



Evaluation of the Sense NI National Lottery project *‘Touching Lives – Transforming Families’*

Dr Paul McFlynn, Dr Jessica Bates and Dr Una O’Connor-Bones
UNESCO Centre, School of Education, Ulster University, Coleraine,
BT52 1SA.

Additional researchers: Dr Allison Campbell, Dr Caroline Courtney
and Dr Christine Shannon.

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Executive Summary

- Sense is a national UK charity that works with children and adults who are deafblind or who have complex disabilities
- ‘*Touching Lives – Transforming Families*’ is a five-year project run by Sense, Northern Ireland and funded by the National Lottery Community Fund. It aims to support children aged 12 and under with a sensory loss with additional needs and their families through practical support, information, training, and a wide range of events. At the end of Year 5, Sense commissioned a research team from the School of Education, Ulster University to undertake an independent evaluation of the project.
- The evaluation was carried out between July and December 2021. It was underpinned by a Community Conversation methodology and involved gathering feedback from project staff, steering group members, members of stakeholder organisations and parents/carers who have engaged with the project. Ethical approval for the research was granted by Ulster University.
- Data was collected through a desk-based review of documents relating to the project, a focus group with project staff, an online survey of parents/carers, telephone interviews with parents/carers, an online survey of steering group members, and an online survey of members from stakeholder organisations.
- The geographic spread of participants was representative of parents/carers from across all five Health and Social Care Trusts.
- There were 88 responses to the online parent survey and 60 of these parents participated in follow up telephone interviews.
- Responses from the staff, steering group members, members of stakeholder organisations and parents/carers were overwhelmingly positive and there was tremendous support of, and appreciation for, the project.
- It was evident from the evaluation that the project is filling a much-needed gap in terms of service provision for these families.
- The report presents the findings from the evaluation, organised in six main sections: summary of Trust service data, focus group interview with staff, online survey of steering group members, online survey of members from stakeholder organisations, online survey of parents/carers, and individual interviews with parents/carers.
- Overall, a rich picture is drawn of the ways in which the project is impacting on the lives of the families involved. Of particular value is the support provided for the children with complex disabilities; the opportunities provided for social interaction; the wider support provided for families to reduce social isolation; opportunities for siblings to meet others in a similar situation to themselves; education and training; information about other services and organisations that are relevant to the family’s needs; and, more recently, the crucial support provided to families during the Covid pandemic which has been a time of particular isolation.

Introduction

Researchers from Ulster University were commissioned by the Northern Ireland (NI) regional office of Sense, the National Deafblind and Rubella Association, to undertake an end of project evaluation of one of their projects, *'Touching Lives – Transforming Families'* in August 2021. *'Touching Lives – Transforming Families'* has run from 2016/17-2020/21, and this evaluation report follows on from a review of the project that was carried out by researchers from Ulster University at the end of year 3 (Bates & O'Connor, 2020). While intended that this evaluation report would be at the end of the project, Sense has subsequently secured funding to continue for the project for a further two years. In light of this development, recommendations are also included to support the project over this additional time span.

The UK charity Sense provides support to children and adults with visual and/or hearing loss and/or other complex disabilities and their families.

  sense.org.uk/about/



About us

For everyone living with complex disabilities. For everyone who is deafblind. We are here to help people communicate and experience the world

Sense offers a variety of services in NI, including housing and individual support, along with outreach centres, education and day services. The organisation was awarded £699,783 by The National Lottery Community Fund in December 2015 for a five-year project *'Touching Lives – Transforming Families'*. The project was designed for families across NI with a child aged 12 years or under where the child is deafblind or has a multi-sensory impairment. Its goal has been to provide a support programme working directly with children at home, school or in community settings that enables families to develop their own confidence and understanding. Services offered include, the family receive support with diagnosis, one-to-one work with the child and parent(s), techniques for interaction and ideas to support learning, home visits to assess individual and family

needs and tailored support. Sense works collaboratively with the five Health and Social Care Trusts (HSCTs) in its delivery of the ‘Touching Lives’ project and also has a role in providing training and support to stakeholders who provide support services to families with a child who is deafblind or has a multi-sensory impairment.

Bi-annual Project Monitoring Forms submitted by Sense to The National Lottery Community Fund provide an overview of the ‘Touching Lives – Transforming Families’ project.

Family engagement with the project across the five year period is presented in Table 1.

Table 1: Number of families who have engaged with the ‘Touching Lives’ project 2016/17 to 2020/21

Year	No. of families	Family members	Parents/carers	Siblings	Disabled children
2016-17	84	265	99	82	84
2017-18	164	539	171	202	163
2018-19	240	838	292	300	244
2019-20	304	1190	455	423	308
2020-21	366	1431	543	516	370

Difference in figures between table 1 and table 2 is due to data being recorded at different points and times.

These figures show a strong and increasing engagement over the duration of the project.

The purpose of this evaluation is:

- to provide an empirical evidence base for Sense NI in relation to the ‘Touching Lives – Transforming Families’ project, specifically in relation to their project outcomes and change indicators for the project;
- to obtain feedback from families that have engaged with the project, Sense staff, steering group members and members of stakeholder organisations on the value and impact of the support and services provided by ‘Touching Lives – Transforming Families’ project; and
- to ascertain what support and services families would most value for the remaining duration of the project, now that it has been extended, and in relation to the ongoing, effective and sustainable ways in which Sense NI can work to empower families going forward.

The Project Outcomes and Change Indicators used by Sense NI to monitor progress in this project are as follows:

1. Project Outcome: Family members have increased skills and knowledge to support their deafblind or multi-sensory impaired children to learn during childhood and beyond more effectively.

Change indicators:

- Family members feel more confident in supporting their children. Families receive support, information and guidance and attend training sessions.

- Family members have increased knowledge and skills to support their children. Families receive specialist support, information and guidance.
2. Project Outcome: Deafblind or multi-sensory impaired children (0-12 years) have improved wellbeing and have more opportunities to be a part of the community resulting in further benefits for wellbeing.
Change indicators:
 - Children/families report their children experience increased community involvement.
 - Children/families report improved mental wellbeing - children are participating in well-being activities.
 3. Project Outcome: Local organisations will have greater capacity and skills to support deafblind or multi-sensory impaired children (0-12 years) and their families to integrate into the community thus reducing family isolation.
Change indicators:
 - Families are provided with more support activities from a variety of organisations.
 - Increased number of activities delivered for families/children.

This evaluation addresses all three Project Outcomes.

Quantitative evidence relating to the above indicators was extracted from the Annual Progress Monitoring Forms for the project. The aim of the Ulster University review was to undertake an independent, academic evaluation that provided quantitative and qualitative data on the experiences of those who Sense have worked with throughout this project. The findings will add to the data already collected by the organisation so that they can gain a deeper insight into the impact of the project and identify priorities for its future work.

Methodology

The evaluation is underpinned by the Community Conversation Toolkit, developed by the researchers (Bates & O'Connor) as a framework for data collection and analysis (see: <https://view.publitas.com/integrated-education-fund/community-conversion-toolkit-final/page/1>). The Community Conversation approach enabled the researchers to gather the views and experiences of the families involved in the project in a way that provided an independent, academically rigorous, and ethically robust evaluation for the organisation. Within this review, researchers have sought to capture the insights and experiences of all stakeholders involved.

There were seven aspects to the data collection:

- a desk review of reports and documents from the project regarding its vision, work, targets, over the 5-year period;
- retrieval of raw data from Sense NI relating to monthly report forms (home visits, advice via phone/email, Access visits/transitions, Group activities/events,

Attendance at support for /meetings appointments and Training support agencies);

- a focus group with the five family support workers employed on the project;
- an online survey with members of stakeholder organisations that received training and support from Sense;
- an online survey with members of the steering groups that Sense established in each of the Trust areas;
- an online survey of parents/carers from families that participated in the project;
- telephone interviews with parents/carers from families that participated in the project.

It was also intended to undertake an online survey with parents/carers who chose not to engage with the project; however, as no replies were received from these parents/carers, the review team have been unable to identify reasons for non-engagement with the project and therefore the review team has not been able to draw conclusions about those families who did not engage with the project.

Scoping and planning work on the evaluation commenced in early July 2021. Ethical approval was sought from, and granted by, Ulster University prior to the start of data collection.

The timeframe for the evaluation is presented below:

July 2021

- Ethical approval for data collection
- Desk review of documentation
- Development of survey for parents/carers who engaged with programme
- Development of survey for parent/carers who did not engage with programme

August 2021

- Online survey of parents who engaged with the programme (2nd – 31st August - using the survey software JISC)
- Online survey of parents/carers who did not engage with the programme (9th – 31st August, using the survey software JISC)
- Retrieval of raw data from Sense NI and subsequent collation and analysis of raw data relating to monthly report form (home visits, advice via phone/email, Access visits/transitions, Group activities/events, Attendance at support for /meetings appointments and Training support agencies)
- Development of survey for steering group members
- Development of survey for members of stakeholder organisations
- Development of focus group questions

September 2021

- Focus group with the 5 family support workers
- Online survey of steering group members
- Online survey of members of stakeholder organisations

- Development of telephone parent interview questions

October 2021

- Telephone interviews with 60 parents who engaged with the programme
- Focus group transcription and analysis
- Analysis of parental survey
- Transcription and analysis of telephone interviews

November 2021

- Analysis of steering group survey
- Analysis of stakeholder survey
- Compilation and design of the final report

December 2021

- Delivery of final report

Summary of Sense Service Provision

The data in this section provides an overview of the number of families who engaged with the project per Trust area and the services that they accessed. Table 2 below shows the number of families across each of the five Trusts and this is followed by a detailed breakdown of family engagement per individual Trust area.

Table 2: Number of families who engaged with the project per Trust area

Trust Area	Number of families that engaged with the project
Belfast	84
Northern	76
South Eastern	58
Southern	72
Western	94

1. Belfast Trust

According to the data, **84 families** received services between September 2017 and August 2021. The analysis is based on those 84 families.

The total number of services provided (disaggregated by type) and the average number of these services availed of per family as well as other descriptive statistics are shown in Table 3 below.

Table 3: Description of services provided by Belfast Trust Sep 2017 – Aug 2021

	Home Visits	Advice via phone/email	Access / transition visits	Group activities / Events	Attendance at / support for Meetings /appts.	Provision of info and advice to support agencies	Visit to support agencies	Training Support agencies	TOTAL across all services
Total	838	10304	11	436	43	181	29	2	11844
Average/Family	9.98	122.67	0.13	5.19	0.51	2.15	0.35	0.02	141.00
Min	0	3	0	0	0	0	0	0	3
Max	59	311	1	26	6	19	8	1	356
Median	7	129.5	0	2	0	1	0	0	143.5
# families receiving 1 or more	78	84	11	54	22	47	10	2	84

Advice via phone or email was by far the most availed of service, followed by home visits. All families received advice, while 78 of the 84 received a home visit. Fifty four families attended at least more than one group activity/event. A very small number received access/transition visits, visits to support services and training support services.

2. Northern Trust

According to the data, **76 families** received services between September 2017 and August 2021. The analysis is based on those 76 families. One family lost their child in 2017 and so is not reported in the analysis. The total number of services provided (disaggregated by type) and the average number of these services availed of per family as well as other descriptive statistics are shown in Table 4 below.

Table 4: Description of services provided by Northern Trust Sep 2017 – Aug 2021

	Home Visits	Advice via phone/ Email	Access / transition visits	Group activities/ Events	Attendance at / support for Meetings/appts.	Provision of info and advice to support agencies	Visit to support agencies	Training Support agencies	Funding Applications	Update to Referring Organisations	TOTAL across all services
Total	870	12935	27	730	64	228	47	16	10	5	14932
Average/family	11.45	170.20	0.36	9.61	0.84	3.00	0.62	0.21	0.13	0.07	196.47
Min	0	4	0	0	0	0	0	0	0	0	4
Max	84	439	4	65	12	17	6	3	3	1	549
Median	6	157	0	4.5	0	1	0	0	0	0	184
# families receiving 1 or more	68	76	15	57	17	48	19	13	7	5	76

Advice via phone or email was by far the most availed of service, followed by home visits. All families received advice, while 68 of the 76 received a home visit. Fifty-seven families attended at least more than one group activity/event. A small number of families received access/transition visits and training support services.

3. South Eastern Trust

According to the data, **58 families** received services between September 2017 and August 2021. The total number of services provided (disaggregated by type) and the average number of these services availed of per family (ID number) as well as other descriptive statistics are shown in Table 5 below. All families with ID numbers availed of at least two services.

Table 5: Description of services provided by South Eastern Trust Sep 2017 – Aug 2021

	Home Visits	Advice via phone/email	Access / transition visits	Group activities /Events	Attendance at / support for Meetings/appts.	Provision of info and advice to support agencies	Visit to support agencies /Contact with social work team during Covid	Training Support agencies	Contact with other charities /grant giving bodies	Total across all services
Total	459	6809	4	424	58	412	176	25	9	8376
Average/family	7.91	117.40	0.07	7.31	1.00	7.10	3.03	0.43	0.16	144.41
Min	0	2	0	0	0	0	0	0	0	2
Max	53	310	2	52	14	33	20	6	2	409
Median	5	103	0	3	0	5	2	0	0	134
# families receiving 1 or more	53	58	3	37	9	45	38	9	6	58

Advice via phone or email was by far the most availed of service, followed by home visits. All families received advice, while 53 of the 58 received a home visit. Thirty-seven families attended at least one group activity/event. A very small number received access/transition visits and training support services.

4. Southern Trust

According to the data, **72 families** received services between September 2017 and August 2021. All families with ID numbers availed of at least six services. The total number of services provided (disaggregated by type) and the average number of these services availed of per family (ID number) as well as other descriptive statistics are shown in Table 6 below.

Table 6: Description of services provided by Southern Trust Sep 2017 – Aug 2021

	Home Visits/ Nursery	Advice via phone/e mail	Access / transitio n visits	Group activitie s/Events	Attenda nce at / support for Meeting s/appts.	Provisio n of info and advice to support agencies	Visit to support agencies /Contact with social work team during Covid	Training Support agencies	Contact with other charities /grant giving bodies	Total across all services
Total	593	7178	36	585	42	157	297	50	41	8979
Average/ family	8.24	99.69	0.50	8.13	0.58	2.18	4.13	0.69	0.57	124.71
Min	0	6	0	0	0	0	0	0	0	6
Max	33	278	4	50	6	14	17	6	10	363
Median	6.5	93	0	3.5	0	1	3	0	0	104
# families receiving 1 or more	66	72	21	57	23	37	56	21	13	72

Advice via phone or email was by far the most availed of service, followed by home visits. All families received advice, while 66 of the 72 received a home visit. Fifty seven families attended at least one group activity/event. A smaller number received access/transition visits and training support services.

5. Western Trust

According to the data, **94 families** received services between September 2017 and August 2021. One family did not avail of any services and were not included in the analysis. The total number of services provided (disaggregated by type) and the average number of these services availed of per family as well as other descriptive statistics are shown in Table 7 below.

Table 7: Total number of services provided by Western Trust Sep 2017 – Aug 2021

	Home Visits	Advice via phone/email	Access/transition visits	Group activities /Events	Attendance at support for Meetings/appointments	Provision of info and advice to support agencies	Visit to support agencies	Training Support Agencies	Referrals to other agencies	Total across all services
Total	465	12787	44	1011	1	778	75	0	19	15180
Average/family	4.95	136.03	0.47	10.76	0.01	8.28	0.80	0.00	0.20	161.49
Min	0	0	0	0	0	0	0	0	0	2
Max	32	456	5	57	1	38	5	0	3	569
Median	2	117	0	5	0	5.5	0	0	0	139
# families receiving 1 or more	66	93	23	74	1	82	42	0	14	94

Advice via phone or email was by far the most availed of service, followed by attendance at group activities/events. 93 of the 94 families received advice, while 74 of the 94 attended at least one group activity/event. Sixty-six families received at least one home visit. A smaller number received access/transition visits while none of the families received training support services.

Findings: Family Support Staff Focus Group

A focus group was undertaken by two members of the research team (one facilitator and one note taker) with four of the family support staff employed by Sense on the project. It took place online via Microsoft Teams on 21st September 2021 and lasted one hour. The aim of this facilitated conversation was to obtain the views of staff directly engaged in the project. It focused on their experiences working on the project and their suggestions for going forward. Describing their role, several key words emerged (Figure 1).



Figure 1. The role of Sense staff on the project

Family support workers recalled the speed with which the project had to change at the beginning of the Covid-19 pandemic;

“As Covid hit, everything completely changed, and the family’s needs changed. ... So, we very much had to rally in a very short space of time but there was a lot of- all organisations, statutory and voluntary came together, to do... We all knew what was happening and what was going on. It was quite a fast approach...”

Support staff’s description of how the project made a difference to families’ lives included:

- providing support for the whole family;
- providing reassurance to parents;
- advising and training parents/carers including about benefits and play techniques;

- providing sibling support;
- providing specialist knowledge and working with children’s schools to explain children’s needs, helping making changes to a young person’s educational experience;
- being a listening ear;
- acting as advocates for the support of the statutory services to families;
- facilitating parents making contact with other parents;
- providing an alternative to support groups;
- providing activities where parents don’t feel they and their children are ‘different’; and
- reducing social isolation.

The family support staff acknowledged that their role was not without several challenges. Difficulty finding the time to support everyone was a real concern, with their thirty contracted hours reported as not always enough to provide families with the help they needed. Providing support, especially throughout the social restrictions and move to largely online engagement of the Covid-19 pandemic, proved difficult as staff described the challenge of separating work from home life. Additionally, staff discussed the importance of always maintaining support and empathy with families, and the particular challenge of remaining professional whilst coping with the death of life limited children:

“... a lot of the children we work with are life limited and whenever you lose a little one you know it really does affect you, but we have to stay professional, and you have to... I don’t know. Cause you get to know these people over the space of a few years. It’s not... it is a lot more personal, but you can’t. I think, I don’t know... you feel like you can’t really show it or something?”

Despite these challenges, all family support staff said that they felt **“well trained”** and **“well supported”** and that there was a lot of experience and specialist knowledge within Sense that they could utilise if required. Aspects of their job identified as most satisfying included: making connections with families, seeing breakthroughs with a family or families they are working with, and witnessing families who have faced a lot of challenges in a good place again.

It was evident throughout the focus group that staff were committed, passionate and reflective about the work that they do in supporting families in their areas. They emphasised the support the team gave to each other and their ability to assess, evaluate and adapt the project to situations as the need arose, especially in the past year and the implications of Covid-19.

Looking forward, staff felt strongly that the unique support provided to families through the project would be missed in the absence of further funding. To make the project sustainable for the longer term, staff felt it important to encourage increased parent-to-parent support that can be sustained naturally without the need for a staff member. Utilising the services of, and making referrals to, other organisations when required was

also seen as beneficial, allowing staff to priorities families in greatest need. A further suggestion was some reduction in financial bureaucracy to introduce monetary floats for staff, enabling them to make quick purchases when a family response was time sensitive.

Findings: Survey of Steering Group Members

An online survey was distributed to steering group members across the five HSCT areas between 22nd September 2021 and 29th October 2021. The survey received six responses from respondents working in four of the five HSCT areas (Table 8 **Error! Reference source not found.**). The respondent's roles included working in partnership with Sense NI, making referrals to Sense NI, attending meetings, team management, managing sensory services, supervising staff who refer users/carers to the project and a sensory support social worker.

Table 8: Breakdown of responses for “What HSC Trust do you work in?”

Trust	
Western	2
South Eastern	2
Southern	1
Northern	1
Belfast	0
Total	6

1. Impact of the Touching Lives - Transforming Families project

Respondents were first asked how the project impacts on the **children it supports** (i.e. in terms of health and well-being, education, confidence and skills). Responses were very positive, mentioning benefits such as the opportunity to meet with peers and to build confidence.

How project impacts on children it supports – quotes from Steering Group members

“This project has been very beneficial for families and siblings to meet up for peer support, build confidence and new relationships and promotes good health & wellbeing for everyone.”

“excellent project. provides opportunities for families to have fun family time together as well as individual work for the child/children”

“opportunity to develop in a supported environment. Being with peers is also invaluable”

“It offers practical hands on support and advice to parents. This compliments the statutory work of the Trust”

“Great support for families and children through services and information”

When asked how the project impacts on the **parents it supports**, respondents noted that the project gives parents emotional support, friendship, encouragement, confidence, reassurance and acknowledgement, as well as providing them with the tools they need and knowledge of services available.

How project impacts on parents it supports - quotes from Steering Group members

“It creates great support networks for parents and indeed has ongoing friendships which is a great source of support”

“gives them more confidence, feel not alone, reassurance, support to try new things, peer support”

“Emotional support as well as learning new tips, approaches. Encouraging that they are doing well “

“Gives them the tools they need to bring on their child's development at home and the confidence to use these tools”

“Great support - keeps them in touch with what is going on, services available.”

“Helps them feel their taxing role is appreciated and acknowledged. Also gives them confidence in their caring abilities- gives them a ray of hope and interesting activities to become involved in. Hopefully signposts them to other services too.”

As part of the project, Sense were keen to provide support to deaf blind parents and their siblings. The families who were referred into the project received a high level of support from the family support worker which included the following: an assessment of support in the home setting, weekly play visits to offer support to the disabled child and to the mum and grandmother, whole family attendance at local family events, sensory play activities, play therapy sessions for siblings, counselling support, cinema visits, Little Critter workshops, benefit advice from Employers for Childcare, support from Baby Basics and food support during Covid on a weekly basis.

Respondents agreed that there were also impacts on **other family members**, saying that events and activities allow the whole family, including siblings, to feel included and to know that others are in a similar situation. The activities also strengthened bonds between siblings.

Are there any impacts on other family members, e.g. siblings - quotes from Steering Group members?

“The project included sibling events so all the family felt included in the activities/days out”

“yes, can feel part of the family by doing a complete family activity”

“Positive that they are not the only one who has a 'different' sibling”

“Touching Lives is a very inclusive programme, including the siblings in all activities they offer to the children in receipt of their service.”

“Services for siblings and outings/events they can take part in.”

“Obviously there has been a spin off there too as they can enjoy some of the same activities and it encourages siblings to engage in activities together thereby strengthening bonds between them.”

2. How to use the additional two years funding

Respondents were next asked how the additional two years of funding could be used to help them support **children** in the project. It was noted by a couple of respondents that Sense NI's work complements the work of the Trusts in providing services and support that the Trusts cannot. Others hoped for a continuation and more (more services, information, training, equipment) of the current work and a return to more face to face visits and activities. One noted that new children will benefit from similar projects as the current group move through the service.

How the additional 2 years funding can help you to support children in the project - quotes from Steering Group members

“It will be great to see ongoing activities set up for families to eliminate the stress of lockdown and hopefully progress to face-to-face home visits to deliver play therapy sessions and interaction visits with families.”

“I find the staff easy to work with. we have a good working relationship where i know the families get the support they need through this project. Sense are able to provide activities the Trust can't, so it is beneficial to us to have that alternative option which we know families will appreciate”

“Continue to do more of the same please”

“As noted before the project complements the statutory work of the Trust. Sense are able to offer families practical support and advice which the Trust does not always have the same resources to offer unfortunately. It means the families we work with together get a holistic service and their needs are better met”

“More services for children, more information for families, equipment and training available”

In relation to how the additional funding could help them support **parents and families** in the project, a couple of respondents seconded their answer to the previous question. Others said the funding could allow them to continue their work in partnership with Sense NI; work that includes advice, support, identifying children who would benefit from the project as well as referrals to the project and signposting other services available to families. One respondent noted the importance of the activities offered to families on a limited budget who could not otherwise afford them. Another highlighted the importance of equipping families to speak up for what they need and also raising awareness about the needs of supported children in communities.

How the additional 2 years funding can help you to support parents and families in the project - quotes from Steering Group members

“I hope to continue to work in partnership with Sense Family Support Worker in [...] and advice and support and identification of children who would benefit from Touching Lives.”

“can continue to make referrals knowing that families and the child/children can enjoy new activities or spend time together, often families have limited budgets so sense give the opportunity to do things they maybe couldn’t afford as a family”

“I am able to signpost parents and families to other services and areas of support”

“No child is an island and any support needs to recognise this and encapsulate the needs of siblings and parents by equipping them with the skills to speak up, speak out and articulate their needs. Also raising awareness in communities as to the real needs of these kids”

To help them support **other professionals that work with these children and families**, one respondent proposed providing ongoing training sessions to professionals across programmes of care. Other suggestions included greater dissemination of information and resources between Sense NI and their partner agencies.

How the additional 2 years funding can help you to support other professionals that work with these children and families - quotes from Steering Group members

“I would propose joint training sessions with Sense & Deafblind Specialist Worker to provide ongoing training sessions to Professionals across programmes of care to include CWD/Autism/Short break teams”

“can inform them that the service is there”

“Sense Family Support Workers can inform of resources which the child would really benefit from to bring on their development. In turn I can then make applications for funding and the resources used at home compliment the work completed by therapists in school and clinics.”

“Easier transfer of information”

3. What could have been done differently

When asked what could have been done differently, a couple of respondents referred to the challenges posed by Covid 19. Respondents applauded the efforts made by Sense NI in response to these challenges and hoped that face-to-face contact could resume in future. One respondent suggested finding better ways to get feedback from parents, as past efforts to engage parents have not always been successful.

Things that could have been done differently in the project - quotes from Steering Group members

“I suppose the challenges of Covid has been difficult especially for children with underlying and complex health needs as Sense were not able to do home visits but were able to provide food parcels and meals to families isolating and activities via zoom which helped to keep the ongoing connection.”

“can’t think of anything”

“no, creative responses to be applauded during Covid”

“Greater effort to engage parents in the service i.e. getting their feedback on what their child needs. Appreciate efforts have been made in the past and parents may not always take time. Worthwhile looking at other ways to encourage parents to engage better”

“Covid impacted heavily on the project in that there could be no face to face contact throughout the pandemic for quite some time. My hope would be that the future will be brighter in this respect and normal contact could be resumed...”

4. How to support the longer term sustainability of the project

To support longer term sustainability of the project, respondents suggested more and recurrent funding. Recurrent funding would allow for ongoing training for parents and professionals and therapy sessions and activities for children and siblings. Raising awareness around the needs of this group so that they can become more involved in their communities was also recommended, as was keeping staff up to date with what is happening so they can pass on this information.

How to support the longer term sustainability of the project - quotes from Steering Group members

“Recurrent funding so the project can be expanded to allow for ongoing training sessions for both parents and professionals as well as play therapy sessions and activities for the children and their siblings.”

“more funding from different grant agencies”

“To keep promoting to staff and keeping up to date what is happening so this can be passed on”

“I guess engagement with resources locally and education and awareness raising around the needs of this group so they can in the future become involved more in their local communities..”

Findings: Survey of Stakeholders

An online survey was distributed to stakeholders across the five HSCT areas between 25th September 2021 and 12th November 2021. The survey received eleven responses from respondents working in at least four of the five HSCT areas (Table 9 **Error! Reference source not found.**). All respondents have been involved in the project for more than a year (Figure 2).

Table 9: Breakdown of responses for “What HSC Trust do you work in?”

Trust	
Northern	4
South Eastern	3
Belfast	2
Southern	1
No response	1
Western	0
Total	11

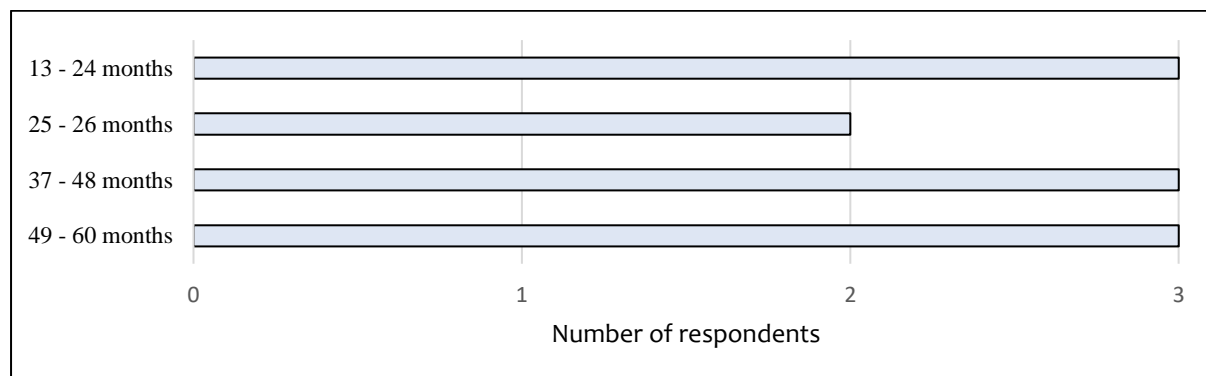


Figure 2: How long respondents have been involved in the project

1. Rewards and challenges

When asked what the most **rewarding** aspect of their job was, three stakeholders simply said it was making a difference or improving lives. Some mentioned working with families, helping families with professional support and access to specialist equipment and going the extra mile to support unpaid carers. For others, it is seeing the development of the children and the parents and the positive impacts of this (see illustrative quotes below). Sense NI’s training has allowed one respondent to better serve the needs of participating families.

Most rewarding aspects of stakeholders' jobs - Illustrative quotes

"...watching the parent learn and interact in a sensory environment with their child. Helping the child develop their senses through play."

"Seeing someone gain independence or a new skill and witnessing how that impacts the lives of them and their families."

"...I have therefore had the ability to see the children gain confidence in communicating with me and participating actively in the activities. Through Sense NI's training I have also been able to develop my service to better suit the needs of the families who participate."

Ten stakeholders outlined the most **challenging** aspects of their job. While one said time management, another said resource management. The short-term nature of the work due to funding limitations and raising the profile of the project were mentioned. Three highlighted the challenges of Covid-19 or lockdown and the difficulties around not being able to offer classes and staying motivated. However, one of these also outlined the success of alternative Zoom sessions. On an emotional level, challenges included dealing with feelings around hearing loss and cases where people have to come to terms with needing indefinite support to complete certain tasks. A respondent also said that funding charities not accepting independent practitioners' judgement was challenging.

Most challenging aspects of stakeholders' jobs- Illustrative quotes

"Raising the profile of our project within the trust and in general.. information is lost if a social worker moves on.."

"Due to the Covid-19 pandemic, much of the work that I would usually do with the group, which is predominantly hands on, in person and sensory had to be carried out online through Zoom sessions. While I had concerns about how this would translate the families and staff were fantastic and the sessions were still engaging and socially beneficial at a time when many felt isolated."

"To continue to stay motivated on a weekly basis and specially over lockdown"

"That sometimes people cannot achieve something independently and letting them come to terms with the fact that they may need support to complete a certain task indefinitely."

2. Impact of the Touching Lives - Transforming Families project

Respondents were asked how the project impacts on the **children it supports** (i.e. in terms of health and well-being, education, confidence and skills) and to give specific examples to demonstrate this. All respondents answered positively, citing several benefits of the project. Responses are summarised in Table 10.

Table 10: Impacts of Touching Lives – Transforming Families on the children it supports

Supports child's learning/tailored support for families
Gives them a break from normal life
Supports parents
Supports families, provides families with advice and skills
Children gain confidence; are provided with a space and support network (peers and staff) to thrive
Provides network for isolated parents
All of the above (i.e. health and wellbeing, education, confidence and skills); recommendations for equipment and sensory toys excellent for physical and sensory development
Activities engage the family (parents and siblings)
Hopefully training participants took practical strategies away and work with families and children to support their communication and development
Fills gaps that other services don't fill.
Supports the social and emotional well-being of the children

In terms of examples to demonstrate these impacts, respondents described some of the activities carried out, such as sensory stories and cookery via Zoom. They also gave examples of specific help, support and advice offered by staff or outlined how they saw children develop as a result of their own work. Some illustrative examples are included below.

Examples of how the project impacts on children it supports – Illustrative quotes

“We offered sensory stories for parents via zoom. Many found the interaction necessary as they had been isolating and needed something new to do. The stories/nursery rhymes would be read with sensory props which the parent would have or could be sent to them. Parents would be able to continue the stories after the session.”

“I have worked with a child who had challenging behaviour due to his sight and hearing loss. The work of the family support worker at that time [...]helped by giving the family confidence and supported them with nursery and school choices to suit the child's individual needs.”

“We recently had a little girl in who has both hearing loss and visual impairment. Mum said that the help she was able to access through Sense was the best she had to date. The ladies have also helped a [...] family we work with and as i say have been able to fill the gaps that other services do have to remit to. they are very flexible and will do what they can in any given circumstance”

“When I first began working with the group, they were understandably hesitant for a number of reasons (the nature of the service I provide, the fact I was a stranger and perhaps even communication barriers which they perceived). However, with the consistent delivery of the service, training and the development of relations with the staff, I have been able to clearly see individual children developing confidence in participation and communication. [...] I could clearly see over the period of time I worked with the children, that they had developed clear transferable skills which will be beneficial to them in school, in extracurricular activities and in potential future careers.”

Stakeholders were next asked how the project impacts on the **parents it supports**, with examples. There were ten responses outlining a range of impacts of the project, most prominently much needed support and providing networks of people around parents, listening, understanding and providing expertise. Impacts on parents are summarised in Table 11.

Table 11: Impacts of Touching Lives – Transforming Families on parents it supports

Get support (mentioned by three respondents)
Receive help to understand sensory, 1:1 work with child, techniques, ideas, home visits to assess needs and tailored support.
Benefit from expertise, someone listening, help finding solutions.
Spend time with staff and other parents, much needed support network. Online sessions during lockdown provided educational experience, social opportunities, set routine in time of little predictability and isolation.
Support vital for their mental health, people around who understand needs of child
Connects families, builds support/conversations/friendships/confidence. Reduces isolation/frustration/vulnerability
Support networks, confidence and trust in practitioners
Benefit from seeing their child gain a positive experience from therapy sessions

Five respondents provided examples and one seconded their previous response. Examples included providing sensory sessions, praise from parents for support and understanding, activities, equipment and Zoom learning (see quotes below).

Examples of how the project impacts on parents it supports – Quotes

<p><i>“We provided sensory teaching to parents on what would be appropriate for their child. This included items parents could participate with their child and create a sensory corner for their child.”</i></p> <p><i>“A parent of a child I had referred praised the project for the support and understanding of their child's specific needs and condition.”</i></p> <p><i>“Saturday clubs, family outings in areas”</i></p> <p><i>“I worked with a family who love to be outdoors. Their son could not join them as he was unable to walk for any distance. A standard pram was too small for him. He got an all-terrain buggy which enables them to be outdoors as a family again.”</i></p> <p><i>“Online structured zoom learning”</i></p>
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When asked if there were impacts on **other family members**, eight stakeholders responded with diverse benefits of the project for siblings. These are summarised in Table 12.

Table 12: Impacts of Touching Lives – Transforming Families on other family members

Siblings can enjoy sensory input and interact with child making an inclusive family unit
Siblings can be involved or use time to pursue own interests
Siblings also feel support as specific activities are organised for them
Provides support, information and opportunity to spend quality time together as siblings. Visits to family groups in homes.
Support for siblings/family members

Equipment which allows siblings to play together helps everyone and reduces impact of disability on siblings
Work as a unit within structured, enjoyable, relaxed setting
Having less stressed and happier parents bound to impact siblings

Five respondents provided examples. These mentioned activities that involve siblings, providing them with support, fun and making them feel part of the child’s journey. According to one respondent, providing specialist equipment allows siblings to play together and so reduces the impact of the disability on siblings. Examples are quoted below.

Examples of how the project impacts on other family members, e.g. siblings – Quotes

“Sibling were interacting with sensory scarves letting them float down from a height, so the child could feel the wind from the scarf, touch the scarf, using a foil blankets in a similar way helping the parent make a tactile parachute. This helps make a secure family unit as everyone feels part of the child's sensory journey.”

“They provide a forum for siblings to meet together and offer each other peer support, whilst having fun.”

“Again clubs and family outings that support siblings, so good”

“In all of the cases I have worked with, provision of specialist equipment has enabled play, and participation.”

“Our cooking and crafting workshops”

3. Professional collaboration and sharing of expertise

Stakeholders were asked about the professional collaboration and sharing of expertise they experienced when engaging with other professionals. There were nine responses. Respondents spoke highly of their collaboration with Sense NI staff who were said to be informative, knowledgeable, understanding, passionate, dedicated, helpful and supportive of the children. They learned from Sense NI staff as well as sharing information and expertise themselves. A few respondents mentioned specific courses and training that they had found useful. Illustrative quotes are included below.

Tell us about the professional collaboration and sharing of expertise that you experienced when engaging with other professionals – Illustrative quotes

“I feel that I gained a wealth of knowledge working collaboratively with [...] as she had so much experience. We also were able to advise each other of any upcoming events or projects that may have been of interest. Having the library of equipment has been a lifesaver for families who want to try things out or borrow things that aren't in their price range and this alone has been a great service.”

“Ever since I began working with Sense NI I have been overwhelmed by the passion and dedication demonstrated by every member of the team that I have been fortunate enough to work with. They are knowledgeable in their field and are extremely open and supportive in sharing this knowledge through collaboration and training. I was even given the opportunity to participate in Sensory Loss Awareness Training which was an invaluable resource for working with the families in the programme but also for being more aware of inclusivity and accessibility in all of the services I provide and in everyday life. “

“As an OT, I was able to share my expertise of sensory processing, and a range of disabilities. In turn, I learned about the mechanisms for charity funding from the SENSE team, and together we were able to solve problems.”

“I observed practitioners and parents coming together to discuss and share ideas and support each other”

4. Benefits of training

The next question asked stakeholders about the benefits of the training their organisation received. One of the seven respondents who answered this question said they did not receive specific training. The respondents who did receive training found it valuable to their practice and said it added to their knowledge base as exemplified in the illustrative quotes below.

How did the training that your organisation received benefit you and your colleagues professionally – Illustrative quotes

“The training that I received was fantastic. Professional and topical. The CVI Training was thoroughly enjoyable and I have a greater knowledge than before. I am looking forward to more. training in the future.”

“The training was beneficial from all aspects. It increased my awareness in general in everyday life but has also been invaluable in understanding the families that I have worked with, the challenges they face and how my service could be delivered more effectively for a better user experience.”

“Added to our knowledge base about something quite specific. Also informed our practice working with all children with sensory needs.”

“I really benefited from the Intensive Interaction training and the training on CHARGE Syndrome. I learned lots of practical techniques on Intensive Interaction that I can now factor into my own practise for children living with a range of special needs. From the CHARGE Syndrome training I benefited from gaining a deeper insight into the impact this condition can have on children and their families. The trainings were online too, which made them really accessible. I'm grateful to have had the opportunity to participate in these trainings and found them invaluable.”

5. Future projects

The next four questions related to how future projects could support respondents' work. Firstly, they were asked how future projects could **develop their own practice**. Four out of seven respondents said training would be useful to them, especially given the difficulties accessing training due to Covid-19 and the expense attached to it. An independent practitioner said their reputation in Northern Ireland is enhanced through working with a respected charity. Another hoped to be kept up-to-date with children's equipment and needs and noted the benefit of a safe space for peer support for parents.

How could future projects help you to develop your own practice? – Illustrative quotes

“I think updating training as Covid has reduced contact for all professional and refresher courses would be great.”

“It is becoming more difficult to access training because of the expense in the Health Service. So any training is greatly valued and it is an opportunity for multi professional training. Personally I would value any training on dealing with and understanding children with complex needs. I would like to find out more about music therapy and play therapy and how our kids can access these if available.”

“I feel that they have helped me keep up to date with children's equipment and needs. This could be continued. A safe space for peer support for parents is also beneficial for future projects.”

Secondly, they were asked how future projects could help them to support **children in the project**. In response, a couple of respondents described the benefits of their services. Others described what support from a project would allow them to do, such as plan for the future and provide services they could not otherwise provide. Specific recommendations included advice, equipment and opportunities for one-to-one art therapies. One respondent called for greater understanding and approaches in relation to additional difficulties on top of deafness.

How could future projects help you to support children in the project? – Illustrative quotes

“It's useful to have a project to support your work and do part sessions and support appts which we are unable to do because of restrictions and time constraints.”

“As before, with OT advice, and support for sensory toys and equipment. I could also provide training on a range of subjects.”

“More understanding of how additional difficulties on top of deafness impact on these children and can compound the situation and how to address this”

“I feel that opening opportunities for children to attend art therapies on a one-to-one basis over a longer term would enhance the scope of a future project to have even more of a positive impact.”

Next, they were asked how future projects could help them to support **parents and families** in the project. Again, a couple of respondents described how their services were beneficial to the children/families they work with and one respondent seconded their previous response. Others spoke positively of the current approach and want it to continue. The only specific suggestion was to raise awareness about what other help is available and how to access it.

How can future projects help you to support parents and families in the project? – Illustrative quotes

“Continue the approach you have now and that will be so beneficial.”

“To help us to continue the needed groundwork that has already started”

“Possibly by just raising awareness of what other help is available and the networks to access this.”

In terms of how future projects could help respondents to support **other professionals that work with these children and families**, suggestions included more training for parents and professionals, providing a safe learning environment for professionals and encouraging multi-professional meetings to increase awareness about the roles of others and what is on offer. A couple of respondents mentioned the benefits they have received/are receiving from Sense NI.

How could future projects help you to support other professionals that work with these children and families? – Illustrative quotes

“By providing a safe sensory learning environment for professionals to develop their skills and learn more about sensory.”

“further training for parents to avail of with conferences for specific conditions”

“I think if more trainings were offered - I could share this info with other relevant professionals so that they too could attend and benefit from these trainings.”

“Encouraging multi-professional meetings where people can meet and become aware of other roles and what is on offer. Maybe now is not the best time but it is evaluable.”

“Knowing that resource is there is helpful for us.”

“Having received the support, knowledge and training from Sense NI, I have been able to make the service more accessible in all situations including schools, events, parties, etc.”

6. Recommended changes for the additional two years

Considering the additional two years of funding that has been secured, stakeholders were asked if there were anything they would change about the development or delivery of the project. Of the nine people who answered, six were happy with the project as it is. One respondent wants more bespoke trainings/workshops and another wants to know how to share suggestions for training. Finally, someone mentioned that Covid-19 had negatively influenced the delivery of the project, but did not know how that would change.

Recommended changes in development or delivery of the project for the additional 2 years – Illustrative quotes

“Just happy that this would be continued but for a longer time”

“Any of the project that I have been directly involved in, has been well organised, well staffed and effectively delivered. I cannot think of any improvements or changes for the project.”

“If we have ideas/suggestions for training can we bring them to you directly to yourselves.”

“At present I feel covid has probably influenced delivery negatively but I don't know that it will change.”

7. Longer term sustainability of the project

In suggesting ways to support the longer term sustainability of the project (beyond the additional two year funded cycle), several stakeholders referred to securing funding. Potential funding sources included the Lottery, government/local council and submitting joint bids in collaboration with others. One respondent suggested using a standardised outcome measure and specific case history examples to demonstrate the effectiveness of the project to funders. Another hoped the health trusts could sustain the work. Continued staffing was also suggested. A couple of respondents did not offer suggestions, but highlighted the importance of a project like this. The recommendations are shown in the quotes below.

What can be done to support the longer term sustainability of the project (beyond the additional two year funded cycle) – Quotes

“It would very sad if the project didn't run after all the input and support put in by everyone. However, I total understand funding is a huge part of keeping it alive. Evidence based from this questionnaire should show evidence based to support a long term project and how necessary it is to keep it going. By submitting evidence from the survey to the Lottery should increase their confidence in the project.”

“continued staffing to work with families”

“A project like this is always needed, if funding allows. It gives people time. This is something no other project offers first and foremost.”

“Long term funding support even though government/local council”

“If not already in place, the management team might consider the use of a standardised outcome measure to show the effect the project has had on families. Specific case history examples could be used to demonstrate effectiveness to funders.”

“We would suggest working collaboratively with recharge cic on joint bids etc.”

“After another two years we will probably wonder how we managed without it.”

“It would be great if the health trust could sustain the great work that has been achieved by the project by continuing its services”

Findings: Survey of Parents/Carers

An online survey was distributed by Sense staff to parents or carers across the five HSCT areas between 22 July 2021 and 17 September 2021. A total of 88 parents and carers responded to the survey questions¹, with nine or more responses received from each HSCT area (Table 13~~Error! Reference source not found.~~).

Table 13: Breakdown of responses for each of the HSCT areas in NI

Trust	
Western	29 (33%)
Northern	24 (27%)
Belfast	13 (15%)
South Eastern	13 (15%)
Southern	9 (10%)
Total	88 (100%)

1. Characteristics of respondents, their households and children supported by the project

As shown in Table 14, most respondents lived in towns or cities, while 30% lived in a rural village or smaller. The vast majority (95%) were female and 92% had English as their first language.

Table 14: Residence, first language and gender, respondents

Area or residence (large/medium/small/rural)	
Large town or city (with more than 18,000 people)	35 (40%)
Rural (village or smaller - with up to and including 5,000 people)	26 (30%)
Small town (with more than 5,000 and up to and including 10,000 people)	14 (16%)
Medium town (with more than 10,000 and up to and including 18,000 people)	13 (15%)
First language	
English	81 (92%)
Other	4 (5%)
Arabic	2 (2%)
Polish	1 (1%)
Gender	
Female	84 (95%)
Male	4 (5%)

In 97% of the respondent's households there was a child or children aged 0-12, therefore 3 households did not include children aged 0-12. It is likely that these households included children who are now over 12 but have benefitted from the project.

¹ 91 respondents submitted the survey, but 3 only answered as far as consent and area you live questions. I have not included these 3.

When asked to enter data on the age, gender and school type for each of up to three children who met the criteria for the project², 53 (60%) respondents entered information for 1 child only, while 34 (39%) entered information for more than one child³. Data was entered for 136 children. Table 15 gives a breakdown of age, gender and school type for all of the children for whom data was entered by respondents. There was a good distribution across ages and gender and a larger proportion of children attend a special school.

Table 15: Breakdown of age, gender, school type of all children described in the survey

Age	
% 0-4	28%
% 5-8	38%
% 9-12	29%
% No age given	4%
Gender	
% Male	49%
% Female	42%
% No gender given	10%
Type of school attended	
% Mainstream Controlled Primary School	14%
% Mainstream Integrated School	10%
% Mainstream Maintained Primary School	9%
% Special School	44%
% Other	10%
% No school type given	13%

Percentages are based on 136 total children for which any data was entered.

As well as hearing and visual impairments, several respondents listed Global Development Delay, Epilepsy, Down’s Syndrome, Cerebral Palsy, Autism, ADHD, learning disabilities and feeding difficulties among the health and medical needs of children who are supported by the Sense NI project. A wide range of other profound needs and medical conditions were mentioned by a smaller number of respondents. A very small portion (about 7%) of respondents listed health/medical needs for more than one child.

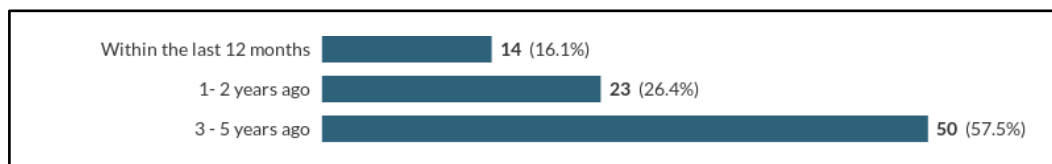
To gain some insight into the socio-economic circumstances of the respondent’s household, they were asked if they had availed of support from grants/funding, for example Cash for Kids Christmas gift appeal or funding for an i-Pad. Of the 87 respondents who answered, 54% said they had and 9% were unsure.

² The criteria was described as “age 0-12 with visual and / or hearing loss with additional/complex needs”.

³ One respondent entered data for no children. If respondents entered a response in all or any of the categories (age, gender, school type) for each child (1, 2 or 3) then this child was counted. Three respondents entered no ages for any children and these correspond to respondents who did not list child/children 0-12 in their household composition. Therefore, they may have been answering based on children outside the 0-12 age category.

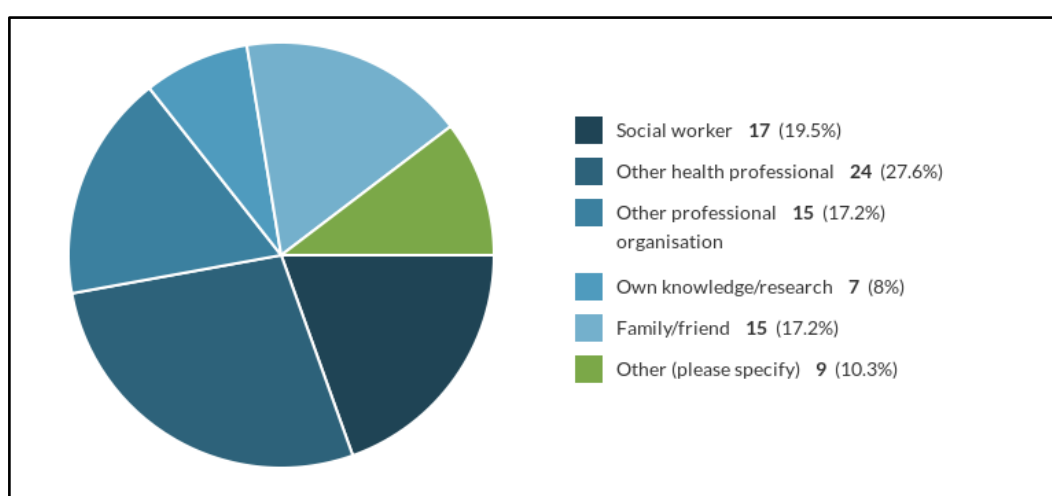
2. Engagement with the project

Over half of respondents had first connected with the project 3 or more years ago (Figure 3 **Error! Reference source not found.**). As can be seen from Figure 4, respondents were signposted to the project by a variety of individuals and sources including, most frequently, other health professionals.



Percentages based on 87 responses.

Figure 3: When did you first connect with the project?



Percentages based on 87 responses.

Figure 4: How were you signposted to the project?

About two thirds of respondents⁴ engage with the project on a regular basis, either monthly (49%) or weekly (17%). The remaining 34% engage less frequently. Examples of activities and services and the time periods during which respondents used or participated in these are presented in Table 16.

Table 16: Activities and/or services respondents used or attended

	Within the last 0-6 months	Within the last 7-12 months	1-2 years ago	2-3 years ago	More than 3 years ago	Number who responded to the question
A home visit that was in addition to the initial visit from a Family Support Worker	27.9%	20.6%	35.3%	14.7%	8.8%	68

⁴ Based on 86 responses

A training event provided by Sense NI	32.8%	17.2%	25.9%	17.2%	6.9%	58
An event / activity aimed at parents/carers	46.8%	19.4%	22.6%	9.7%	4.8%	62
An event / activity for children who have visual and/or hearing loss	43.1%	23.6%	26.4%	5.6%	6.9%	72
An event / activity aimed at other siblings	48.2%	17.9%	25%	3.6%	7.1%	56
An event / activity aimed at the family	53.6%	14.5%	24.6%	7.2%	2.9%	69

Respondents were able to select more than one time period for each activity/service.
 Percentages represent the percentage of the question's respondents who selected that time period.

Figure 5 **Error! Reference source not found.** shows questions relating to engagement with the project and with other parents/families in a similar situation as a result. There was a lack of consensus in terms of difficulty attending events and activities due to their timing or location, with the largest proportions neither agreeing nor disagreeing. However, a relatively small proportion of respondents did not see the benefit of attending events or activities and almost all intended to continue engaging with support and services. Most respondents (83%) agreed/strongly agreed that the project had helped them meet parents and families in a similar situation.

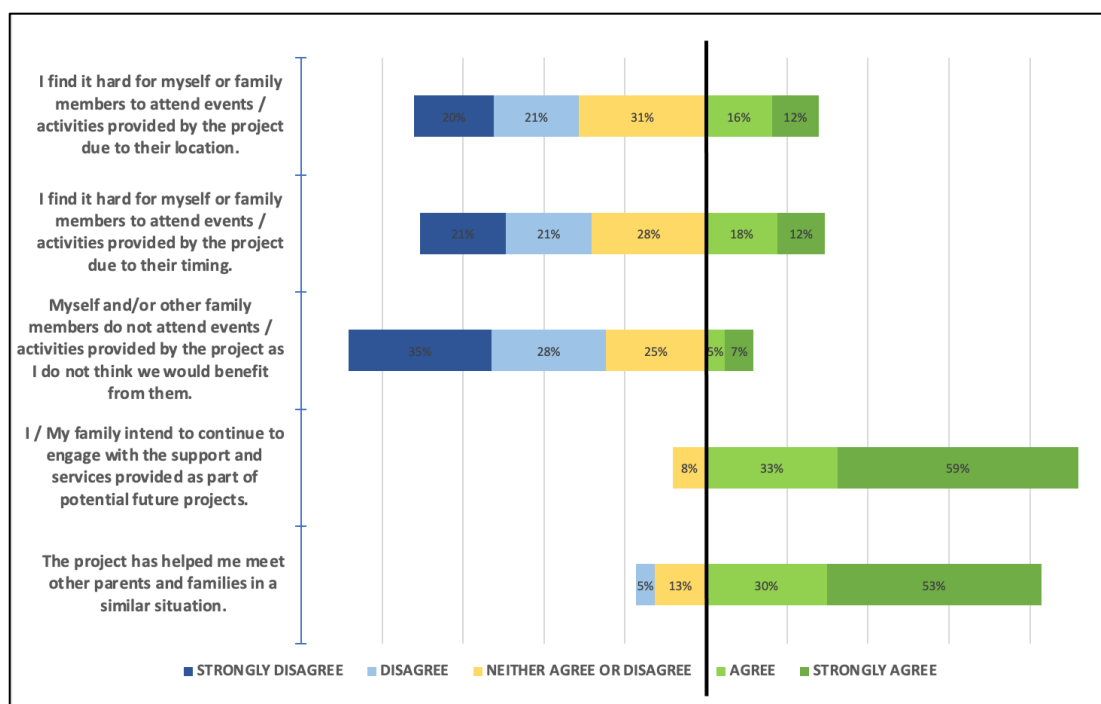


Figure 5: Engagement with the project and others

3. Value of support and activities to respondents and their families

The vast majority of parents/carers either agreed or strongly agreed that the support/activities provided by the project had been valuable to themselves (Figure 6), their child/ren (Figure 7) and the family as a whole (Figure 8). Only 26% of those who responded agreed/strongly agreed there had been no tangible benefits to their child/ren (Figure 7).

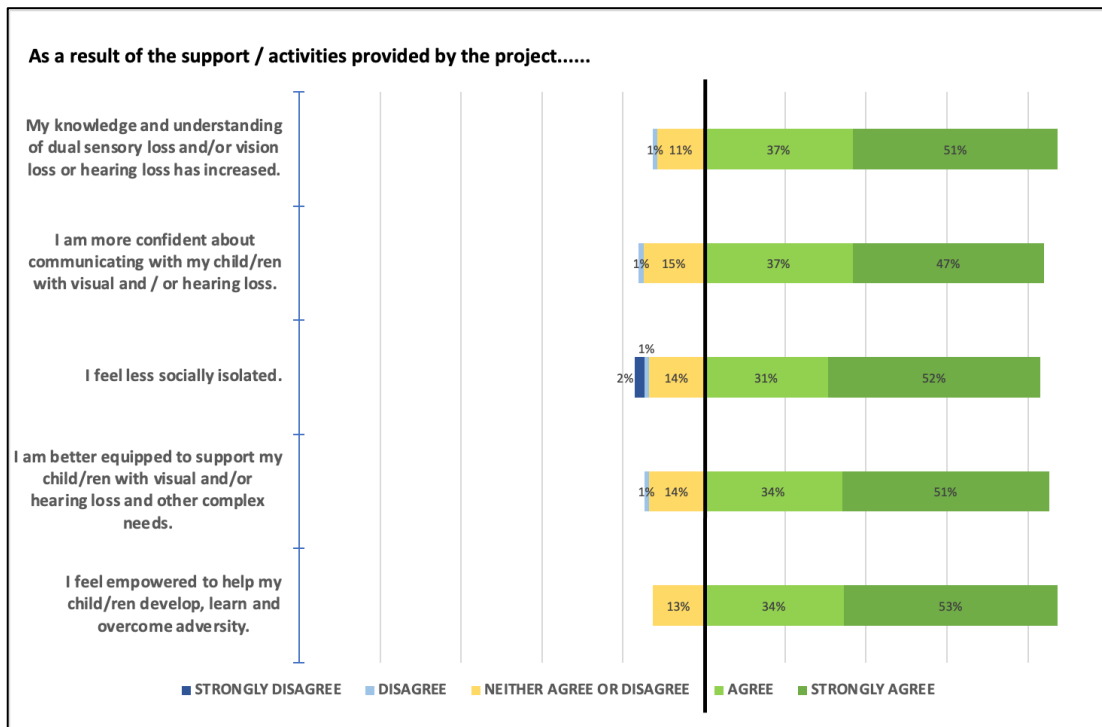


Figure 6: Impact of the project on parents/carers

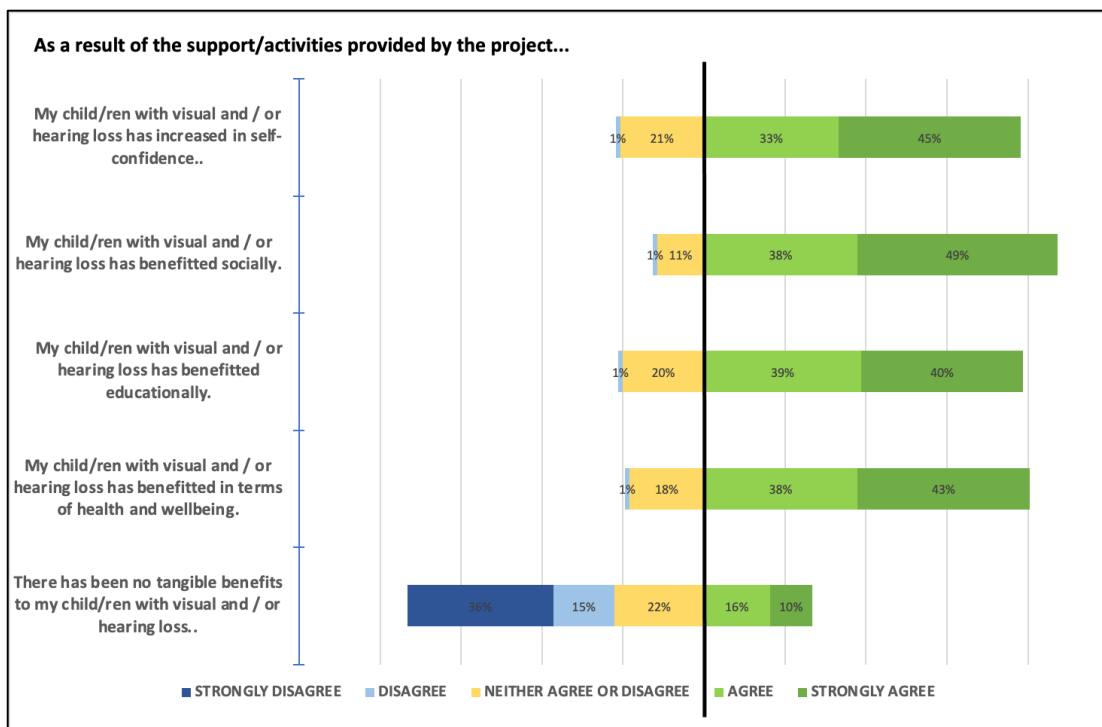


Figure 7: Impact of the project on child/ren with visual and/or hearing loss

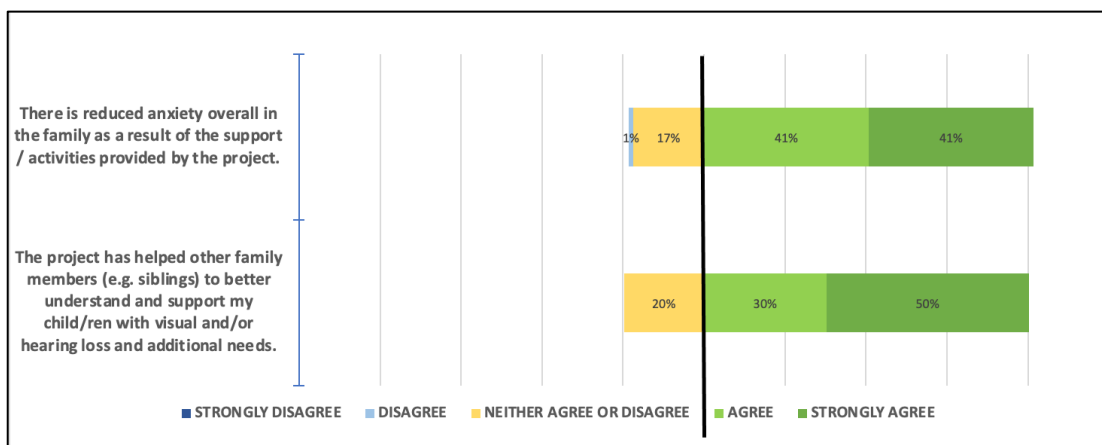


Figure 8: Impact of the project on the family as a whole

4. The impact of Covid-19 on engagement with the project

There were 80 responses to an open-ended question on how Covid-19 had impacted engagement with the project. Similar responses were grouped into categories and the results of this categorisation are shown in Table 17. A greater number of respondents referred to the negative impact of the pandemic on face to face contact such as meet-ups, in-person activities and home visits. While some have found this particularly difficult, other respondents applauded the efforts of Sense NI in continuing to offer support and implementing alternative ways to connect. Many respondents mentioned engaging with the project through Zoom calls and other online activities. Most respondents described the move online as a positive alternative, but some found it difficult for their children to engage with online activities. A number commended Sense staff for their efforts

throughout and showed appreciation for their much needed support. Some illustrative quotes are included below.

Table 17: Respondent views on the impact of Covid-19 on engagement with the project

Impact of Covid-19 on engagement	Number of mentions
Face to face/meet ups/activities/home visits affected/cancelled	36
Zoom calls/online support and other alternative means of communication used including phone calls and socially distanced house calls	28
Comments about helpful efforts by Sense staff or positive comments about activities	18
Yes (with no specific details)	7
No (with no specific details)	6
Respondent is new to Sense NI	5
Have been/were shielding	5
Impediments not related to COVID	3
Less/little contact from Sense NI	2

The impact of Covid-19 - Illustrative quotes

“Greatly, shielding for a year and not being able to meet face to face has had a huge impact on me.”

“There has been less face to face contact however Sense have provided invaluable online support. This has made a real difference to feeling connected to others during a time when we couldn’t leave the house.”

“As a family we have really benefited from all Zoom classes which were tailored to all our needs however we have really missed our group gathering”

“Sometimes I find it difficult to encourage my child to engage with Zoom sessions”

“Unfortunately Covid-19 has had a negative impact on my engagement with this project. Having said that the staff should be commended for their efforts during this time.”

“Like all else it has moved online the project understands the complex needs involved in our house they were one of the few who carried on their involvement and it was hugely appreciated”

5. Strengths of the project

A second open ended question asked parents/carers about the strengths of the project based on their experiences. Seventy-seven people responded, with many listing more than one strength. Strengths were many and varied (Table 18). Over 60% of respondents valued the much needed help and support offered by Sense NI. Many lauded the advice and guidance available as well as the variety of appropriate events and activities organised. Such events brought families in similar situations together and this was seen as a major strength of the project. According to responses, the staff themselves were a great asset to the project and were highly commended. Some illustrative quotes are included below.

Table 18: Respondents views on the strengths of the project

Strengths	Number of mentions
Help and support for families/children, there when needed	48
Advice/guidance/signposting/information/wealth of knowledge	18
Bringing parents/children/families together, social interaction, opportunities to engage with others (especially people in a similar situation), making friends	17
Access to beneficial/suitable activities/events, good variety of activities	13
Commendable staff/positive characteristics of Sense staff (e.g. generous, friendly, helpful, etc)	11
Contact/keeping in touch/communication	8
Someone to listen, helps with loneliness/isolation	8
Family get-togethers and days out	8
Inclusive of everyone/whole family	7
Beneficial for siblings/focus on siblings/sibling events	6
Benefits to child (e.g. confidence, new friends)	5
People who care/understand	4
Facilitates learning/understanding of conditions, learning new skills	3
Gives parents a break while children are entertained/having fun	2
Carer's wellbeing sessions/self-care activities for carers.	2
Mum's and tots group	1
Visits from Sense	1
Tries to have something for everyone	1
Holistic approach	1
Great leader and families	1
Never feel like you don't belong	1
Sharing experiences, solutions and suggestions with other families	1
Doorstep surprises	1
A distraction	1
Attention to detail for the parent events and workshops	1
Family support worker check ups	1
No question is too stupid	1
Excelled in delivering their service remotely	1
Like a family	1
Considerate of your needs	1
They have transformed families	1

Strengths of the project - Illustrative quotes

“The activities and family days and the attention to detail for the parent events and workshops. Sense is truly my favourite place to meet other families and we have made loads of friends and done amazing activities and had fun as a family. Even my boys love going to sense fundays it really is a family affair. Plus again [staff] getting workshops that we need or ask what we might like to do they are an amazing team. [...] also for all her help for funding she really is a star we can't thank her enough for all she does for us she really is an inspiration and she knows exactly where to look for things and who to apply to for help on your behalf.”

“there has been no limit from sense NI helping in any way possible... days can be long and hard sense NI have always been helpful in so many ways make life easier & the family days out give that all over family treat & engage with others in the same situations.”

“Their knowledge about individual children's needs and how to help both them and their families. They are always happy to help.”

“Amazing. I would be lost without the help and information provided by SENSE. They are a great support to my family.

[...] .. She is without doubt a God send. She is beyond helpful in every situation I find myself and my family in She has helped so much on our journey.”

6. Difficulties in relation to support / services / events

While most said they had not experienced difficulties in relation to support, services or events, a small number (ten) said they had. Over half of these mentioned difficulties attending events either due to work and other responsibilities or because they were too far away. A few felt that some or all services/events were unsuitable given the nature of their child's disability. A respondent reported having only received contact and support from one member of the team. Another had not been signposted to a new, age appropriate group when their child outgrew the one they were previously in. The small number of responses are quoted below.

Difficulties in relation to support/services/events - Quotes

“There is issue right across the children’s sector of ‘too high of an expectation’ of what families who care for children with disabilities are actually able to participate in. Some of these parents are working full time jobs as well as looking after a number of children- I often feel my inability to attend or engage is offending. I hope this is not the case.”

“Attending if event was out of our area”

“We used to benefit greatly as my daughter went to the nursery but as she is now older and her disabilities are so severe I don’t know what support they could really give us.”

“I work part time and between that and appointments it was hard to attend a lot of the events. Also along with his vision impairment he has severe complex needs and some of the events weren't applicable”

“As we both work full time during term time it’s not possible to attend, but we try during holidays”

“It’s been difficult with the zoom/teams get together, as much as the program was great it was too difficult for my son to handle due to the sensory issues he has. Therefore we couldn’t take part in many.”

“The only person I have had contact with is my support worker. If she didn't tell me about events etc I would never know. I have never had contact from any other members. No emails, no mail, no updates other than that of my support worker. I wouldn't even know who to contact if I didn't have her. My support worker has been a lifeline.”

“Sometimes sessions are during my working hours or when my child is at nursery so unable to attend”

“I can't go to events as I don't drive and they are far away from me”

“Just the past 18 months through covid. We know he’s no longer part of the younger group but we haven’t been told what age group he can join. He gets so much out of it, it’s a shame things haven’t started up again or being told what group to join.”

7. Future support

Finally, respondents were asked if there was anything else they would like to see Sense NI do to support their child/ren and family in the future. The majority of the 63 people who answered this question were very appreciative of the current support and simply want it to continue (Table 19). A smaller number were very eager for the return of the face-to-face events and activities that have ceased due to Covid-19. Others wanted events and activities (especially family events such as fun days) to take place more frequently. For some having more events closer to where they live was important. Some illustrative quotes are included below.

Table 19: What respondents would like to see Sense NI do to support their child/ren and family in the future

Future support	Number of mentions
Continue as they are/they are doing good work	30
No or N/A	10
Meet up once Covid is over/bring back group sessions soon/more face-to-face when safe (Covid related)	8
More family events (e.g. fun days)	5
More events closer to where I live	3
More events/programmes/activities (unspecified)	3
Group play dates	1
Local afterschool activities	1
Opportunity to meet up with other families of complex needs/events for children with complex needs (feels child is too disabled for events provided by Sense NI- see last quote).	1
More updates on what is going on/ more information	1
Continue with monthly zoom	1
More weekend events	1
More resources for the staff to enable their good work	1
More sensory workshops	1
Occasional informal home visits	1

Future support - Illustrative quotes

“No. I have felt the whole project has been invaluable to us as a family. Each one of us have gained from being part of it.”

“at moment i feel they help in all corners ... well done sense NI in helping change life's & making them that little bit more easier 😊”

“Post Covid 19, will be great to be able to attend the classes and events again, we really enjoy them. Can't think of anything additional to what Sense currently do, we have benefitted hugely as a family from the sessions and events that we have attended.”

“I would love face to face support to come back but only when safe to do so.”

“Events like funday at jungle NI should be more frequent, as that event practically helped us spend some quality time with family, which we were missing because of our sons complex needs.”

“Most recently we attended a family fun day which was excellent and we all really enjoyed this so much. We definitely feel more of these outings would be so beneficial to us as it gives the children and parents a chance to meet others in similar situations and makes you realise your not the only family dealing with similar disabilities.”

“I would really like to have more things going on in my own town as I'm not confident driving to other places”

“I have no idea. I wish there was the opportunity to maybe meet up with other families of complex needs. Or events for children with complex needs. I think the problem is my daughter is just so disabled - not that sense don't provide events”

Parent Interviews

Overall, sixty telephone interviews were completed with parents/carers involved in the 'Touching Lives – Transforming Families' project across all five HSCT areas. Interviews were arranged by Sense but conducted by members of the research team to ensure confidentiality. On average, telephone interviews lasted between 15-20 minutes and focused on discussing the support and activities the families had received from the project.

Of the sixty interviewees, fifty-seven were female and three were male, fifty-seven of whom were parents, two grandparents and one a foster carer. In total they represented sixty-one children (thirty-one female and thirty male) meeting the criteria of the project, forty-two of whom attended a special school. Each HSCT was represented: fourteen interviewees were from the South Eastern HSCT, thirteen from the Northern HSCT, twelve from Belfast HSCT, eleven from the Southern HSCT and ten from the Western HSCT.

Overwhelmingly, interviewees described their involvement with the project as “exceeding [their] expectations” and going “above and beyond” or “the extra mile” when it came to meeting the needs of their child/family. Many described the project as a “lifeline”, and it was consistently reported how their involvement had positively benefitted the entire family not just the child.

“A charity that really, really cares about you, you and your child and your family, not just one of you- the whole lot of youse”. (Interviewee 41)

“Honestly, they have been a life saver, for so many years... trying to find something to include everyone and also to give him [other child] some support”. (Interviewee 30)

“Sense has been brilliant, absolutely brilliant... they are more like a family rather than organisation”. (Interviewee 33)

It was acknowledged and appreciated by interviewees how Sense had adapted their activities to go online and continue during the Covid-19 lockdowns when most other things had shut down. This was said irrespective of whether interviewees had engaged with these activities as some explained that their child was not interested in Zoom either due to age or condition.

“Sense have been really good, out of all the charities, Sense has probably been the best one. During lockdown they had loads on Zoom... like fitness and animal ones, and cooking ones for me and my wife and all, they’ve been very good”. (Interviewee 11)

“Especially through Covid, we felt we were left behind by the Trust and just left to it, apart from Sense and another charity... they kept in touch, we felt cared for and that someone was looking out for us”. (Interviewee 11)

The variety of activities offered via Zoom during Covid for family members (for example cookery, bingo, story time, singalongs, wreath making) was praised, as were the thoughtful gestures parents received during this time, for example, flowers on carers day, pamper packs, phone calls, support when children were in hospital and help with meals when a family had Covid. This recognition of parents and carers by Sense was greatly appreciated and valued.

“I know it’s not much, but the girl came out with flowers for me, I never get flowers, I felt so special and quite often I think parents and siblings are forgotten about, I felt so special to be thought about...” (Interviewee 4)

“They go above and beyond- it’s not tokenistic gestures, they go one step further”. (Interviewee 37)

“They have thought of a lot of things especially during Covid”. (Interviewee 32)

Outside of Covid lockdowns, parents listed numerous ways their child and family had engaged with Sense, these included family fun days, walking groups, playgroups, sibling events, play therapy, music therapy and training.

Project support workers were routinely commended for the work that they did, for being friendly, supportive, understanding, approachable, kind, thoughtful and enabling them to help their child/children through their advice and guidance. Parents appreciated their informal drop ins, willingness to listen, advice, signposting knowledge and many had benefited from their help applying for benefits and in helping them source or apply for funding for specialised equipment for their child.

“... the local support that we receive here, the contact that we get from the support worker here, it’s just, do you know what, you can’t measure that.... Someone who wants to support you in a way that makes you feel listened to and has a really strong understanding of what’s going on.... it has been exquisite”. (Interviewee 34)

The knowledge that parents/carers had Sense to help them, and the knowledge and moral support of their support worker was very important to parents, they reported this as encouraging them, alleviating pressure, promoting self-care, increasing their self-worth, boosting their confidence to ask for more support and making them feel less alone. Engagement with Sense and the opportunities they provide to meet other families in similar situations was attributed to parents forming social networks and support bases reducing feelings of isolation. In some cases, attending activities with Sense helped parents feel more comfortable about going out as a family.

“Really good to just feel a part of a group...it is very isolating having a child with a learning disability, you know because you can’t see your friends, you can’t do this, you can’t do the other”. (Interview 37)

“It’s good to take him there because he can be himself...you don’t have to worry about him running around switching lights on and stuff”. (Interview 31)

Parents described the positive impacts of their child engaging with Sense, they reported increased confidence, self-worth, independence, general and social development and increased social and emotional well-being. A number of parents credited interacting with other young people with similar visual and hearing loss at Sense activities and events with their child understanding themselves better and feeling more at ease with their hearing and or visual loss.

“The impact on X has been phenomenal”. (Interviewee 23)

Interviewees readily acknowledged that Sense had provided their child with safe environments and opportunities to make friends and participate in activities and events that usually would not be options for them as individuals or with their families.

“She doesn’t get a lot of opportunities; you are not being looked at or stared at these kinds of events. I don’t mind who looks, but for herself, she doesn’t understand herself, but the thing is for her wee self, she’s being included, and she can take part in things she normally wouldn’t be able to take part in because they tend to completely book out the place where the event is going to be. Therefore, I’m not worried about her going over and pulling at other kids that won’t understand – everybody understands. For her it has been great because she’s been able to be included and it has been a positive experience for her, and she would always be very happy”. (Interviewee 51)

One parent explicitly said, regarding beginning their relationship with Sense, that they thought ***“putting that intervention in when we did paid off massively”.*** (Interviewee 42)

Sense encouragement of siblings to participate in activities and events along with their brother or sister was seen as beneficial by parents; in some cases this was the only way this had ever happened. It enabled them to *“get attention in their own right”*, helped with loneliness, made them feel more involved with their sibling, helped them make friends with young people in a similar role and helped them realise *“it’s not just their family”*.

“The activities were specifically for him and then his siblings were absolutely thrilled that he was involved and that it was designed for all three of them, so it was really special actually, it doesn’t happen very often.” (Interviewee 12)

Few interviewees reported any difficulties with their engagement with Sense. Of those who did, such difficulties were in relation to their child’s complex needs, problems with transport to events and one parent who was disappointed they had not been informed

when the worker assigned to their family had left. Overall interviewees when asked if they had experienced any difficulties in relation to support, services and events from Sense commented that *“nothing is ever off putting”, “[they are] very accommodating”* and *“[they] try to help me regardless”*.

In terms of what interviewees would like to see provided in terms of support and activities going forward with the project, the majority of parents/carers voiced that the project *“seems to hit the mark right”*, that they were *“happy as long as it continues”* and were looking forward post Covid to a return to more face-to-face activities. In addition to what is already provided, suggestions were made for more family fun days; pamper days and trips away for parents; coffee mornings; groups specific for complex needs; joint events with other services; different age ranges of support for siblings; an additional Sense nursery; gymnastics and dance; a specialised sitting service; more home-to-home sessions for children who cannot get out because of health and or medical needs; music therapy, speech and language therapy; occupational therapy and for staff to have easier access to finance to help families when a time bound response is required. Training was requested on Makaton, sign language, behaviour and development and extended sessions on mindfulness with several parents asking for training sessions at night-time to facilitate them working during the day.

Some interviewees admitted that when they started with the project, they did not know anything about Sense. This links to the belief highlighted by several interviewees that they felt Sense really needed to promote the project more.

“They could do something about selling themselves around the actual amazing things they do”. (Interviewee 28)

Conclusions

How is the project Transforming Families? In the words of those that participated in this Community Conversation Evaluation, it is:

- building relationships and bridging gaps in terms of access to appropriate services;
- supporting families – parents, children and siblings, including those for whom English is not their first language;
- educating and equipping parents to be able to better support their children; and
- reducing social isolation and providing opportunities for families, children and siblings to meet socially.

There was a strong consensus from Sense staff, steering group members and members of stakeholder organisations that the project had a positive impact on the children, parents and siblings. Each group noted the challenges presented by the pandemic and how Sense had to adapt very quickly to supporting families via Zoom.

Almost everyone who is currently engaged in the project intends to continue their involvement. Very few parents/carers had experienced any difficulties in relation to the project, and in the small number of instances where they had, it was mostly to do with inconveniences relating to the time or location of events.

The data from this evaluation provides strong evidence of the progress in relation to the Project outcomes and Change indicators put forward by Sense for the project.

Project Outcome 1: Family members have increased skills and knowledge to support their deafblind or multi-sensory impaired children to learn during childhood and beyond more effectively.

This evaluation shows, that through the *‘Touching Lives – Transforming Families’* project, parents/carers have gained in knowledge, skills, and confidence in supporting their children and, in doing so, have achieved a sense of empowerment.

- Eighty-eight percent of survey respondents either strongly agreed or agreed with the statement: My knowledge and understanding of dual sensory loss and/or vision loss or hearing loss has increased as a result of the support provided by the project.
- Eighty-seven percent of survey respondents either strongly agreed or agreed with the statement: I feel empowered to help my child/ren develop, learn and overcome adversity as a result of the support / activities provided by the project.
- Similarly, eighty-five percent of survey respondents either strongly agreed or agreed with the statement: I am better equipped to support my child/ren with visual and/or hearing loss and other complex needs as a result of the support / activities provided by the project.

- Eighty-four percent strongly agreed or agreed with the statement: I am more confident about communicating with my child/ren with visual and / or hearing loss as a result of the support provided by the project.

It is clear from the research evidence presented here that family members are receiving specialist support, information and guidance with many parents/carers noting that the programme exceeded their expectations with staff going above and beyond what was expected. Whilst a few parents noted that the move to online support via Zoom was challenging and created difficulties in relation to child engagement, the majority of parents commended the support staff on how they adapted to the challenges presented by Covid-19.

Project outcome 2: Deafblind or multi-sensory impaired children (0-12 years) have improved wellbeing and have more opportunities to be a part of the community resulting in further benefits for wellbeing.

In both the parent survey and interviews with parents, there is clear evidence that parents/carers can see improved well-being and increased community involvement for their children. In the survey, responses in terms of benefits to their children with visual and/or hearing loss (and other complex needs) show that parents/carers saw gains as a result of the support / activities provided by the project in relation to: increased self-confidence, health and well-being, social interaction, and education. Evidence from both the steering group survey and stakeholder survey support these views.

In terms of wider feedback from families on the value and impact of the support and services provided by *'Touching Lives – Transforming Families'*, 82% of parents agreed or strongly agreed that there is reduced anxiety overall in the family as a result of the support/activities provided by the project. The parents also noted that the project positively impacted siblings both in terms of helping them understand how to support the child/ren with visual and/or hearing loss and additional needs and being involved in activities that allowed them to engage with their brother and sister. Evidence from the steering group survey and stakeholder survey support these views with steering group members noting that sibling involvement allowed siblings to realise that others are in a similar situation and to strengthen the bond between siblings, whilst the stakeholder feedback emphasised that sibling involvement allowed them to be part of the child's journey and that it reduced the impact of disability on them as individuals.

Project Outcome 3: Local organisations will have greater capacity and skills to support deafblind or multi-sensory impaired children (0-12 years) and their families to integrate into the community thus reducing family isolation.

The evidence presented from the stakeholder survey demonstrates that the various organisations benefitted from the professional collaboration and sharing of expertise with other professionals, particularly Sense NI staff. They noted that these sessions allowed them to develop their knowledge and understanding of how to support children and their families more effectively. The training provided by Sense NI has increased knowledge and informed practice, most of which has been focused on specific areas that the organisations

appear to have required. It is also clear that the sharing of expertise was a reciprocal process whereby Sense staff and stakeholder members were sharing their expertise with each other, creating what seems to be a rich learning experience for all involved. It is clear from the stakeholder members that this training and increased knowledge allowed them to provide children and their families with effective support and opportunities for children and family members to socialise and interact with other families. This evidence has been supported by the parent survey where eighty-three percent agreed or strongly agreed that they felt less socially isolated and the parent interview findings where access to support and engagement with activities reduced feelings of isolation.

From the evidence presented, it is clear that the project has met all three outcomes and surpassed all expectations in relation to navigating Covid-19 restrictions and mitigations. However, there are a few points that Sense NI should consider in order to improve the already excellent service provided through the 'Touching Families- Transforming Families' project. These include:

- More multi-professional meetings where Sense support staff can meet with stakeholder members and other professionals as this enhances opportunities for sharing of expertise
- More training opportunities for stakeholder organisations
- Building upon the excellent response to Covid restrictions and evaluating how the progress made in the area of online support might be utilised alongside a return to face-to-face provision

All participants in this evaluation have identified the importance of the project continuing with many parents seeing the project as a 'lifeline'. Recurrent funding is required for Sense NI to conduct appropriate programme planning. It is also important to note that the work done by Sense NI through the 'Touching Lives – Transforming Families' project provides valuable complementary support to that provided through formal education.