Picture-it
A digital tool to support living with autism
Katie Gaudion
About the research partners

The Kingwood Trust
Kingwood is a registered charity providing support for adults and young people with autism. Its mission is to pioneer best practice which acknowledges and promotes the potential of people with autism and to disseminate this practice and influence the national agenda. Kingwood is an independent charity and company limited by guarantee.
www.kingwood.org.uk

The Helen Hamlyn Centre for Design, Royal College of Art
The Helen Hamlyn Centre for Design provides a focus for people-centred design research and innovation at the Royal College of Art, London. Originally founded in 1991 to explore the design implications of an ageing society, the centre now works to advance a socially inclusive approach to design through design research and projects with industry.
www.hhcd.rca.ac.uk

BEING
Being was commissioned by the Kingwood Trust to shape and manage this ground-breaking project with the Helen Hamlyn Centre for Design. BEING is a specialist business consultancy that helps organisations in the public, private or charitable sectors achieve their goals through the effective application and management of design.
www.beingdesign.co.uk
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At the Kingwood Trust we are acutely aware how vital our staff are to the quality of life enjoyed by the people we support. They play an important role in providing assistance with meal preparation, shopping, managing money, leisure activities, personal care and, above all, offer support and companionship. This helps each individual to develop a greater degree of independence in order to unlock their potential and live full and active lives.

Central to the person-centred support programme at Kingwood is the relationship between the support staff, family members and adults with autism. Each person plays an important role. In combination they create a rich and diverse pool of skills, knowledge and experiences, to develop a better understanding of how the people that Kingwood support perceive and experience the world. It is imperative that such experience and expertise gets shared, and systems are in place to ensure it is not lost or forgotten.

This project investigates how meaningful interactions can be captured and documented so that expertise, knowledge and insights are connected and communicated to enrich person-centred support. It forms another critical part of providing exemplary holistic support to adults living with autism and adds to the impressive body of work already conducted and being implemented by the Kingwood Trust and the Helen Hamlyn Centre for Design.

Foreword
Lady Hornby, Chairman, Kingwood
The role of the Expert Reference Group was to provide guidance and support for the project, broaden its perspective and assess the findings and results. A formal meeting was held at the Royal College of Art in April 2014.

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Introduction

Sharing positive experiences

This publication is the fifth in a series that describes design research projects carried out by the Helen Hamlyn Centre for Design at the Royal College of Art in partnership with autism charity the Kingwood Trust, which provides support and accommodation for adults with autism.

The overall aim of the work is to improve the everyday experiences of those with autism spectrum disorders (ASD) through better understanding of their needs, aspirations and environment.

Past studies have focused on housing design, sensory props and settings, garden design and the adaptation of household objects to encourage greater participation in everyday activities. This latest project explores the development of a digital tool to help support staff at the Kingwood Trust to capture and share positive experiences in the lives of the adults with autism they support.

Autism is a lifelong and complex neurodevelopmental condition that affects the way a person communicates and relates to other people and the world around them. As a spectrum disorder it affects people in different ways. People with autism may have rigid routines and special interests; they can be sociable or find social relations difficult; some have learning disabilities whilst others possess high levels of intellectual ability.

In addition to this, people with autism might be over-sensitive or under-sensitive to the sensory elements of the environment. Sensory sensitivities are now recognised as a core symptom of autism and in 2013 they were included in the fifth edition of the diagnostic and statistical manual of mental disorders (DSM-5) for autism spectrum disorder. With an estimated prevalence rate of one in 100, autism is by no means rare.

Most of the people who contributed to this study have limited verbal communication skills and additional learning disabilities, live in supported housing and are described as having high support needs (defined as receiving more than 15 hours per week). In some cases they require constant support. Depending on individual needs, this ranges from a few hours a week to provide emotional support or help with managing finances to 24 hour cover, with personal care and house-related tasks (including shopping, meal preparation, and cleaning).

With an increasing number of people being diagnosed with autism, and with parents of adults with autism getting older and less able to provide care, many are seeking opportunities to live outside traditional care homes or their parental home. An important consideration in this process is the quality of the support that services provide – and this is partly determined by the ability to capture, share and celebrate best practice. It is in this context that Picture-it was developed.
Left and above: Kingwood staff pictured with the people that they support
'You wear about 50 different hats; one minute you are a cook, then cleaner, then swinging from trees; you’re helping the psychologist to make the right diagnosis, you’re calming someone down after a period of anxiety; you have to have so many skills.'

Kingwood Staff Member

First-hand accounts by people with autism, online blogs, forums and You Tube clips all help inform our understanding of how people with autism perceive and experience the world around them. But what about autistic people with additional learning disabilities who find it difficult to verbally communicate?

Through their collective observations, family members and support staff can be pivotal in understanding how an autistic individual perceives and experiences everyday life. They are often well placed to notice what a person enjoys and responds to, as well as what might trigger stress and anxiety. For example, the research team on this project would not have known to ask a taxi driver to stop on the other side of the street to where Mary lives had her support worker not told them that she does not like the sound of a car engine running.

At Kingwood Trust the support staff play an important role in the lives of people with autism, providing assistance with meal preparation, shopping, managing money, leisure activities and personal care. This support helps each individual to develop a greater degree of independence in order to help unlock their potential and live full and active lives.

Central to the person-centred support programme at Kingwood is the relationship between the support staff, family members and adults with autism. In combination, they create a rich source of skills, knowledge and experiences to inform a better understanding of how adults with autism perceive the world. But sometimes it is questionable as to how much of this experience and expertise gets shared. As good support practice grows, it is important that it does not become isolated and forgotten. This project investigates how meaningful interactions can be enriched and documented so that expertise, knowledge and insights are captured, connected and communicated to enrich person-centred support.

To get to the root of the problem the research team on this project engaged in participatory observation and interviewed support staff. These activities highlighted just how much valuable information gets lost as handwritten notes are passed from one staff member to another. This, coupled with a growing interest in tablet computers at Kingwood, set the context for exploring how digital technology might address the challenge of enhancing the lives of the people Kingwood support.

In co-creation workshops, staff were asked to describe how computers are currently used by those they support and to design their own digital tools. This led to two digital trials to capture additional design ideas and explore the pros and cons of using Pinterest, the popular digital photo-sharing platform. The first trial invited the people that Kingwood support to create a visual diary to be shared
with their family members. The second trial invited support staff to capture their insights and methods to be shared with their colleagues.

The digital trials informed the design of Picture-it, a digital tool to capture positive practice and experiences as they grow and evolve according to the changing interests and skills of the people that Kingwood support.

Picture-it creates a support network by:
• Inviting adults with autism to build their own visual diary of their positive experiences and achievements, to share with their family.
• Empowering support staff by ensuring that their good practice is captured, connected and celebrated, in order to enrich person-centred support and foster collaboration.
• Supporting families by enabling them to contribute and feel more connected with the daily lives of their family member.
The research team used a variety of methods to access insights into the everyday experiences of Kingwood’s support staff and the autistic people they support.

Shadowing and interviewing support staff helped to: reveal essential insights into different techniques and approaches of support staff; investigate use of digital technology; and explore how information is currently communicated between support staff and family members.

The insights and feedback derived from participatory observation helped to identify and map key opportunities for innovation. Building on this base, the study used a workshop process and two digital trials adopting the Pinterest picture-sharing platform to design and develop the digital tool, Picture-it.

**Shadowing and interviewing support staff**
The research team shadowed and interviewed support staff to explore how their expertise, tacit knowledge, understanding and experiences are communicated and disseminated. The support staff at Kingwood are creative in the way they tackle this issue. The study revealed that staff independently create an assortment of methods to help them communicate and structure personalised activities for the people they support.

**Participatory observation**
The research team investigated how some of the people that Kingwood support are currently using their computers (illustrated below).
The aim of the workshop was to encourage the participants to share and exchange their different everyday experiences with the person they support and create a picture of the day in the life of a support worker. Working in pairs, they exchanged experiences through story-boarding, which were brought to life through the making of three-dimensional theatre sets and mini productions to share with the rest of the group. Two storyboard examples are shown on the right.

The workshop generated discussion around the questions:
• Why did they decide to work with people with autism?
• What did they learn about themselves and autism?
• What do they like and dislike about their work?
• What methods have they developed?

**Storyboard 1:** Millie likes cooking. She rips the lid off the bin and brings it to the table to chop the carrots. She likes to feel the carrot skin between her fingers before putting them individually into the bin. She gives me a high five and is pleased with herself.

**Storyboard 2:** Lena enjoys going to the disco with her housemates. She also likes going for a drive back home but on the way back it’s dark and raining and there’s lightening which Lena doesn’t like. She is anxious and just wants to get back home. She is happy to be home and she enjoyed the disco.
A co-creation workshop entitled Digital Me invited support staff to explore how digital tools could facilitate communication and be incorporated within everyday life at Kingwood.

The workshop involved a series of interactive activities such as making a tablet computer out of cardboard and plastic cups. Support staff were asked to reflect on their everyday experiences at work by writing them down on paper, putting them inside plastic eggs and inserting the eggs into the relevant categories displayed on their cardboard tablet computer. The exercise created a visual accumulation of knowledge and experience. By working in groups the participants explored how this could be captured, connected and communicated between them.

This process generated discussion around the pros and cons of using digital tools such as tablet computers to support themselves and adults with autism. The workshop also revealed examples of how tablet computers are currently used within their workplace, as described on the right.

‘If they were in a street he would become anxious, but now he has started to look at a picture and he knows that it’s a dog and he knows it won’t hurt him – the next step will introduce the sound of the dog’s bark and see whether hearing it is going to keep him on a level.’

‘We started off with the (Argos) catalogue but he got frustrated trying to find the page again in the book, but on the tablet it kept the pages open. So I would say to him ‘Wardrobe’ and he would click onto the top one and up it came, it is instant rather than, what page is it?’
Pinterest is a visual digital tool that enables people around the world to collect and share their interests. The research team used the Pinterest platform to conduct two digital trials with adults with autism and support staff.

Pinterest has a simple interface, visual format and navigation, making it an ideal tool. The aim of the trials was to investigate how the participants interact with both the tablet computer and a visual digital tool to collate and share information. The valuable insights and ideas derived from both trials were used to inform the design of a new digital tool for Kingwood, which is now in development.
**Research Methods**

**Pinterest Trials**

**Pinterest Trial 1 – adults with autism**

The research team invited three adults with autism to take part in a six-week Pinterest trial. In preparation for the trial a Pinterest account was set up for participants on their tablet computer. To ensure each Pinterest was private and inaccessible to the general public, the trial took place within the secret board section of Pinterest. To avoid confusion and information overload, a minimum of three subjects within the secret boards were set up for the participants entitled; Arts & Crafts, Activities at Home and Outings.

Clear instructions were given to each participant and their support worker on how to use Pinterest. With the help of their support staff the participants were encouraged to add photographs and information about their everyday experiences that relate to the three chosen subjects. The aim of this trial was to explore the challenges and benefits experienced by autistic adults in creating their own visual diary of the things they like to do, which could be shared with support staff and family members.

**Feedback on the trial:**

'I email Tracy’s mum and tell her what she is doing every week, but I would love to show her pictures to back it up.'

'Matt’s mum would love getting the messages, she would be over the moon about it I think, she likes knowing what he gets up to.'

'It’s great to see the activities people are involved in, the fact that I’m not here for two weeks at a time, it’s good to have a simple way of catching up. It could give me a simple and quick way of finding out how someone is.'
Pinterest Trial 2 – support staff

The research team invited five support workers who support different people within the same service to take part in a six week Pinterest trial. The format was similar to the first trial when each support worker was given a tablet computer with a Pinterest account.

Eight subjects were set up within the secret board section for each participant which included: Arts & Crafts, Activity Ideas, Outings, Sensory Sensitivities, Communication Tools, Tips and Questions. In addition to this the support staff were encouraged to create their own subjects.

The aim for this trial was for the support staff to share and add images and information with their colleagues about their everyday experiences with the person they support. The participants were able to see each other’s secret boards, which enabled them to share insights, ideas, methods and techniques.

Feedback on the trial:

‘We need activity ideas for staff that are on a day-to-day basis, like Art and Crafts, something they can do if Tim doesn’t want to go out.’

‘I’ve learnt to do more and capture it whilst you’re doing it, rather than let the moment go and nobody else knows what you’ve been doing.’

‘It’s easier to have the iPad with you because you are then able to capture it then and there.’

‘New staff members are able to come in and have a look, it gives them an easy way of quickly getting up-to-date. It shows them for example that Tim likes to go out for lunch’

“There’s other staff that work across three services who can just flick on it and have a catch up on what activities are happening.”
The design research methods used in the project generated a range of useful insights that guided development of the digital tool.

- A large amount of densely written paperwork is used to exchange information between staff, meaning that relevant information can, on occasion, be lost or be difficult to process and digest (especially if English is not the person’s first language).
- In most instances support staff document the daily experiences of people they support, which can exclude the adult with autism from recording their own experiences.
- Apart from formal meetings, support staff members have minimal contact with colleagues and limited opportunity to discuss and share their experiences due to the fact that support is provided in people’s own homes across a wide geographical area.
- There is little communication between different residential sites, leaving some staff members feeling isolated on occasions.
- Methods and techniques developed by staff sometimes fail to get captured or shared.
- Meetings are sometimes focused on problems and challenges rather than achievements and positive outcomes.

- Information is static and does not grow and evolve with the changing interests of the adults with autism.
- Due to geographical divides it can be difficult for family members to visit on a regular basis.
- The trajectory of a person’s progress and achievements is undocumented.
- The trajectory of a support worker’s progress and achievements is sometimes undocumented.
- Due to a person’s learning disability, they may need extra support to use a tablet computer or to try more than one activity on a single computer.

'We don’t know what other services are doing – it would be brilliant to learn from them and they can learn from us... it can be a challenge to each other which is good. It will drive staff as well if we have ideas that other people are using. We can’t share them now because we work in individual houses across a wide geographical area.'

Support worker
Picture-it is a new, secure digital tool designed in collaboration with adults with autism and their support staff.

The aim of the tool is to enrich person-centred support by enhancing the relationship between autistic people, family members and support staff:

- Picture-it has an autism-friendly interface so that an autistic person can take control and ownership in building his/her own visual diary.
- The diary grows and evolves through their changing interests, experiences and achievements, which they can choose to share with their family and friends.
- Picture-it brings family members closer to their relative by connecting with them on a daily basis to share the things they like to do, thus giving family members peace of mind.
- Picture-it ensures that good practice by support workers gets captured, connected and celebrated to encourage more communication, collaboration and co-creation between staff to enrich person-centred support.

To demonstrate the benefits of Picture-it, a short animation was produced. It can be viewed on: http://ow.ly/D9iTw (on the Royal College of Art website)

The Kingwood Trust website: www.kingwood.org.uk

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**Picture-it animation script**

**This is a story about three people on a Tuesday afternoon using a new secure digital app designed in collaboration with adults with autism: Picture-it.**

- Fred is Sally’s support worker. Fred works with Sally most days helping her with things like cooking, managing money and shopping.
- Fred enjoys his job but like a lot of support workers he can sometimes feel isolated and would like to find ways to share ideas and have more contact with his colleagues.
- Sally’s mum Jane, and her little brother Billy live 50 miles away and only get to visit Sally a couple of times a month, they miss Sally and often wonder what she’s up to.

**This is a story about Sally:**

It’s a sunny day and Sally decides to go into her garden and pick some apples from the trees.

- There are so many apples and soon enough Sally’s basket is completely full, she is really happy.
- Fred asks shall we ‘picture-it’? Sally nods, ‘yes’.
- Sally opens Picture-it and on her home page she taps the garden section and Fred takes a photo of Sally with her apples, which instantly uploads into Sally’s garden timeline.
- Sally likes the picture and decides to share it with her mum.

**This is a story about Sally’s mum Jane:**

Jane is at work and receives a notification that Sally has just added a photo into Picture-it.

- Jane clicks on the notification and sees the photo of Sally, it’s brightened up her day and she can’t wait to show Billy when she gets home.
- To show that she enjoyed the picture Jane sends a customised symbol back to Sally, in this case yellow bubbles are chosen to reflect one of Sally’s favourite things.
- Sally receives the notification from her mum and the yellow bubble is added to her picture, which makes her smile!
This is a story about Sally’s support worker Fred:
Fred wonders what to do with all the apples... so he goes onto his Picture-it account into the Tips & Ideas section shared by fellow support staff.

- In the food section he types apples and comes across Amy’s apple crumble recipe, Sally’s favourite!
- Using Amy’s visual recipe Fred and Sally make the apple crumble, they go through each step imitating the pictures on the screen.
- When the crumble is made, Fred and Sally decide to ‘Picture-it’ into Sally’s food timeline, and to show how much they enjoyed it they decide to share it with Amy.

- Amy gets a Picture-it notification and is thrilled to see her recipe being used and sends back a smiley face, which gets tagged to the photo.
- At the end of the day Sally looks back at what she has achieved and is really happy and adds a yellow smiley face to her entire day.

Thanks to Picture-it: Sally can now take control and ownership over her life by building her own visual diary that grows and evolves through her changing interests, experiences and achievements, which she enjoys to look back on and share with her family.

Thanks to Picture-it: Jane and Billy now feel closer to Sally and are able to connect with her on a daily basis and take great delight in learning more about her interests and the things she likes to do which gives them peace of mind.

Thanks to Picture-it: Fred and Amy’s good practice gets captured, connected and celebrated to encourage more communication, collaboration and co-creation between staff to enrich person-centred support.

Picture-it: 'Where Caring is Sharing.'
Picture-it
Key features

Emotion record
An important feature of Picture-it is the ‘how do you feel?’ page. At the end of a day this feature enables a person to express how they feel by tapping onto the appropriate emotional expression. A person with autism may have difficulty understanding their emotions, but by enabling a person to express and record how they feel each day will help them to develop more understanding about how they feel, and so be able to manage their feelings better. This feature will also aid support staff in learning more about a person’s likes and dislikes.

Customised home pages
Picture-it provides three customised home pages for adults with autism, family members and support staff, with different contents and privacy settings relevant to the needs of each participant. For example, the home page for the support staff has additional features relating to their support programme such as a pictorial forum enabling staff to exchange tips and ideas.

Personalised symbols and colours
The autistic participants can choose personalised symbols that relate to their interests. These symbols act as a simple form of communication exchange and positive reinforcement between those participating.

Simple interface
A person’s hyper and/or hypo sensitivities were considered during the design of Picture-it. The interface is simple and uncluttered; information is compartmentalised to prevent visual and information overload. Block colours are used and patterns are avoided with sufficient colour contrast for the foreground and background.

The features on each page are ordered, balanced and symmetrical, with a consistent style throughout.

Age-appropriate
Whilst Picture-it is for all ages, it was important to ensure that the design was appropriate for adults.

Logical navigation
Picture-it has a clear and logical navigation system that is sensitive towards people who have a limited
concentration and attention span. To ensure a person does not get lost or confused, there are clear navigational routes to relevant information on the home page, with no more than three clicks to get to the right destination. Unpredictable features, such as animated or moving images are avoided.

**Pictorial**
Picture-it is a visual communication tool which enables people with limited verbal communication, or simply a preference to communicate via technology, to express themselves through pictures – a universal language for everyone. Picture-it empowers people with autism by enabling them to take photographs of themselves so they can reflect upon their own positive achievements.

**Audio feedback**
Customised audio feedback is available to support a person and to help them navigate through the tool.

**Secure**
Picture-it is a secure digital tool that can only be accessed via a person’s own unique user name and password. Photographs and information remain private until a person makes the decision to share them with others.

**Digital activity planner**
Visual timetables are an effective tool to support people with autism who need a clearly defined structure and routine. An important feature of Picture-it is the personalised visual activity planner. Its simple format gives autistic people autonomy in mapping out their activities for the day, week, month or year head. Importantly, this will enable a person who has a limited concept of time and difficulty in organising and predicting a sequence of events to anticipate what is going to happen. It removes surprises and helps to build confidence.

**Mobile and accessible**
Picture-it can be used on mobile phones, tablets and laptop computers, making it extremely mobile and accessible. Pictures can be uploaded and shared within any environment and context and activity planners can also be accessed and amended on the go.
**Katie Gaudion** is a Senior Research Associate in the Helen Hamlyn Centre for Design at the Royal College of Art. She holds a Master of Philosophy in Textile Design from the RCA, and received a Helen Hamlyn Design Award in 2010. Katie's design research celebrates neurodiversity and she has presented her work at a number of international conferences at countries that include China, India and the USA. Katie's specialist interest lies in designing with adults and children with learning disabilities and neurodevelopmental disorders. She is interested in discovering the latent needs of people whose experience of the world is individual and unique. Katie's work with the Kingwood Trust received the prestigious Autism Professionals Award for Best New Innovative Technology.

Katie is the founding member of Angles between Curves, a design research practice that focuses on materials development and people-centred design to create tactile, interactive and performance textiles for products and environments. In 2012 Katie began a PhD by Practice at the RCA entitled 'A Designers Approach to Exploring and Enriching Everyday Experiences for Adults with Autism.'

Katie's Doctoral research is supported by the Kingwood Trust, and brings together three distinctive and relevant forms of expertise: the people-centric design ethos of the Helen Hamlyn Centre for Design, the innovation and making orientation of RCA's Innovation Design Engineering programme and the autism expertise at the Centre for Research in Autism and Education (CRAE).

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**We would like to thank the following people for their help and support during the project:**

Lady Hornby and Sue Osborn of the Kingwood Trust; Colum Menzies Lowe of BEING; and Jeremy Myerson, Rama Gheerawo, Margaret Durkan and Mark Byrne at the Helen Hamlyn Centre for Design, Royal College of Art. A special thank you to Helen Fisher for her dedication, help and inspirational ideas. A big thank you also to David Lopez for his drawing and animation, Pete Ziegler for his help with storyboarding, Gus Pirelli for sound and Kevin Molly for his wonderful voice.

The following people generously gave their time and expertise to the project: members of our Expert Reference Group; Kate Allen and her team at Kingwood Headquarters; Sarah Baldock and her team at Kingwood College; Amy Brooks and her team at Carterton, Stuart Noble and Belinda Mcleod; Lynn Longwood and Liz Sandith who helped to organise the workshops, and all the staff members who participated.

Thank you to everyone who participated in the Pinterest Trial including family members and Kingwood support staff, especially the people they support, for taking part in the research and inviting us into their homes.

We would also like to thank the Monument Trust for making this work possible.
This publication describes a novel research project to develop a new digital tool to capture, share and celebrate best practice in supporting adults with autism in everyday life. Entitled Picture-it, the tool brings potential benefits to autistic individuals with autism and the support staff who help them on a daily basis, as well as family members who are brought closer to their relatives.

This is the fifth in a series of publications describing a pioneering collaboration in design for autism between the Kingwood Trust and the Helen Hamlyn Centre for Design at the Royal College of Art.