor.

Throughout the last 3 years we have supported some 315 individuals and 75 Families.

"I don't like to burden my family with some of the worries I am having but being able to talk to someone else made me feel so much better, Helen was so lovely, made me feel relaxed, did not rush me and when I came out, I felt like a load had been taken off me."

(Parent from Parent Forum)

g) Deliver age-appropriate activities and programmes for siblings

We believe this objective was fully met. Although this objective was not fully met in the way we originally thought, we learnt a lot from a group of siblings from our long term members. As they were in their 20's they have grown up having a sibling with a disability and have come to terms with this part of their life. They did however provide us with some excellent advice for future sibling programmes, the following were discussed during the meetings with them:

- Age range should ideally be in the range 5 to 14 years.
- Explaining why their sibling is different in a simple, understandable way.
- Provide some 'own' time in a fun and social setting away from parents and sibling with a disability.
- Organise some 'family fun' events but with activities which can include the whole family.

"My older sister has a disability, so I have never known anything different. It was when I was at school, that I realised that not every family was the same as mine. I didn't know what it was like to have a sister who I could play with and talk to, the way my friends did, and they would have talked about their sisters being BFF's. Now that I am older, I have a better understanding and have a good fun relationship with my sister and enjoy going out with her."

(Sibling)



h) Develop communication networks to enable parents and siblings to have contact with others who have shared experiences.

We believe that this objective was fully met. The focus of this objective was changed, as mentioned above, the core group of siblings felt that they had mastered this and were able to have an honest conversation with their parents in relation to their siblings and the concerns they have. One area which was highlighted within this communication was that siblings wanted to know what happens when parents are no longer with them. We delivered a number of 'family activities' and workshops via Zoom and face-to-face, so that whole families could spend quality time together but also continue the discussion after them.

To address this and other similar queries we delivered workshops which were open to parents and siblings. Subjects included:

- Direct payments.
- Wills & Trusts.
- Supported Living Exhibition Day.
- Family Quiz Nights.
- Yoga Sessions.
- Saturday Saunters.
- Bingo Night.
- Annual Celebration Events.

"I always thought I would be left with caring for my brother, but having attended Autonomie's events, I was able to have a more informed idea of other options, and was able to join with others in similar situations and openly discuss it with my parents."

(Sibling)

i) Further develop parents' forum to enable monitoring, evaluation and to identify gaps in services for parents & siblings

We believe that this objective was fully met. The parents' forum has increased in membership over the 3 years, as more and more topics of concern were raised. Originally the membership was 6 and it is currently sitting at 14. This group has supported the Family Voice Hub staff to identify workshops, events and plans for the future – short, medium and long term. They were fully involved in the development of 'A Guide to Help you on your Journey Through Disability' which was recently produced by CYPSP (Children & Young People Strategic Planning).

The parents' forum meet fortnightly and has provided feedback on the Family Voice Hub and the journeys and experiences they have had, they also provide 'peer support' to other parents as the majority have vast experience of living with a child/young person with a disability.

"I felt so grateful to Family Voice Hub and the support they gave me, that I had no hesitation in joining the Parents Forum, as I wanted to share my real life experiences with others. I now feel passionate about ensuring that the Family Voice Hub continues to help other families".

(Parent from Parents Forum)

3.3 Financial evaluation

A full set of accounts is available for review. However, we have summarised the expected financial position of the programme at the end of September 2023 in the following table.

	Year 1	Year 2	Year 3	Totals
Grant funding allocated	64,475.81	64,475.81	64,475.81	193,427.43
Actual Spend	43,759.41	61,170.50	73,789.77	178,719.68
Annual over/underspend (£)	-20,716.40	-3,305.31	+9,313.96	-14,707.75

The underspend in Year 1 of the project was due to a combination of the onset of the Covid pandemic and a delay in recruiting staff for the project. Year 2 spend was largely on budget and the overspend in Year 3 was due to the impact of the Cost of Living Crisis which significantly increased our running costs (in particular the costs of utilities).

The overall underspend in the budget is being used to fund the project in October and November as we have no other sources of funding available at present. This has been approved by the National Lottery Community Fund.

3.4 Project governance

The FVH project team reports directly to the Autonomie Chief Executive. The FVH project manager presents progress reports to (and answers questions from) the Autonomie Management Committee every other month. This committee is made up of representatives of:

- The young people;
- The Education sector;
- The Careers Service; and
- 2 parents of the young people.

Minutes of all meetings are formally recorded and are available for review, if required.



4. Conclusion & Future Plans

4.1 Introduction

Having assessed the success of the FVH project in meeting its forecasted outcomes over the last 3 years, this section of the evaluation report looks at what we can conclude from the experience gained, the lessons we have learnt and our plans for the future of the FVH.

4.2 Overall conclusions from the project

We believe that the Family Voice Hub project has provided an essential service to families of children and young people with disabilities and their siblings. Operating during an unforeseen pandemic, and now the cost of living crisis, this service has become vital to the wellbeing of families in navigating through some very dark and uncertain times.

- One of our key assumptions at the start of Family Voice Hub was a belief that there is a real gap in service provision for families of children & young people with a disability, where all key information could be found in one place with support and reassurance. We could not have forecast how much more essential this service became during and after Covid-19, and how this would impact on the statutory support provided to these families.
- This project is unique in a number of ways, we provide support to the whole family unit, by providing information, guidance, and signposting to relevant agencies. We pride ourselves in providing a one stop shop, where families can get up to date information. Another uniqueness is that the Family Voice Hub staff team are also parents who have a child/young person with a disability, so have personal experience of the challenges the families are facing. The project also offers a 'never closed' approach, whereby once a family has contacted the Family Voice Hub, they can dip in and out without having to have a re-referral completed.
- The Family Voice Hub does not only deal with the immediate challenges which families face, they offer support and advice to them to make short, medium and long-term plans. They also ensure information is kept updated when legislation or guidance changes.
- To ensure that signposting meets the needs of the family or members of the family, we continually network with other support agencies and service providers. A database is maintained and updated on a regular basis, and any further information is added. We want families to have confidence in the high quality service.
- The provision of a BACP registered counsellor has added a further dimension to the Family Voice Hub as the impact of Covid-19 had a massive affect on the mental health of every family member, and especially with children/young people who questioned if they were in danger or were their parents going to die.
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*"I was so glad the Counsellor did some work with my daughter, as when she heard about the death of *****, she kept asking if she was going to die because she had similar conditions".*

(Parent)

"Autonomie have been a great help to myself and my family. Would have been lost without them, happy, friendly people and easy to open up to, they helped a great deal with my son and getting us through his diagnosis process".

(Parent)

4.3 Lessons learnt

Autonomie (at both an organisation and a project level) has learnt a lot from the delivery of the Family Voice Hub and we believe that we are in a much better position to support families with a child/young person with a disability. The key lessons we have learnt can be summarised as follows:

- **A 'one stop shop' support hub is absolutely vital** - this was the biggest learning point for the Autonomie team. When families talked about being passed from pillar to post, it became evident that we needed to ensure we had information available or the ability to access the information quickly and accurately. Many parents indicated that not knowing where to turn, they felt they were fighting a continuous battle to access the information they needed. Coming to terms with having a child/young person with a disability was challenging in itself and all available information seemed to be based on medical conditions. However, there was no one available to provide emotional and practical support for parents, carers, siblings and other family members.
- **Parents find it very difficult to 'connect the dots'** – there are a wide range of organisations who provide different services for people with disabilities in Northern Ireland. Feedback from our families indicate that they find it extremely difficult to navigate their way through this complex, changing environment. The Family Voice Hub has developed contacts with a wide range of organisations and is able to direct families to the services which they feel are best suited to their needs. By way of example, the Supported Living Event brought parents, carers and other family members together with around 30 external organisations which dramatically increased their partnership working networks.
- **Social inclusion has become even more of an issue for young people with disabilities (and their families) over the last 3 years** - with the ongoing reduction in access to statutory services and emotional and practical support we have found that the services which the Family Voice Hub are even more needed than we originally thought. Consequently, we have had to continually change, adapt, and upskill to deliver the range of services we provide. For example, we provide a greater range of counselling and holistic therapies than we originally thought.
- **Siblings in the age range 5 to 15 are not getting the support they require** - we originally targeted the siblings of our longer term members. However, it quickly became clear that, as they were now in their 20's they have grown up having a sibling with a disability and have come to terms with this part of their life. Consequently, we changed our focus to siblings in the 5 to 14 year old age range to help them come to terms with their sibling with a disability and provide them with some 'me time' in a fun and social setting away from parents and sibling with a disability. We believe there is a real need for these services going forward.

"When our daughter was diagnosed with a disability at 3 years of age, we had no idea where to get any practical, emotional or relevant advice or support. We had to find out about all the difference services and information for ourselves. If the Family Voice Hub had existed at this time it would have been such a ray of sunshine in what were some dark and troubled days."

(Core Parent/Parent Forum Member)

4.4 The future for the Family Voice Hub

We are extremely grateful to the Big Lottery Community Fund for providing the funding which allowed us to deliver the Family Voice Hub project over the last 3 years. As stated previously, we believe that there is a continuing need for a project such as the Family Voice Hub to provide ongoing support to a badly neglected area of the community. We further believe that this requirement will only increase in the current environment where the availability of statutory services have been greatly reduced over recent years due the funding crisis within public services in Northern Ireland.

Our greatest challenge in achieving this objective will be securing the funding which will allow us to deliver such services over coming years. To this end, we have been working on applications for further funding from a range of potential funders. However, both the Covid pandemic and the Cost of Living crisis have made securing funding extremely difficult at present (especially for a relatively small charity such as Autonomie).

As an Award winning charity our strategic plan for the next 3 to5 years is to secure our current programmes and to attract funding to further develop services which will meet the changing needs of our families and the challenges of every family member getting older. Due to the ongoing political stalemate in Northern Ireland government, securing statutory funding is almost impossible, and this situation presents a massive challenge for all voluntary sector organisations.

We are determined to secure funding for the Family Voice Hub to ensure that families with a child/young person with a disability are not left drifting and isolated during these difficult times.



Figure 3 below provides an overview of the environment in which the Family Voice Hub operates and the services which it provides both now and in the future.

Figure 3 – The Family Voice Hub Operating Environment & Services Provided

