Editorial

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The first paper in this issue, from Derek Moore, John Oates, Peter Hobson and Julia Goodwin – a UK research team from the University of East London, the Open University and University College, London – explores the social nature of early development and the way in which social and cognitive development interacts. They have looked at the development of a group of infants with Down syndrome longitudinally, from 6 to 18 months of age. The paper provides readers with a review of research in this area, and the methodological and theoretical issues that need to be considered, as well as providing a summary of their findings. The authors point out that *'the functions and structure of the brain are not entirely predetermined, they are also dependent on experience and interaction with the world'(pp. 43-44)*. It is, therefore, important to explore the way in which infants are interacting with their world and the way in which carers scaffold their learning, in order to gain an adequate understanding of the influences on early development. In one strand of the research, this team have explored the early attentional capacities of infants with Down syndrome, using visual discrimination tasks. Using the model provided by Colombo (2001), they divide attentional control into four subsystems, *alertness* - anticipatory readiness for stimuli, *spatial orienting* – the shifting of attention to and from particular stimuli, *attention to object features* – systems for analysing the visual properties of stimuli that will lead to their identification, and *endogenous attention* – volitional capacities for directing, holding or inhibiting the direction of attention. When comparing infants with Down syndrome at 6 months of age with typically developing infants matched for cognitive level at 4 months of age, they report that infants with Down syndrome showed significantly lower *alertness* and *endogenous attention* but were equivalent in *spatial orienting*. The authors suggest that these attentional processes may underpin cognitive development and provide relatively pure measures of information processing capacities. They point out tests which aim to assess early cognitive development are affected by social, motor and language development and they have developed a subset of tests from the Bayley Scales to use for matching infants to try and reduce these effects.

In a second strand to their research, the team have considered the influence of the infants' cognitive profiles on their mothers' social interaction with them. They provide a review of studies in this area and the findings of their own work. In a *'still face'* paradigm study they found the babies with Down syndrome behaved similarly to typically developing babies but that their mother's behaviour differed. They describe the mothers' tendency to a style of interaction which they describe as *forceful warmth* – a more intensive interactional style used to engage with their babies. While this adapted style may be effective in maintaining the babies' attention and responsiveness, what are the long term effects?

In third research strand, the team have considered the transactional nature of development and looked at the longitudinal effect of the mother's adaptive styles on social and cognitive development. Within the group of infants with Down syndrome, the mothers who displayed more *forceful warmth* when the babies were 6 months old, had infants who were less responsive to a tester's prompts for *'joint attention'* at 18 months. This may suggest a dependence on parental scaffolding of their behaviour which has reduced their responsiveness to the interactions and requests of other adults. However, another interpretation is possible. Perhaps the mothers who showed the most 'forceful warmth' at six months were already responding to individual differences among the infants with Down syndrome. Perhaps they had adjusted to prompt a maximum level of response from less responsive infants. Without the level of *'forceful warmth'* their mothers had developed, their infants may have been even less responsive at 18 months, even with their parents.

The work of this research group and others working in infancy is extremely important for those working in early intervention. We need more detailed studies of this period of development in order to provide guidance to families in the early months and years, but we need to be very cautious in drawing conclusions without more studies of these complex issues.

The next two papers in this issue report on case studies of educational progress, one looking at number teaching and one looking at literacy teaching. The first, from Ruth Germain at the School of Education, University of Birmingham, UK, looks at the inclusion of a four year old with Down syndrome in numeracy teaching in a mainstream classroom. In the UK, some 80% of children with Down syndrome will begin their full-time education fully included in a local mainstream school and many will be

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included in age–appropriate classes with assistant support for the whole of their education to 16 years of age. It is, therefore, important that we engage in detailed studies of effective teaching and support strategies for these children. Outcome research has tended to concentrate on benefits for the children's individual academic, language and social progress and there is little detailed work to inform classroom practice.[1] In UK schools, the national curriculum prescribes a daily numeracy hour and a literacy hour for all primary age children. In this study, the child with Down syndrome, Paul, is in a class of 30 children and he has support from a Learning Support Assistant for 60% of the class time. Paul was part of a smaller group of 12 children withdrawn from the class for some of his literacy and numeracy teaching. This is not common practice for reception age children in the UK, most schools will teach the whole class together at this stage, using small groups within the classroom. All children with special educational needs have an individual education plan, and may have their own literacy and numeracy targets to work on during these lessons. The study considered Paul's behaviour and progress in achieving targets during whole class, group and individual instruction times. Perhaps unexpectedly, Paul demonstrated less inappropriate behaviour when he was taught as part of the whole class. He was more successful in his independent attempts at tasks in individual and group settings and he experienced high success rates for tasks with adult support during these sessions. The implications of these findings may be to encourage the development of individual support for the child within the whole class teaching sessions. In this situation, the child feels part of the class and is included by the teacher whenever possible in answering questions, but he or she has assistant-help near to enable them to keep on task and complete work successfully.

The second educational case study, from Kelly Gallaher, Christina van Krayenoord, Anne Jobling and Karen Moni, of the Schonell Special Education Research Centre, University of Queensland, Australia, reports the reading progress of a young adult with Down syndrome taking part in a literacy and technology programme. There has been an increasing awareness of the benefits of literacy instruction and the literacy achievements of children with Down syndrome in recent years. However, literacy instruction often ends with formal schooling and may even be limited during secondary school education. This team have developed a literacy programme for young adults, with a strong emphasise on supporting success by scaffolding student's literacy progress, by working as a group to complete a piece of work and by making full use of computer technology in the project. This paper reports on the progress of one student, Abbie, during a series of 12 individual tutoring sessions, which formed part of Abbie's literacy experience on the project over a 7 month period. The sessions were analysed in detail and the information supplemented by video- and audio-taped information and interviews with Abbie's mother. At the start of the study, Abbie's literacy skills are described as emergent – she enjoyed books, had some sight-word ability but no phonics strategies and could write letters.

The paper contains useful and important practical information on the activities used to increase Abbie's reading and writing skills. The teaching included extending Abbie's understanding of words, sentences and text, sight word and phonics instruction, and composing text. Abbie made some progress in all areas, increasing her sight vocabulary and her use of phonics. She still made semantic errors in her reading and she was progressing in her engagement with text and in writing activities. This progress was achieved in a short time and this paper should encourage others to continue literacy instruction with adults and to begin literacy instruction with young adults who have not made any real progress during their school years.

The next paper, from Anthony Sullivan, formerly at Goldsmith's College, University of London, turns to the relatively neglected topic of father's adjustment to having a child with Down syndrome. This paper explores the coping strategies of mother and fathers of children and adults with Down syndrome, using the COPE inventory. The study looks at findings from parents of children aged between 3 months and 39 years of age, and separately at the findings from parents of children up to 5 years of age. Overall, parents demonstrated evidence of wide use of positive coping strategies such as *active coping, planning, seeking emotional and instrumental social support, positive reinterpretation and acceptance.* However, in all age groups, mothers used some positive strategies to a significantly greater extent than fathers. These were *seeking emotional and instrumental social support, focus on and venting of emotions and suppressing competing activities.* For the parents in the all age group, but not in the birth to 5 year group, mothers were significantly more likely to find *turning to religion* helpful. Contrary to theoretical predictions, there were no differences in mothers' or fathers' use of negative, unhelpful strategies such as *denial, mental or behavioural disengagement or use of alcohol or drugs.* The findings of this study support the general research literature on the coping styles of families of children with Down syndrome in that the majority were using predominantly positive coping strategies, which should be reducing family stress and enabling them to manage all their family demands effectively.[2] However, the findings do also highlight some differences between fathers and mothers, suggesting that the male role in UK society and expectations for male behaviour may have some effect in reducing fathers' use of the most effective coping strategies. More research on father's feelings and reaction is needed, particularly in different cultures, but the findings of this study may be useful to those working in family support services in western cultures and to fathers themselves.

The final two papers are on health and ageing issues. The first, from Stephen Donaldson, formerly of the Department of Psychology, University of Birmingham, addresses a care issue for staff caring for individuals with Down syndrome and dementia. This paper collected information from 60 care staff working in day centres in a large city in the UK and explores the question of work stress for staff caring for adults with Down syndrome and dementia. Psychological well-being was assessed using The Thoughts and Feelings Index and The General Health Questionnaire. There were no significant differences on the measures of well-being between staff caring for clients with dementia and those not caring for these clients. However, when clients' level of challenging behaviour is taken into consideration, there was a relationship between the level of challenging behaviour and staff well-being. The reported well-being of staff decreased as the level of challenging behaviours of clients that they worked with increased. This finding has important practical implications as it highlights the need to recognise the stress caused by difficult behaviours and the need to have good behaviour management skills in the staff team. It is not clear that difficult behaviours occurring in clients with Down syndrome and dementia will be amenable to change so that a further implication is the need to recognise the additional demands on care staff and to provide appropriate work patterns and support for these staff.

The second paper from Monica Pinto, Joaquim Neves, Miguel Palha and Manuel Bicho, of the Hospital de Santa Maria, Lisbon and the Down Syndrome Association of Portugal, explores the evidence for a link between anti-oxidant mechanisms and ageing in individuals with Down syndrome. Sixty children with Down syndrome took part in this study and 29 siblings of these children. Blood samples were collected and plasma GSH/GSSG, red blood cell TMR and MHR were measured (see article for glossary of abbreviations page 81). In the literature, higher levels of reactive oxygen species are reported for children with Down syndrome and these could be having a damaging effect linked to accelerating ageing. This study was looking for evidence that children with Down syndrome would show evidence of higher levels of the anti-oxidant mechanisms that compensate and remove these reactive oxygen species. Their results indicated no significant differences between the groups, possibly indicating that the children with Down syndrome will have tissue damage over time leading to premature ageing. This is an important area for further research into the basic mechanisms involved and into any significant effects of therapeutic doses of anti-oxidants.

We are pleased to include the abstracts from the last meeting of the UK Down Syndrome Research Forum at the end of this issue. This group meets for a 2-day session annually and provides a stimulating opportunity for researchers to meet and share their work in progress. The reader will see that the Forum covers a wide range of topics. The group is informal and is particularly supportive of students and new researchers. If you would be interested in attending and would like to be kept informed about future meetings, please let us know. Readers in other countries might like to consider developing a similar Research Forum.

1 Buckley, S. & Bird, G. (2000). *Education for Individuals with Down Syndrome – An Overview.* Portsmouth, UK: Down Syndrome Educational Trust.

2 Buckley, S. (2002). *Issues for Families with Children with Down Syndrome.* Portsmouth, UK: Down Syndrome Educational Trust.

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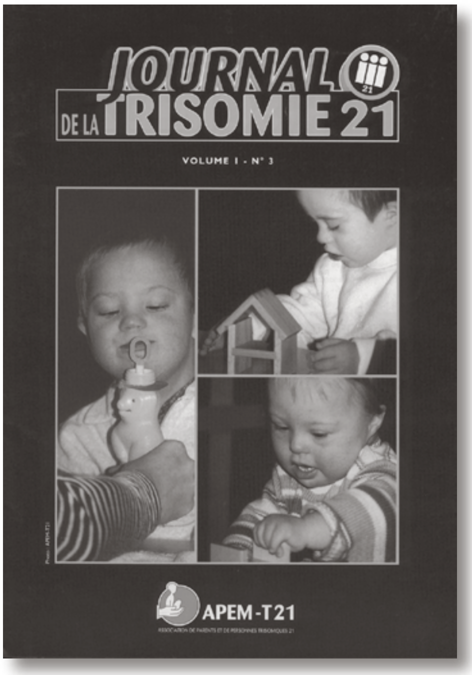

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