



Stand up for Autism

World Autism Awareness Day 2011 Survey Results



www.waad.org.uk

PROVIDING EVERYDAY SERVICES FOR CHILDREN AND ADULTS WITH AUTISM

INTRODUCTION

World Autism Awareness Day (a United Nations initiative) takes place on 2 April each year and to mark this day in 2011 a consortium of 36 of the UK's autism charities launched a public survey to explore with those providing common everyday services how these can be made more accessible and less daunting for children and adults with autism. The survey was targeted at the following service sectors throughout the UK: healthcare, education, social care, criminal justice, employment, transport, personal services, leisure services and retail.



The survey, carried out on a pro bono basis for the autism charities by Publitas Consulting, was launched online as well as being distributed by the autism charities themselves to their own contacts. Publitas Consulting LLP also emailed the survey directly to some 10,500 individuals across all the sectors listed above but predominantly within the public sector. Around 100 of these individuals were the heads of professional and trade associations representing large numbers of service workers who were asked to

distribute it on to their members. There is no way of knowing how many did so but it is clear from the responses that a number did support the survey in this way.

The responses to the survey are in no sense representative of either the service sector as a whole, or any specific service within it, but they are a helpful guide to general levels of awareness of autism within the service sector, and how willing and able people are to make adjustments to the services they provide to make them more accessible to people with autism. The most encouraging aspect of the survey is the finding that there is wide understanding of why service adjustments are necessary and considerable willingness on the part of service providers to make them. Also encouraging is that this is seen as largely a matter of attitude rather than of policy and so something that can be achieved on a bottom-up basis at little or no extra cost. In times of financial stringency this is a very positive message, and shows that what is needed on the part of policy-makers and managers is a willingness to allow individual initiative to take the lead.

The survey, conducted using Survey Monkey, was open for five weeks from Saturday 2 April to Saturday 7 May and during this time it was completed by 566 people. A full tabular analysis of the survey results is appended to this document.

WHO RESPONDED TO THE SURVEY

Of those who completed the survey three quarters were women, reflecting the overall bias towards women in the service sector, and 80% were between 30 and 59 years of age – the key working years. A third were aged between 40 and 49. Just 3% were either too young or too old to be in work.

The majority of responses (71%) came from people in England, with 18% from Wales, 4% from Scotland, 3% from Northern Ireland and a balancing 4% from countries outside the UK. Only 60% of those who contributed identified their ethnic group: of these a large majority (91%) gave this as white, with other ethnicities at around 1.5% each.

WHAT JOBS DO THEY DO?

Around 80% of those who completed the survey told us where they worked. The largest single group – 28% of those who answered this question - worked for local authorities, with a further 23% working in education, 18% working in the private sector, 16% working in the voluntary sector, and 10% working in healthcare. Within the private sector the largest number of replies came from people providing business, personal and financial services.

In terms of what jobs they do, around a third of those who took part were in roles (such as teacher, executive officer or customer representative) that bring them into direct contact with service users: half of these identified that they are in specialist roles (although these were not further defined). Around a quarter were in management roles. Small minorities were currently still in education, or were neither studying nor currently employed.



DO PEOPLE WITH AUTISM USE THEIR SERVICES?

The overwhelming answer to this question is 'yes'. Of the 80% who answered this question, 80% were confident that people with autism did use the services provided by their organisation: 10% were confident that they did not, whilst a further 10% didn't know. Given the apparent bias towards the public sector and towards specialist services in those who took part in the survey this is perhaps not surprising: but it may also suggest that there is good general understanding of autism as a relatively widespread condition within the UK population: a point explored further by the survey.

WHAT AND HOW DO PEOPLE KNOW ABOUT AUTISM?

Only one person who took part in the survey acknowledged knowing nothing about autism and only 8% of those who took part said they knew only what they had read or watched. Of those who did report knowledge of autism 5% were themselves autistic, 55% knew someone with autism, 24% knew the carer of someone with autism, 34% had received training in autism, and 43% worked for organisations assisting people with autism (multiple answers were possible so percentages add up to more than 100%).

When we asked people to provide further information about where their knowledge of autism had come from, around 70 people or 12% of those taking part had conducted their own research using a mix of reading, on-line sources, conferences and talking to parents of and professionals working with people with autism. 96 people (16% of those who took part in the survey) reported an immediate family connection to someone with autism of which 68 were parents, and a further 25 people reported a personal but not family connection. 36 people either held or were studying for a professional qualification in autism, and a further 28 had attended autism-related training courses. 74 reported experience of working with people with autism in a non-professional capacity such as a volunteer.



It is clear from these results that many of those who took part in the survey were indeed well-informed about autism from personal or professional experience. Indeed the survey provides some evidence of overlap between people's personal and professional lives with people's personal connections to individuals with autism sometimes (here in 8 cases) leading them to work in this field. This high level of knowledge may be in part a function of the way the survey was distributed through the autism charities as well as directly and the fact that it would naturally appeal most to people with a keen interest in autism. But another interpretation is that knowledge of and interest in autism is becoming more widespread alongside increasing public recognition that it is not a rare or unusual condition. What it also means is that we can be confident that the views we then explored on whether and how services might be adapted to meet the needs of those with autism came from knowledgeable and sympathetic people.

OVERCOMING THE HURDLE OF VERBAL COMMUNICATION

Many everyday services rely upon verbal communication, which can be a source of challenge to people with autism, many of whom tell us they think in pictures rather than words. Some have limited or even no speech and others find the to-and-fro nature of verbal interaction confusing and difficult. Yet when we asked those who took part in the survey how important verbal communication was in delivering their service, 63% of those who answered this question said it was very important and a further 20% said it was fairly important: a pretty conclusive and discouraging result.

So we were delighted to discover that when we explored whether other forms of communication could be used instead the response was firmly positive. Only 7% of those who replied said that no other forms of communication were possible: fully 63% thought that information could be exchanged using pictures or symbols, 60% thought that the exchange could be in writing matched to the individual's level of understanding, and 43% thought that communication through a friend or carer would be possible. 16% thought that other methods, such as signing, would also be possible.



When we asked how easy it would be for people to make these changes and what would stop them doing so the replies fell into two clear categories: for those already familiar with non-verbal forms of communication the answer was 'easy', reflecting the well-established alternatives already available, although several commented that time and some resource was needed to develop new materials. Those not familiar with the alternative approaches already in use or on offer tended to see this as more difficult but still saw this as something that could be done with appropriate guidance. Two people raised concerns about confidentiality if a friend or carer were present. One key point made by a number of people was that it was important to establish the preferred communication method of the individual and to accommodate this if possible. Others noted that visual information is easier for everyone to absorb.

BUILDING ON GOOD PRACTICE

Government policy on services for people with autism has developed rapidly in recent years in most parts of the UK, as research conducted by the National Audit Office, Welsh Assembly Government and others showed that service provision was patchy, often poor and provided poor value for money. In particular poor awareness of autism on the part of service providers and poor training for teachers, health and social care professionals

was identified as a major inhibitor of good services. We used the survey therefore to explore how those actually involved in service provision felt about how their organisations performed.



Around 70% of those who took part in the survey answered these performance questions: around half of these felt that their organisations were good at providing specific staff training to better help customer groups such as those with autism and a similar number said their organisations provided a quiet area for autistic people if needed. This figure dropped to 40% for adapting working arrangements and to a third for developing materials accessible to people with autism. A significant proportion of those who answered – around 18% - were not able to assess their organisation's performance and around the same number confessed that their organisations were not good at any of these things. Around a quarter assessed their organisations as neither good nor bad. It might be argued that given that there was a fair contingent of service managers amongst those who took part, a

generally positive response might have been expected here, but our further exploration showed that there were plenty of suggestions for how organisational improvements could be achieved.

WHAT CAN ORGANISATIONS DO BETTER?

The largest number of responses related to the need for a broader base of understanding and knowledge about autism and how it impacts upon people right across service organisations. It was not seen as sufficient to provide awareness and training only for those directly providing services for people with autism. A number of those who commented expressed frustration that their own awareness was not shared by colleagues, some of whom held out-dated and negative views. It was also suggested that where autism-specific staff training is provided it is important that it incorporates up to date information on research and best practice, and is informed by the views and experience of people with autism. Access to good, current and reliable sources of information on autism was also mentioned and a recurrent theme was the need to work closely with people with autism not only to understand their individual needs better but in order to enable better communication and more effective services.

Time was mentioned a number of times as a limiting factor: time to prepare, time to do a proper job and time to develop a relationship with each individual. Money was also mentioned, but largely in the context of creating employment opportunities for people with autism rather than additional funding for existing services. Creating a suitable service environment for people with autism was also mentioned a number of times, as was the need to use forms of communication known to work for people with autism.

AND FINALLY....

We invited people completing the survey to tell us about their service delivery for people with autism. Nearly a quarter of those taking part took up this invitation, spread across education, social care and specialist service providers. Whilst many of these provided examples of good practice across a spectrum of services from basic care needs to active integration of people with autism into the wider community there was also an underlying sense that the way forward lies in making all services more accessible to people with autism through a combination of wider social understanding, service adjustments and giving people with autism the skills and confidence they need to navigate everyday services for themselves.

