

# Wellbeing Hub Year One Annual Report

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[Centre for Autism Wellbeing Hub Website](#)

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# Wellbeing Hub Year One Annual Report

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## Executive Summary

In response to the national mental health crisis amongst autistic children and young people, the Centre for Autism Wellbeing Hub began in August 2023, with the aim of co-developing impactful support services, training future professionals, and advancing autism research. Funding has been provided by the University of Reading Alumni and supported by the School of Psychology and Clinical Language Sciences (PCLS).

### Key Achievements:

1. **Launch and Community Engagement:** The Hub was officially launched on 9 November 2023, attracting around 600 attendees, both in-person and online. The event set the stage for the Hub's mission, with significant contributions from autistic advocates and a live research activity on autistic thriving. A scoping study was undertaken with autistic young people and their parents to find out more about what helps autistic people to thrive. Creation of a newsletter and website has allowed community engagement to grow.
2. **Wellbeing Activities:** A series of monthly online talks were facilitated by autistic adults and advocates, focusing on topics related to thriving and wellbeing. Additionally, the Hub partnered with a local organisation (ASSIST) to begin developing a group programme to support autistic young people, and work to pilot the NeuroBears program, aimed at helping children understand autism and neurodivergence, has been started.
3. **Parent Support:** During the summer of 2024, the Wellbeing Hub ran several focus group discussions with autistic and non-autistic parents and carers to explore their support needs. The data from these discussions is currently being analysed and will be used to inform the development of future parent-centred support activities. In addition, a series of anxiety workshops were delivered, providing parents and teachers with tools to better understand and manage anxiety in autistic children with intellectual disabilities, receiving positive feedback from participants.
4. **Training and Professional Development:** The Hub provided placement opportunities for four MSc students, offering training in clinical governance, autism acceptance, and research skills, as well as direct clinical experience working with autistic children and families. The Practitioner Special Interest Group (SIG) was reactivated, providing a platform for autism practitioners to network and learn from expert speakers.
5. **Research Initiatives:** Following the findings of the scoping study, The Hub won funding for the "Being Me" project, which involved creating a series of videos with autistic young people reflecting on their experiences. These resources will be used in future training and educational activities.

**Plans for Year Two:** The Hub plans to continue its existing activities while expanding its support offerings. Key initiatives include further development of the NeuroBears program, delivering further workshops in special schools, and engaging the community through surveys and advisory groups (with autistic children and with professionals) to shape future projects.

**Challenges and Future Outlook:** The Hub faces the challenge of securing long-term funding beyond staff salaries. However, the success of its first year has laid a strong foundation for future growth. The Hub aims to scale up its support services and continue making a meaningful impact on the lives of autistic young people and their families.

## Funding and Remit

The Centre for Autism was established in 2014, comprising research-driven clinical services and research exploring fundamental and applied questions relevant to autism. Funding for the new service was generously awarded by University of Reading Alumni, covering salaries for two part time clinic staff and part time executive support for a start-up period of 5 years, August 2023 to July 2028. Additional funding for the Wellbeing Hub Clinical Director is provided by the School of Psychology and Clinical Language Sciences (PCLS).

The remit for funding recognises the national mental health crisis for children and young people, and the additional barriers faced by autistic children and young people in accessing timely and appropriate help. The funding was granted in order to:

1. Deliver an impactful service that supports the local community and tackles the chronic shortage in the provision of mental health services for autistic children and young people, their families and support networks
2. Provide training opportunities for the practitioners of the future, by providing students with work placement opportunities
3. Support autism research activity

## Wellbeing Hub Team

The Wellbeing Hub has 4 staff members, all of whom are part time. Our team consists of 1.4WTE clinical staff, and 0.5WTE executive support.

Dr Fiona Knott – Clinical Director and Clinical Psychologist

Dr Jo Billington – Autism Researcher

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## Identifying our Focus

We quickly recognised that it would not be possible or appropriate for us to offer mental health interventions due to the small size of our team. When considering what we could offer instead, we realised that although a lot is known about autistic distress and mental ill health, almost nothing is known about autistic wellbeing or thriving, particularly from the perspectives of autistic children and adults. This means that many of the supports and interventions that are offered are based on what non-autistic people tell us are helpful. Placing autistic voices at the heart of everything we do, our overarching aim is to work with autistic people and their allies to build creative and meaningful solutions to support autistic young people to lead their best lives.

## Scoping Study

To help us identify our focus and possible activities that we could offer from the Hub, we ran a small scoping study. We talked to local professionals from voluntary and statutory services to identify local strengths and gaps in existing support provision. We then ran a qualitative study with 11 autistic young people aged 15-24 years and four parents. We asked participants what helped them live their best lives when they were younger, and what got in the way and asked them to generate ideas for activities that we could run. Autistic young people identified that key factors to thriving included: having individuals (family, friends, professionals) who they could trust and who involved them in decisions; being able to engage in meaningful activities (e.g. hobbies), having structure and routine; and being able to make sense of themselves (e.g. through diagnosis and through engagement with the autistic community). Parents also identified the factors that had helped their children to thrive. These included: being a supportive family (e.g. being understanding, adapting to the child's needs, providing opportunities for their child); ideas about how to be a supportive family (e.g. considering parent needs too, the need for education about autism); and having support beyond the family (e.g. schools, friendships, professional support for the child). Suggestions for activities that could be provided by the Wellbeing Hub included information and support for: sensory processing, pre-diagnosis support, emotions and regulation, understanding oneself, signposting, meeting other autistic young people, disclosing your diagnosis, life skills, self-advocacy and transitions.

Figure 1: Activities & support the Wellbeing Hub should provide? Scoping study themes.



## Initial Set Up

Over the course of our first year, we have recruited our full complement of staff and have set up the processes and documentation necessary to allow us to run efficiently and smoothly. These include:

- Finance
- Contracts
- Infrastructure to allow us to run webinars and other events, including IT platforms and ticketing
- Health and safety risk assessments
- Clinical governance
- Placement student processes and paperwork
- Ensuring all research projects have received ethical approval from the University of Reading research ethics committee

## Launch 9 November 2023

The launch was attended by around 600 people, with about 200 in person and 400 online. The evening included introductions by Vice Chancellor Professor Robert Van de Noort and Head of Psychology and Clinical Language Sciences Professor Carmel Houston-Price and a description of our remit and initial plans for the Wellbeing Hub. Sarah O'Brien, autistic advocate and University of Reading Alumnus set the scene with a powerful talk entitled 'Thriving or Surviving?'. Attendees took part in a live research activity, answering the question 'what does autistic thriving mean to you?'. Finally, those who attended on campus joined the Centre for Autism Wellbeing Hub team and Centre for Autism researchers for a chance to chat over refreshments and cake and view posters showcasing current research.

Figure 2: Launch attendees

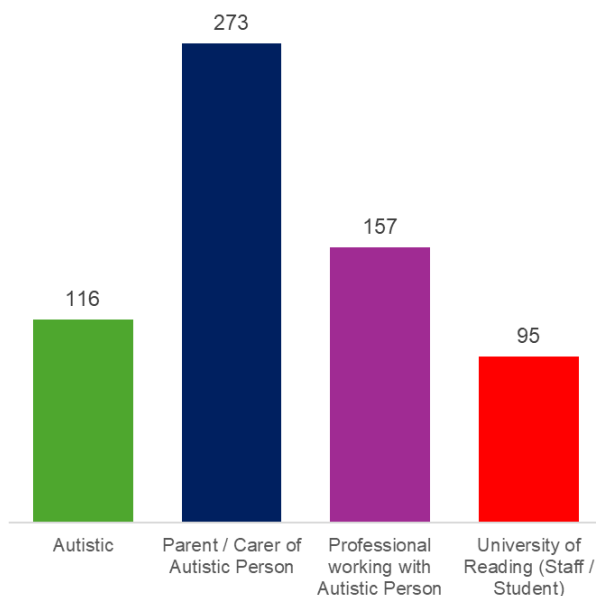
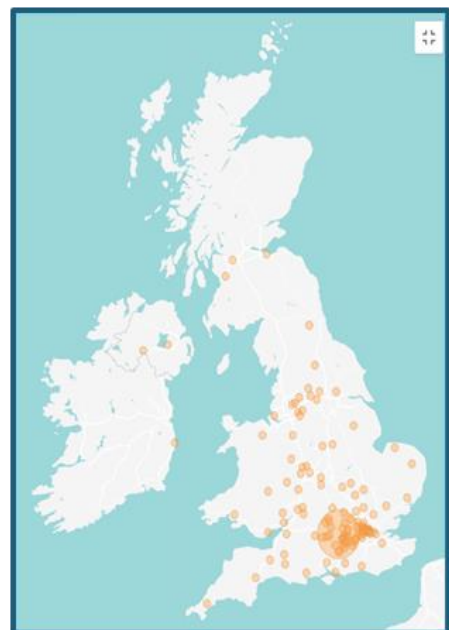


Figure 3: Distribution of online attendees



# Meeting Our Aims:

## Connecting With Our Community

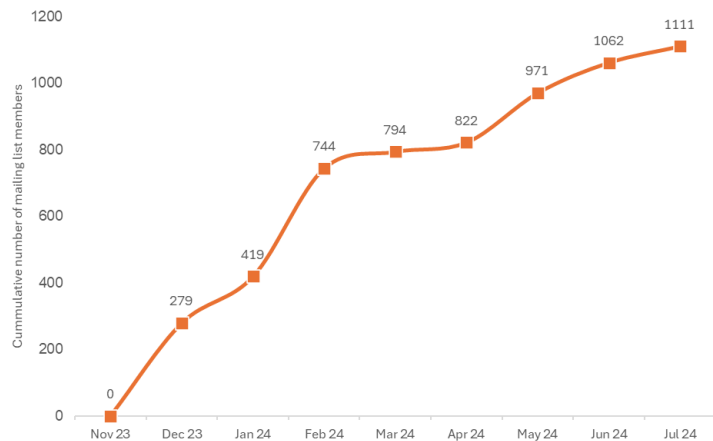
### Newsletter

The Centre for Autism newsletter was redesigned and relaunched under the ownership of the Wellbeing Hub team in December 2023 and has delivered 7 issues to date. Its aim is to maintain an ongoing communication with the Wellbeing Hub community (reaching over 1000 mail-list members) and to promote our work.

Figure 4: Newsletter



Figure 5: Mailing list growth



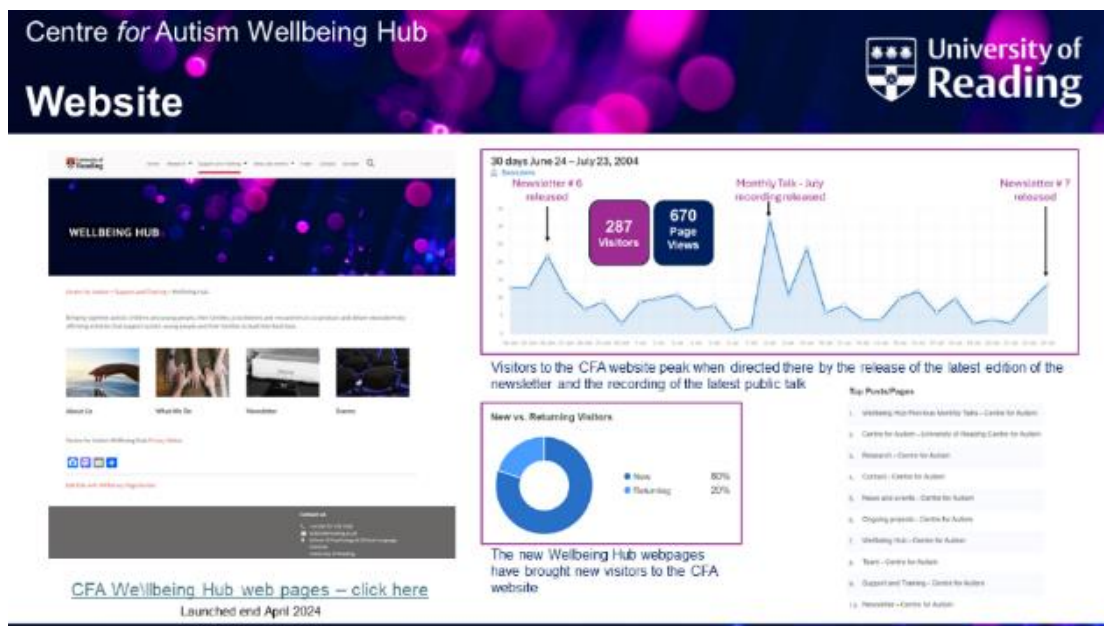
## Website

The Centre for Autism website has been reviewed and amended, with the addition of newly designed and built Wellbeing Hub pages. Our community of autistic people, parents and carers of autistic young people, professionals working with autistic young people and researchers working in the area can use the website to access the latest information about the Wellbeing Hub.

The website includes who we are and what we do, and includes details of the Wellbeing Hub's activities including research, talks, networking events, training and supporting activity and group intervention. Completed in April, the Wellbeing Hub website provides a channel to share newsletters and access to recordings of our monthly online talks and has pulled new visitors to the Centre for Autism website with 287 visitors in July, 80% of whom were new.

Click link to view the website: [Centre for Autism Wellbeing Hub](https://www.cfa-reading.ac.uk/)

Figure 6: Website



## Wellbeing Activities

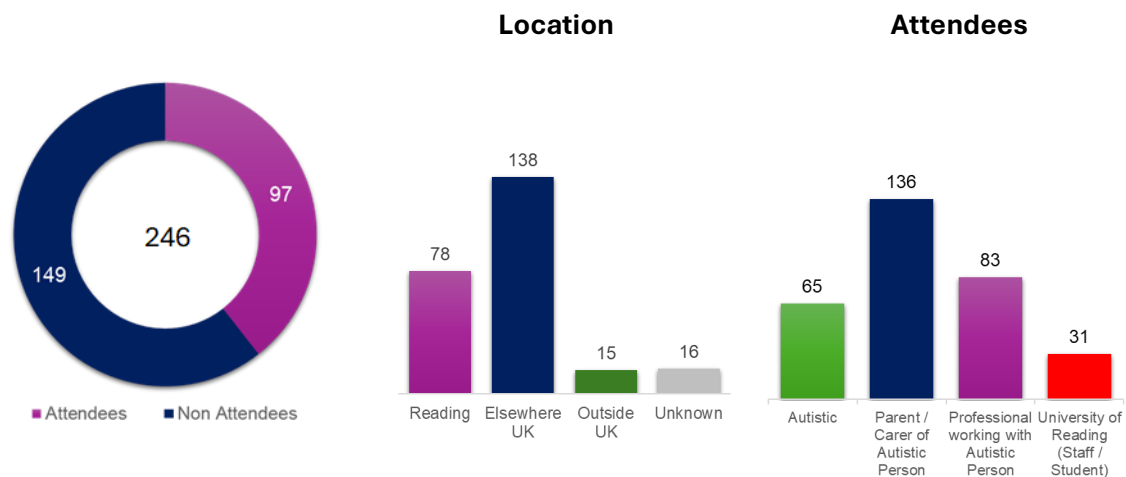
### Online Talks

This year we have facilitated 6 monthly online talks from autistic adults about thriving and wellbeing. Most talks are recorded and are available on our website for those who were unable to attend on the day. An average of 246 people have registered with about 1/3 joining the live event. Participants are drawn from all over the UK and include autistic adults, parents, professionals and University staff and students.

January	<b>Pete Wharmby</b> (Autistic speaker & writer) – Sensory Comfort For Autistic People
February	<b>Andy Smith</b> (Spectrum Gaming founder) – Creating Hope Through Autistic Community
March	<b>Sarah-Jane Critchley</b> (Autistic author and founder of Different Joy Partnership) – Autistic Joy: From Why To Wow
May	<b>Nic King</b> (Creator of NeuroBears) – Young autistic people and the importance of self-understanding
June	<b>Elaine McGreevy</b> (Speech and language therapist) – How to create enabling communication environments for autistic children and young
July	<b>Barney Angliss</b> (Autistic trainer, writer & consultant) – Breaking my silence how I came to advocate for myself



Figure 8: Average talk sign up and attendance



## Activities for Young People

Led by Dr Emma Harris, this year we have been identifying projects that we can develop to support autistic young people.

### *Partnership with ASSIST*

ASSIST is a local organisation which supports autistic young people and their families. The Wellbeing Hub have partnered with ASSIST to develop a group for autistic young people, based on the needs of autistic young people who access ASSIST. This will involve undertaking focus groups with young people who use ASSIST to find out what they would like, and then developing a group with their involvement and guidance. Access to the group will be provided to families who access ASSIST, and the group will be evaluated to help determine how useful it was for autistic young people. The Wellbeing Hub will provide support with developing the group, and undertaking research about its effectiveness.

### *NeuroBears Programme*

NeuroBears is a programme created by autistic individuals, to help autistic children (aged 8-14 years) with understanding autism and neurodivergence. It consists of a series of videos explaining different autistic experiences, with worksheets and questions to prompt reflection. The Wellbeing Hub are piloting the delivery of this programme via University of Reading MSc students who are undertaking a professional placement with the team. Families will be invited to participate in the NeuroBears programme with a clinical psychologist, for the purpose of creating training videos for students. Students will then be trained in the delivery of NeuroBears, and we will invite families to participate in NeuroBears with facilitation from a student. We will evaluate whether this is feasible for the Wellbeing Hub to do, and evaluate how useful children and families found the programme.

## Parent Support

Led by Dr Jo Billington, we have been working with small groups of autistic and non-autistic parents of autistic children to explore their support needs and how these might change over time. To this end, we have recruited participants to the following three groups:

- Non-autistic parents and carers of recently diagnosed autistic children
- Non-autistic parents and carers of autistic children who were diagnosed 2+ years ago
- Parents and carers of autistic children who identify as autistic themselves

The data from our discussions with our participants is currently being analysed and will inform a survey we intend to distribute to our wider community in the autumn. The results of these focus groups and a survey planned for autumn 2024 will shape the offers of support we make to parents and carers in year two.

## Anxiety Workshops: Understanding and Supporting Your Anxious Child

Led by Dr Fiona Knott, a four-session workshop series has been created for parents and teachers of children with autism and intellectual disability. The series aims to give attendees up to date information about anxiety and autism and to enable them to better understand their child's anxiety. Each workshop series consists of four linked sessions and each workshop lasts two hours combining talks, discussion and practical activities. Drawing on a cognitive-behavioural model of anxiety, parents and teachers work together to develop a tool-box of neurodiversity affirming strategies for use at home and school.

Three workshop series took place in the spring and summer 2024, delivered by Dr Fiona Knott. Parents of 26 children attended in total alongside school staff members including teachers, teaching assistants and autism support staff. Four University of Reading MSc placement students attended the workshops and collected feedback from parents by phone. Staff gave feedback using a survey.

The workshops series were received positively by parents and staff alike. Very few parents dropped out and most attended all sessions. Some parents said they realised the extent of their child's anxiety for the first time. They were able to develop strategies to support the child and made changes to their own approach: *'Calmer, less reactive so he's less reactive. Adopting the mindset of 'mum has this under control'.* The opportunity for parents and teachers to work together was highly endorsed by all who attended. A teacher commented *'Really interesting working so intensively with parents - I thought it was so beneficial for both parent and teacher, both learned a lot about what the other sees of the child in their context'.* Parents also valued the opportunity to meet and talk to other parents.

## Training Future and Current Professionals

### Placement Students (Theory and Practice in Clinical Psychology)

This year we have worked with four placement students, two clinical and two research.

**Training:** Students have completed mandatory and core training relating to clinical governance and clinical skill development, as well as 5 x 3hr autism awareness and acceptance training sessions, including topics such as: history of autism, models of disability, the neurodiversity paradigm, autism and education, autism and wellbeing, and reasonable adjustments.

**Research Skills and Clinical Experience:** Students have developed their research skills as part of their placement with the Wellbeing Hub, including topics such as: participatory research

practices, conducting research with autistic young people and their families, reflexive thematic analysis, conducting literature reviews, and evaluation of the parent anxiety workshops through parent feedback interviews.

**Clinical Experience:** Students have gained direct experience of working with autistic children and their family members. Clinical work undertaken by the students has included a 7-week placement at a local mainstream primary school where they were involved in a range of different activities with autistic pupils across all year groups, including: whole-class and individual child observations, 1-1 work supporting academic skills such as reading comprehension and numeracy, small group work supporting peer relationships, playground support during breaks, and spending time with children using the specialist sensory room.

Students also supported with the delivery of the parent anxiety workshops, working with autistic children with intellectual disability, and their parent/carers and teachers. This provided opportunities to observe clinical intervention and develop interpersonal skills when working with children and families.

## Practitioner Special Interest Group (SIG)

We have re-activated our termly SIG, a twilight in-person meeting for autism practitioners with a speaker and chance to network over tea. These have been attended by approximately 30 people, consisting of professionals, students and University of Reading staff.

- |          |   |
|----------|---|
| February | <b>Dr Mairi Evans</b> (Neurodiversity Lead, Berkshire Healthcare Foundation Trust) – Developing a Neurodiversity Strategy |
| May      | <b>Dr Jiedi Lei</b> (Research Clinical Psychologist, University of Oxford) – Strength-based Assessments                   |

## Research

All our activities are underpinned by research, both by drawing on existing literature and through the creation of new projects. This year we also won funding for a standalone project, described below. All projects received ethical approval to proceed from the University of Reading Research Ethics Committee.

### Being Me Project

In accordance with the broader evidence-base, the young people in our scoping study told us that they frequently felt misunderstood by many of the non-autistic people around them. This motivated us to apply for funding from the NIHR Oxford Health Biomedical Research Centre (BRC) Mental Health in Development theme's Small Grants Awards. The funding, awarded in January 2024 enabled us to work with 7 autistic young people aged between 10 & 17 to explore the idea of 'being me'. We asked our group of participants to reflect on what they would most like other people to know about what it is like to be an autistic young person. We then worked with each member of the group individually to identify the topics they felt were most important. We then collaborated with a video production company to record a series of videos with the young people discussing their thoughts and reflections on the topic. These videos are currently

being edited and the results of the discussions with the young people are also being thematically analysed. At the end of the project, we will have a library of themed videos which we will use in our student teaching and in our work with young people and families. We will also submit a research paper for publication.

## Plans for Year Two

### Continuation of Existing Activities

We will continue to run our program of monthly talks and our practitioner SIG. Plans are in place to deliver anxiety workshops in local special schools and to work towards formal evaluation. We will also continue to develop our offer for young people by piloting and running the NeuroBears program with a cohort of young people. We will support a new cohort of placement students and plan to evaluate the autism acceptance training we offer, subject to funding from the University's Diversity and Inclusion Initiative.

### New Activities

#### *Psychological Perspectives in Education and Primary Care (PPEPCare) Training.*

PPEPCare trains and supports experienced mental health practitioners to deliver high quality evidence-based training to practitioners working in education, healthcare and wider settings. In 2016, Fiona Knott and Tom Loucas created and later updated two sets of training materials for the project, autism awareness and autism & mental health which have been delivered to numerous teams in Berkshire, Oxfordshire and Buckinghamshire since then. Working with host organisation Brighter Futures for Children (<https://brighterfuturestogether.org.uk>). Dr Fiona Knott is in the process of updating the materials and will train appropriate mental health practitioners from local NHS Trusts in the autumn. These practitioners will then roll out over the training over the coming year.

#### *Parent Support*

Based on feedback from parents, we are planning to organise a range of activities for parents and carers of autistic children with and without intellectual disability. These activities will include drop-in sessions, talks and workshops held both at the University and in our local partner special schools.

#### *Shaping Future Plans*

In line with our core value of keeping autistic voices at the heart of everything we do, we plan to engage with the community to hear more about what support is needed, and to seek ongoing guidance on projects we are delivering. At present, we have three developments planned, as outlined below.

**Survey:** In the early autumn, we plan to run a survey to invite local autistic people, parents and professionals to share their ideas about other activities we could run, and how these would be best delivered. The survey will help us shape our future offer to parents and young people.

**Autistic children and young people advisory group:** We have been awarded funding by PCLS Research Committee to work with young autistic people to help us plan and develop an advisory group. We plan to recruit and work with at least 6 young people and their families over the coming academic year to explore the purpose of an advisory group and to seek their views

about topics relating to the development of such a group, such as recruitment, ensuring diversity, inclusion of those who speak few words, group format and likely activities.

**Steering Group:** We are planning to create a steering group of autism professionals working locally and autistic adults to help sense check and steer the activities and support provided by the Wellbeing Hub. The scope of the group is likely to include oversight of activities, acting as a sounding board, supporting with decision-making, and creating links and opportunities to collaborate with local services.

## Plans for Year 3 and Beyond

In year 3 we plan to continue to deliver the activities and support we are currently providing and developing. Evaluation will be a key focus and we will undertake research and gather data to help establish how autistic families have been supported by the Wellbeing Hub and what support might be needed next. The biggest challenge faced by the Wellbeing Hub is funding, as currently funding does not extend beyond staff salaries. However, we are proud of how much has been accomplished and hope to be able to scale-up the support we provide and sustain the Wellbeing Hub for future years.