

# Evaluation of the Proactive Grants Programme in Autism

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**Report to the Clothworkers' Foundation**  
February 2014



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# Executive summary

## The evaluation

In April 2013, the Clothworkers' Foundation commissioned independent consultant Linda Redford and the Office for Public Management (OPM) to evaluate the Proactive Grants Programme in Autism (PGPA). The evaluation considered the impacts of the six funded projects, and generated learning around the proactive grants process.

The evaluation included interviews with the Clothworkers' Foundation, recipients of proactive and open grants, beneficiaries of the funded projects and stakeholders in the wider autism sector, as well as online surveys and a review of project documentation.

## The Proactive Grants Programme in Autism

The PGPA was established in 2008, with £1.25 million allocated over five years. In 2011 the programme was extended by a year with an additional £250,000. Carefully selected organisations were invited to apply for a grant or to compete via a tender process.

The aims of the PGPA were broadly to improve the lives of people with autism and their families/carers, improve awareness, knowledge and understanding of the condition and contribute to raising the profile of the sector at a local and national level.

## Impacts of funded projects

While the funded projects were very different in their focus and activities, they all contributed to the same overarching aims. Below is a brief assessment of the impact of the programme as a whole.

### *Improving the lives of people with autism and their families/carers*

People with autism at different stages of life (from childhood, through transition, to older age), and their families and carers, have been impacted in a number of positive ways. For example, young people have directly benefited from attending Ambitious about Autism's New Pathways College, from accessing short breaks with carers who have been trained in autism through the Reaching Out project, and from involvement with the Centre for Research in Autism Education (CRAE) and Research Autism in research projects. Families have felt these benefits directly too. Indirectly, people with autism have and will experience the impacts of improved research and practice, and improving awareness and profile of autism, as set out below.

### *Improving research and practice in autism*

Considerable contributions to research on autism have been made by the programme, notably CRAE's wide range of research activities (and exemplary practice of involving people with autism in research). Without the funding from the Clothworkers' Foundation

it would not have been possible to establish CRAE. The PGPA commitment to establish the two CRAE posts (Director and Senior Lecturer) was key to levering in further funding. The PGPA also enabled the work of New Philanthropy Capital on mapping the autism voluntary sector and developing their analysis model for use with large charities, and Research Autism's Quest study into social and emotional aspects of autism.

Improvements in practice were evident in a wide variety of ways including: the increased skills and confidence of carers after attending a Short Breaks Network training course; the increased capacity of college staff to work with young people with autism due to Ambitious about Autism's New Pathways College; the development of transition pathways also by this project; the involvement of head teachers with CRAE research via its links with the Pan London Autism Schools Network; the development of diagnosis tools for emotional and social problems associated with autism by Research Autism; and the provision of resources and training for those working with older people with autism.

### *Improving awareness of the condition and raising the profile of the autism sector*

As a whole the programme has been effective in improving awareness and raising the profile of autism at different levels. Locally projects have raised awareness of children, parents and practitioners, as in the case of the shorts breaks training and provision (different locations around the UK), the post-19 education provision (based in north London and attracting attention from a wider area), and the participating local authorities in the Quest research. Ageing and autism, a previously under-acknowledged area, has enjoyed an increased profile through the National Autistic Society's influencing and campaigning at local and national level. CRAE's contribution to this aspect of the programme has been especially notable and had a national reach, due to its impressive engagement strategy.

### **Learning around grants delivery**

#### *The proactive approach*

Many strengths of the proactive approach to giving were identified by the evaluation:

- It gives organisations the freedom to innovate (especially in the current economic climate, in which innovation may be stifled as funders 'play it safe').
- Donors tend to be more involved with recipients, giving more direction and interest in ensuring the work continues after the grant.
- By funding several projects concurrently in the same sector, the overall impact is amplified (the whole is greater than the sum of its parts).

During the PGPA, several autism charities received grants under the Foundation's open grants programme for capital projects. The two grants programmes enabled the Foundation to cover the autism sector in greater depth and with a wider geographical reach. Learning around awarding proactive and reactive grants in the same sector included the importance of a clear protocol for inclusion in the proactive programme and of building both funding streams into an overall plan.

### *Working with the Clothworkers' Foundation*

Grantees appreciated the Foundation's effective communication and support, good understanding of the autism sector, and senior level and face to face contact. Light touch reporting requirements were supported, but many commended the greater rigour introduced later in the programme. Collaboration between recipients was lacking during the programme; recipients would have liked opportunities to share learning and ideas.

### Conclusions

The Clothworkers' Foundation's contribution to the autism sector is considered by all stakeholders to have been very significant. The PGPA funding, and concurrent reactive grants funding, enabled organisations to:

- Create educational and social opportunities for people with autism, and ease the burden on families through improving short breaks and post-19 opportunities.
- Further research on autism, particularly on social and emotional aspects, and increase the involvement of people with autism, families and schools in research.
- Improve practice of professionals working in autism including carers, head teachers and school and college staff, and those supporting older people.
- Raise awareness of autism locally, around individual projects, and nationally, through the online engagement and events of CRAE.

### Recommendations

- 1. Target a sector, strategically:** Define the overall aims of the funding programme, and select the mix of organisations based on their combined capacity to meet the aims.
- 2. Develop an understanding of the sector:** Get to know the sector, in order to see how a potential project will fit into the sector and make a difference.
- 3. Offer a mix of proactive and reactive grants in the given sector:** Have a strategic approach to the mix of proactive and reactive grants.
- 4. Facilitate collaboration between grant recipients:** Provide opportunities for recipients to share learning and create relationships beyond the life of the projects.
- 5. Ensure clear governance and oversight:** Provide clear governance, such as appropriate requirements for reporting and monitoring.
- 6. Build in evaluation from the outset:** Help projects to identify performance indicators and outcome measures to demonstrate impact.
- 7. Build in attribution of impacts to funding:** Grantees should acknowledge Clothworkers' funding in their outputs, so wider stakeholders are aware of it.
- 8. Continue a supportive and flexible approach:** To enable recipients to respond to an evolving environment during the lifespan of the project.

# Introduction

## Background to the evaluation

In April 2013, The Clothworkers' Foundation commissioned independent consultant Linda Redford and research organisation the Office for Public Management (OPM) to evaluate the Proactive Grants Programme in Autism (PGPA). The evaluation considered the impacts of the six projects funded under the programme, as well as generating learning around the proactive model and grants delivery process.

### *The Proactive Grants Programme in Autism*

The Clothworkers' Foundation established the PGPA in 2008, with £1.25 million allocated over five years. In 2011 the programme was extended by a year with an additional £250,000.

The aims of the PGPA were broadly to:

- Improve the lives of people with autism and their families/carers
- Improve awareness, knowledge and understanding of the condition
- Contribute to raising the profile of the sector at a local and national level

The PGPA sought to achieve the above aims by funding organisations/projects which offered one or more of the following:

- Effective research to improve timely diagnosis and early intervention
- Improved services for people with autism (including children, those at the transition to adulthood stage, and older people) and their families/carers
- Enhanced provision of knowledge and information for autism professionals including the development, implementation and sharing of good practice
- The potential to engage, and influence, the external (i.e. not autism-specific) environment.

The PGPA was not an open grants programme. Instead, carefully selected organisations were invited to apply for a grant proactively, or to compete via a tender process. Six organisations were funded under the programme. A summary of the projects and funding allocated can be found in Appendix 1.

## Aims and objectives of the evaluation

The evaluation sought to assess the following:

- Whether, how, and to what extent the funding contributed to improving the lives of people with autism (including children, those at the transition stage and older people) and their families/carers



- Whether, how, and to what extent the funding contributed to improved research and practice for people with autism
- What contribution, if any, the funding made to a) improving early diagnosis rates of autism in children and b) appropriate subsequent intervention
- Whether, how, and to what extent the funding contributed to improving awareness of the condition and to raising the profile of the autism sector
- What impact, if any, the funding had on the wider autism sector.

As well as assessing the impacts of the funded projects, the evaluation also sought to explore the effectiveness of the proactive model of grant giving, and grant recipients' experiences of working with the Clothworkers' Foundation, in order to generate learning to inform the delivery of future grants.

## Methodology

This section provides a brief summary of the evaluation methodology. A full methodology complete with a list of data collected can be found in the Appendices.

We undertook a scoping phase including a review of key documentation relating to each of the funded projects, drawing on aspects including each project's: funding, timing, intended aims, activities and beneficiaries, impact measurement and achievements to date.

The main fieldwork phase included the following activities:

- **Proactive grant recipients:** Semi structured interviews were held with representatives from each funded project. These interviews focused on two areas: impacts of the project, and reflections and learning from the proactive grants process.
- **Beneficiaries of funded projects:** We identified individuals who had benefited from the funded projects including practitioners working in autism, academics or researchers and people with autism or their carers. The majority of beneficiaries were interviewed by telephone, and for one project (CRAE) an online survey was circulated via the organisation.
- **Wider autism sector:** A small number of interviews and an online survey gave wider sector stakeholders (not necessarily directly connected with the funded projects) the opportunity to give their views on the funded projects and the proactive grants process.
- **Virtual practice group:** Other grant funding organisations that deliver funding by programmes were invited to contribute their views by phone or email. They reflected on the strengths and weaknesses of using a proactive model compared to alternative models of grant giving.
- **Reactive grant recipients:** Interviews were held with autism organisations who have received grants from the Clothworkers' Foundation under their reactive (open) grants programme, to better understand the implications of awarding different types of grants within the same sector (autism).

### **Note on demonstrating impact**

As the evaluation got underway we noted a number of factors affecting the ability to demonstrate the programme's impact, which should be kept in mind while reading this report.

- All of the funded projects are different and have demonstrated impact in different ways. Several of the projects are removed from direct beneficiaries (e.g. focusing on research or profile-raising) and therefore the evaluation found evidence of activities and 'outputs', more so than impacts per se.
- In some instances, the relevant staff and beneficiaries of the funded projects were no longer at or involved with the grantee organisations, therefore they could not be accessed in order to contribute their views to the evaluation.

### **This report**

The rest of this report is as follows:

- a summary of developments in the autism sector, to set the funded projects in context
- the impacts of each funded project
- the impact of the programme as a whole
- learning around grants delivery, including the proactive model
- conclusions and recommendations.

# Context: the autism sector and the PGPA

## *History of the autism sector<sup>1</sup>*

- **1943** autism is first identified as a condition
- **1944** Asperger's syndrome is first described
- **1962** National Autistic Society is founded by a parent advocacy group
- **1977** study by Rutter and Folstein identifies the genetic link to autism
- **1979** the idea of an autism spectrum is first presented
- **1980** the Diagnostic and Statistical Manual of Mental Disorders (DSM) recognises autism
- **1989** World Autism Awareness day is celebrated for the first time
- **1989** the first diagnostic criteria for Asperger's are described
- **1994** Diagnostic and Statistical Manual of Mental Disorders (DSM) recognises Asperger's as separate from autism
- **1997** *Autism: the international journal of research and practice* is founded
- **2000** the All Party Parliamentary Group on Autism (APPGA) is founded
- **2003** the charity Research Autism is established
- **2009** the Autism Act 2009 is introduced
- **2009** the autism-led group Autism Rights Movement UK is formed
- **2010** Government publishes an Adult Autism Strategy to ensure adults with autism get the services they need
- **2011-2013** National Institute for Health Care and Excellence (NICE) announce guidelines for the identification, diagnosis and treatment of people with autism

## *New Philanthropy Capital report - A Life Less Ordinary*

In 2007 New Philanthropy Capital (NPC) published the report 'A Life Less Ordinary: People with Autism'<sup>2</sup>. The report looked at the needs of people with autism and its impact on them and on their families/carers, at government and public attitudes to autism, and at the role of the voluntary sector. The report serves as a guide for donors and funders looking to assist charities working with people with autism.

The report concluded that there were four priority areas where donors could make the largest impact: research (medical and educational); transition from school to adulthood; supporting adults with autism; and improving information and advice for parents and individuals with autism.

<sup>1</sup> Dates and events taken from 'A Future Made Together: Shaping Autism Research in the UK', Liz Pellicano, Adam Dinsmore and Tony Charman, available at: <http://www.ioe.ac.uk/research/88499.html> (accessed 14.01.14) and the National Autistic Society's Timeline of Key Events, available at <http://www.autism.org.uk/news-and-events/about-the-nas/who-we-are/timeline.aspx> (accessed 14.01.14)

<sup>2</sup> 'A Life Less Ordinary, People with Autism: a guide for donors and funders', (2007, Adrian Fradd and Iona Joy), available at: <http://www.thinknpc.org/publications/a-life-less-ordinary/> (accessed 24.01.14)

### *The Clothworkers' Foundation's response*

The rationale for establishing a proactive programme was to allow the Clothworkers' Foundation to become more informed about particular areas of giving, and thereby identify priorities and interesting projects. The Foundation also wanted the flexibility to influence the shape or focus of a particular piece of work.

This was a significant step for the Foundation, moving from a very broad and largely reactive approach, and was seen as potentially being an initial move towards greater targeting in its grant-making.

Although there is some flexibility, proactive programmes generally have a five year life.

The Clothworkers' Foundation has had a longstanding interest in supporting people with autism, having followed and supported the development of specialist autism schools Priors' Court School in Berkshire and TreeHouse School in London.

The publication in 2007 of NPC's report 'A Life Less Ordinary' was pivotal in the decision to develop a Proactive Grants Programme in autism and the selection of the projects to receive funding under the programme. Having chosen autism as the theme for the proactive programme, trustees were committed to making the most difference possible with the funds available to a sector that, at the time, was not well known or understood by funders:

*'We knew we wanted to be strategic and made good use of the NPC 2007 report. We wanted to identify where the money could make the most difference.'* (Stakeholder, Clothworkers' Foundation)

A proactive autism committee, substantially supported by the grants team, was established to undertake further research and to develop the new programme.

Findings from the NPC report were used to guide the selection of a range of charities and activities that represented the breadth of the sector. Grants were awarded for both research, strategic and practical support, including a mixture of projects that would produce both fast and 'slow burn' impacts.

The PGPA focused initially on autism research, via a major grant to establish an academic autism and education centre in London and a research grant to improve early detection and intervention of behavioural difficulties in children with autism. Following this, a grant was given to improve advocacy for parents/carers through a project to train more carers to look after children with autism, and promote good practice in care provision.

Recognising the value of the original NPC report, a grant was made to this organisation to produce an updated report on the autism sector, including an in-depth analysis of a major autism charity.

The next part of the programme focused on autism in adulthood. Leading autism charities were invited to tender for a project to deliver work supporting the transition from school to adulthood. The final grant was made to a project addressing autism and ageing, an area identified in the NPC report as being severely under-resourced.

## Impacts of the funded projects

This section gives a short description of each funded project and presents the impacts of the project based on the data gathered during the evaluation. Projects are presented in chronological order according to when they received their PGPA grant (starting with the earliest).

### Centre for Research in Autism and Education: Institute of Education and Ambitious about Autism

#### *About the project*

**Description:** The Institute for Education (IoE) and Ambitious about Autism received funding to establish the Centre for Research in Autism Education (CRAE) at the Institute of Education. The project has involved establishing Director and Senior Lecturer posts to be active in five key areas of work: scoping and augmenting autism education research (in the UK and internationally), building a research/practice interface, developing programmes of teaching, contributing to the policy and practice climate and enhancing the work of the IoE's existing programmes. In practice, this has involved producing funding bids and securing grants, securing premises, providing a base for doctoral students, working with families and children at an observation site developed in the IoE (with additional IoE funding of £50k), and developing an engagement strategy for dissemination of research.

**Aims and context:** The aims of the project were to establish a Centre to: undertake research into how to remove barriers to learning and participation in schools and society for people with autism, determine how autism education practice in school and society as a whole can be evaluated more effectively, promote the translation of research into practice to ensure that it has impact where it is needed most, and enhance existing work by supporting researchers and evidenced based practitioners in the autism field throughout the UK. Without the funding from the Clothworkers' Foundation, it would not have been possible to establish CRAE.

**Funding:** The Clothworkers' Foundation provided £700k, originally to be spread over five years but subsequently agreed to be paid over two years in order to allow CRAE to lever in significant additional funding from the Higher Education Funding Council for England. Funding was also received from the Pears Foundation and Kirby Laing Foundation. Funding covered Director and Senior Lecturer posts for five years, with some flexibility allowed to cover start-up and running costs including events and engagement activities and to enable bids for research grants.

The Psychology and Human Development Department at the IoE will take over funding of the Director and Senior Lecturer posts after the end of the Clothworkers' Foundation funding. Any additional costs will be funded through fundraising.

*Changes:* There was significant underspend in the last year of funding (2013), because of delays in appointing new staff, which means that the original funding will continue to cover CRAE's costs through to December 2014. Initially funding was not intended to be used for research projects but the Clothworkers' Foundation agreed that it could be used in this way.

### **Evaluation activity**

- Document review: grant application, assessment and offer letter, financial and annual reports and minutes of advisory group meetings.
- Interviews: two stakeholders at CRAE, one at the IoE, two students who have autism and who undertook work experience placements at CRAE, a head teacher and three wider sector stakeholders in academic/research roles.
- Online survey: circulated to CRAE's distribution list<sup>3</sup>; 10 responses were received, a small number in each of range of roles including students, professionals and parent/carers.

### **Impacts**

CRAE's key (linked) areas of impact have been enabling research and teaching about autism, and engagement of the broader autism sector and public to create dialogue and bring researchers and the autism community together. As described by stakeholders:

*'CRAE's research adds value because it's applied. It creates real impact by pulling together high quality research. The Centre has made a huge effort to reach out – Liz [the current Director] is fantastic at engaging the user community.'* (IoE stakeholder)

*'CRAE now has a clear presence; it has a good reputation because of the people involved and because of the autism research in general that it engages in. There is a clear impact from the dissemination of research findings and speakers that CRAE facilitates; they do research and dissemination.'* (Wider stakeholder, academic/research)

Effective linking with other organisations and networks across the autism sector has also helped CRAE to raise the profile of its work and increase its impact.

### **Research and teaching**

As already noted, the commitment of the IoE to continue funding key posts at CRAE after the grant funding, and to support fundraising to meet other costs, is testament to CRAE's high status within the Institute. CRAE takes a psychological and educational approach as opposed to a bio-medical model; these aspects are perceived as critical in terms of improving outcomes for people with autism.

Before the establishment of CRAE, the IoE lacked expertise in autism; they now have a **Masters programme** in Special Educational Needs and Psychology which is enhanced

<sup>3</sup> CRAE's email list has over 3,000 contacts, but many of these are no longer active

by modules on autism. Having CRAE staff with autism expertise, research experience and time has meant that autism feeds very strongly into the taught Masters programmes, thereby expanding the pool of professionals who include autism in their area of expertise and spreading evidence of what works:

*'Special Educational Needs [professionals], Educational Psychologists and, to some extent, research PhD students spread [their knowledge throughout] the field – this has impact and momentum of its own.'* (CRAE stakeholder)

The number of **dissertations** around autism has increased significantly because CRAE is able to provide high level supervision. Around 47 dissertations (five doctoral and the rest Masters) have been supervised by CRAE staff to date. A further 11 Masters students' dissertations, four doctoral students (two in educational psychology and two in education) and three PhD students are currently being supervised.

*'CRAE is generally well integrated within the IoE. The staff and Centre are highly regarded.'* (IoE stakeholder)

CRAE has also provided one **undergraduate placement** each year, with the exception of one year when the quality of the applications was poor, as well as placements for psychology students (three to date). Two respondents to our online survey had taken part in a placement or internship and both gave the experience 100% positive feedback.

To extend the teaching offer, CRAE is currently considering offering **short courses**, for example, on sensory sensitivities in autism. The market development unit at the IoE is exploring potential demand for these.

CRAE offered **work experience** to a secondary school pupil with autism in summer 2013, and a further opportunity in the autumn half-term holiday. The summer work experience was regarded as positive both for the research assistants at CRAE, and by the participating pupil:

*'I expected to be shuffling paper around, but I was very involved and active.'* (Work experience pupil, CRAE)

This young person has used his CRAE experience and CRAE materials to design a talk which he will deliver to school staff, to help them to understand more about diagnostic measures and ways of supporting children with autism at school. He intends to begin the talks when he has more free time from his studies.

Involving children, young people and families in setting the research agenda has been a key aspect of CRAE's approach. Feedback from those helping to shape and **participating in research** was also very positive. Respondents to our online survey uniformly reported benefits from their involvement including improved knowledge and understanding of autism, improved access to evidence-based resources and information, and ability to spread awareness of autism to others.



One research participant with autism, who attended a CRAE conference and then became involved in a research project as a participant and reviewer of the draft report, reflected on his positive experience of participation:

*'I was pleased by the way I was involved in this project. I talked for more than what the time allowance was for, and yet this did not become an issue and I felt I was being listened to and respected in my views. I was pleased with the final report that came from this project and glad to have been involved in it. [...] I am involved with many similar organisations and projects, and I think CRAE did a good job of this work. There is much variety in how one is treated - and CRAE does well in comparison.'* (Research participant, CRAE)

The participant noted an ongoing need for collaboration between researchers and people with autism, and involvement of researchers who themselves have autism. The participant felt that CRAE had the potential to build on this, in terms of determining future research priorities and engaging people with autism in research activities.

#### Leveraging of other funding

The PGPA commitment to establish the two CRAE posts (Director and Senior Lecturer) was key to levering in further funding, for example, two years funding from Pears Foundation was contingent on the setting up of CRAE. In addition, a small grant was received from Kirby Lang Foundation, as was funding from the IoE, including alumni funding (which is significant within the IoE and reflects the fact that CRAE regularly gives talks to the alumni).

CRAE has applied for and secured many research grants during the lifetime of the project<sup>4</sup>. Since 2009, 22 research projects have been funded, a list of which can be found in Appendix 5.

#### *Engagement of the autism community*

##### Events

Since 2009 CRAE has organised **annual lectures** with prominent speakers from the autism community. There has been a gradual increase in attendee numbers from 40 to 150 and the 2013 event was fully booked within eight hours. The lectures provide a platform for discussion for a wide range of interested members of the autism community. They have been very positively received: as well as the increasing demand for places, staff observed that *'people don't want to go home'* at the end of the events.

In addition to the CRAE annual lecture there are events approximately every six months at the IoE, taking the form of **discussion panels** on controversial issues. Topics have included: who should speak for autistic people and in which circumstances, and recent changes to diagnostic criteria (350 attendees).

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<sup>4</sup> Details of CRAE's research activities (and events and publications) can be found on the Institute of Education website at <http://www.ioe.ac.uk/research/28033.html> (accessed 24.01.14)

A 1-day **conference** on ethics looked at cure and prevention, vs. autism as difference rather than a disability. A hundred and seventy people attended, representing a huge diversity of views. This event was considered by CRAE to have been ‘pivotal’ in establishing a forum for people to share their views.

CRAE has also organised **film screenings**, including one of the film “Too sane for this world”, based on the lives of 12 autistic adults in the US. Around 200 people attended. A showing of the film “Citizen Autistic” is planned for January 2014 and CRAE plan to build on this to develop debate and thinking about autism rights.

CRAE events have had good attendance and received positive feedback anecdotally, as well as in our online survey (across all types of events, respondents rated their attendance as very or quite effective in terms of improving their knowledge, awareness and ability to share learning about autism). Events have given people with autism a voice, because their participation has been strongly encouraged and facilitated.

As a parent who has been involved with CRAE engagement channels noted:

*‘CRAE is an exceptional organisation because it places its role and its research in the real work and sees the benefit of connecting with the community, especially the autistic community. They clearly look for practical results and want an interactive approach to learning about autism education. They benefit people connected with autism and we in the autism community can help CRAE with their research as best we can. This is quite unusual in research organisations and I consider them a beacon of good practice as a result.’* (Parent and consultant in learning disabilities)

The possibility of using iPads to obtain feedback immediately after events is currently being explored.

#### Online and print engagement

The range of online and print engagement channels being used by CRAE to reach a wide range of stakeholders includes the following:

Communication channel	Activity <sup>5</sup>
<b>Website</b>	<ul style="list-style-type: none"> <li>— Almost 7,000 visits to the CRAE landing page by over 2,000 visitors in the year to September 2013</li> <li>— Most popular pages were ‘research’ (1,835 views), ‘publications’ (761 views), ‘events’ (509 views) and ‘news’ (447 views).</li> </ul>
<b>Emails</b>	<ul style="list-style-type: none"> <li>— Emails to CRAE’s email database, for example about events and surveys, have exceptionally high ‘open rates’ (i.e. the number of recipients opening the email) of around 45-50%</li> </ul>

<sup>5</sup> All information provided by CRAE, September 2013

	<ul style="list-style-type: none"> <li>— This is considerably higher than average open rates, and higher than high profile email communications by other IoE departments).</li> </ul>
<b>Facebook</b>	<ul style="list-style-type: none"> <li>— Used particularly by parents of children and young people with autism</li> <li>— 150 members of the Facebook site.</li> </ul>
<b>Twitter</b>	<ul style="list-style-type: none"> <li>— Particularly used by researchers and adults with autism</li> <li>— 700 'followers' on Twitter</li> <li>— In an example week (during September 2013) there were around 200 'clicks' showing users to be actively accessing the feed</li> <li>— Of respondents to our online survey, those who follow CRAE on Twitter all or nearly all found this channel 'very effective' in enabling them to connect to others in the autism sector and share learning about autism with others.</li> </ul>
<b>Newsletter</b>	<ul style="list-style-type: none"> <li>— Produced 6-monthly and has 4,000 recipients</li> <li>— Mainly goes to special schools and resource bases in London, and schools then distribute it to parents</li> <li>— Available in paper version in order to reach people who do not use email</li> <li>— The number receiving the email newsletter has increased from 300 in 2009 to 1,500 in 2013</li> <li>— Respondents to our online survey reported that newsletters, e-news and reports from CRAE had improved their access to evidence-based resources and information about autism.</li> </ul>
<b>YouTube</b>	<ul style="list-style-type: none"> <li>— Used by CRAE to deliver live webcasts</li> <li>— CRAE are the first part of IoE to have established a YouTube channel</li> <li>— 333 viewings between June and September 2013.</li> </ul>
<b>Publications</b>	<ul style="list-style-type: none"> <li>— These are designed and presented in a 'glossy' format, in response to feedback from schools and others that publications are better received when they are more visually appealing.</li> </ul>

CRAE interviewees reported anecdotal feedback from parents that they value the opportunity to hear about new research and evidence via accessible and convenient channels such as those above (as parents are often limited in their capacity to travel to events due to their caring responsibilities). In the words of the young person with autism who undertook a work experience placement with CRAE:

*'I have only known CRAE a few months but they do good work in raising awareness and taking it out to the public, through Twitter etc. People often talk about autism and have no scientific backing to what they are saying, it's just their opinion. So to see them using scientific evidence, it's really good.'* (Work experience pupil, CRAE)

## Media coverage

As well as its own communications and engagement activities, CRAE research has received some high profile media coverage, including in peer-reviewed medical journal The Lancet and on the BBC's Today programme.

## Links with other autism organisations

CRAE has built links and established a presence in a number of fields and formats in order to further disseminate research evidence relating to autism.

### Pan London Autism Schools Network

CRAE works closely with the **Pan London Autism Schools Network (PLASN)**, made up of 14 head teachers in London. The network meets termly or 6-monthly and has led to more head teachers being involved in research, and greater co-production. A head teacher in the network reported a number of benefits of their involvement with CRAE:

- Head teachers have gained greater confidence to support children with autism and their families
- PLASN members have offered ideas and helped to shape and design research studies
- PLASN schools have enabled access to large pools of children to participate in research studies
- Parents and children have felt empowered and positive about their involvement, through having their contribution acknowledged in CRAE reports and publications (CRAE sends copies to participating families).

*'CRAE is now listening to children, young people and families about the areas of research that it would be helpful to focus on.'* (Head teacher, PLASN)

CRAE and PLASN set up the **Research Practice Network**, which also involves Bangor University and other universities, to further extend their reach and capacity.

### Other links

CRAE supports a **special interest group for educational psychologists** on autism, providing a venue as well as sourcing key note speakers.

A large number of autism professionals are reached by CRAE through the **National Autistic Society (NAS)**. A CRAE interviewee reported that NAS's Research In Practice and Autistica now look to CRAE to provide leadership, and CRAE staff have written articles for NAS's web-based network of professionals including a piece entitled "A Future Made Together".

Other relationships include:

- CRAE supports a research group focussed on outcomes, with the **Autism Education Trust**
- CRAE staff sit on the scientific advisory group for **Research Autism**.

## Quest research project: Research Autism

### *About the project*

**Description:** The Quest research project gathered data showing the prevalence of emotional and behavioural problems and of psychiatric symptoms among young children with autism, as well as evidence on the stability of symptoms over time. The project also developed questionnaires for diagnosis that are acceptable to parents, as well as reliable and valid, and that could be incorporated into practice in child mental health services<sup>6</sup>.

**Aims and context:** Research Autism was set up in 2003 at the instigation of parent members of the National Autistic Society (NAS) to focus on research into interventions and social aspects, as opposed to research from a clinical perspective. Research Autism was featured in the first NPC review of the autism sector, and judged to offer good value for money to donors. The funded project was designed based on research carried out in 2004/5 which surveyed the NAS membership to identify their priorities. A key priority that emerged was the early identification of problem behaviour. As a result, the project had already been identified when Research Autism was offered funding by the Clothworkers' Foundation. The project aimed to ascertain the prevalence, severity, impact and pervasiveness of a wide range of emotional and behaviour problems in a sample of children aged 4-8 years who have autism; determine the prevalence of psychiatric disorders using agreed diagnostic classification systems and assess which of two questionnaires was best for routine use in clinic.

**Funding:** Research Autism received £158k initially (in 2007) for the Quest project; this was topped up in 2011 with an additional £10k.

### *Evaluation activity*

- Document review: grant offer letter, assessment of application, progress reports (2008-2011).
- Interviews: three stakeholders from Research Autism and one from the wider academic/research field.

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<sup>6</sup> Quest study: Ascertaining prevalence, severity, impact and pervasiveness of emotional and behaviour problems in children with autism. See [http://researchautism.net/pages/research\\_autism\\_projects\\_studies/research\\_autism\\_project\\_022](http://researchautism.net/pages/research_autism_projects_studies/research_autism_project_022) (accessed 24.01.14)

## Impacts

### *Key findings of the Quest research project*

The Quest research project demonstrated two key findings: the high prevalence of emotional and behavioural problems and of psychiatric symptoms among young children with autism; and the high stability of symptoms over time. It also gathered sufficient data on girls within this group to enable gender comparison, for the first time. Some excerpts from the Quest study final report (September 2011) illustrate the key findings:

*'Our analyses confirm a 70% rate of behaviour problems in this group of young children with ASD, stable over time, judged by parents to be of significant impact and pervasive in that they occur at home and at school.'*

*'Eighty six per cent of parents who experience behaviour difficulties with their children had asked for help but were still reporting significant problems.'*

*'Twenty five per cent of all parents surveyed experienced significant personal distress which was correlated with the impact of the behaviour.'*

### *Impacts on practice*

Stakeholders at Research Autism reported the following impacts of findings of the Quest research:

- changes to the way that children with autism are assessed for problem behaviour
- a new protocol for clinicians to assist in the identification and treatment of associated behaviour problems
- a new protocol for follow up children that will provide the means of evaluating the effectiveness of treatment for behaviour disorders.

The findings of the study also provided information of value to those providing education, health and social care support to the children which is expected to have a positive impact on the quality of service provided to the children in the study and other children with autism who will be coming up through the two local authorities involved in the study over the coming years. These professionals will have a better understanding of the needs of children with autism and emotional, behavioural or psychiatric needs, leading to the development of more effective services for them.

A wider pool of professionals working with children with autism may be impacted in the future, when four papers detailing the outcomes of the research are published (Research Autism can assist with dissemination of these as and when this takes place).

### *Impacts on children and parents*

Impacts on children follow on from improved awareness and understanding of professionals and services. In the short term, parents of the 258 children who were seen

in school for IQ and language assessments have commented that the assessments and subsequent feedback reports were useful to them, both in terms of providing an insight into their child's learning abilities and as a basis for planning for the future.

### *Impacts on the organisation*

Involvement in the Quest research project had a number of positive impacts for Research Autism as an organisation:

- It made Research Autism think about how to work with the research project team and what they need from them in order to report back to funders in an accessible way, and to develop processes in order to do this
- It gave Research Autism the opportunity to demonstrate their ability to manage a significant level of funding
- It helped clarify Research Autism's role in relation to funders and academic/health researchers: Research Autism can act as a conduit between the two parties and help to access funding from funders who would not usually fund academic/health research directly
- Research Autism is a young organisation and has gained credibility by having received a grant from the Clothworkers' Foundation.

### *Unintended impacts*

The Quest project has been used as a launching pad to gain a programme grant from the National Institute of Health Research (NIHR) to intervene in the management of behaviour problems in children and young people with autism. A key part of the study will be revisiting the Quest families and seeking their views on what is most difficult for them, what they think influences behaviours and what treatments they would find helpful. The researchers feel that the value of having access to a cohort of children for longitudinal follow up cannot be overestimated.

They also say that without the Clothworkers' Foundation funding, this project would not have been possible and that therefore they would not have been able subsequently to secure the NIHR grant for the follow on project:

*'Funders like the Clothworkers' are invaluable as they can fund the small scale research projects that can provide the 'proof of concept' for them to then take the idea to the big funders; NIHR won't look at anything without this.'* (Stakeholder, Research Autism)

## Reaching Out project: Short Breaks Network

### About the project

**Description:** Short Breaks Network (known as Shared Care at the time of the grant award) ran a carer training programme across the UK, involving free one-day training courses for (professional) carers, focusing on looking after children and young people with autism, in order to improve the quality of care during short breaks.

**Aims and context:** Through the carer training programme, the project aimed to develop the organisation's work in autism as part of the Reaching Out campaign. It aimed to share good practice in providing breaks to children with autism through the regional network of 200 short break schemes. It also aimed to increase the number of children with autism UK-wide receiving short breaks, and to improve the short breaks services they receive.

**Funding:** The Clothworkers' Foundation awarded a grant of £145k to the Short Breaks Network for the Reaching Out project.

### Evaluation activity

- Document review: grant invitation letter, assessment of application, progress reports (2008-09).
- Interview: with a stakeholder from Short Breaks Network. Short Breaks Network also provided feedback from professional carers and parents.

## Impacts

### Impacts on carers

Eighteen one-day training courses were held and all of the days were oversubscribed. The courses provided training for 254 carers. This is likely to have impacted around 1,850 family members, in families with a child with autism.

Short Breaks Network contacted participants after the training to ask them to report any changes to their practice. The response rate was low (as is usually the case for Short Breaks Network training), but responses indicated that, following the training:

- More carers were providing a service to a child with autism
- Those who were already providing care to a child with autism reported that the training had helped them in their role and increased their confidence.

Comments from carers included:

*'Useful ideas included using photos and flash cards as prompts – the ideas for sensory play activities and how to simplify everything, speech and actions.'*

*'[I] learnt to keep language simple and clear, and to wait [for the response].'*



*'Saying the child's name before asking a question has reduced misunderstandings.'*

### **Impacts on parents and children**

Carers who attended the training were asked to pass on a survey questionnaire to the parents of the child they looked after, to assess whether parents had noticed any changes in their child's care<sup>7</sup>. Parent noted that, following the training:

- Their carer was more confident in looking after their child
- The training helped their carer to understand some of their child's behaviours and therefore be more able to meet his/her needs
- The training gave their carer practical strategies and tips to use with their child
- There were improved communications between carer and child
- There were reductions in the child's levels of anxiety.

Asked what short breaks meant to them, parents' responses included:

*'[They are] a lifeline. Time to re-charge our batteries and do family things without having to 'think autism'.'*

*'[Short breaks] keep our family functioning.'*

### **Impacts on the organisation**

The Clothworkers' Foundation grant was timely for the Short Breaks Network, coming at the beginning of the Government initiative *Aiming High for Disabled Children*. This initiative had a focus on short breaks funded by the Department for Children, Schools and Families (now Department for Education). The initiative brought a new level of attention and profile to the work that Short Breaks Network had been doing for many years, and in which they were perceived as experts, having provided evidence to the Government about what worked. However, Aiming High made it harder for the organisation to maintain this high profile, as large private companies moved in to bid to deliver government contracts. The Clothworkers' Foundation funding therefore provided the necessary boost to keep Short Breaks Network's profile high at this time.

*'The door was opened by the funds from the Clothworkers.'* (Short Breaks Network stakeholder)

Short Breaks Network built in sustainability to their project by choosing to develop training modules on autism that would build on and fit into their existing training modules. While the funding has ended, its impacts continue through the training modules which are still being used. Short Breaks Network continues to offer the training to individual participants, as well as training local authority teams.

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<sup>7</sup> Seven parents responded. The number of questionnaires distributed is not known: not all of those who attended training were already caring for children with autism, so would not have been able to pass on a questionnaire to a parent.

*'Previously autism felt like an add-on – now it is embedded in our work.'* (Short Breaks Network stakeholder)

## Changing Lives report: New Philanthropy Capital

### *About the project*

**Description:** NPC's 'Changing Lives' report<sup>8</sup> presented an analysis of the autism voluntary sector, with a focus on the preceding three years. As well as this report, NPC carried out an in-depth analysis of one charity in the sector using a methodological framework. This was the National Autistic Society (NAS), which was selected as it is the largest and most important charity in the sector. At the time, it had undergone recent changes in its strategy and senior management.

**Aims and context:** NPC produced an earlier version of the report in 2007, entitled 'A Life Less Ordinary' which was used by funders and charities, including the Clothworkers' Foundation, to inform their priorities and increase their effectiveness. Since then, NPC had continued to stay up to date with developments in the sector and provide ongoing advice to clients, and through the funding to produce the updated report, 'Changing Lives', sought to update and deepen this knowledge and reflect the significant changes that had occurred during the intervening three years.

**Funding:** The Clothworkers' Foundation grant of £35k was used to fund the research report update and the analysis of NAS.

### *Evaluation activity*

- Document review: grant proposal, assessment of application, 'Changing Lives' report (NPC, 2010), in-depth charity analysis of NAS.
- Interviews: two stakeholders at NPC and two stakeholders in charities.

## Impacts

### *Impacts on NPC*

The process of producing the report and the charity analysis contributed significantly to NPC's understanding of how charities function as institutions and of disability issues more broadly.

It also contributed to the development of NPC's framework for the analysis of individual charities. Although it was not the first such analysis undertaken, it was only the second

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<sup>8</sup> 'Changing Lives: a report on the autism voluntary sector' (2010, Adrian Fradd and Sarah Hedley), available at <https://www.thinknpc.org/publications/changing-lives/> (accessed 24.01.14)

one undertaken with a large charity such as NAS; the model had been developed initially for analysis of smaller charities.

*'There was a lot of in-house learning in carrying out the NAS analysis. There were so many people to talk to in such a large and complex charity; it was geographically spread and was going through a time of transition; it was an uncertain time for staff.'* (NPC stakeholder)

Developing an analytical model to apply to charities' activities fills a gap in current research methodologies, as explained:

*'The research world is dominated by the medical research world which doesn't always listen to families and those directly involved; they are focused on research methodology and especially randomised controlled trials (RCTs) which are not always possible when carrying out more social research.'* (NPC stakeholder)

Additionally, the project helped to launch NPC into the consultancy sector:

*'The research work carried out for the Clothworkers' Foundation gave credibility to NPC for further activities.'* (NPC stakeholder)

### **Impacts on NAS**

In NPC's earlier (2007) report, NAS had not received a wholly positive write-up. In the update report and the charity analysis (2010), the new CEO of NAS hoped to see an honest and independent assessment of the organisation, which would demonstrate the progress made in three years. NAS welcomed the independent external viewpoint and challenge of undergoing NPC's analysis:

*'I welcome anything that brings in an intelligent spotlight on the work of the charity.'* (Stakeholder, NAS)

The update report and the analysis provided NAS's Board of Trustees with the external reassurance they had wanted, that the charity was going in the right direction. The positive findings of the analysis enabled NAS to use it to show to funders and potential funders, including the Clothworkers' Foundation, to demonstrate the achievements and credibility of the organisation.

### **Impacts on wider sector**

The 'Changing Lives' report was posted on NPC's website and has received over 400 downloads. The media coverage of the launch of the report, which included coverage in The Guardian, helped raise awareness and increase knowledge about autism and disability issues in general.

*'The publicity around the launch of the report raised the profile of the autism sector.'* (Stakeholder, Resources for Autism)

NPC stakeholders interviewed felt that 'Changing Lives' was a useful source of evidence for the Clothworkers' Foundation, to inform decision making on the ongoing grants programme in autism and thereby ensure that future funding could be directed effectively.

## New Pathways College: Ambitious about Autism

### *About the project*

**Description:** Ambitious about Autism received funding to set up the New Pathways College, a college-based support service for young people aged 19+ and their families, including siblings. Many of the young people graduate from TreeHouse School which is also run by Ambitious about Autism, before going on to the New Pathways College. The service is based at and delivered in partnership with Barnet College, a mainstream college with a strong history of supporting students with learning disabilities, but which was not equipped to meet the needs of young people with complex autism. It marries domiciliary care with meaningful further education; tutors make home visits.

**Aims and context:** Research had demonstrated a demand for post 19 education, with around 250 young people with autism leaving school each year in north London, where Ambitious about Autism's school, TreeHouse, is located, and having very limited options to continue their education (the main option being residential out-of-area placement). TreeHouse's strategic review found that without adequate provision post 19, return on investment in education would be limited. As well as supporting young people to continue their education post 19, and to support families of young people with autism during this stage of their education, the project also aimed to provide training and experience to staff at Barnet College and build capacity, establish pathways and a model for post 19 provision for people with autism in mainstream HE settings and generate learning around what works.

**Funding:** The Clothworkers' funding of £200k was used to fund the Head of Service post for two years, administration of the service, recruitment costs and a Saturday Pathway Group. Additional funding was secured from BBC Children in Need to fund a Family Resilience Officer.

**Changes:** Funding was used as planned with the exception of the Saturday Pathways group. The group was intended for pupils of Treehouse and some other schools to help with transition to post 19; however, early on it became clear that the group format was not appropriate because there was a need for greater personalisation of this element of the transition pathway. Building on this experience, some students who would start college in September 2013 started attending at the end of the summer term, in order to become familiar and comfortable with the environment before they were joined by other students. The change was agreed with the Clothworkers' Foundation.

### *Evaluation activity*

- Document review: grant application, assessment and offer letter, four progress reports (2011-12).
- Interviews: three stakeholders at Ambitious about Autism; one parent of a young person with autism.

### **Impacts**

#### *Impacts on young people and families*

##### Number of young people attending college

Four young people commenced college attendance in September 2012. A further 10 were attending by Christmas 2013. Two more will be starting at the end of February 2014. It is intended that intake will reach 36 young people per year by autumn 2016. Young people can attend college for two or three years according to their needs and preferences.

##### Impacts on young people

Interviewees reported that young people with autism attending the college have had the opportunity to progress into **mainstream further education** that they would not have otherwise had. They have been able to access training and employment opportunities that are suited to their individual needs and aspirations, and to dip in and out of different activities in order to explore their strengths and interests. Each student has benefited from a **personalised curriculum**, for example:

- a student who had previously been excluded from another college undertook a brick-laying course
- another student focused on independent living skills and using amenities in the local community.

The college has provided a setting for **social interaction**: young people have been able to mix with other young people both with and without disabilities. They have had the opportunity to **access facilities** including leisure facilities, and to use the college canteen. Using this type of facility alongside others has helped young people develop life skills and confidence in everyday social settings:

*“This represents a big achievement for these young people.”* (Ambitious about Autism stakeholder)

Interviewees from Ambitious about Autism also felt that they have demonstrated that introducing young people with complex ASD to vocational activities can decrease incidences of **challenging behaviour**.

The positive impacts on young people and families who have attended so far have been reflected in an increase in the number of **enquiries** about joining the college that are

being received, many on behalf of older young people who had fallen out of the system some years ago due to the lack of post 19 provision at that point.

As well as interest from individuals, there have also been **requests for support from other colleges** in other London boroughs (Southwark and Hackney). Colleges are looking to the New Pathways College to support them to include young people with ASD and complex needs in their post 19 provision in mainstream FE settings.

### Impacts on families

Families naturally experience knock-on benefits from seeing their young people thrive as they take up new activities and opportunities. Specifically, families were reported by Ambitious staff to have experienced:

- reduction in levels of **stress and worry** about their young person, as they know that the young person is taking part in positive activities that support their transition to adulthood
- less **tiredness**, because they have to spend less time caring for their young person and on making plans and arrangements for their future.

Transitions (between educational settings or between education and other setting) are often particularly difficult times for families of young people with autism (or any additional need), which can be experienced over long periods as families look ahead to the next step. Especially at the post 19 stage, where options were limited before the college provision was in place, the worry and stress on family members could be very detrimental to health and wellbeing. Families feeling less stress during the transition than they would otherwise have been likely to is an extremely important impact.

In addition, staff reported that families **raised their expectations** of their young people and of post 19 education as a result of the project. They were more prepared for their young people to take part in work experience 'tasters', and more willing to set ambitious targets for their young people's achievements.

### *Impacts on organisations*

Ambitious about Autism stakeholders felt that their key achievements at the organisational level were:

- establishing themselves in the FE landscape (having previously been associated only with school education)
- setting up strong working relationships with Barnet College
- developing a model for post 19 education.

The project helped them to obtain an 'outstanding' rating from Ofsted. In more detail, interviewees noted the following impacts on their organisation and others involved in the New Pathways College.

### A more future-focused school curriculum and ethos

There have been changes to the school curriculum which start the pathway to post 19 sooner. A vocational pathway has been introduced into TreeHouse School as a result of the college-based services, as it has become clear that vocational activities should start before 19.

The pathway includes support for work experience for pupils aged 14+, and promotes the ambition for young people to live independently and, where possible, to participate in employment. Other local special schools have noted this change too:

*“The pathway has surprised local special schools, such as Oaklodge in Barnet – they’re challenging and breaking the traditional pathway.”* (Ambitious about Autism stakeholder)

The change in curriculum reflects a shift in the ethos of the school, raising expectations that following school young people will move into FE and supported living. For example, two young people are spending a day a week at college, with support, raising expectations that this path is both feasible and desirable for young people with autism.

### More links with community partners

Since the project started, Ambitious about Autism has established new links and partnerships to give young people a wider variety of work experience opportunities.

These include links to Wharf Lane and Capel Manor around horticulture, and catering opportunities within school and in the community at a bakery in Muswell Hill (a social enterprise), St James Church café and Paul’s bakery in the City, and links with Dimensions, a not for profit organisation providing services including supported housing and employment to people with autism or learning disabilities.

### Increased capacity of staff at Ambitious about Autism and Barnet College

Staff at Barnet College, where the New Pathways College services are based, are more aware of autism and received training on working with young people who have autism.

Staff at Ambitious about Autism feel that they are part of the College and that it is a mutually beneficially relationship. Interviewees felt that this demonstrated the importance of investing in staff to build capacity, and working towards a hub & spoke model with a focus on learning rather than on domiciliary care.

### Modelling good practice and raising awareness

Ambitious about Autism have engaged more with the 19-25 agenda and have gained an increased understanding of FE and HE as well as the role of different agencies including the Department for Business, Innovation and Skills. Interviewees felt clearer about the challenges as well as the policy and practice. The New Pathways College experience over the past two years provided a strong narrative for their campaign for education post 19 (the ‘end of school’ campaign) enabling them to influence policy.

By working with CRAE and by funding work on outcomes by Bangor University, a tracking system was developed which shows progress by evidencing outcomes through communications activity, independence of young people and incidence of challenging behaviour. This helped to influence other colleges, special schools and local authority commissioners, by demonstrating an effective model for post 19 provision. The project also influenced these wider stakeholders by demonstrating the use of personal budgets and an alternative pathway to independent out of area residential or semi secure placements.

Ambitious about Autism are also currently working with the College of Enfield and North London (CONEL) on a co-located model of FE provision.

#### Leveraging additional funding

The PGPA funding was a crucial lever to enable Ambitious about Autism to attract additional funding, including:

- Department of Health, capital grant for refurbishment of the labs at Barnet College to create their base
- Social Enterprise Investment Fund, capital funding for refurbishment
- City Bridge, funded an Employment Worker
- St James Place, funded a part time Family Support Worker over three years
- BBC, funded a Family Resilience Officer over three years - as a result of PGPA-funded project showing that transition is a key challenge point for families
- Department for Education, two year grant of £650k to set up four area hubs nationally, working with mainstream and special schools, FE, young people and parents, SENCOs, and other organisations, including the Association of Colleges, on building and developing a transition pathway
- Autism Education Trust, grant to develop materials for colleges, including standards.

## Autism and Ageing project: National Autistic Society

### *About the project*

**Description:** The Autism and Ageing project identified issues for older people with autism via a survey, and then developed resources to support professionals working with older people with autism. The other aspect of the project was to raise awareness and influence policy, by holding an Autism and Ageing Commission in the House of Lords, and training older people with autism in campaigning.

**Aims and context:** Ageing had received little attention in the autism community and therefore the National Autistic Society (NAS) wanted to focus on this topic in practical ways, by collating and sharing knowledge and good practice, and gaining attention for autism at the policymaking level. The overarching aims were that professionals coming into contact with older people with autism have increased understanding of how to



support them; and that key influencers are engaged to make improvements in the lives of older people with autism.

**Funding:** The Clothworkers' Foundation awarded £217k to cover the cost of a project manager and other project costs.

### *Evaluation activity*

- Document review: grant offer letter, grant application, assessment of grant, progress reports (2012-13).
- Interviews: four stakeholders at NAS, a relative of an older person with autism, and two stakeholders in the wider sector (research/academic, policy).

### **Impacts**

#### *Impact on the focus of autism research*

The research community has shown a strong interest in the issues of autism and ageing in recent years: at least three research projects have begun or have been proposed during the lifetime of the Autism and Ageing project, and ageing has recently become a research priority at Autistica (the medical research charity for autism). This represents an expansion of the scope of autism research, which has historically focused on autism in children. This is a positive and inclusive development:

*'If you apply to funding bodies you are usually successful if your research proposal is about children; if it is about older people, you never get funding.'* (Stakeholder, research community)

*'More people are starting to be interested in the subject – it is a worthwhile area for research.'* (Stakeholder, research community)

*It was good that the focus was on older people with autism as usually everything is geared for younger children with autism.'* (Family member of an older adult with autism)

#### *Impact on cross-sector working (autism and ageing)*

For the first time, the ageing sector and the autism sector have joined forces over their shared interests. Many of the UK's largest organisations for older people took an active role in the project's events and advisory group. Other autism charities were included in all the activities of the project, especially in the Autism and Ageing Commission. NAS acted as a catalyst for this partnership activity and worked in an inclusive way to involve all partners constructively.

#### *Impact on policy- and decision-making*

The issues about autism and ageing were aired at two Autism and Ageing Commission meetings within the House of Lords. Eight peers sat on the Autism and Ageing

Commission. This led to a question in parliamentary debate, as well as the report<sup>9</sup> which received a successful launch at the House of Lords.

*'The inclusion of the question on older age and autism in the local authority questionnaire was influenced by the NAS project.'* (Stakeholder, Department of Health)

The Department of Health responded positively and showed great interest in the issues raised. The Autism Policy lead gave evidence to the Autism and Ageing Commission, along with others from the Department of Health.

*'The Commission is important to inform the views of policymakers.'* (Stakeholder, Department of Health)

*'It is good to involve the parliamentarians; it means that they understand the issues when they then subsequently arise in parliament.'* (Family member of an older adult with autism)

A key success resulting from this influencing activity was the inclusion of the topic of autism in older age in a **local authority self-assessment questionnaire**, which assesses progress on implementing the autism strategy in each local authority area. The questionnaire is sent to all local authorities in England.

The NAS has also been able to lobby successfully for changes to the Care Bill, particularly on advocacy, as a result of this project.

*'Not a lot is known about autism and ageing; the report and the activities of the project are a foundation for moving forward.'* (Stakeholder, Department of Health)

#### Other awareness raising activities and impacts

Campaigning on the issue also took place outside Westminster. Fourteen older people with autism were trained in campaigning techniques. These campaigners helped to design a **poster for GP surgeries** to raise awareness of autism. This was a direct response to the identification of access to healthcare as a key issue in the report on older age.

**Media coverage** was good, with over 30 newspapers, radio programmes and online publications also featured stories on autism and ageing. These had a collective reach of over 3.7 million readers and listeners.

The NAS have produced two **resources for professionals**: a handbook and an e-learning resource. These were launched at an event in autumn 2013 which was well attended by people with autism, their families and professionals from across a wide range of sectors (it is not yet possible to assess the impact of these resources).

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<sup>9</sup> 'Getting on? Growing older with autism, A policy report' (2013, National Autistic Society), available at: <http://www.autism.org.uk/gettingon> (accessed 24.01.14)

### *Impacts on the organisation*

NAS have integrated the work on autism and ageing into all of their activities: training offered, the website, topics on the forums for both professionals and families. It remains a priority issue for the NAS. Their 2012 survey of 8,000 people with autism, their families and professionals, showed that there is significant concern from parents and family members of someone with autism about their worry, fear and lack of planning and support for people with autism as they get older<sup>10</sup>.

The NAS was able to use the project, funded by the Clothworkers' Foundation, as leverage to secure further funds to continue their work on autism and ageing. This is a 3-year programme to include the launch of a volunteer "Person to Person" service to support older adults with autism, as well as the establishment of a part-time specialist post on the NAS Case Work Team to support older people with autism and their families on issues related to an ageing autistic population.

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<sup>10</sup> 'The way we are: autism in 2012', National Autistic Society, available at <http://www.autism.org.uk/get-involved/50th-birthday/survey-report.aspx> (accessed 24.01.14)

# Impacts of the programme as a whole

## Summary of impacts against PGPA programme aims

The following table gives a broad picture of how the aims of the PGPA were met by the six funded projects. It illustrates the effectiveness of the mix of different projects in meeting the aims of the programme as a whole.

Funded project	Aims of the PGPA			
	Improve the lives of people with autism and their families/carers	Improve awareness, knowledge and understanding of the condition	Contribute to raising the profile of the sector at a local and national level	
			Local	National
New Pathways College: <b>Ambitious about Autism</b>	✓	✓	✓	✓
Centre for Research in Autism and Education: <b>Institute of Education and Ambitious about Autism</b>	✓	✓	✓	✓
Autism and Ageing project: <b>National Autistic Society</b>	✓	✓		✓
Changing Lives report: <b>New Philanthropy Capital</b>		✓		✓
Quest research project: <b>Research Autism</b>	✓	✓	✓	
Reaching Out project: <b>Short Breaks Network</b>	✓	✓	✓	

While the funded projects were very different in their focus and activities, as shown in the table above they all contributed to the same overarching aims of improving lives, improving awareness and understanding and raising the profile of autism. Below is a brief assessment of the contribution of the projects as a whole, drawing on the research

data collected during the evaluation, i.e. the impact of the programme in relation to the following:

***Improving the lives of people with autism (including children, those at the transition stage and older people) and their families/carers***

People with autism and their families and carers have been impacted in a number of positive ways by the programme. For example, young people have directly benefited from attending Ambitious about Autism's New Pathways College, from accessing short breaks with carers who have been trained in autism through the Reaching Out project, and from involvement with CRAE and Research Autism in research projects. Families have felt these benefits directly too. Indirectly, people with autism have and will experience the impacts of improved research and practice, and improving awareness and profile of autism as set out below.

***Improving research and practice in autism***

Considerable contributions to research on autism have been made by the programme, notably CRAE's wide range of research activities (and exemplary practice of involving people with autism in research), and those of NPC mapping the autism voluntary sector and developing their analysis model for use with large charities. The funded projects focused more on intervention than diagnosis, and improvements in practice were evident in a wide variety of ways including: the increased skills and confidence of carers after attending a Short Breaks Network training course; the increased capacity of college staff to work with young people with autism due to Ambitious about Autism's New Pathways College; the development of transition pathways also by this project; the involvement of head teachers with CRAE research via its links with the Pan London Autism Schools Network; the development of diagnosis tools for emotional and social problems associated with autism by Research Autism; and the provision of resources and training for professionals working with older people with autism.

***Improving awareness of the condition and raising the profile of the autism sector***

As a whole the programme has been effective in improving awareness and raising the profile of autism at different levels. Locally projects have raised awareness of children, parents and practitioners, as in the case of the short breaks training and provision (different locations around the UK), the post-19 education provision (based in north London and attracting attention from a wider area), and the participating local authorities in the Quest research. Ageing and autism, a previously under-acknowledged area, has enjoyed an increased profile through NAS's influencing at local and national level. CRAE's contribution to this aspect of the programme has been especially notable and had a national reach, due to its impressive engagement strategy.

## Learning around grants delivery

As well as looking at the impacts of the projects funded under the PGPA, the evaluation also offered the opportunity to:

- consider some of the advantages and disadvantages of the proactive model of delivering grants
- collate learning from grant recipients' experiences and perceptions of working with the Clothworkers' Foundation.

We sought views on this from grant recipients under the PGPA, as well as from organisations working in autism who had received a grant from the Clothworkers' Foundation under their open (or 'reactive') grants programme and from several other large grant-giving foundations.

### The proactive model

#### *Strengths of the proactive approach*

The following common themes were highlighted by interviewees in all three types of role (proactive recipient, reactive recipient, other foundation).

#### Logistics and resources of the funder

From a **logistical and resources** perspective, proactive funding allows the funder to be more strategic and is time effective, because having selected the sector and the candidate charities, the funder does not have to sift through large numbers of grant applications for suitability (as is the case with open programmes). However, it is dependent on the depth of research carried out into the potential options, and the quality of the advice sought and given.

#### Supporting innovation

Recipients under the PGPA strongly appreciated the proactive approach because they felt that it allowed them the **freedom to innovate**. This meant designing, shaping and testing a project that they believed would be valuable and worthwhile (rather than have to design their project according to more restrictive funding criteria). The proactive model actively '**creates space**' for organisations to innovate and test out ideas.

This is especially important in the current economic climate in which, due to squeezed funding, there is a danger that innovation is stifled and only applications for 'tried and tested' projects succeed as funders 'play it safe'. This benefit was also highlighted by another grant funder:

*'The backing of a funder may give organisations with the appropriate knowledge and skills the confidence to undertake a programme of work which they might otherwise*

*struggle to secure funding for or where there might be concerns about the level of risk.'*  
(Stakeholder from other grant giving organisation)

#### Engagement between funder and recipient

Recipients who had experience of both proactive and reactive grants observed that typically, with proactive grants, donors are more involved, giving more of a steer and direction as well as having an interest in ensuring the work carries on beyond the life of the grant. Their involvement and commitment from the start can result in greater impact:

*'A proactive programme will usually start with a period of research and consultation to analyse the need and current responses, and the findings will be shared across the funder including trustees and officers. This means there is a high level of knowledge at the outset and before grants are awarded. This often leads to greater engagement at all levels within the funder.'* (Stakeholder from other grant giving organisation)

#### Maximising impact on a sector

By having several projects funded concurrently in the same sector, the overall impact of the programme is amplified (through links between organisations and by their ability to leverage in additional funding). Therefore, by choosing a sector in which to concentrate resources, the funder can really make a difference in that sector. As described by one proactive grant recipient:

*'The whole is greater than the sum of its parts. The interconnectedness of the [autism] community means people and organisations often collaborate. When there are several initiatives, you get a spurt of activity.'* (Proactive grant recipient)

#### **Limitations of the proactive approach**

The proactive approach requires a great deal of research by the funder. Additionally, even if this work is very thorough, some deserving and potentially impactful organisations may not appear 'on the radar' and therefore not have the opportunity to access funding:

*'Being proactive means that the funder doesn't have an opportunity to hear from organisations which are not on its radar or perhaps the most obvious organisation to undertake such work. Or put another way, it may not hear from those who are leftfield, maverick or bring a fresh perspective on how a particular problem or issue might be addressed.'* (Stakeholder from other grant giving organisation)

This problem is one that is less likely to arise under the reactive grants model, whereby organisations can apply for funding under an open programme.

## Synergy between proactive and reactive (open) grants programmes

### *Benefits of synergy*

During the five-year period of the PGPA, several autism charities received grants under the Foundation's open grants programme for capital projects. There was a complementarity between the two grant programmes, the proactive programme, involving **strategic projects**, and the open programme under which **capital projects** were funded.

The synergy between the two grants programmes enabled the Clothworkers' Foundation to **cover more of the autism sector** in greater depth, including post-19 education, residential and college provision and a new school. One trustee was a member of both the proactive and open grants committees, which helped in selecting projects to add to the overall range of projects in the sector.

Additionally, the organisations receiving a reactive grant represented a wider **geographical spread** than those in the proactive grants programme alone. Often, charities outside of London and the south east can feel overlooked by London-based funders. It is harder for funders to visit them and to establish and maintain relationships which are often key to securing ongoing funding. As a result, the receipt of this reactive grant was especially significant for some of the organisations:

*'I can't thank the Clothworkers' enough I can still remember the day when our fundraiser came into my office with the offer letter. I couldn't believe it! I almost banged my head on the ceiling, I jumped so high for joy.'* (Recipient of funding under the open grants programme)

Like proactive grant recipients, open grant recipients also used the funding awarded by the Clothworkers' Foundation to **leverage other funding** from elsewhere:

*'We couldn't have done the building without the Clothworkers' funding. It was great leverage. It gave us great credibility when going to other funders to have this endorsement from the Clothworkers'. It was a massive benefit.'* (Recipient of funding under the open grants programme)

### *Learning about synergy*

A small number of organisations invited to apply for funding from the PGPA were unsuccessful once their applications had been reviewed by the autism committee.

The Foundation was also able to make grants for capital projects to autism charities under its open (reactive) grants programme through its *Disabled People* programme area. It continues to make grants to autism charities via this programme.

Some of the recipients were aware of the PGPA and that they had been considered for it, and (incorrectly) perceived their capital grant as 'compensatory' for not being included.



- It may have been beneficial to have had a **clearer protocol** for inclusion in the PGPA and thus a more transparent communication with those who, after consideration, were not included.

While the two different grant models worked well together to maximise the Foundation's overall impact on the sector, this was facilitated almost incidentally by having a trustee on both of the relevant committees.

- More could be achieved when targeting future sectors by building both funding streams into an **overall plan**, as noted by stakeholders in other grant giving organisations:

*'The answer must be to have a mix of action learning open access programmes topped up with proactive engagement at the higher giving end. The proactive programme will do [many] positive things [...] but in the end much of the support that is required is front line service delivery and to enable that to happen, applicants need to have open access. Interest free/soft loans to large organisations may well form part of the stable in future as well as small scale start-up funds for community initiatives/ social enterprises and the grant making foundations must keep flexible in order to respond to these initiatives.'*

*'It helps if you can create cross fertilisation across the different parts of the funding.'*

## Working with the Clothworkers' Foundation

Many stakeholders had comments on their experience of receiving a grant from the Clothworkers' Foundation, which may not be specific to a proactive model but are of interest nonetheless, including the following points.

### Communication and support

#### Positive and flexible

Recipients generally reported **positive relationships** with the Clothworkers' Foundation, perceiving the staff they worked with to be accessible, supportive and flexible.

- They valued this flexibility, for example, being able to use funds differently than had originally been agreed.

*'They were positive, flexible and open to dialogue.'* (PGPA grant recipient)

*'Adjectives that describe the Clothworkers: intelligent, flexible, generous, open, interested in learning about the work; they are strategic in using the knowledge and insights; they have a public commitment to share knowledge.'* (PGPA grant recipient)

During the lifetime of the PGPA, there were several **changes in personnel** at the Clothworkers' Foundation. Grant recipients found these transitions difficult at times and lines of communication with some of the smaller charities, especially those out of London, were perceived to have been quite poor at times.

— However, those who became involved during the latter period expressed satisfaction with the communication and relationship with the Clothworkers' Foundation, especially with the Grants Manager:

*'Clothworkers [staff] were engaged but not interfering; they asked challenging questions and listened to responses.'* (PGPA grant recipient)

#### Understanding of sector

Some grant recipient charities (both proactive and open programmes) had prior relationships, and have ongoing contact, with the Clothworkers' Foundation. This generated a **depth of understanding** in the Clothworkers' Foundation of the work of these charities and of the autism sector. It served to enhance the quality of relationships between funder and grant recipient:

*'When [representative from the Clothworkers' Foundation] visited, he put us through our paces, but no more than you would expect. But unlike most other funders, they knew about autism. He was very well informed and showed a good understanding of the issues and what we were trying to do. With other funders it is harder – you have to spend time explaining about autism.'* (Open grants recipient)

*'Two key differences about working with the Clothworkers' (compared to other grant givers): they are familiar with what you are trying to achieve; and you have a more meaningful conversation along the way based on an informed understanding of what you are trying to do.'* (PGPA grant recipient)

Following on from this, several interviewees felt that, having developed knowledge of the autism sector and positive relationships with organisations within it, the Clothworkers' Foundation should look to build on this by continuing to focus on autism:

*'It seems odd to choose a sector then to stop funding it; you could build on it.'* (Other grant giving organisation)

*'It was a shame that the relationship just stopped when the project ended. We were full of ideas about how to develop things. We would have liked the relationship with the Clothworkers to progress.'* (PGPA grant recipient)

#### Senior level and face to face contact

Two **practical tips** for more productive relationships between funder and recipient were offered:

— Fostering a direct relationship with the CEO and/or senior managers at recipient charities (rather than solely with the fundraising team) enables the funder to understand more fully the work and impact of the charity, through meetings, visits and attendance at events:

*'The relationship between the funder and the charity is better if it is guided by the CEO and senior staff and not through the fundraising team.'* (Grant recipient)

— Visits to projects by Clothworkers' Foundation staff, especially to those projects outside London, were much appreciated and welcomed:

*'I would like them to visit to come and see the difference their money made. In this region we are always scraping around for pennies and to get such generosity from the Clothworkers' was amazing.'* (Open grant recipient)

### Reporting and monitoring

Recipients generally supported the fairly **'light touch'** reporting requirements. They felt that the Clothworkers' Foundation trusted them to design and implement their projects and this was appreciated.

— However, many appreciated the greater rigour introduced by the current Grants Manager and it was felt to be important that the funder encourage, if not require, the recipient to have **clear aims and action plans** in place.

- This helps to ensure the project stays true to its overall aims in the event of any changes, and that there is clear documentation in place to be revisited as necessary. This is particularly useful if there are personnel changes, as may well happen over the course of a long-term project.

There was a sense that progress reports focused on **process rather than outcomes**; some advice on what outcomes to measure and how to evidence these may have been useful at the outset.

*'Clothworkers' could build in to funding that six months after the end of their grant they do some sort of impact analysis; charities need to be able to answer the 'and so?' question after receiving funding.'* (PGPA grant recipient)

### Collaboration between recipients

Many of those interviewed for the evaluation reported that they had not been aware of the other organisations receiving a grant under the PGPA or the open programme. They felt that there had been a missed opportunity in not **bringing together grant recipients** in autism, in order to network, share learning and identify possibilities for collaboration.

*'It would have been good to get together with other grant recipients within the programme and to have time with each other.'* (PGPA grant recipient)

*'We were not really aware of who else was in the proactive grants programme; this would have been useful.'* (PGPA grant recipient)

— This kind of opportunity may help to get more added value out of future proactive programmes.

# Conclusions

## Conclusions

*'Clothworkers' hugely helped to make a step-wide change. They were part of the momentum that has raised standards. There has been a step-wide change in the delivery of services to children and young with autism and the Clothworkers' are very much part of that.'* (Open grant recipient)

The Clothworkers' Foundation's contribution to the development of the understanding and awareness of autism, research into autism and provision for children, young and older people with autism in the UK is considered by all stakeholders to have been very significant. Their decision to fund projects in the autism sector happened at a time of great momentum and of significant change: the Autism Act 2009 and the subsequent Autism Strategy, and the raising of public awareness through campaigns at a local and national level. The PGPA funding, and concurrent reactive grants funding, offered the opportunity for the autism sector to move forward rapidly on many fronts by enabling organisations to:

- Create educational and social opportunities for people with autism, and have eased the burden on families through improving short breaks and post-19 opportunities.
- Further research on autism, particularly on the social and emotional aspects of autism, and increase the involvement of people with autism, families and schools in research.
- Improve practice of professionals working in autism including carers, head teachers and school and college staff, and those supporting older people with autism
- Raise awareness of autism locally, around individual projects, and nationally, through the online engagement and events of CRAE.

The Clothworkers' Foundation made a great effort to understand the autism sector, through published research such as the 2007 NPC report *A Life Less Ordinary*, and through their informal expert advisers. They also boosted their overall impact on the autism sector by awarding grants to other autism organisations, under their open programme.

# Recommendations for proactive grant-making

The following recommendations are offered in order to help the Clothworkers' Foundation to build on the existing strengths of its approach to giving, and make suggestions for further improvements.

## 1. Target a sector, strategically

- Define and articulate the overall aims of the funding programme from the start, and make amendments as necessary, as learning about the sector develops.
- Choose organisations strategically,
  - » based on their capacity to meet the programme's aims – not only based on pre-existing relationships
  - » taking into account what each organisation will contribute to the programme aims and whether, combined, they will meet the overall aims.

## 2. Develop an understanding of the sector

- The chosen organisations need not only the funder's financial resource, but the time and energy of the staff and trustees, to get to know the sector and the organisations working within it and develop relationships with them.
- If the funder has this knowledge and understanding of the sector, then they can more readily see how a potential project will fit into the bigger picture and make a difference.

## 3. Offer a mix of proactive and reactive grants in the given sector

- There should be an overarching strategic approach to designing the mix of proactive and reactive grants.
- This will help to maximise impacts on this sector.
- Be transparent with potential recipient organisations about the reasons for their inclusion or exclusion from the proactive programme.

## 4. Facilitate collaboration between grant recipients

- There is added value to be gained from funding a programme where the different parts link up and are supported proactively by the funder to do so, rather than being treated as individual stand-alone projects.
- This can be done by providing channels for recipients to share learning, resources and ideas.
- It can create lasting relationships beyond the life of individual projects, forming the basis for further collaboration.

- Collaboration events or other activities could be open to grant recipients under both proactive and reactive programmes, to maximise linkages.
- They could even be extended to include other stakeholders and organisations: this would offer an opportunity for the Clothworkers' Foundation to act as a broker, helping recipients to build contacts and networks, and influence the right bodies/agencies.

#### **5. Ensure clear governance and oversight**

- Funded organisations appreciate clear governance, for example, setting appropriate requirements for reporting and monitoring will ensure that grant recipients are not overburdened, but do have sufficiently detailed plans, milestones and KPIs to drive progress.
- This will help projects to maintain fidelity to the overall aims, regardless of any changes during implementation.

#### **6. Build in evaluation from the outset**

- This will help projects to identify appropriate key performance indicators (KPIs) and outcome measures and be able to demonstrate their impact; this will help organisations to leverage other funding.
- It will help organisations to generate learning about what works, which they can apply to future projects and share with others.
- Evaluations should aim to hear directly from people with autism and their families or carers, to validate the views of staff working with them.
- Think about the timescales over which projects may be expected to demonstrate impact, and build in plans to revisit and assess impact in the longer term if appropriate.

#### **7. Build in attribution of impacts to funding**

- It can be difficult for wider stakeholders in a sector to comment on the impacts of a programme such as the PGPA, as they may not be aware of the link between a project and a funder, or that a project is part of a programme.
- Therefore it may be worth considering building in a requirement for grant recipients to acknowledge the Clothworkers' funding in their outputs (online presence, publications and other materials), so that wider stakeholders are aware of it and can more readily attribute impacts to the funding

#### **8. Continue a supportive and flexible approach**

- This will enable recipients to respond to an evolving environment during the lifespan of the project.

## Appendices

### Appendix 1a. Summary of projects funded (proactive)

Organisation	Grant amount / year of award	Project	Status
<b>Institute of Education / Ambitious about Autism (formerly Treehouse)</b>	£700,000 (2007)	Research initiative focussing on educational methodologies.	Complete
<b>Research Autism</b>	£158,000 (2007)	Early detection of challenging behaviours in children with autism, with the aim of improving assessment and intervention.	Complete
	£10,000 (2011)	Top up grant to enable analysis completion	Complete
<b>Short Breaks Network (formerly Shared Care Network)</b>	£145,000 (2007)	Increase in provision of short breaks through training of carers and distribution of resource materials to a network of carers' schemes across the country.	Complete
<b>New Philanthropy Capital</b>	£35,000 (2010)	Update on the 2007 autism report and analysis of the National Autistic Society	Complete
<b>Ambitious about Autism</b>	£200,000 (2011)	Development stage of setting up a College to support young people in the transition stage to supported independent living, social, and employment opportunities.	Ends 2014
<b>National Autistic Society</b>	£217,000 (2012)	Autism and ageing project involving production of a practical guide for professionals and a campaign to raise awareness of the issue	Complete

### Appendix 1b. Summary of projects funded (reactive)<sup>11</sup>

Year	Organisation	Project	Grant
2012	North East Autism Society	Refurbishment of a disused secure unit in Durham to create a centre for people with autism	£200,000
	Kingwood Trust	Residential college accommodation in Berkshire for young people with autism making the transition to adulthood	£50,000
	Autism Wessex	Purchasing and equipping a house for four adults with autism	£20,000
	Hampshire Autistic Society	Conversion of a building into a learning resource centre	£20,000
2011	Prior's Court Foundation	Renovation of cottages adjacent to the school site to provide a specialist learning and residential environment for young people aged 16-25 with autism and complex needs in Berkshire	£200,000
	Step by Step: a school for autistic children	Development of an outside play area at a school for children with autism in East Sussex	£25,000
2010	Wargrave House	Refurbishment of a new residential teaching college for post-16 students with autism in the North West	£50,000
	St Christopher's School	Refurbishment of a property in Bristol to accommodate children with severe learning disabilities, including autism.	£40,000
	Woodside School Fund	Specialist outside play area to develop the physical, communication and social skills of children with autism	£20,000
2009	Nottingham Regional Society for Adults and Children with Autism	Refurbishment and equipping of a school for children with autism	£40,000
2008	Wirral Autistic Society	Building costs of a respite unit for people with autism	£50,000

<sup>11</sup> Reactive projects focusing on autism and receiving funding of more than £20k



	Rowdeford Charity Trust	Performance studio providing psychotherapy for children with complex and profound learning difficulties, including autism	£20,000
	Autism Cymru	Development of on-line technology to provide web-based autism training opportunities	£25,000
	Sussex Autistic Society	Vehicle to facilitate programme of community activities for young people with autism	£20,000
<b>2007</b>	Sussex Autistic Community Trust	Fit out of supported living scheme for adults with autism	£30,000

## Appendix 2. Evaluation methodology

### *Scoping and design*

Our understanding of the PGPA and the aims of the evaluation was informed by an initial scoping meeting with relevant staff and trustees at the Clothworkers' Foundation.

We then undertook a document review, including documentation relating to each of the funded projects (applications, correspondence, reports etc). The document review drew out the key aspects of each funded project including: funding, timing, projects' intended aims, activities and beneficiaries, impact measurement and achievements to date.

### *Fieldwork*

Our initial fieldwork plan was to include interviews with PGPA grant recipients, an online survey and interviews with direct beneficiaries, an online survey and interviews with those in the wider autism sector, and a 'virtual practice group' of other grant giving organisations.

However, following the first stage, interviews with proactive grant recipients, it became clear that our approach would need to be tailored more specifically to each project, depending on the type of work they had been doing and what type of beneficiary was involved.

Therefore the fieldwork involved the following types of stakeholders and methods. Details of participants can be found in Appendix 3.

#### Proactive grant recipients

Semi structured interviews were held with a number of representatives from each of the funded projects. These interviews briefly clarified the information obtained through the

document review and then focused on two main areas: impacts of the project, and reflections and learning from the proactive grants process.

We asked interviewees to suggest potential beneficiaries of their projects to be contacted for an interview with us.

The discussion guide can be found in Appendix 4.

### Beneficiaries of funded projects

For each of the funded projects, we identified in consultation with staff at each organisation a number of individuals who could contribute their views on the funded project. These included practitioners working in autism, academics or researchers and people with autism or their carers. For one of the projects it was not possible to access any beneficiaries; for others the majority were interviewed by telephone, and for one project (CRAE) an online survey was circulated via the organisation.

### Wider autism sector

An online survey sought the views of wider sector stakeholders, not necessarily directly connected with the funded projects. It invited views on the funded projects and reflections on the proactive grants process. A small number of stakeholders were interviewed to give their views on the overall impacts or influence of the PGPA.

### Virtual practice group

We invited other grant funding organisations to contribute their views on the proactive grants process, from which the Clothworkers' Foundation might obtain some useful learning. We approached five organisations that have an established model of grants delivery that is about funding by programmes, and invited them to respond to four questions either by email or via a telephone conversation:

- What do you think are the main strengths of a proactive model of grant funding?
- What do you think are the main weaknesses of a proactive model of grant funding?
- How does the proactive model compare to other models of grant funding in terms of advantages and disadvantages?
- What would be the impacts if more grant giving foundations were to use a proactive model, or alternative models of grant giving?

### Reactive grants recipients

Following the presentation of the evaluation's interim findings to the Clothworkers' Foundation, it was agreed to hold additional interviews with a number of the autism organisations who have received grants from the Clothworkers' Foundation under their reactive programme during the period of the PGPA<sup>12</sup>. The purpose of this was to

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<sup>12</sup> Fifteen autism organisations received grants in the reactive programme between 2007 and 2012, totalling £810,000

understand the synergies of awarding different types of grants within the same sector (autism) and the wider impacts resulting from this.

The discussion guide can be found in Appendix 4.

### *Analysis and reporting*

The data was analysed using a thematic framework, based on the topics covered in the interview guides. The framework organises all the data under common headings, such as 'context for the project' and 'impacts on people with autism', so that it is possible to see the relevant data from all sources (interviews with different stakeholders, survey responses) together in one place. For reporting, data was organised into two broad sections:

- Data relating to impacts of the funded projects. This is reported by project, as each project is different. Cross cutting impacts (that were generated by more than one project) and overarching impacts (generated by the PGAP as a whole) are also reported.
- Data relating to the proactive grants process. This is reported across all projects, also taking into account the views of stakeholders who are not linked to a specific funded project.

## Appendix 3. Data collection

### Scoping

Interviews were conducted with two stakeholders at the Clothworkers' Foundation:

- Grants Manager
- Chair, Proactive Autism Committee

### Fieldwork

Proactive projects

Project	Data collected
<b>Establishing a Centre for Research in Autism and Education (CRAE) at the Institute of Education</b> <i>Institute of Education and Ambitious about Autism</i>	Interviews <ul style="list-style-type: none"> <li>• 3x grant recipients</li> <li>• 2x work experience placement students (people with autism)</li> <li>• 1x school head teacher</li> <li>• 3x wider sector stakeholders (research/academic)</li> </ul> Online survey <ul style="list-style-type: none"> <li>• 10 respondents</li> </ul>
<b>New Pathways College</b> <i>Ambitious about Autism</i>	Interviews <ul style="list-style-type: none"> <li>• 3x grant recipients</li> <li>• 1x parent</li> </ul>
<b>Autism and Ageing Project</b> <i>National Autistic Society</i>	Interviews <ul style="list-style-type: none"> <li>• 4x grant recipients</li> <li>• 1x relative of a person with autism</li> <li>• 2x wider sector stakeholders (research/academic, policy)</li> </ul>
<b>'Changing Lives' report – update to 'A Life Less Ordinary' report</b> <i>New Philanthropy Capital</i>	Interviews <ul style="list-style-type: none"> <li>• 2x grant recipients</li> <li>• 2x wider sector stakeholders (other charities)</li> </ul>
<b>Quest research project</b> <i>Research Autism</i>	Interviews <ul style="list-style-type: none"> <li>• 3x grant recipients</li> <li>• 1x wider sector stakeholder (research/academic, health)</li> </ul>
<b>Reaching Out project</b> <i>Short Breaks Network; formerly Shared Care Network</i>	Interviews <ul style="list-style-type: none"> <li>• 1x grant recipient</li> </ul>

### Reactive projects

Interviews were conducted with one representative from each of the following organisations working in the autism sector, which received a grant under the reactive programme:

- Wargrave House
- Prior's Court
- North East Autism Society
- Kingwood Trust

### Wider sector

Our survey was sent to the following organisations to invite them to respond and/or disseminate the survey link to their memberships and networks. A small number of surveys were completed (5).

- All Parliamentary Group on Autism / APPG Advisory Group
- Association of Colleges (Greater London branch)
- Autism Education Trust
- Autistica
- Autism Alliance
- Autism Research Centre, University of Cambridge
- Council of Disabled Children / National Children's Bureau
- ICAN
- Mencap
- NASEN
- NASS
- Network Autism (National Autistic Society)
- Research Practice Network / Pan- London Autism School Network
- University of Birmingham
- CEDAR at Warwick University
- SEN Policy Research Forum at Exeter University

Some of those interviewed in relation to a funded project also had views on other projects or on the programme as a whole and its impact on the wider sector.

### Virtual practice group

Contributors to the virtual practice group, staff from other grant-making foundations who were invited to give their views on the proactive giving model, included those from the following organisations:

- Esme Fairbairn Foundation
- Mercers Company
- Pears Foundation

## Appendix 4. Evaluation tools

### 1. Topic guide for interviews with proactive grants recipients

#### *Introduction*

The Clothworkers' Foundation has commissioned an independent evaluation of the Proactive Grants Programme in Autism. The evaluation is being carried out by Linda Redford, an independent consultant with many years' experience in the autism and disability sector, with the Office for Public Management (OPM), an organisation specialising in evaluation.

The evaluation has two purposes:

- to **consider the impacts** of the funded projects
- to **generate learning** around the Clothworkers Foundation's grant-giving process.

The evaluation will include interviews with grant recipients, and surveys and interviews with direct beneficiaries of the funded projects and key individuals and organisations in the autism sector.

We are speaking to you today to find out about your funded project and its impacts, and to get your views on the grants programme as a whole.

If there is anything you would like to tell me that you would like us to report anonymously or keep confidential within the evaluation team, please let me know. [Seek permission for audio recording if applicable. Recording will not be shared outside the evaluation team and will be destroyed after the end of the evaluation]

#### *About your funded project*

- your **role** in relation to the funded project
- **how your organisation got involved** with the Proactive Grants in Autism programme
  - how did you hear about it?
    - were you approached by the Clothworkers' Foundation?
    - did you have an existing relationship with the Clothworkers' Foundation?
  - why did you decide to get involved?
- any **contextual factors** we should be aware of
  - e.g. changes to the organisation / wider environment during the course of the funded project

*[next questions to be covered briefly, as we should already have this info from the documentation]*

- the **aims** of your funded project
- the **intended beneficiaries** of your funded project
- an **overview of the activities** of your funded project

- has the project **ended**
  - if so, when
  - if not, when will it end

### *Funding*

- the ways in which the Clothworkers funding was used
  - e.g. to full- or part-fund the project
  - If part-, what other sources of funding did you draw on, and did the programme funding help you to secure other funding
- did you use the funding as originally planned or were there any changes during the course of the project?
- what proportions of the funding were for core and project specific spend?

### *Impacts*

- the impacts of your funded project **on** (as applicable depending on the nature of the project):
  - the **beneficiaries** of your organisation (e.g. people with autism and their families / professionals working in autism) your **organisation** (e.g. impacts on your staff / profile of your organisation / links with other agencies)
  - the **wider sector** (e.g. other autism organisations, other relevant agencies including local authorities, health / education)
  - any **other impacts**, including **unintended outcomes**?
- what would you say are the **key successes** of your project
- How would you assess the contribution of your project (as applicable depending on the nature of the project) to the following aims of the Proactive Grants in Autism programme:
  - **improving the lives** of people with autism (including children, those at the transition stage and older people) and their families/carers
  - **improved research and practice** for people with autism
  - **improving early diagnosis** rates of autism in children and appropriate subsequent **intervention**
  - **improving knowledge and awareness of autism** and to **raising the profile** of the autism sector at local and national level
  - the **wider autism sector**
- how do the outcomes compare to your **original intentions** – is there anything you did not achieve that you wanted to, and if so, why was this
- how far can these impacts be **attributed to the Clothworkers funding** – would they have happened anyway? Would you have got funding from another source, and if so, where?
- **how do you know** you have achieved these impacts (what evidence do you have)
  - have you **measured** impacts and outcomes
  - can you give us any **impact data** that you have collected [check what we already have from Philip to avoid duplication]

### Grants process

- **Views on the process** of gaining a grant from the Proactive grants programme.
  - What worked well or less well
  - Prompt, in relation to:
    - Application process
    - Amount received
    - Communications at each stage
    - Flexibility (e.g. being able to re-allocate funds)
    - Monitoring and reporting requirements
    - Nature of programme as ‘proactive’ as compared to ‘open’
    - Nature of programme as being focused on autism
    - In kind support (as well as financial contribution)
    - Follow up (e.g. opportunities for further funding)
    - Any other comments
  - In what ways did the Clothworkers’ funding **add value** to your funded project
    - E.g. opportunities to work or share learning with other grant recipients
- What **advice would you give to another organisation** approached by the Clothworkers’ Foundation to apply for potential funding from its Proactive programme?
- You may have received **other grants from the Clothworkers’ Foundation**
  - If so, was this under a Proactive or Open programme
  - How would you **compare** the experience of this with the **experience** of the Proactive Grants in Autism programme, and the **impacts** your project was able to make
- You may have received **grants from other organisations**
  - E.g. Mercers / Pears / Shirley Foundation / local authority / other
  - If so, what were these, and for which project
  - How would you **compare** the experience of this with the **experience** of the Proactive Grants in Autism programme, and the **impacts** your project was able to make
- **Suggestions for the Clothworkers’ Foundation** in relation to future grant-giving
  - changes to the existing model
  - ways to improve or add value
  - alternative models

### Next steps

- Check we have **names and contact details for up to two other interviewees** for this project and if not, request these

*[If applicable – i.e. if project has direct beneficiaries]*

- We will be producing an **online survey for direct beneficiaries** of the funded projects. Would you be willing to circulate this on our behalf to the relevant people?



- We would also like to **interview a number of direct beneficiaries** of your funded project to ask them about the impacts on them. Could you think about who we might invite to participate in this, and we will ask you to put in touch with them at a later date

### Summary and checklist

[Run through to check that all topics have been covered]

<b>Topic</b>	<b>Covered?</b>
<b>About the project</b>	
Your role	
How and why got involved	
Aims, intended beneficiaries and activities	
<b>Funding</b>	
Full or part funding / enabled match or other source of funding?	
<b>Impacts</b>	
Impacts on individuals / organisation / wider agencies or sector	
Other impacts including unintended ones	
Impacts in relation to programme aims: improving lives, services / research and practice / awareness and profile	
Attribution of impacts to your project / the funding	
Evidence / measurement of impact	
<b>Grants process</b>	
What worked well / less well / was there any added value	
Comparison with experience of other Clothworkers' grants	
Comparison with experience of other organisations' grants	
Advice for other organisations considering an application	
Suggestions for Clothworkers re future grant-giving process	

## 2. Topic guide for interviews with beneficiaries (indirect or direct) of funded projects

*[Interviewer to modify guide to make sense for each project and the role of the interviewee]*

### **Introduction**

The Clothworkers' Foundation provided grant funding for a number of project in the autism sector, including one which you have had some involvement in (or are aware of): [name of relevant project].

The Clothworkers' Foundation has commissioned an independent evaluation of the programme under which the projects were funded, the Proactive Grants Programme in Autism. The evaluation is being carried out by Linda Redford, an independent consultant with many years' experience in the autism and disability sector, with the Office for Public Management (OPM), an organisation specialising in evaluation.

The evaluation has two purposes:

- to **consider the impacts** of the funded projects
- to **generate learning** around the Clothworkers Foundation's grant-giving process.

The evaluation include interviews with the organisations who received funding and the people who have been involved with these projects like yourself.

We are speaking to you today to find out about your views on the project and [if relevant] your views on the grant programme as a whole.

[Person] at [organisation] suggested we speak to you. We won't use anyone's names in our report, but if there is anything you would like to tell me that you don't wish to go into the report, please let me know.

[Seek permission for audio recording if applicable. Recording will not be shared outside the evaluation team and will be destroyed after the end of the evaluation]

### **Nature of involvement and activities**

- Can you tell me how you were involved with the project?
  - how did you hear about it?
  - why did you decide to get involved?
  - What were you hoping to get out of it?
  
  - What kind of activity or activities were you involved in?

### **What worked well and less well**

- What was good about it (what did you like)?

- What wasn't so good (what didn't you like)?

### *Impacts*

- What did you get out of being involved with the project?
- What were the benefits?
- Did it meet your original expectations or hopes?
- Were there any disadvantages or negative outcomes of being involved?
- Is there anyone else who you think benefited in different ways from this project?
- Have you been involved in any other projects / services / organisations that provide a similar service to this project? If so:
  - How did it compare in terms of the outcomes (better, worse – why?)
- How could it have been improved to make a bigger impact for you or others?
- Would you advise other people to get involved in this project (why, why not?)

### *Proactive programme aims*

- How would you assess the contribution of the project (as applicable depending on the nature of the project) to the following aims of the Proactive Grants in Autism programme:
  - **improving the lives** of people with autism (including children, those at the transition stage and older people) and their families/carers
  - **improved research and practice** for people with autism
  - **improving early diagnosis** rates of autism in children and appropriate subsequent **intervention**
  - **improving knowledge and awareness of autism** and to **raising the profile** of the autism sector at local and national level
  - the **wider autism sector**

**End of questions. Is there anything else you would like to tell me?**

### 3. Survey of CRAE beneficiaries

#### Introduction

This survey is about the Centre for Research in Autism Education (CRAE), which was set up by the Institute of Education (IOE). We are interested in the views of anyone who has been involved with any of CRAE's activities. This survey is being conducted on behalf of a grant-funding organisation, The Clothworkers' Foundation, who provided funding for CRAE under their Proactive Grants in Autism Programme.

Please answer any questions that you feel are relevant to you. It doesn't matter how many or how few questions you respond to. Your response will not be personally identifiable.

The survey should take about 10 minutes to complete. The survey is being conducted by OPM, an independent research organisation. Any data that you provide will not be identifiable to anyone at CRAE, the IOE or the Clothworkers' Foundation.

If you have any questions about the survey, please contact Tim at OPM, on 020 7239 7806 or [tvanson@opm.co.uk](mailto:tvanson@opm.co.uk).

1. Which of the following CRAE activities have you been involved in?

	Yes	No	Unsure
<b>I have attended a CRAE conference/workshop (e.g. the 2009 1-day conference on Autism, Ethics and Society, workshop on Noisy Brains?)</b>			
<b>I have attended a CRAE film screening (e.g. the screening of the film 'Too sane for this world')</b>			
<b>I have attended a CRAE discussion panel event at the IOE</b>			
<b>I have used the CRAE YouTube channel</b>			
<b>I have attended a CRAE Annual Lecture</b>			
<b>I have been involved in a research-practice initiative with CRAE (e.g. PLASN research network; Educational Psychologist SIG)</b>			
<b>I am a secondary school pupil who has been given a work experience placement</b>			
<b>I have undertaken an undergraduate placement or internship at CRAE</b>			

<b>I have taken part in one or more research projects or activities (e.g. Brain Detectives) conducted by members of CRAE?</b>			
<b>I have received one or more of CRAE publications (e-news, newsletters, reports, research papers)</b>			
<b>I follow CRAE's activities on Twitter and/or Facebook</b>			

Other activity (please specify):

2. How effective has this activity been in:

	<b>Very effective</b>	<b>Quite effective</b>	<b>Not at all effective</b>	<b>Don't know / not applicable</b>
<b>Improving your knowledge and understanding of autism</b>				
<b>Helping you to connect with other people in the autism sector</b>				
<b>Helping you in your everyday practice</b>				
<b>Enabling you to share learning and spread awareness of autism to others <u>inside</u> the IOE</b>				
<b>Improving your access to evidence-based resources or information on autism</b>				
<b>Enabling you to share learning and spread awareness of autism to others <u>outside</u> the IOE</b>				

3. Overall, how effective do you think that CRAE has been in contributing to the following aims?

	<b>Very effective</b>	<b>Quite effective</b>	<b>Not at all effective</b>	<b>Don't know / not applicable</b>
<b>Improving the lives of</b>				

<b>people with autism and their families</b>				
<b>Improved research and practice in the autism sector</b>				
<b>Improving knowledge and awareness of autism and raising the profile of the autism sector <u>at local level</u></b>				
<b>Improving knowledge and awareness of autism and raising the profile of the autism sector <u>at national level</u></b>				

4. If you would like to comment on any CRAE activity please do so here

--

### *About you*

5. What is your role in relation to the autism or children's disability sector (please tick all that apply)?

<b>A person with ASD</b>	
<b>A parent/carer/family member of a person with ASD</b>	
<b>A professional directly working with people with ASD (please specify)</b>	
<b>Research / academic (Institute of Education)</b>	
<b>Research / academic (other)</b>	
<b>Policy</b>	
<b>Charity</b>	
<b>Organisation representing people with ASD</b>	
<b>Organisation representing professionals working in the autism sector</b>	
<b>Organisation representing people with disabilities</b>	

<b>Organisation representing professionals working in the children's disability sector</b>	
<b>Other (please specify)</b>	

Would you be willing to take part in a telephone interview to explore these topics in greater depth? It would take about 30 minutes. If so, please give us your contact details and we may contact you to invite you to take part.

Please note that all survey data will remain anonymous and we will not link your name or organisation to your survey response in our report.

<b>Name:</b>	
<b>Organisation:</b>	
<b>Role:</b>	
<b>Email:</b>	
<b>Telephone:</b>	

Thank you for taking part. Your input will help the Clothworkers' Foundation to know how well their proactive grants programme works and will inform their future grant giving for initiatives like CRAE and other projects.

## 4. Wider sector survey

### Introduction

This survey is being conducted on behalf of a grant-funding organisation, the Clothworkers' Foundation. The survey is part of an evaluation of the Clothworkers' Foundation **Proactive Grants in Autism Programme**.

Please answer any questions that you feel are relevant to you. It doesn't matter how many or how few questions you respond to. Your response will not be personally identifiable.

We would like your views on:

- The impacts of one or more of the projects which have been funded under the programme

If you don't know about any of these projects, you can skip this section

- The proactive grant-giving model and its relative strengths and weaknesses

If you don't know about the Clothworkers' proactive programme, you can give your views on the proactive model in general

The survey should take about 10-15 minutes to complete.

The survey is being conducted by OPM, an independent research organisation. Any data that you provide will not be identifiable to the Clothworkers' Foundation.

If you have any questions about the survey, please contact Lucy at OPM, on 020 7239 7882 or [lsmith@opm.co.uk](mailto:lsmith@opm.co.uk).

### Projects funded under the programme

1. Are you aware of the Clothworkers' Foundation?

Yes / No

2. Are you aware of any of the following projects which were funded under the Clothworkers' Foundation Proactive Grants in Autism Programme?

	Yes	No	Unsure
Establishing a Centre for Research in Autism and Education (CRAE) at the Institute of Education (Institute of Education and Ambitious about Autism)			
New Pathways College (Ambitious about Autism)			



Autism and Ageing Project (National Autistic Society)			
'Changing Lives' report – update to 'A Life Less Ordinary' report (New Philanthropy Capital)			
Quest research project (Research Autism)			
Reaching Out project (Short Breaks Network; formerly Shared Care Network)			

[If none, go to question 4]

3. For each project which the respondent is aware of...
  - a) How effectively do you think that this project has met its specific aims and objectives?

	<b>Very effective</b>	<b>Quite effective</b>	<b>Not at all effective</b>	<b>Don't know</b>
Establishing a Centre for Research in Autism and Education (CRAE) at the Institute of Education (Institute of Education and Ambitious about Autism)				
Improved research and practice for people with autism throughout their lives, extending the evidence base beyond early interventions into school, further and adult education settings, as well as care settings offering lifelong learning				
Awareness of autism good practice in all UK educational delivery streams, such as National Strategies, the curriculum subject associations and professional groups				
Greater integration of autism education research with other areas of autism research				
Greater commitment among evaluators to use common measures and research protocols in order to promote true comparisons across interventions				
Evaluation and measures of learner progress will be in widespread use				
Evidence based good practice in schools will be the norm rather than the exception				

Those working with people in autism will be skilled, knowledgeable and enthused				
New Pathways College (Ambitious about Autism)				
To enable young people with autism aged 19-25 years to learn, be healthy, stay safe enjoy and achieve, make a positive contribution, achieve economic wellbeing.				
To enable families/carers to support their young people with autism through their years at college and transition to adulthood				
To enable other organisations working with young people with autism to develop their staff and services to support them				
To enable other organisations working with young people with autism to develop their staff and services to support them.				
To create local and sustainable pathways to supported living, social and leisure activities, and employment and enterprise opportunities for young people with autism				
To establish a centre for excellence to develop and disseminate evidence and best practice				
To ensure that Treehouse school has the plans, people, resources to support the college				
Autism and Ageing Project (National Autistic Society)				
Professionals coming into contact with older people with Autism have increased understanding of how to support them				
Individuals and families are empowered to improve healthcare for older adults with autism				
Key influencers are engaged to make improvements in the lives of older people				

with autism				
'Changing Lives' - update to 'A Life Less Ordinary' report (New Philanthropy Capital)				
To provide information on: the needs of those living with autism, its impact on them, their families and carers, government and public attitudes to autism and the role of the voluntary sector				
To guide funders in making decisions about where to provide funding in relation to autism				
Quest research project (Research Autism)				
Give service providers information about number, severity and impact of behaviour problems at home and at school for children with ASD and their families				
Services provide effective and timely interventions to address behavioural needs				
Changes to the way that children with autism are assessed for problem behaviours				
A new protocol for clinicians to assist in the identification and treatment of associated behaviour problems				
A new protocol for follow up with children that will provide the means of evaluating the effectiveness of treatment for behaviour disorders				
Dissemination of the project nationally and internationally to inform public policy and practice, thereby affecting and influencing large numbers of children and their families				
Reaching Out project (Short Breaks Network; formerly Shared Care Network)				
Children with ASD currently on waiting lists for breaks will be linked to carers				

Children with ASD and their families currently receiving breaks will benefit from better breaks				
Short break carers currently looking after children/a child with ASD will benefit from information and training to improve the short breaks they provide				
More people will become short breaks carers				
Organisations who link children with carers in their community will benefit from improved knowledge, skills and efficiency, reducing waiting lists and improved quality and provision of short breaks for children with ASD				
Children with ASD who are currently not accessing family or community short breaks, will be able to access these breaks for the first time				

Please comment on your response if you wish

- b) Are there any other outcomes or impacts of this project that are not listed above?

- c) How effectively do you think that this project has contributed to the overall aims of the Proactive Grants in Autism Programme?

	<b>Very effective</b>	<b>Quite effective</b>	<b>Not at all effective</b>	<b>Don't know / not applicable</b>
<b>Improving the lives of people with autism</b>				
<b>Improved research and practice</b>				
<b>Improving early diagnosis rates of autism in children and subsequent</b>				

<b>intervention</b>				
<b>Improving the knowledge and awareness of autism and raising the profile of the autism sector <u>at local level</u></b>				
<b>Improving the knowledge and awareness of autism and raising the profile of the autism sector <u>at national level</u></b>				

Please comment on your response if you wish

d) To what extent do you think that the outcomes or impacts of this project can be attributed to the Clothworkers' Foundation's funding?

- Completely
- Partly
- Not at all
- Don't know

Please comment on your response if you wish

### *Grant funding models*

The Clothworkers' Foundation is considering the possible ways in which it could deliver grants in the future.

The Foundation used a proactive funding model for its grants programme in autism. A proactive funding model means that the grant-giving organisation selects potential grant beneficiaries to be invited to apply for the funding. Unsolicited applications are not accepted.

4. What do you think are the main **strengths** of a proactive model of grant funding?

If you wish, please refer to any of:

- the Clothworkers' Foundation proactive programme in autism
- other grants programmes in the autism sector
- grants programmes in other sectors.

If you wish, please comment on how the proactive model **compares to other models** of grant funding.

5. What do you think are the main **weaknesses** of the proactive model of grant funding?

If you wish, please refer to any of:

- the Clothworkers' Foundation programme in autism
- other grants programmes in the autism sector
- grants programmes in other sectors.

If you wish, please comment on how the proactive model **compares to other models** of grant funding.

### **About you**

1. What is your role in relation to the autism or children's disability sector (tick all that apply)

- A person with ASD
- A parent/carer/family member of a person with ASD
- A professional directly working with people with ASD (please specify)
- Research / academic
- Policy
- Charity
- Organisation representing people with ASD
- Organisation representing professionals working in the autism sector
- Organisation representing people with disabilities
- Organisation representing professionals working in the children's disability sector
- Other (please specify)

2. Would you be willing to take part in a telephone interview to explore these topics in greater depth? It would take about 30 minutes. If so, please give us your contact details and we may contact you to invite you to take part.

*Please note that all survey data will remain anonymous and we will not link your name or organisation to your survey response in our report.*

- Name
- Organisation
- Role

- Email
- Telephone

Thank you for taking part. Your input will help the Clothworkers' Foundation to know how well their proactive grants programme works and will inform future grant giving.

## 5. Topic guide for interviews with recipients of reactive grants

### *Introduction*

The Clothworkers' Foundation has commissioned an independent evaluation of the Proactive Grants Programme in Autism. The evaluation is being carried out by Linda Redford, an independent consultant with many years' experience in the autism and disability sector, with the Office for Public Management (OPM), an organisation specialising in evaluation.

The evaluation has two purposes:

- to **consider the impacts** of the funded projects
- to **generate learning** around the Clothworkers Foundation's grant-giving process.

The evaluation will include interviews with grant recipients, and surveys and interviews with direct beneficiaries of the funded projects and key individuals and organisations in the autism sector.

In addition to this, we feel it would be useful to speak with recipients of reactive grants, in order to enable us to compare what works well and less well about the two different models of grants delivery.

**Please note that this aspect of the evaluation is only intended to facilitate this comparison, as part of the evaluation of the PGPA. Your organisation's use of the grant you received is not being evaluated as part of this exercise.**

We are speaking to you today to find out a little bit about your funded project and its impacts, to get your views on the process of obtaining a reactive grant from the Clothworkers' Foundation, and to get your views on what works well and less well about different models of grants delivery.

If there is anything you would like to tell me that you would like us to report anonymously or keep confidential within the evaluation team, please let me know.

[Seek permission for audio recording if applicable. Recording will not be shared outside the evaluation team and will be destroyed after the end of the evaluation]

### *About your funded project*

- your **role** in relation to the funded project

- **how your organisation got involved** with the reactive capital grants programme
  - how did you hear about it?
    - were you approached by the Clothworkers' Foundation?
    - did you have an existing relationship with the Clothworkers' Foundation?
  - why did you decide to get involved?
- any **contextual factors** we should be aware of
  - e.g. changes to the organisation / wider environment during the course of the funded project

*[next questions to be covered briefly, as we should already have this info from the documentation]*

- the **aims** of your funded project
- the **intended beneficiaries** of your funded project
- an **overview of the activities** of your funded project
- has the project **ended**
  - if so, when
  - if not, when will it end

### **Funding**

- the ways in which the Clothworkers funding was used
  - e.g. to full- or part-fund the project
  - If part-, what other sources of funding did you draw on, and did the programme funding help you to secure other funding
- did you use the funding as originally planned or were there any changes during the course of the project?
- what proportions of the funding were for core and project specific spend?

### **Impacts**

- the impacts of your funded project **on** (as applicable depending on the nature of the project):
  - the **beneficiaries** of your organisation (e.g. people with autism and their families / professionals working in autism)
  - your **organisation** (e.g. impacts on your staff / profile of your organisation / links with other agencies)
  - the **wider sector** (e.g. other autism organisations, other relevant agencies including local authorities, health / education)
  - any **other impacts**, including **unintended outcomes**?
- what would you say are the **key successes** of your project
- The Proactive Grants in Autism programme has the following aims. How would you assess the contribution of your project (if relevant, depending on the nature of the project) to these? (we are asking you this in order to explore the differences and similarities between the impacts of grants awarded under the reactive and the proactive programmes)



- **improving the lives** of people with autism (including children, those at the transition stage and older people) and their families/carers
- **improved research and practice** for people with autism
- **improving early diagnosis** rates of autism in children and appropriate subsequent **intervention**
- **improving knowledge and awareness of autism** and to **raising the profile** of the autism sector at local and national level
- the **wider autism sector**
- how do the outcomes compare to your **original intentions** – is there anything you did not achieve that you wanted to, and if so, why was this
- how far can these impacts be **attributed to the Clothworkers funding** – would they have happened anyway? Would you have got funding from another source, and if so, where?
- **how do you know** you have achieved these impacts (what evidence do you have)
  - have you **measured** impacts and outcomes

### *Grants process*

- **Views on the process** of gaining a grant from the reactive capital grants programme.
  - What worked well or less well
  - Prompt, in relation to:
    - Application process
    - Amount received
    - Communications at each stage
    - Flexibility (e.g. being able to re-allocate funds)
    - Monitoring and reporting requirements
    - Nature of programme as being focused on autism
    - In kind support (as well as financial contribution)
    - Follow up (e.g. opportunities for further funding)
    - Any other comments
- In what ways did the Clothworkers' funding **add value** to your funded project
  - E.g. opportunities to work or share learning with other grant recipients under the programme
- What **advice would you give to another organisation** considering applying to the Clothworkers' Foundation for funding from its reactive capital grants programme?
- **What are the advantages of a 'reactive' programme** as compared to 'proactive' (and as compared to any other model of grant-giving)

- **What are the disadvantages of a 'reactive' programme** as compared to 'proactive' (and as compared to any other model of grant-giving)
  
- You may have received **other grants from the Clothworkers' Foundation**
  - If so, what type of programme was this under
  - How would you **compare** the experience of this with the **experience** of the reactive capital grants programme, and the **impacts** your project was able to make
  
- You may have received **grants from other organisations**
  - E.g. Mercers Company / Pears Foundation / Shirley Foundation / local authority / other
  - If so, what type of grants were these, and for which project
  - How would you **compare** the experience of this with the **experience** of the reactive capital grants programme, and the **impacts** your project was able to make
  
- If given the choice, **would you rather** apply for a grant under a proactive programme or a reactive programme? Why?
  
- **Suggestions for the Clothworkers' Foundation** in relation to their future grant-giving activities
  - changes to existing models (reactive / proactive)
  - ways to improve or add value
  - alternative models

End of questions. Is there anything else you would like to tell me?

Thanks & close

## Appendix 5. List of CRAE research projects funded since 2009

### Liz Pellicano (Director of CRAE)

Co-Investigator (with Michelle Heys and Anthony Costello, UCL). Pilot study to understand child behaviour and development in Nepali and UK children: qualitative study of parents and professionals. IOE/UCL Incubator Fund, £2,000, 2014.

Principal Investigator (with Stephen Hailes and Anthony Costello, UCL). A feasibility study on the effectiveness of yoga therapy for pupils with autism. IOE/UCL Strategic Partnership Research Innovation Fund, £14,946, 2013-2014.

Co-Investigator (with Catherine Manning). "Noisy brains? The role of internal noise in typical and atypical development" Workshop bursary from Experimental Psychology Society (EPS) to be held at the IOE in September 2013. £1500

Co-Investigator (with Joseph Mintz and Sara Price). Developing technology industry links for medical- and education-related apps via an IOE-SME collaboration on persuasive mobile tech for emotional regulation. IOE HEIF Next Generation Fund, £19,043, 2013-2015.

Bloomsbury Colleges PhD studentship. 'Culture and autism: How cultural norms shape the neurocognitive development and societal understanding of autism'. PI: Atsushi Senju (Birkbeck); CI: Liz Pellicano, £57,500, 2013-2016.

Co-Investigator (with Tony Charman). 'A feasibility study of the National Autistic Society's EarlyBird parenting programme'. Waterloo Foundation, £41,696, 2013-2014.

Principal Investigator (with David Burr) (MR/J013145/1). "'I do not see the world as others do.'" Diminished perceptual adaptation, hypo-priors and autism'. Medical Research Council, £583,132, 2012-2015.

Co-Investigator (with Tony Charman and Research Autism). 'Re-mapping autism research'. Funded by Inge Wakehurst Trust, Charles Wolfson Foundation, and Waterloo Foundation. £70,561, 2012-2013.

Principal Investigator (with David Burr). 'Number sense in autism.' Nuffield Foundation Social Science Small Grant Scheme, £14,936, June – December 2011.

Bloomsbury Colleges PhD studentship. 'Mechanisms of social influence in typical development and autism'. PI: Liz Pellicano; CI: Geoff Bird (Birkbeck), £56,500, 2011-2014.

Co-Investigator (with Tony Charman and Julie Dockrell), 'What is good practice in autism education?' Autism Education Trust (funded by Department for Education), £20,000, January – June 2011.

Co-Investigator (with Kerstin Witemeyer, Karen Guldberg, Natasha Macnab, Tony Charman, Sarah Parsons, Patricia Howlin, Vicky Slonims, Richard Hastings, and James Cusack). 'Planning meaningful outcomes for children and young people on the autism spectrum'. Autism Education Trust (funded by Department for Education), £80,000, January – July 2011.

Co-investigator (with 28 other PIs), 'ARC Centre of Excellence in Cognition and its Disorders'. Australian Research Council, Au \$21 million, 2011-2018.

ESRC quota award. 'Probing the sensory atypicalities in autism' (1+3). Liz Pellicano (IOE), £56,500, 2010-2013.

Co-Investigator (with Kristine Krug, Oxford, and Andreas Mojzisch, Göttingen), 'Social conformity: why do humans and monkeys make weak decisions under social influence?' VolkswagenStiftung (Germany), €398,736, 2010-2013.

Principal Investigator (with Beth Winter). 'Learning with the help of others: Do children with autism learn via social contact?' Experimental Psychology Society's Undergraduate Research Bursary Scheme (£2000), 2010.

### **Tony Charman (Former Head of CRAE)**

Medical Research Council. Green (PI), Charman (CI) and other, *Pre-school autism intervention and autism development: a longitudinal follow-up*. 01/10/2012-31/01/2015

Innovative Medicines Initiative. Murphy (PI), Charman (CI) and others, *European Autism Interventions – A Multicentre Study for Developing New Medications (EU-AIMS)*. 01/04/2012-31/03/2017

Autism Speaks. Simonoff (PI), Charman (CI) and others, *Why do people with autism spectrum disorders fare so differently in adult life? Role: Co-Investigator*. 04/01/2012-03/31/2015

NIHR Health Technology Assessment. McConachie (PI), Charman (CI) and others, *MeASURe: Measurement in autism spectrum disorder. Role: Co-Investigator*. 04/01/2012-03/31/2014

Wellcome Trust. Norbury (PI), Charman (CI) and others, *Specific language impairment and comorbidity: development over the first three years of schooling*. 01/01/2012-31/12/2015

BM1004 European Science Foundation, Charman (PI), COST Action: Enhancing the Scientific Study of Early Autism (ESSEA). Role: PI. 15/12/2010-14/12/2014