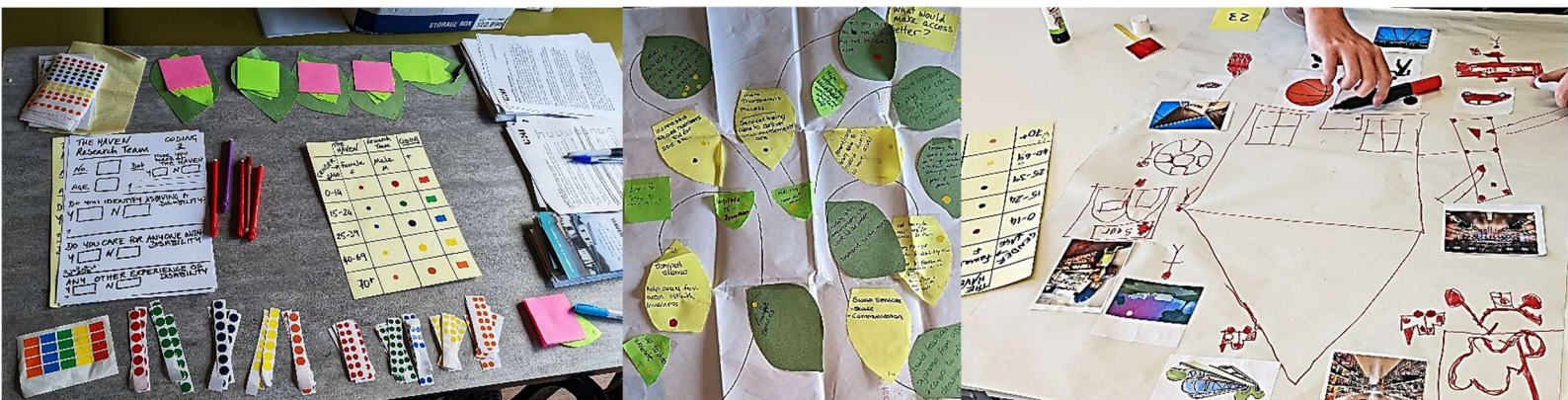




Your Vision for The Haven

Creating Smiles in Highland



July 2024

Innovation Voucher Report

Centre for Living Sustainability, UHI Inverness

Funded by Scottish Funding Council and the Elsie Normington Foundation





Ewen Weatherspoon Photography
The Haven Centre

Acknowledgments

A dedicated group of volunteers have worked with researchers at UHI's Centre for Living Sustainability to explore experiences with and hopes for disability services.

This research was carried out by the full research team: Vicky Johnson and Sarah Wagner at UHI Inverness' Centre for Living Sustainability; and volunteer peer researchers, Heather Bain, Deborah Hart, and Amelia Williamson.

This work has also relied on the dedication of the team at the Elsie Normington Foundation and Kirstin Mackay who has supported with the coordination of research events and activities at The Haven Café and liaised with the Board of Trustees in the design and delivery of this research work.

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This project arose through a partnership between the Elsie Normington Foundation and the Centre for Living Sustainability at UHI Inverness and was supported by a dedicated team of volunteer researchers.

A wide range of community stakeholders were involved in participatory workshops and case studies over a three-month period in spring 2024 where they provided input about their experiences with learning disability services and their vision for how the Haven Centre could best address their needs. This report is designed to inform planning at the Haven and support the Elsie Normington Foundation to continue their important and dedicated work to inclusively respond to families' needs.

Background to this project

About the Haven Centre

Written by the Elsie Normington Foundation

The Elsie Normington Foundation was established as a charity in May 2013 by learning disability campaigner Elsie Normington, following the launch of her inspirational book, 'The Silent Doorbell' (2012), a personal memoir of raising her son, Andrew, who has a severe learning disability. Elsie's story resonated with parents who shared in her experience of raising a disabled child with no or limited access to play services or overnight respite care. This desperate need identified by families of disabled children in Highland inspired Elsie Normington Foundation which was set up to raise money for a specialist centre in the region. These ambitions led to plans for the Haven Centre, Scotland's first multi-purpose centre for children and young adults with severe learning disabilities and complex needs, and a £4 million fundraising campaign, which was successfully achieved in 2021. Work started on the Haven Centre, Smithton, Inverness in March 2022, and the Centre was officially opened in August 2023.

With the Haven Centre up and running, the Elsie Normington Foundation wants to continue to enhance services for children and young people with severe learning disabilities and complex needs, support families and expand opportunities for these young people. The vision is for all young people to have access to opportunities, which allow them to socialise, have fun and make new friends. The mission is to deliver inclusive, community spaces in the Highlands and Islands where children and young people with severe profound, and multiple learning disabilities and

complex needs have access to facilities where their social needs are met. The Elsie Normington Foundation works alongside partners to provide opportunities for children and young people to have fun, play, socialise, develop, and grow; where outcomes are improved through access to training, work experience and education, and lives are enriched through community cohesion.

How the project came about

This project arose from the Elsie Normington Foundation's dedicated interest in meaningfully involving community members in their vision. Working with an academic team at the Centre for Living Sustainability at UHI Inverness, representatives at the Elsie Normington Foundation co-designed a research project aimed at identifying priority areas where the Foundation can make the most difference in their continued work to bring positive social impact for young people with learning disabilities and their families. The project was awarded an Innovation Voucher through Interface and is co-funded by Elsie Normington Foundation and the Scottish Funding Council.

The project set out to work collaboratively with community members to develop priorities for action. As a collaborative piece of research, the aims and objectives were informed initially by a Reference Group of stakeholders from the Elsie Normington Foundation, partnering organisations, and community stakeholders and were redesigned by the research team following input from participants. The research team itself involved three community stakeholders who co-developed and co-led the project. Having collaborative input throughout the project was an important way to meaningfully bring in community perspectives and develop priorities that represent the Elsie Normington Foundation's stakeholders.



Members of the peer research team working on the analysis at The Haven Cafe

Our Aim

To influence positive practice for children and young people with severe learning disabilities and complex needs by developing understanding on how the Haven can best contribute to positive experiences in play, learning, and development and support for families.

Our Objectives

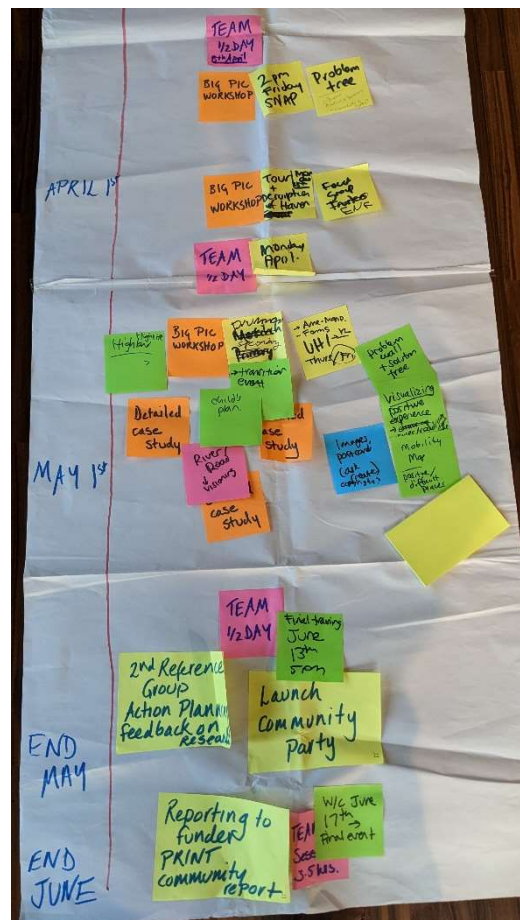
- 1) Develop understanding on people's lived experiences with learning disability services and barriers to accessing resources and support
- 2) Identify ways to support people who have difficulty accessing services to benefit from what the Haven offers
- 3) Outline priorities for how the Elsie Normington Foundation can best support families and develop further links with community groups, businesses and charities
- 4) Develop an action plan to keep the conversation going and embed the new ideas developed through this research

Timeframe

The project began with a Reference Group meeting in February 2024 which provided initial guidance on key stakeholders to involve in the research, and key issues to address.

Following this initial meeting, a peer research team was put together in March 2024 to co-conduct the research activities. Training activities with the peer research team started in April and were held throughout the project at key stages.

The research work was conducted between April and June 2024 and concluded with a public event where stakeholders had opportunity to verify and provide further input on the analysis.



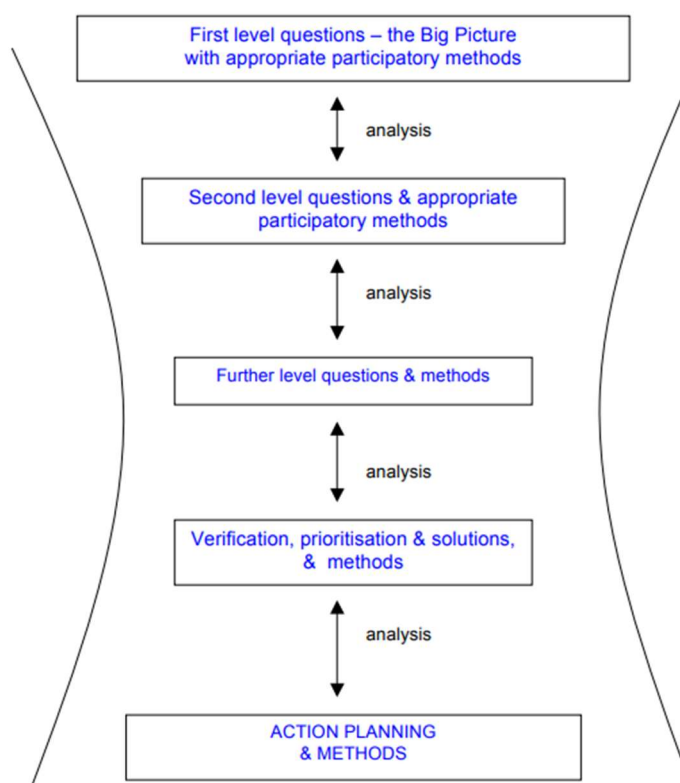
Timeline for the project co-developed with the peer research team in April '24

The research was conducted collaboratively with key stakeholders following a methodology used at the Centre for Living Sustainability to ensure meaningful and valuable community input.

Community Assessment and Action

The methodology we used in this project is based on the ‘Community Assessment and Action’ method developed by team member, Prof Vicky Johnson with her colleague Dr Robert Nurick (<http://www.developmentfocus.org.uk/>). This methodology was originally devised during pilot trialling of participatory methods from the global South and subsequently applied across the UK (in 38 regeneration, local government and third sector programmes) and internationally (for example, in Nepal, South Africa and Indonesia). This community-driven approach develops in-depth evidence on local values and priorities through creative and participatory methods, alongside the collection of participant profiles.

A key part of this method is that the research itself is co-conducted by stakeholders. Community stakeholders are trained in visual and participatory methods, concepts of participation, and ethics and safety aspects. For this project, the research team involved three stakeholders who attended three in-depth training sessions at key points in the research to develop their confidence coding and documenting findings, applying different research tools, and co-facilitating activities.



The research process in Community Assessment and Action, reproduced from Johnson & Nurick, 2006

The stages of the process

Setting up the team and developing the aims, objectives and timeframe

A Reference Group meeting was held in February 2024 involving 8 members, including trustees of the Elsie Normington Foundation, people who have related professional experience in learning disability services, and community stakeholders. The Reference Group members put forth ideas about who to invite to the peer research team and provided guidance on key issues that the project should address. The aims and objectives were initially informed by the project proposal that was co-designed with the Elsie Normington Foundation and were revised and refined by the research team throughout the project to better meet stakeholders' interests and needs.

Identifying people to visit and places to go

The work of identifying places to go began at the initial Reference Group meeting in February where members outlined organisations and people who could be involved in the research. The wide array of ideas put forth on the Reference Group's initial Access Map (shown below) were refined by the peer researchers, who identified three locations where we could involve diverse experiences with disability services, including people who were both familiar and not familiar with the Haven Centre. This was important as one of our research objectives was to support people to access services at the Haven Centre, so we also wanted to talk to people who had not yet heard of the Centre. These locations included the Haven Café during the out-of-school care provision, a Skillsbuilder course at UHI Inverness, and a multi-sports activity at Culloden Leisure. Following the workshops at these locations, we conducted more in-depth case studies with families to provide further insight into our findings.



Access mapping planning sheet developed with the Reference Group members

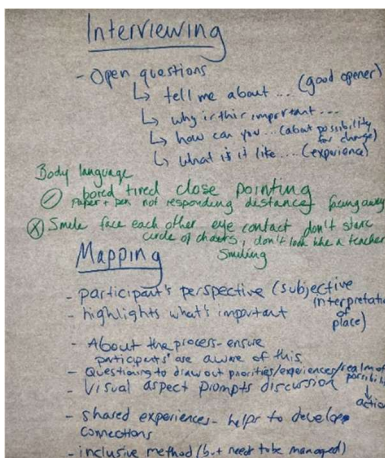
Developing a safety and ethical framework

An important part of the research process was to ensure that our methods were ethical and safe for all those involved. When designing our research activities, we considered how to meaningfully involve stakeholders in the project, including people who may have difficulty expressing their opinions or reading and writing. To help more people get involved, we used visual methods such as drawing and selecting images to convey opinions and ideas.

The chart below shows some of the planning work for our ethical framework, which was developed collaboratively with our peer researchers. The project received ethics approval from the University of the Highlands and Islands Research Ethics Committee (ETH2324-0041).



Planning the safety and ethics framework with the Peer Research Team



Example of training sheet co-developed with the research team when practicing research techniques

Developing and facilitating the tools

At the peer research training sessions, members were introduced to a wide range of participatory methods and visioning tools. At these sessions, the peer research team decided which tools they felt would be most appropriate to use with different participant groups. We then had practice sessions with interviewing and visioning methods so that the team members became comfortable with the methods before applying them in the workshops and case studies. The section further below, 'Our research tools', provides further details about three tools we used in this research.

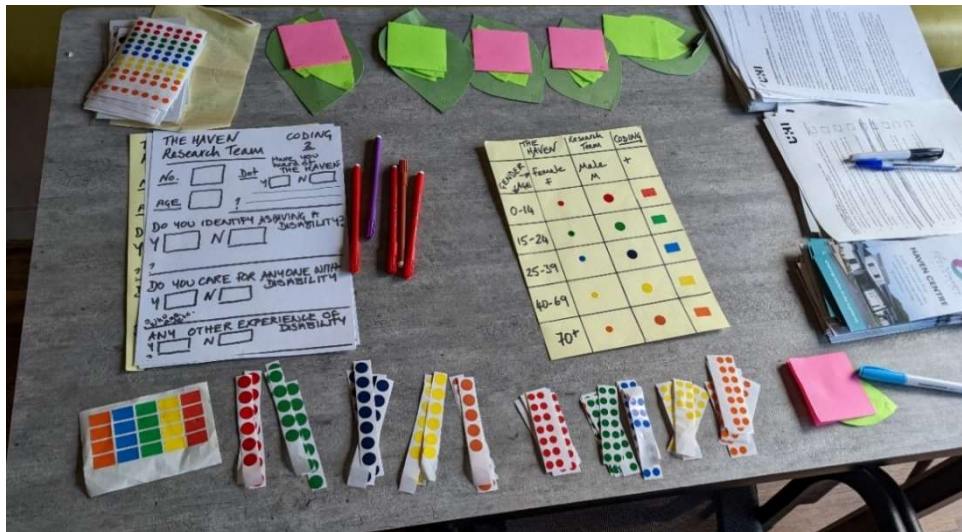


Coding documentation sheet used in this project to gather relevant details about participants.

Coding and documentation

A coding system was developed to monitor who was involved in the research and to ensure that the different issues and actions identified could be traced to individual participants. The coding sheet recorded details on participants' age and gender identity, as well as whether they identify as having a disability, they care for someone with disability, or they have other related experience with disability services. Space was provided on the form to collect further details about individual situations, such as the person's needs or the type of service they provide.

Each participant was then assigned a number so that they did not identify themselves on the activity sheets. The coding system ensures that stakeholder viewpoints are kept confidential while enabling the researchers to collect detailed information on the needs and priorities for different stakeholder groups.



Coding system set up at a workshop at the Haven Café

Analysis, verification and prioritisation

In Community Assessment and Action, the analysis is ongoing throughout the project and informs the next steps in the research process. In this project, the research team conducted an initial analysis of findings following the first three workshops. This resulted in the identification of some key themes arising in the research, which the team grouped together in a chart. Following this analysis, the team reviewed the project objectives, and considered what further information would be needed. Case studies were then conducted with families using a River or Road of Life map. All materials were then analysed over two afternoons to develop

an initial chart of actions. The project concluded with a public event where participants and other stakeholders could come to view all research findings displayed on flipcharts and prioritise the actions.

Who we spoke with

The project involved 51 people in total across the workshops, case studies and verification event. The chart below outlines the age range and gender identity of participants.

Age	Gender identity			Total
	Male	Female	+	
0-14	2	1	0	3
15-24	5	3	1	9
25-39	0	7	0	7
40-64	6	25	0	31
65+	0	1	0	1
Total	13	37	1	51

Information collected on our coding documentation sheet enabled us to track participants’ related experiences so we could better understand peoples’ different perspectives and needs. The research involved individuals who identify as having disability, people who care for others with disability, and people involved in service provision.

14 identify as having a disability

Most participants we spoke with who identified as having a disability were youth, aged 10 to 22 years of age. Outside this age category, we spoke with four middle-aged women who both identify as having a disability and provide care for others with disability.

27 care for someone with a disability

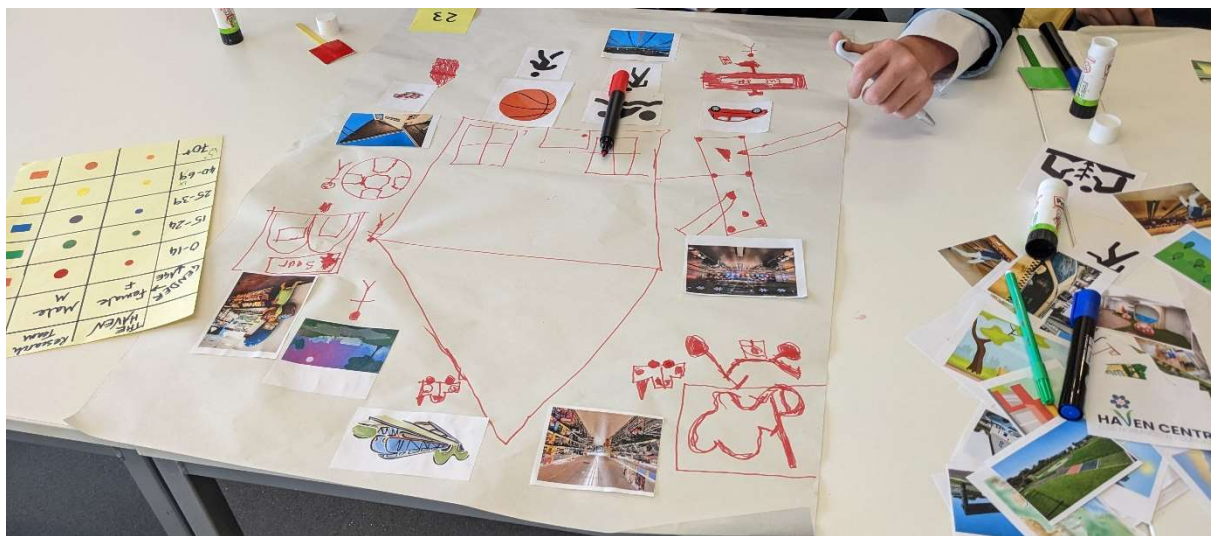
This included 21 parents of a child with learning disabilities and complex needs. Other caring responsibilities included support for a parent or family member with disability and helping one’s peers.

22 have professional experience in learning disability services

This included activity coordinators, carers and support workers, pupil support assistants, and a social worker. Seven of these participants also care for a family member with disability.

Mobility maps

We worked with young people with learning disability to create mobility maps that visually represented their everyday life experiences. This activity provided participants with opportunity to map out their everyday activities, including how they get from one place to another, and invited them to reflect on aspects of their daily lives that were enjoyable or challenging and to associate different emotions with different parts of their daily routines. By creating an individual mobility map, participants reflected on their own experience before coming together in a group to develop a chart about what they find enjoyable and not enjoyable in their everyday lives. This provided us with insight into youth perspectives on services and support systems.



Creating mobility maps with young people

River or Road of Life

In our case studies we used a River or Road of Life activity to ask people about their experiences with disability services over the years. This provided opportunity for in-depth reflection on challenges encountered when signing up for and using different services and supports and reflection on the aspects of best practice that contributed to positive experiences. In a River or Road of Life, participants can visually represent both difficult points and positive experiences, for example with dams and potholes or bridges and green lights. Through discussion with participants typically for over an hour, key details were noted on the River or Road of Life sheets that enabled us to develop insight into the issues outlined in the Problem Wall activity sheet.

Our findings are presented across three main areas: What different people told us about their experiences with learning disability services; What people told us about accessing resources and support; and, What people told us the Haven could do to support families.

Different points of view on learning disability services

The project involved people with different standpoints on learning disability services, including young people and children with learning disability, their parents and family carers, and people who work as service providers. This section provides some insight into these different groups' points of view on learning disability services.

Children and young people with learning disability

Key points

Young people were interested in having more opportunities to support their independence, and in particular volunteering opportunities. Being able to go to activities nearby was preferred as this allowed them to be more independent. Young people in Inverness enjoyed being able to walk places on their own and being able to take public transport with their support worker, while those living further away felt restricted by having to rely on funding for transport.

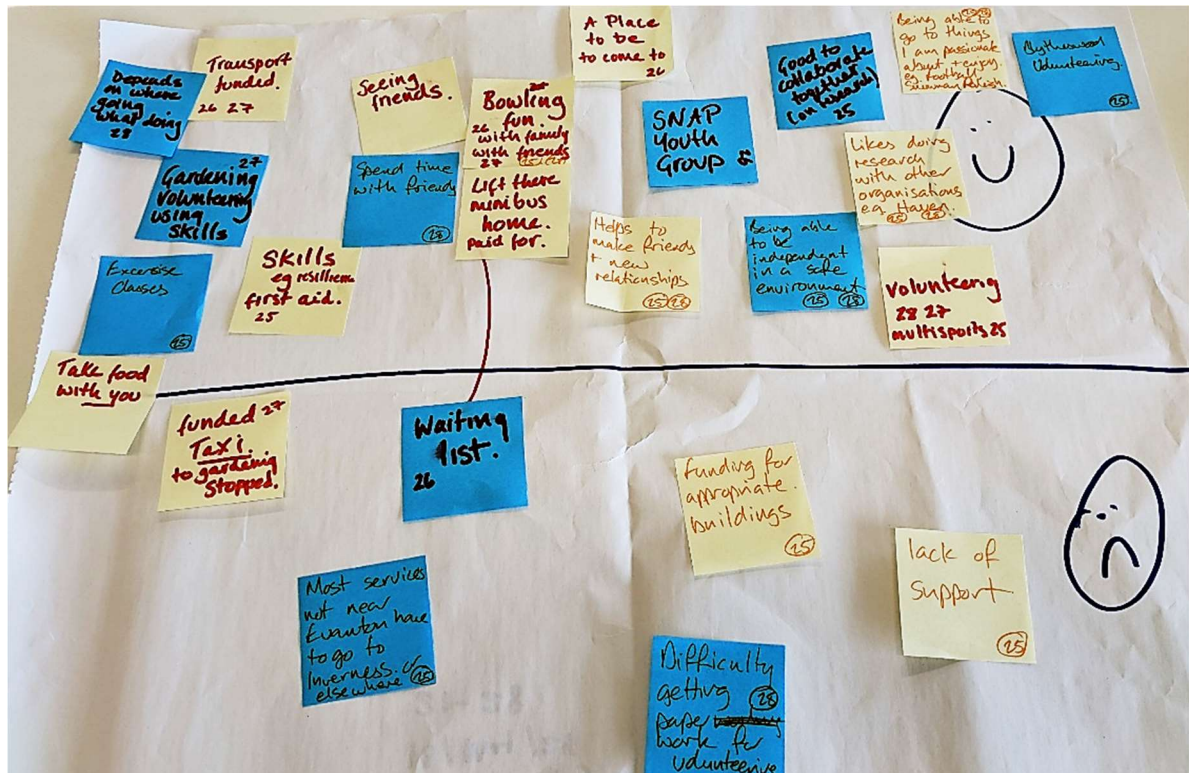
Children and young people were also aware that what they could do depended on how much information their parents had, and how easily their parents could sign up for different opportunities. For example, a 10-year-old participant added the following comment to our 'Problem Wall' sheet, "I want to come to [the Haven] for services but my mum always finds it hard to get me in here", and he suggested on our 'Solution' chart, "For my mum to easily arrange for me to come here". Other young people also described challenges with paperwork and finding funding for activities.

We asked eight young people attending a Skillsbuilder course at UHI Inverness about their everyday lives. What follows is what they told us about what they enjoyed and didn't enjoy.

FINDINGS

What's enjoyable	What's not enjoyable
<p>Volunteering and using skills</p> <p>Learning new skills, like first aid, and going to college</p> <p>Spending time with friends and youth groups</p> <p>Family fun activities, e.g. bowling, and spending time with family</p> <p>Having funded transport</p> <p>Walking places on my own</p> <p>Exercise, multi-sports activities, and swimming</p> <p>Having lots of options to choose from</p> <p>Having someone to talk to when things are hard</p>	<p>Not having activities nearby; always having to go into Inverness</p> <p>Difficult to get paperwork for volunteering</p> <p>Having to be on waiting lists</p> <p>Not having enough support with daily activities</p> <p>Not having appropriate places to go to</p> <p>When funding for transport is stopped or buses get cancelled</p> <p>Having to wake up early to go to college and feeling tired</p>

What young people said about what's enjoyable and not enjoyable in their everyday lives



Example of 'Things you enjoy and don't enjoy' chart created with young people

Parents and family carers

Key points

Parents and family carers of children and young people with learning disability described stressful experiences when trying to navigate and sign up for services.

Transition points in the education system cause substantial stress for parents as the onus is put on them to find a suitable placement. Parents described the uncertainty of not knowing if their child would be accepted into a certain programme or school and the stress of applying for placements when not knowing whether an appropriate option would ever be found. Parents also described situations where their current placement was deemed no longer suitable, and their child was “kicked out” without an alternative being provided. A parent of a child with complex needs explained, “Finally we got a placement at the preschool nursery, but they decided our daughter’s needs were too much for them and they couldn’t keep her, and this was devastating” (Female, 40-64 yrs.) Parents described long waiting lists and periods of uncertainty when trying to find other options.

Parents explained that they needed to advocate for support and that this was exhausting. As a parent of a child with complex needs explained, “Mum and Dad put on their armour to fight [for access to services], but just want to be heard without being at crisis point” (Female, 38 yrs.) Parents also explained frustrations with the lack of transparency and inaccessibility of information about what services are available.

This lack of information also meant that some parents felt that they didn’t know what kinds of support would work best for them and that because of this it was difficult to know how to interact with the different organisations providing support. For example, a parent of a teenager with learning disability explained that the parent support groups offered by local organisations “were lovely, but I didn’t know what to ask so didn’t go back” (Female, 40-64 yrs.)

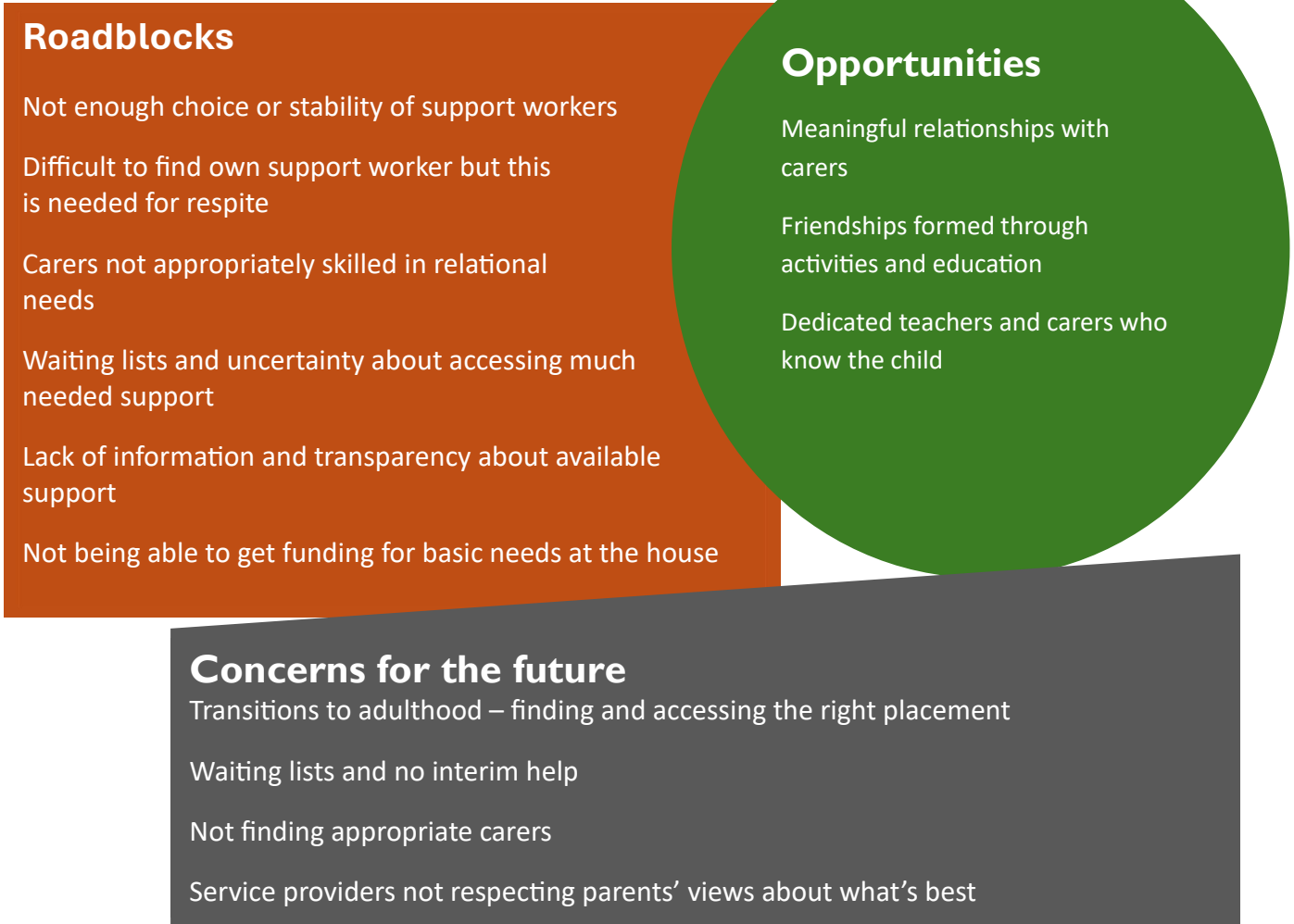
Parents also described challenges finding appropriately trained support workers. Parents of children with complex needs relied on finding carers with a certain skillset that often was not available and felt there was critical need for upskilling and training of carers so that they could provide meaningful, relational care. There were also frustrations with changeovers in support workers which can result in significant stress for families as they need to build up trust and meaningful relationships.

A common theme that arose in our case studies was that families need dedicated support workers who can advocate on their behalf and ensure that suitable services and supports are found so that this stress is not carried by the parents. As a parent

FINDINGS

of a child with complex needs explained, “Having a social worker from the beginning would have helped a lot to guide me... [and now looking ahead] it would really help to talk to someone who can say this is who you need to talk to [about available supports]” (Female, 40-64 yrs.) Parents explained that because of the challenges they had experienced accessing services and navigating long waiting lists, they looked ahead with stress and uncertainty about their child’s transition to adulthood.

The figure below presents some key points from five case studies with parents of young people with disability, including what they told us about the roadblocks and opportunities they had encountered with disability services, and the concerns they have for the future.



Key points brought up by case study participants in the River or Road of Life Maps

FINDINGS



Ewen Weatherspoon Photography
Treehouse Room at The Haven Centre

Service providers

Service providers participating in this research highlighted the lack of ‘joined-up thinking’ between organisations: “Disconnect between service providers is apparent - collaboration is key!!” (Male, 50 yrs.)

There were concerns that services can be duplicated by providers, and that the lack of coordination between organisations means that the onus is on parents to seek out and advocate for appropriate services and support. Service providers suggested that the Haven could provide a role in signposting families to available funding and services and supporting them with the application process.

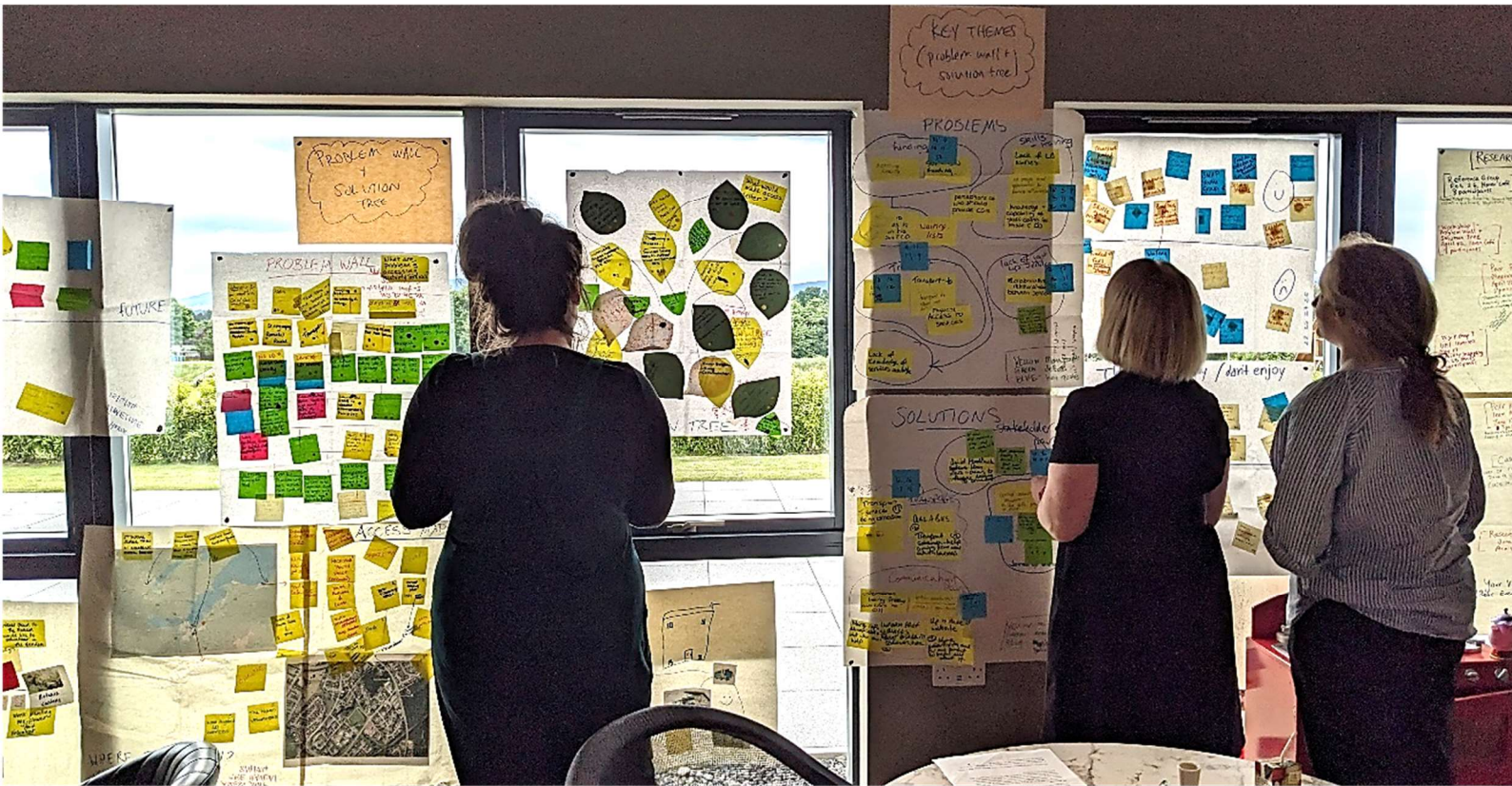


Timeline chart created with the Elsie Normington Foundation staff and trustee

What people told us about accessing resources and support

One of our main objectives for this research was to better understand the barriers and challenges people experience when accessing learning disability services and support. The Problem Wall and Solution Tree workshops invited participants to add their perspectives on the barriers to accessing to suitable support. In the case studies, we used River or Road of Life mapping to work with participants to understand in more detail the barriers, challenges and opportunities they had experienced over the years with a wide range of disability services.

This section outlines six main themes that arose across what people said in the workshops and case studies about issues they have experienced with learning disability services. These themes cover issues relating to the process of signing up for and obtaining appropriate placements as well as gaps in service provision or areas that need to be developed further. Each of the themes outlined below includes one or two quotes from participants followed by key points relating to the theme that were brought up by multiple people during the course of this research.



Participants viewing and adding to charts at the concluding event at The Haven Café

Theme 1: Disability services are disconnected, and there is no individualised help accessing them

"Lack of joined up working between health, care and education, so the parent becomes the key worker."

Parent of child with complex needs (Female, 40-64 yrs.)

"Advocating repeatedly for our needs with social care is exhausting!"

Parent of child with complex needs (Male, 54 yrs.)

What participants told us about Theme 1:

- There needs to be better collaboration between service providers [11 participants]
- Paperwork is overwhelming and needs to be easier to navigate [11 participants]
- Because there's not enough staff or support with Self Directed Support (SDS) it is difficult to access funding [6 participants]
- Advocacy services are needed that cover the region [6 participants]

Theme 2: Lack of information and transparency about what's available and who's eligible

"Why are some parents getting package A but a family with the exact same needs get a different package with next to no help?"

Parent of child with complex needs (Female, 31 yrs)

"More information is needed - it's a minefield working out who can help"

Parent of child with complex needs (Female, 38 yrs)

What participants told us about Theme 2:

- Families need help to know what services there are and what's on offer [10 participants]
- Accessing funding is difficult [10 participants]
- Need for better communication and transparency about entitlements and availability of contact details of service managers [6 participants]

Theme 3: The choice of care services and appropriately trained carers is limited

"Not enough choice of services - you are 'lucky' to access anything even if it's not the right fit for the individual"

Care provider (Female, 34 yrs)

What participants told us about Theme 3:

- Waiting times for social work assessments and Self Directed Support are very long [8 participants]
- Difficult to find suitably skilled carers [7 participants]
- Care staff need better training and more pay so that their role and career is valued [4 participants]
- No interim support while on waiting lists and no back dated funding [2 participants]

Theme 4: Respite and stability of carers are important for avoiding crisis

"Knowing the carers, and the child having built up relationship with them before overnights brings peace of mind for parents"

Parent of child with complex needs (Male, 54 yrs)

"When the 'crisis' team are called, due to the fact they don't personally know the families, there is nothing they can do."

Parent of child with learning disability (Female, 40-64 yrs)

What participants told us about Theme 4:

- Better anticipatory care services are needed to avoid crisis [3 participants]
- Families need regular respite, and to be able to access respite more easily [3 participants]
- It would be helpful if care staff were offered at respite as it can be difficult to find suitable carers [2 participants]

Theme 5: Getting to activities and services is difficult, especially for people living outwith Inverness

“Costly and tiring – respite is not respite. Pick up at school, transport, waste 2.5 hrs in town, and pick-up”

Parent of child with complex needs (Female, 38 yrs)

“Transport schemes are needed to help people come from areas outwith Inverness”

Parent of child with disability (Female, 50 yrs)

What participants told us about Theme 5:

- Long journeys and transport are difficult [10 participants]
- Dial-a-bus or a similar service to the Haven would be very helpful [5 participants]
- It's not just transport to the Haven, but transport is needed to other supported activities [3 participants]

Theme 6: More social activities and better support with transitions to adulthood are needed

“Transition from child to adult services is clunky”

Care provider (Female, 51 yrs.)

What participants told us about Theme 6:

- More events and information to support young people and their families plan for transitions to adulthood are needed [13 participants]
- More support is needed to help young people arrange work experience or volunteering [9 participants]
- There's a lack of social activities outwith school times, such as family fun events [7 participants]
- There's not enough stepping into work opportunities for young people with disability [4 participants]

Priorities for action

Throughout the research, participants suggested ideas that would improve learning disability services. These were collected on the Solution Tree and were noted in the case studies and mobility mapping with youth. In the analysis, the research team brought together these ideas and developed an actions chart, outlining some priority areas for learning disability services and actions that could be taken forward by the Elsie Normington Foundation. At a public evening event concluding the research, 22 participants had opportunity to prioritise these actions by adding their 'sticky dot' to the actions chart. They also had opportunity to add new actions.









The table of 'Recommended Actions' displayed on the following page shows the level of participant support for the actions identified in this research. Each 'dot' represents an individual participant who supported the action at any of the research workshops, case studies, or the public event. In each row, individual participants are only counted once even if they supported the same action at multiple events. The coding chart below shows the age range and gender identity that the participants' dots represent. For example, a small yellow dot (●) represents a participant who identifies as female and is 40 to 64 years of age.



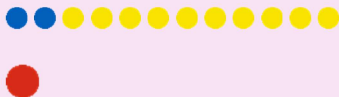






	THE HAVEN	Research Team	CODING
GENDER → AGE ↓	Female F	Male M	+
0-14	●	●	■
15-24	●	●	■
25-39	●	●	■
40-69	●	●	■
70+	●	●	■

Above: Coding chart showing the age range and gender identity represented by participants' sticky dots.



Right: Action planning charts displayed at the concluding public event with participants' dots indicating their support of actions

Issue	Recommended Actions for Elsie Normington Foundation	Number of participants supporting this action
Services are disconnected and difficult to navigate – families need individualised support to access appropriate services and funding	Provide designated support workers to help families navigate available supports and funding	
	Provide advocacy services and work with families to influence policy	
	Support local organisations to collaborate and work together to provide more joined up services	
Families need more information about what services are available and what they are eligible for	Provide easy to access and transparent information about available services and support on the website	
	Provide touchscreens in public areas at the Haven with information about services	
There are not enough suitably trained carers and waiting lists are long	Offer regular care staff at the respite suites	
	Provide interim support for families on waiting lists	
	Provide local opportunities for high quality training for paid carers	

Families need support managing crisis and simplified access to respite	Provide direct access for families to sign up for services at the Haven	
	Provide parenting support groups	
Transport is difficult and there are limited offerings outwith Inverness	Set up a dedicated transport service to the Haven	
	Look into offering additional respite sites in other areas in Highland	
Young people and families need more support with transition to adulthood and social and life skills development	Host regular events providing support and information about transition to adulthood	
	Support young people with disability to complete the paperwork and organise volunteer or work experience	
	Provide volunteer/work opportunities for young people with disability at the café and garden	
	Offer regular social activities and family fun events	
	Offer life skills support sessions at the suites during the daytime	

The Recommended Actions table above shows all actions that were brought up by or supported by at least three participants. Some of the actions are longer term projects that may not be feasible for the Foundation to address in the near term. Furthermore, these actions were not assessed in terms of feasibility, but rather prioritised in terms of need as identified by stakeholders, and feasibility and cost will be considerations the Foundation will need to take into account when prioritising next steps.

Research limitations

This report presents findings from a short-term project that relied on people generously volunteering their time. The empirical research was conducted over a three-month period and included a total of 51 people.

A wide range of stakeholders were invited to participate in the project, but not all had the time or availability to join our sessions, and for this reason the project did not include some key stakeholders, such as Drummond School. The findings presented in this report specifically reflect the perspectives of the 51 people who participated in the project, including young people and children with learning disabilities, their parents, and a range of service providers. Using visual methods, we supported young people with learning disabilities to participate in the project. However, due to the complex needs of some people with learning disabilities we were not able to include all stakeholders' voices, and in many cases, we relied on the insights of parents and carers. While the research team made efforts to include a wide range of stakeholders, we recognise that the research will not have captured all viewpoints due to the above limitations. As qualitative, participatory research, our findings are not meant to be generalisable, but rather they provide timely insights into some key issues experienced by stakeholder groups, which can inform future planning.



Ewen Weatherspoon Photography
The Haven Centre

Conclusion

The newly opened Haven Centre is providing much needed specialist support for families and young people with severe learning disabilities and complex needs. This short-term research project, funded by the Elsie Normington Foundation and the Scottish Funding Council and conducted by researchers at the Centre for Living Sustainability, UHI Inverness, along with a dedicated group of volunteers, brought together community perspectives to better understand families' needs and wishes for disability services. This has allowed us to outline some priority areas that will support the Elsie Normington Foundation as a forward-thinking organisation to continue to be at the forefront of meeting families' needs.

The priorities for actions outlined above were developed collaboratively with parents, young people with disability, and service providers over a series of participatory workshops and case studies. Service providers included in this study highlighted the lack of coordination among organisations providing disability services, while parents explained frustrations with navigating complex and disjointed services. Advocacy work both at the individual and institutional level would support families to more easily obtain appropriate access to services which would reduce periods of stress and uncertainty.

At the individual level, families could be provided with a dedicated support worker that would guide them through the process of identifying services they are eligible for and accessing funding and suitable placements. Paperwork can be overwhelming and particularly at points of transition, families often struggle to know what their options are and how to obtain a placement. Families feel they need to be their own advocate and fight for funding and placements. They would benefit significantly from being able to unload this stress by having a dedicated person that takes ownership over the process of navigating paperwork and waitlists and obtaining funding and suitable care providers.

At the institutional level, the Elsie Normington Foundation could support better coordination among organisations and more joined-up ways of thinking across education, health and support work. This could involve bringing together information on what's available to reduce any overlaps in service provision. This could also involve encouraging transparency among service providers and developing a coordinated list of contact points. Transport is often difficult particularly for people living outwith Inverness. An important part of supporting coordination and effective access to services could be ensuring appropriate transport options. This could involve providing a bus service or developing better connections with or information about existing transport services.

Another key area this research supports is the work of the Elsie Normington Foundation to harness work experience and volunteer opportunities for young people with disability. Families, young people, and service providers included in this study all highlighted the need for further support services with transitions to adulthood. In addition to information events and offering volunteer opportunities at the Haven Café, the Elsie Normington Foundation could provide direct support to young people with finding and obtaining appropriate volunteer and work placements. Further issues brought up by participants were the need for improved training for carers in relational needs and support with finding appropriate carers, particularly for respite.

This short-term study brought together stakeholder perspectives and worked with community members to outline priority areas that could be taken forward by the Elsie Normington Foundation to address existing gaps in learning disability services. Further research could explore specific issues and themes in more detail to identify concrete next steps. Further research could also inform the development of an evaluative tool that the Elsie Normington Foundation could use to inform planning at key stages and ensure continued community input in the vision for the Haven Centre.



*Ewen Weatherspoon Photography
The Haven Centre*



Keeping the conversation going

We would be very interested to hear from you with any ideas you have related to this research, or any feedback on our findings. If you would like to learn more about this project, view our ethics documents, or learn more about the participatory research methods we use at the Centre for Living Sustainability, we'd be happy to share further information with you.

For questions, comments, or further information please contact Sarah Wagner, Senior Researcher at the Centre for Living Sustainability, UHI Inverness:

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