

Introduction

Dr Glenys Jones, GAP Journal Editor, 1999 to 2010

This reader celebrates 10 years of the *GAP Journal* and brings together a selection of papers published in the Journal during that time. The papers have been selected to represent the writings of parents and carers, people on the autism spectrum and professionals working across all services and sectors. In deciding what to include, papers have been chosen which cover issues that are still current today in relation to practice and suggest strategies to enhance the quality of life of all concerned. Inevitably, there are many which we have had to leave out due to the constraints of word length, but we are very pleased that all papers published in the *GAP Journal* from October 2007 onwards are to be available electronically, via Ingenta, in the near future – thus reaching a wider and much larger readership both nationally and internationally.

Aims of the Journal

The main purpose of the Journal when it was set up in 2000 was to promote and disseminate good practice within the UK. Over the last 10 years, practitioners have become much more directly involved with the evaluation of services and interventions and have been expected to measure the impact and examine the processes of the work in which they are engaged. In the past, this was often only done by external researchers. The *GAP Journal* has provided a vehicle to publish and publicise some of these evaluations.

Establishment of the GAP Journal: its history and its partners

Prior to the founding of the *GAP Journal* and its launch by BILD in May 2000, there were two occasional publications (entitled *Good Autism Practice*) edited by Glenys Jones and published by the University of Birmingham in April and September 1999. At that time, these were produced in partnership with the West Midlands Autistic Society and the Autism Services Accreditation Programme. These contained papers written by practitioners and parents and were very well received and sold out. This gave us the confidence to produce a regular, six-monthly journal and to seek an

appropriate publisher. It was an exciting development when in January 2000, Professor John Harris, the former Chief Executive of BILD agreed to publish the journal. Two of the original founding partners continued in this venture with BILD (ie the University of Birmingham and autism.westmidlands) and were joined by Autism Cymru whose Chief Executive, Hugh Morgan, became a Co-Editor of the *GAP Journal* with Glenys Jones. A management group and an editorial board were convened with members from the four key groups and a list of associate editors drawn up from different services and settings in the field of autism (see Appendix 1 for the list of those who have served on the Management, Editorial Boards and for the Associate Editors). For the first eight years of GAP, Christopher Dyer wrote a column on current government initiatives and media issues in the field of autism, and retired from this role in 2008. Reviews of books and DVDs and other resources are included in each issue, plus an updated list of accredited courses offered in autism and Asperger syndrome at higher education institutions throughout the UK.

In May 2002, the decision was taken by the Management Board to accept submissions from international authors too, whilst keeping the majority of papers from the UK. Originally, only papers from authors working in the UK were published as a main aim of the Journal was to increase the dissemination of good ideas and practice which had been developed and were being used in UK services. So, the international version of the *GAP Journal* was born and launched at the first World Autism Conference held in Melbourne, Australia. In addition, six GAP conferences have been held during the last 10 years, in different locations in the UK, where authors of some of the papers in GAP have been keynote speakers or have run workshops – so bringing the Journal contents alive and enabling further elaboration and discussion with delegates.

The *GAP Journal* has a very wide readership and subscription list which includes those working in early

years settings, teachers, support assistants, staff working in residential and day services for adults and in further and higher education, social care workers, parents and carers, advisers, speech and language therapists and occupational therapists, educational and clinical psychologists and students in addition to people on the autism spectrum themselves.

In 2008, Hugh Morgan retired from his role as Co-Editor and this was taken up by Elizabeth Attfield, from autism.westmidlands. She is the Training and Development Manager for autism.westmidlands and the mother of a young adult on the autism spectrum.

Selection of the papers

On the whole, the papers chosen are those which are of interest to a wide readership in terms of their relevance across the lifespan and across agencies. They are also papers whose key messages are still as relevant today, despite being written some years ago in the first issues of the Journal. Some of the most poignant and powerful papers have been written by people on the autism spectrum. They have the ability to vividly convey how autism affects their lives and how the response of services and agencies can be helpful or a barrier to their well-being and success.

The papers have been ordered in the year of publication, with the exception of papers 2 and 3 which appeared in the pre-journal GAP publications produced in 1999. Of the 20 papers, five have been written by adults on the autism spectrum, four have been written by parents of children on the autism spectrum, eight have been written by practitioners working in different settings and three have been written by academics. That said, authors in each of these categories often occupy more than one category. For example, Olga Bogdashina is a parent and an academic; Linda Woodcock is a parent and a professional working in a service giving advice on understanding and managing behaviour. David Andrews, Wendy Lawson and Heta Pukki all have academic qualifications in autism and are involved in training others. Ros Blackburn and Paula Johnston are also involved in speaking on autism at large conferences and training events. So the knowledge and experience base for papers published in this reader and the *GAP Journal* generally is very rich and wide-ranging. Most of the articles in this reader will be of interest to those working or living with adults or children on the autism spectrum whatever the setting as there are

important messages within them for all. They cover the following:

1. How autism is viewed by people with autism themselves (Blackburn; Andrews; Johnston; Lawson; and Pukki)
2. What makes an effective service and a good practitioner in autism (Peeters and Jordan; Allison; Peeters; and Rigg)
3. Mental health issues and prevention (Andrews; and Moran)
4. Social understanding and developing relationships (Eddas; Thorne; and Etherington)
5. Anger management (Fitzpatrick)
6. Gaining the views of individuals on the autism spectrum (Peeters; Williams and Hanke; and Moran)
7. Sexuality (Pukki)
8. Education of pupils with Asperger syndrome (Rigg)
9. Managing challenging behaviour (Woodcock, Hatton and Burden)
10. Parents and siblings (Woodcock, Hatton and Burden; Cooke and Semmens; and Anon)
11. Sensory issues (Bogdashina)
12. Sharing the diagnosis (Jones)

Changes made to the original papers

The papers published here are given as they originally appeared in the Journal except for some changes in the editorial commentaries which update details of the authors' place of work or qualifications, where known.

A note on terminology

When the Journal was founded, the term autistic spectrum disorder was used to cover all subgroups. In 2009, a decision was taken by the Editorial Board to change this to autism spectrum.

Changes seen in the field of autism practice over the last 10 years

Trends seen over the last 10 years since the *GAP Journal* was founded have been the increasing attention given to the involvement of children and adults on the autism spectrum in decision-making and in the evaluation of services and interventions. Parents and carers have been invited to join strategy and planning

groups more often by local authorities, primary care trusts and voluntary and independent organisations, before decisions are made. In the past, parents and carers were often only consulted after the plans had been drawn up. There has also been a number of initiatives to address the particular needs of brothers and sisters of children on the autism spectrum.

In terms of interventions, there is now more of a focus on altering the environment and the behaviour and interactive style of staff and carers, rather than on changing the child or adult on the autism spectrum to fit within existing systems and settings. This has been driven by the evidence from research and the words and actions of people on the autism spectrum who have argued very effectively against interventions which have focused on persuading them to be or to become 'normal' or 'typical'. There has also been a growing recognition of the sensory differences in autism and Asperger syndrome through the writings of authors such as Olga Bogdashina.

Future developments in the field of autism

It is recognised that in the UK and internationally there is still much to be done to develop effective services and support for all children, young people and adults on the autism spectrum and their families. However, papers published in this reader and in the *GAP Journal* provide evidence that practice is improving in services for adults and children and that new ideas, strategies and initiatives have been developed which do enhance the outcomes and quality of life for this population. There is much more of a consensus on what needs to be done and more dissemination of models and examples of how to work effectively in education, care, health, employment, leisure and housing services. Consulting individuals and parents to assess needs and at the start of planning support or provision is crucial. So too is focusing on strengths and interests and understanding and respecting the perspective and behaviour of those on the autism spectrum. Wendy Lawson ends her paper with a plea to professionals – *Please listen. Please be*

part of the solution and not the problem. Much of what is published by people on the autism spectrum has been written by intellectually able people who can communicate in conventional ways which others understand (eg speech; written words). These accounts can be very useful when working with those whose communication we are less able to understand at present. Currently, it is often assumed that those on the autism spectrum have similar responses and areas of difficulty, irrespective of their ability to communicate and their intellectual ability. However, there is a need to develop new technologies to enable those that do not use speech to be understood so that their actual views and needs are known and not guessed at or ignored. There are some case studies showing that some children and adults who were assumed not to be capable of communicating in written language or symbols have been able to communicate using keyboards or other technological aids. Work in this area, including effective assessment strategies and aids to alternative communication, needs to be expanded and explored so that a growing number of individuals on the autism spectrum are heard and understood.

The papers written by the authors with autism and Asperger syndrome in this reader are very powerful and instructive in informing professionals and parents on how to respond and meet the needs of this group. All those involved in the *GAP Journal* look forward to the next 10 years as they continue to publicise and celebrate success in the field.

To subscribe to the *GAP Journal*, e-mail Pam Mazurek, Subscriptions Administrator at BILD (p.mazurek@bild.org.uk). Papers are invited from all readers and draft papers relating to children's services and practice should be sent to Dr Glenys Jones (g.e.jones@bham.ac.uk) and those on adult services and practice should be sent to Elizabeth Attfield (elizabetha@autismwestmidlands.org.uk).

**Dr Glenys Jones
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