

# Report of Research Directions Symposium

Sue Buckley

## The symposium

From the 23<sup>rd</sup> to 27<sup>th</sup> October, 2007, a multi-disciplinary group of 80 leading scientists and practitioners from across the world came together in Portsmouth, UK, to

- review our understanding of Down syndrome
- identify and prioritise future research directions and
- identify best practice in development, education and health care.

The participants included representatives of major Down syndrome support organisations, parents and family members.

## The aims

The over-riding aim of this meeting was to identify what we, as world experts in this field, should be doing to improve quality of life for children and adults with Down syndrome in the next 5 years.

In a tightly packed programme for a full 3 days, we set out to explore a number of important themes:

- The current state of knowledge in genetics, neuroscience, developmental, cognitive and educational psychology, communication science and key areas of health and behaviour.
- The leading hypotheses of current interest and future directions in research
- The opportunities for interdisciplinary collaboration and pooled data resources
- The best practice in research methods and study design for working with people with Down syndrome
- The practical implications of current research for effective educational and developmental interventions and preventative healthcare
- The factors involved in transferring knowledge from research to practice
- The outcomes from research and practice for quality of life improvements for people with Down syndrome

## The process

### Papers prepared in advance

All the participants had put in a considerable amount of work in advance to enable us to meet these aims and to cover as much ground as possible. In topic-specific expert groups, they prepared reviews of the knowledge in their area, addressing the issues set out above.

### Plenary sessions only

One aim of the meeting was to share knowledge across the different disciplines all working in this field. Researchers in different disciplines do not always have the opportunity to learn about the work in other disciplines and discuss issues together therefore everyone attended and participated in all sessions. This was a valuable part of the symposium with much lively debate between those from different backgrounds during the sessions and in breaks and mealtimes.

### Views from different perspectives

A further aim was to share views from different perspectives as practitioners and parents often have different priorities from those of researchers – and different perspectives on the issues that researchers are studying. This worked well and there was much sharing of views but, on reflection, practitioners should have been given more time on the schedule to actually present their work and experience to researchers rather than contribute mainly through the discussions which followed the research presentations.

### Broad cover and an ambitious programme

The topic sessions covered what is known about the genetics and molecular biology of Down syndrome, brain-imaging, brain development and brain function, attention, memory, early social-emotional, motor, and cognitive development, family adaptation, sleep, hearing, vision and autism/dual-diagnosis, early intervention, behaviour, speech and language, literacy and numeracy. Other sessions considered

the methodological challenges of conducting developmental research, what developmental research suggests about key opportunities for interventions and the challenges faced when trying to translate research findings into practice.

### What are the next priorities?

The final half day of the main meeting was devoted to pulling together the outcomes of the earlier sessions and identifying how we can move science and practice forward – what were the key issues, challenges and priorities for improving quality of life for children and adults with Down syndrome in the next 5-10 years. In this session we also drew on the experience of other ongoing review groups and the examples of some other disability organisations.

The full programme and list of participants is available at <http://www.downsed.org/news/2007/10/symposium-hosted.aspx>

## The outcomes

### A knowledge update

The first and very significant outcome of the symposium was that we all learned a great deal from all the presentations in the course of the 3 days. Papers based on these presentations are currently being published in full in *Down Syndrome Research and Practice* starting in this issue (online at <http://www.down-syndrome.org/research-practice/advance-online/>). They provide a review of *what is known, what is known that can be applied in practice and what the next research questions* are in each specific area. These are the first steps towards drawing up a priority list of research studies and finding funding for them.

### Future priorities

The second outcome was a consensus on a number of issues that we need to tackle as a community. A number of common concerns emerged – specifically the need for more *longitudinal studies*, including studies designed to *understand development over time* and *key influences on developmental trajectories*, the need for *larger data sets* which could be achieved by

*multi-centre studies and collaboration*, the need to develop *shared protocols* so that a data bank could be established and *data shared* and the need to carefully consider *study design* and control group matching in order to be able to compare studies. The importance of more multi-disciplinary work was emphasised – the need to bring together the expertise, perspectives, tools and techniques from different disciplines to answer questions about brain/behaviour relationships and development. The complexity of understanding development overtime, the interacting effects of strengths and weaknesses in different aspects of development and the issues involved in capturing family complexity across the life span were discussed as were the benefits of cross syndrome comparisons.

### A focus on beneficial outcomes

The third outcome was an agreement on the *need to think a bit differently* when we plan research and to *focus on the benefits of the findings* for individuals with Down syndrome and their families rather than only on the research/academic interest of the questions to be asked. The challenge is to *design studies which really will make a difference* – for example, to develop research programmes that commit to finding ways to improve speech clarity, improve short-term memory, improve literacy and numeracy achievements, reduce challenging behaviours, improve education and inclusion in community and school, better understand how to support parents in fostering their child’s development from birth, better understand the reasons for the wide range of developmental outcomes by adolescence, reduce family stress and involve families and children from all ethnic groups in research.

### A commitment to continue the work of the symposium

The fourth outcome was a firm commitment from all the participants to look forward and to continue this work. To this end, it was suggested that *Task Forces* be set up to work on particular issues. It was agreed that these Task Forces should be *multi-disciplinary* and should include *researchers, parents, and practitioners* in order to continue to *build the bridges between research and practice* that are

so badly needed – and to *benefit from all the knowledge, insights and expertise* which parents and practitioners can bring to understanding the issues. Currently researchers rarely do benefit from these perspectives and progress in basic research may be slower as a consequence. The involvement of parents and practitioners may also increase the number of research studies that focus on the *development and evaluation of practical interventions*.

### Support for the ongoing work

Down Syndrome Education International was asked if they could provide some *practical support and co-ordination* from their offices for the establishment of Task Forces and agreed to do this.

### The approach succeeded

At the end of the main science meeting, there was much praise from the participants for the value of the meeting and the way it had been planned and conducted. There had been much individual benefit and contacts established which may lead to *new collaborations* as well as benefit for the future of the worldwide research effort. There was a general consensus that *further meetings in a similar format* would be valuable.

### Moving forward

On the fourth day, a smaller group of some 30 participants and sponsors stayed on to discuss how Down syndrome organisations and research groups can work together to maintain the momentum of the symposium, find funding and establish the mechanisms which will help to ensure the plans can be realised. The first 3 days provided a programme for priorities and actions i.e. ‘what we need to do’ and on day 4 the task was ‘how to make it happen’. This was a lively and productive meeting.

The main action points agreed were:

**1. Communication:** that contact is maintained for all symposium participants to continue to work together via the listserv set up by Down Syndrome Education International for the symposium. This has now been done and DSEI also agreed to set up other more specialised listserv groups if required. At present this group has the title Down Syndrome Research Directions.

The more catchy title RAPID has been proposed (Research Action for People with Down Syndrome).

**2. Multi-centre working:** it was agreed that a bid be developed to have video-conferencing facilities installed in all participating centres (to include research and practice groups and DS organisations and clinics). It was acknowledged that successful collaborative working depended on building trusting relationships between partners.

**3. Shared protocols:** it was agreed that working on these could be a good first step towards data sharing but the difficulties around data sharing are quite considerable given ethical guidelines and data protection laws. It was suggested that funding requirements can play a part – obtaining funding can be made dependent on working with other groups to agreed protocols and sharing data.

**4. Best practice guidelines:** it was noted that there is a significant need to publish best practice guidelines now – as many practitioners (in education, health, early intervention and community services) are not well informed or up-to-date in their knowledge of best practice and this was a cause of considerable stress for families. It was also noted that finding resources for translations of guidelines to as many languages as possible should be a priority.

**5. Parent and practitioner perspectives:** it was noted that a survey to find out what parents and practitioners consider to be the most important research questions would be valuable and could increase the likelihood of gaining funding from some funders. This might be something to be carried out before the next full meeting of the Down Syndrome Research Forum in 2009 in Dublin. Surveys of the *knowledge of parents and practitioners* on specific issues could also yield a wealth of valuable information but is rarely collected in systematic ways. Designing ways to capture this wealth of knowledge – may be using internet technology - should be a priority.

It was also noted that the willingness of families to take part in research studies will be determined by how valuable they consider the work and

how much confidence they have in the researchers (including their assessment of the real interest the researchers have in the welfare of people with Down syndrome). The need to further develop working with families as *equal partners in research* was noted and the need to always feed full results back to families. This discussion suggested that some *research standards and guidelines* could be established on these issues.

6. **Task forces:** the proposal for the establishment of Task Forces was supported – both cross disciplinary groups and also small specialist working groups. It was agreed that funding for Task Force/small group meetings would be a very productive way to make progress. If the RAPID title is popular then these will become RAPID Action Groups.
7. **Intervention/translational research:** It was agreed that such research is urgently needed but is not always a priority for academic researchers. There is a need to explore the reasons for this and to establish further funding sources to specifically encourage this work. The potential of intervention evaluation studies in providing a common ground for multidisciplinary studies (e.g. involving developmentalists, systems neuroscientists and animal models) was noted.
8. **Funding sources:** it was agreed that there is a need to work together to increase the amount of funding available worldwide from all possible sources, including governments, research funding bodies, companies, foundations, private donors and Down syndrome associations. The potential benefits of charities and universities working together to unlock funding was noted – this works for some funding sources in the UK (e.g. ESRC Case studentships).
9. **DS Associations role in funding:** it was agreed that many associations could support research but at present this is not often part of their mission or strategic plans therefore there is some work to be done here in engaging associations with the research agenda.
10. **Supporting young scientists:** The importance of attracting young scientists into Down syndrome research

was acknowledged and the need to find specific sources of funding for this noted. The need for better training for young researchers was noted, including the need for them to learn across disciplines if possible – giving them the chance to learn about a wider range of tools, techniques and perspectives. It was also noted that young scientists would benefit from collaborations between charitable associations, parent and practitioner groups and University departments – giving them a range of views on the issues early in their career.

11. **Future meetings:** There was a recognition of the value of face-to-face meetings for the large symposium group, with the benefits of the diverse contributions, and discussion of how to arrange these – possibly annually if funding can be found – and in different locations. It was agreed that possibilities for a meeting in 2008 would be explored but that a meeting of the Down Syndrome Research Forum would definitely be held in Dublin, Ireland, in August 2009 alongside the 10th World Down Syndrome Congress.

Sue Buckley is at Down Syndrome Education International, Portsmouth, Hampshire, UK. email: [sue.buckley@downsed.org](mailto:sue.buckley@downsed.org)

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- The University of Portsmouth
- The Education Centre for Children with Down Syndrome

## Next meeting of RAPID

Research Action for people with Down syndrome



Wednesday 19th August

at

The 10th World Down Syndrome Congress

Dublin City University  
Dublin, Ireland

The aim of this meeting will be to share the progress made since the first meeting and agree an agenda for further action. A joint meeting with Down Syndrome Medical Interest Group (DSMIG) is also planned.

For full details of the WDSC, registration and accommodation go to <http://www.wdsc2009.com/>



If you would like to join the RAPID list-serv:

Send an email to: [listserv@listserv.down-syndrome.net](mailto:listserv@listserv.down-syndrome.net) with "SUBSCRIBE DS-RESEARCH-DIRECTIONS" (no quotes) in the body of the message