

# The whole child with developmental disorders

***Developmental disorders commonly overlap and, rather than being discrete conditions, are on a continuum. Given the evidence for this it is proposed that clinical services need to develop integrated approaches and pathways, working with education as this has potentially positive time, cost and quality outcomes.***

There is extensive evidence that developmental disorders such as attention deficit hyperactivity disorder, developmental coordination disorder (also known as dyspraxia), dyslexia, specific language impairments and autism spectrum disorder, rather than being categorical diagnoses, are in fact on a continuum and commonly overlap with one another. Despite this knowledge there remain difficulties delivering UK-wide consistent interdisciplinary approaches for children with these diagnoses. A poignant review of integrated and inter-professional working from Galvani and Forrester (2009), for the Welsh Assembly Government, warns that users ‘cannot be treated as bundles of complex problems each of which needs separate specialist input, but need a holistic service able to deal with such complex issues’.

## Terminology

Twenty years ago, Caron and Rutter (1991) highlighted that a failure to attend to comorbid patterns may lead to misleading conclusions by researchers and negative intervention results from practitioners. This remains as true today. If children and their families remain being seen in separate diagnostic ‘boxes’, moving from service to service to be assessed, this is not only an injustice for the families but has potential cost and time implications for effective delivery.

Terminology remains confusing, with terms such as comorbidity being commonly used. One definition of this is: ‘The presence of co-existing or additional diseases with reference to an initial diagnosis or with reference to the index condition that is the subject of study. This is two or more “diseases” with separate and different aetiologies which can present simultaneously or sequentially’ (Perrin and Last, 1995).

However, as this term implies a separate aetiological basis for each of these disorders it may not be the appropriate term to use, as increasing evidence has shown that in some disorders there may be a shared genetic basis. For example, Willcutt et al (2007) investigated a population sample of twins, with at least one twin member with a reading disability or attention deficit hyperactivity disorder. Forty per cent of the proband twins met criteria for the other disorder. The patterns of comorbidity in the twin pairs suggested that the co-occurrence of these two disorders may be largely attributable to shared genetic

influences. Another example is the shared genetic basis for some forms of specific language impairments and dyslexia which has also been noted (Bishop and Snowling, 2004).

Other terms used also include: ‘co-occurrence’, i.e. an accompaniment: an event or situation that happens at the same time as or in connection with another. This can imply causal relationships; ‘co-existing’, i.e. existing at the same time; and ‘overlap’, i.e. coinciding partially or wholly. The latter term may be more appropriate when referring to developmental disorders in light of a shared aetiology.

## Evidence of overlap

Starting with any developmental disorder, overlap is the rule rather than the exception and in the series of articles on developmental disorders published in this journal all authors have highlighted this.

Work by Kaplan et al (1998) demonstrated that in a population of children with developmental coordination disorder, attention deficit hyperactivity disorder and dyslexia overlap occurred frequently. Nearly 25% of those with one developmental disorder were found to have all three, 10% had both attention deficit hyperactivity disorder and developmental coordination disorder, and 22% had dyslexia and developmental coordination disorder.

In addition, Green et al (2002) found that in a study sample of eleven children with autism spectrum disorder 100% also met the criteria for motor impairment and, in a sample of 83 children with autism spectrum disorder, Sinzig and colleagues (2009) found that 53% fulfilled the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) criteria for attention deficit hyperactivity disorder. Further examples of the overlap between the developmental disorders are also reported by:

- August and Garfinkel (1990) – in a sample of 115 boys with attention deficit hyperactivity disorder, 39% also had specific reading difficulties

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- Kadejso and Gillberg (2001) – 87% of the children with attention deficit hyperactivity disorder had one or more comorbid diagnosis
- Mayes and Calhoun (2006) – in their sample of children with learning difficulties 67% also had autism spectrum disorder.

### Explaining the reasons for overlap

Most developmental disorders are behaviourally defined and the aetiology is complex. They are caused by the interaction of multiple genetic and environmental risk factors. Some of these disorders are also co-heritable. A number of researchers have described models to explain this complex and interacting mesh of influences. These include:

- Sargeant's (2000) 'cognitive-energetic model' (first described by Sanders in 1983), which discusses impairment at three levels of cognitive processing (encoding, central processing and organization; arousal, activation and effort; executive functioning) in attention deficit hyperactivity disorder and associated disorders
- Morton's (2004) 'causal modelling' which theorizes the effect that biological basis of developmental disorders has on cognitive processes which subsequently manifest in the behavioural patterns associated with the disorder.

### Implications for health and education provision

In order to support a complex group with a 'continuum of risks' Harley et al (2003) described needing a 'continuum of service options' organized around individual interventions, requiring creativity in reducing obstacles going beyond the jurisdiction of their own agency. Despite the knowledge of overlap, health and education services deliver widely variable models of practice across the UK and are often putting together local solutions and 'rules' for entry and exit criteria for access, including different health professional groups providing attention deficit hyperactivity disorder services. Anomalies abound in education also. The recently completed All Wales Dyslexia benchmarking exercise, which is currently reporting, mapping dyslexia provision in Wales has shown great variability for both entry and exit criteria for support for children among the different local authorities. Pathways into services from education can vary extensively and may include self-referral models, defined pathways or an informal process via the GP or educational psychologist. Age limits for provision also exist despite extensive evidence, as noted previously, that developmental disorders are lifelong conditions.

### Moving forward: developing a developmental pathway

In their 2007 paper, Salmon and Kirby state that 'a potential approach to the management of developmental

disorders is to provide a common clinical and educational pathway. The need for inter-disciplinary, inter-agency input into the diagnosis and management of developmental disorders is in line with the current emphasis on the importance of partnership working (Department for Education, 1994; Health Advisory Service, 1995; Department of Health, 1997; House of Commons Health Select Committee, 1997; Audit Commission, 1999; Department for Education and Skills and Department of Health, 2002; Welsh Assembly Government, 2002, 2004; National Autism Plan (National Initiative: Autism Screening and Assessment, 2003; Department for Health, Department for Education and Skills, 2004). The document *Removing Barriers to Achievement: The Government's Strategy for SEN* (Department for Education and Skills, 2004) specifically highlights the importance of partnership working to improve outcomes for children and young people with Special Educational Needs'.

The article goes on to say that 'the Special Educational Needs (SEN) Code of Practice (Department for Education and Skills, 2001; Welsh Assembly Government, 2002) highlights the importance of agencies working in partnership with each other and suggests that partnership working should be based on a number of principles including:

- Early identification
- Continual engagement with the child and parent(s)/guardian(s)
- Focused intervention
- Dissemination of effective approaches and techniques
- Integrated high quality, holistic support focused on the needs of the child
- A flexible, child-centred approach to service delivery.

The need for effective information sharing and communication between agencies both at management and also at practitioner level is also emphasized' (Salmon and Kirby, 2007).

### Developing joint services

In describing an integrated care pathway in community mental health services, Rees et al (2004) suggest that tools are required to map out the pathway both clinically and administratively with events and activities for all those providing care and for user groups. In addition, it requires a chronological pathway made clear to all, with management tools to ensure audit, communication and planning of provision. The difficulty of operationalizing this approach has been noted. Challenges for success have been ascribed to a lack of planning of resources to support implementation, the balance between providing a strategic direction and gaining practitioner involvement, and the pressure at times to rush the changes through because of short-term funding, legislative change or specific delivery deadlines for an initiative.

The question that must remain at the fore is whether joint provision can and does make a real difference and

whether it can be evaluated in terms of: 'the extent to which it has added value and achieved a greater impact than would have been achieved without its existence' (Atkinson and Maxwell, 2007). A well-demarcated child and family pathway seems to be of paramount importance. Douglas (2009) emphasizes the need to establish a baseline which requires a process of benchmarking. This is helpful to establish current practice, can then be used to reflect on changes that have occurred and be used as an active learning tool. As previously described, the All Wales Dyslexia benchmarking exercise has been helpful in highlighting areas of excellent provision and practice, and may also be useful as a potential means of pooling resources rather than reinventing them again and again locally.

### What limits success in interagency working?

Most of the literature about multi-agency working, including Tomlinson (2003), while giving guidelines on practice, lacks a theoretical basis for this approach to joint service working. Practitioners can work successfully at a local level on small and focused projects, but descriptions on how to bring these into the mainstream are limited by separate processes, procedures and structures at a more senior level. The commitment to delivering interagency working may at times be rhetorical rather than real. This has been described as 'vertical' organizational ambivalence and results in expansive small-scale innovations being initiated but which remain truncated because they are isolated within the macro-organizations (Engeström, 2001). It is essential to consider the overall system and the professionals in it for change to be made longer term.

### Increasing the chances of success in interagency working

A successful pathway requires buy-in at all levels, with both a financial and political will coming from the different service providers. This needs to be achieved at the highest levels otherwise it is unlikely to permeate to lower levels. Percy-Smith (2006) and Wolstenholme et al (2008) have shown some common factors for success. These include:

- A shared understanding of aims and objectives
- A common understanding of the threshold for need (often contentious when there are financial pressures)
- Confidence in information sharing between parents and professionals (a need for common record systems)
- Co-location of services (informal communication building bridges and saving time)
- Joint budgetary control
- Regular sharing of audit and research findings.

Interestingly, a large follow-up study which mainly concurred with the above findings suggested that good qual-

ity services did not always equate with better service outcomes for the children (Glisson and Hemmelgarn, 1998) and called for further research in this area.

Joint inter-professional training is a positive way to encourage knowledge sharing. Training before qualifying has been seen as beneficial (Jacobsen and Lindqvist, 2009). Key factors in success included developing a common language of terminology to encourage dialogue. Clear understanding of people's roles and responsibilities can also lead to better joint working (Mukherjee et al, 2002).

There is a need for health-care professionals to be trained across the developmental disorders and not just in separate professional silos. Kirby et al (2007) showed that not all child and adolescent psychiatrists regularly ask about motor disorders in children with attention deficit hyperactivity disorder, despite the common association.

Teacher training is essential to embed an understanding of typical development in order to recognize children presenting atypically. A successful programme by Sayal et al (2006) demonstrated the effectiveness of providing training for teachers about attention deficit hyperactivity disorder. The intervention took the form of a 45-minute educational session for teachers, delivered by a child and adolescent psychiatrist and a research worker in an interactive fashion. It combined video clips with handouts. Areas covered included a description of attention deficit hyperactivity disorder, how it presents at school and at home, long-term outcomes, diagnostic challenges including differential diagnosis and comorbidity, and finally, medical, behavioural and classroom management. Following the sessions, there was an increase in the proportion of children regarded by teachers as having probable attention deficit hyperactivity disorder and improved agreement between teacher recognition and a diagnostic algorithm. This approach could be extended across all the developmental disorders especially if centrally produced generic materials could be provided and then locally tailored.

### Creating pathways

In order to develop a pathway (other terms used include tiers or waves) a decision needs to be taken about where the process begins and how it is to be followed. There are some examples of successful integrated pathways, but some are limited by their lack of measuring the experience from a parent or child perspective.

One example of multi-agency pathways for children with attention deficit hyperactivity disorder, autism spectrum disorder and developmental coordination disorder has been developed in Swansea by Salmon et al (2006). When describing the attention deficit hyperactivity disorder pathway they describe filtering processes acting as a funnel to appropriate support (Sloan et al, 1999) and likened this to the special educational needs graduated response (Department for Education and

Skills, 2001; Welsh Assembly Government, 2002). Their three pathways are described separately but have some common themes. First, they started off with health and education jointly developing the services with schools identifying and providing an initial level of support and seeing whether this is adequate. Schools also have a clear role in information gathering before health services are engaged. The health professionals are responsible for providing clinical support, as well as providing training in schools and for parents.

Other examples of developmental pathways include the Mid Cheshire attention deficit hyperactivity disorder pathway (Burgess, 2002), similar to the Swansea attention deficit hyperactivity disorder model, with a filtering process where referrals pass to the community paediatrician, and a school nurse based in a local clinic for a baseline examination.

### What do the pathways have in common?

- A shared ethos of responsibility
- Listening to concerns from parents or teachers
- Inclusive practice within the school setting
- Clarity of the pathway starting in education, e.g. working with the special educational needs coordinator
- Local solutions, from an evidence base, for specific areas of difficulty, e.g. reading, writing
- Referral to a local clinician(s) for first stage assessment – only after information has been gathered from home and school and school-based intervention has been tried and evidenced
- A two-way system of information, advice and feedback
- Ongoing training
- Shared notes between services, with some cases of parent-held records.

### Intervention: place and people

It is essential to consider a range and mix of service delivery options to meet the needs of children with differing patterns and severity. This requires a consideration of the effectiveness of differing models of practice. This can be considered from an economic perspective as well as considering outcomes for the child and family. In addition providing direct intervention may not be possible for the numbers of children with developmental disorders who require support across all age bands.

In the National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) guidelines for attention deficit hyperactivity disorder this is discussed in some detail, and highlights the work of Dretzke et al (2005) who assessed the cost effectiveness of three parent training or education programmes for children with conduct disorder which differed in their mode of delivery and the setting: a group community-based programme, a group clinic-based programme and an individually delivered, home-based programme. A meta-analysis had shown the clinical

outcome was the same for all three methods. The economic analysis showed that the group clinic-based programme was the dominant option among the three parent training or education programmes, as it provided the same health benefits (same clinical effectiveness) at the lowest cost.

Indirect work can take a variety of forms and a range of potential models have been described. For example a randomized controlled trial by Boyle et al (2007) compared direct *vs* indirect approaches and individual *vs* group modes of speech and language therapy, and demonstrated that no method was superior over others. They suggested several potential models of integrative service delivery such as the partnership between speech and language therapy and schools, cluster models of delivery via integrated community schools, and the involvement of class teachers, classroom assistants and parents or carers.

In another study Parow (2009) describes a speech and language therapy intervention for children with social, emotional and behavioural difficulties where a mixture of direct and indirect approaches were used. The indirect intervention included advice and programmes, while the direct intervention involved working directly with the children and with the professionals to develop appropriate verbal interactions. This study highlighted the fact that specialist interventions need not always be direct interventions and direct interventions do not always mean that the child needs to be present.

Another example of an indirect approach to intervention (Erhardt and Meade, 2005) demonstrated success being achieved by clarifying roles. This was a collaborative intervention between parents, occupational therapists, physiotherapists and school who worked on motor control and handwriting difficulties.

Sugden and Chambers (2003) also demonstrated delivering a mix of direct and indirect interventions for children with developmental coordination disorder using both parents and teachers to provide the intervention. They showed that both 'teachers and parents were able to provide effective intervention with the majority of the children improving during two periods of intervention' equally well. They also argued cogently in a follow-up article (Sugden and Chambers, 2006) that the strength of the indirect approach was that it was not only an effective approach from a management and cost-effectiveness perspective but by using parents and undertaking support in home and in school it also builds interventions into young people's daily lives rather than them taking place in a clinically remote context.

### Parents as partners and experts in their own children

Parents have a right to be key partners at all stages of the pathway and are not only essential for delivering successful outcomes but provide a cost-effective approach as

they are usually motivated to make a difference to benefit their children and also have expert knowledge of their own children.

The parents' role can be in both identification and intervention. For example, they have been shown to accurately identify childhood disabilities (Glascoe, 1996), and may also increase the likelihood of physicians identifying psychosocial difficulties and mental health problems (Lynch et al, 1997; Glascoe, 2003) which are often associated with developmental disorders. Parents have been shown to express accurate developmental, emotional and behavioural concerns regardless of ethnicity or parental education (Glascoe, 2000; Wu et al, 2008).

However, a study of children at risk of attention deficit hyperactivity disorder conducted by Sayal et al (2006) found that the parents' perception of their child's behavioural problems was associated with their likelihood of seeking their GPs advice regardless of the severity of hyperactivity or comorbidity present. On the other hand, the GP in these cases based recognition of the disorder on both the parents' perception and the severity of the child's problem (Sayal et al, 2006) before diagnosing attention deficit hyperactivity disorder.

### Conclusions

The wealth of evidence supporting the common ground between developmental disorders has implications for identification through to intervention and support. The move away from a targeted approach to an individual difficulty towards a more holistic and integrated one is indicated. This can be best facilitated in the first instance by adopting a common terminology, i.e. that both health and education use terms consistently so that parents can understand better how the language used to describe their children's difficulties has meaning to them, e.g. deciding when to use terms such as autism spectrum disorder, Asperger's syndrome, autism and autistic spectrum disorder.

Research has also shown that developmental disorders represent a complex continuum caused by a range of environmental and genetic factors requiring an interdisciplinary, inter-agency approach to diagnosis and management. Indeed the call for separate agencies to work in partnership with each other to provide a service centred

around the needs of the child has been highlighted as a priority in a number of government documents from both health and education.

Although the theoretical underpinning is sound, putting inter-agency working into practice has proved problematic. A good starting point for change would be undertaking shared training across the developmental disorders for health and educational professionals so that the roles of both parties are understood and there is a common baseline of understanding. The next step would be to provide clear pathways of service delivery, developed jointly by health and education practitioners, with joint funding in place.

Parental involvement is essential in this process and can provide great insight into the child's difficulties providing much more detailed information than a snap-shot assessment in one place and time. The partnership between professional and parent coupled with the engagement of the child in the identification and intervention process should not be an 'add on' but regarded as both an essential and cost-effective approach to service delivery. This is particularly important given that developmental disorders are far more than 'just' of paediatric concern but are acknowledged as having a lifelong impact. **BJHM**

*Conflict of interest: Professor A Kirby has a son with attention deficit hyperactivity disorder, dyslexia and developmental coordination disorder; Dr M Thomas: none.*

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### KEY POINTS

- It is well established that developmental disorders commonly overlap.
- It is essential that an interdisciplinary interagency approach is used in order to fully support children with developmental disorders.
- The use of common terminology can further facilitate communication between these services.
- The development of clear service delivery pathways by both health and educational professionals that involves and engages parents and their children is called for.

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