

Appendix 1

Young Children who Stammer: The Case for Early Intervention

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1 Introduction

There is a large and growing body of clinical evidence and agreement amongst specialists that early intervention with young children who stammer – that is intervention as close to onset as possible – is not only desirable but essential.

Treating young children who stammer as close as possible to the onset of the disorder is not only time and cost-efficient but also clinically effective.

Delaying treatment exposes young children who stammer to the risk of this condition becoming a pervasive, life-long disorder. This can result in potentially debilitating effects on the individual, their health and well-being and their ability to contribute to society, leading to long-term, costly and complicated health and social care issues.

This document is designed to summarise expert opinions of the leading specialists in dysfluency and evidence-based research from the UK and abroad published in peer-reviewed journals, to support the case for early intervention for pre-school dysfluency.

2 The Case for Early Intervention

2.1 INCIDENCE OF STAMMERING

Recent research has indicated that by three years of age, the cumulative incidence of stammering onset is between 7 per cent (Dworzynski *et al.* 2007) and 8.5 per cent (Reilly *et al.* 2009).

Dworzynski *et al.* (2007) analysed stammering data, based on parental reports, from the Twins Early Development Study (TEDS) (Trouton, Spinath & Plomin 2002). TEDS is a longitudinal study of all twins born in the United Kingdom between 1994 and 1996. 25,830 twins were surveyed with regard to stammering at ages two, three, four and seven years. The prevalence of stammering was between 1 and 3 per cent for the different age groups. Incidence across the age range was 7 per cent. This is much higher than previously thought to be the case (e.g. Bloodstein 2007).

Conservative estimates indicate that somewhere in the region of 25 per cent of the children speech and language therapists see are at risk of stammering persisting into adulthood (Stewart & Turnbull 2007, Yairi & Ambrose 1999). At this very young age, it is currently difficult to predict which of these children will persist and therefore all children need to be seen to evaluate the risk factors associated with persistence (Kully 2008).

2.2 EARLY INTERVENTION IS ESSENTIAL FOR EFFICACIOUS OUTCOMES

Research has shown us that children who have been stammering for more than three

years are likely to persist with stammering throughout their lives (Yairi, Ambrose, Paden & Throneberg 1996). A lack of improvement in fluency in the first 12 months of stammering is also significant. It may well be that early intervention at this stage can be preventive and, at the very least, will help to promote positive coping strategies and attitudes to stammering (Stewart & Turnbull 1995). Indeed any intervention which ensures that stammering remains as no more than tiny lags and disruptions (Van Riper 1990, p.317) is to be recommended at this stage, especially when one considers that stammering which decreases over time is more likely to lead to a future of fluent speaking (Yairi & Ambrose 1992, Yairi et al 1993).

There is a large and growing body of evidence which tells us that early intervention with young children who stammer can be time and cost effective as well as clinically effectual (Hunter 2007, Manning 2001). Early intervention means effective intervention! (Christie 1996)

Many early intervention programmes are available which show favourable results in the treatment of young children who stammer and all should be regarded as better than no treatment (Millard et al 2009, Millard et al 2008, Jones et al 2008, Franken et al 2005). With early intervention, therapists have access to therapy models which provide comprehensive and clear directions for treatment (Manning 2001). At this early stage even small adjustments in the child's environment, aimed at alleviating communicative stress, can effect significant improvements (Stewart & Turnbull 2007, 1997, 1995).

Indeed, therapy for young children who stammer, if accessed early, shows recovery rates above those that could be explained by spontaneous recovery (Hunter 2007, Jones et al 2005, Harris et al 2002, Fosnot 1993, Meyers & Woodford 1992). Giving early therapy aimed at reducing stammering in young children is seven times more effective than not giving treatment (Jones et al 2008).

In terms of the child's neurological development, early intervention is also highly recommended. Research into the development

of children's brains shows us that there is a limited time frame in which to maximise the chances of success in therapy. For this reason, early intervention is critical (Smith 2008).

In terms of health economics, there is a strong argument for early intervention. Stammering is a complex disorder which becomes more complex as children get older and continue to stammer (Packmann & Kuhn 2009). As such, treatment in older children must tackle a much wider range of variables (Murphy et al 2007) and this can involve a wider range of health professionals (Packmann & Kuhn 2009). Children with severe stammering take longer to treat than those whose stammering is less severe (Kingston et al 2003, Jones et al 2000),

and for some children stammering will become more severe the longer they have been stammering. (Kully 2008, p5)

Other researchers provide evidence which allows an even longer term, lifespan view to reinforce this argument. Studies show that young children who stammer need a shorter duration of therapy and make faster progress (Manning 2001). In later years, treatment may be required for longer and the speech that results from later treatment may sound less natural with a greater probability of relapse (Lincoln & Onslow 1997, Starkweather 1997). Older children and adults who stammer often require repeated courses of speech therapy (Packmann & Kuhn 2009). Given this data, it is essential that the effects of stammering on the child be addressed as early as possible (Packmann & Kuhn 2009) and to recognise that it is not acceptable to delay treatment for an extended period of time (Lattermann et al 2007).

A recent major Canadian report reinforces the view that early intervention is vital: Kully writes that "all cases require attention within a short time-frame" (Kully 2008, p2). The report recommends that intervention be carried out from six weeks to a maximum of 12 weeks from referral (Kully 2008, p4).

Given that stammering is a condition that responds well to treatment, best practice dictates that services not be delayed (Kully 2008, p2).

3 STAMMERING AS AN ADDITIONAL SPEECH, LANGUAGE AND COMMUNICATION NEED

Early intervention in stammering needs to be co-ordinated with early intervention in other speech, language and communication needs.

Stammering often co-exists with other difficulties and dovetailing stammering services with early intervention for other speech, language and communication needs (SLCN) is essential. Phonology¹ in young children is a good example.

Research shows that a third of children who stammer exhibit different degrees of phonological disorder (*Conture 2000, Hunter 2007*). Children who stammer and who also have severe phonological disorder are more likely to continue to stammer for longer (*Mansson 2006*). Indeed, children with phonological delay are more likely to continue to stammer into adulthood (*Paden et al 1999*). Conversely, it is also likely that difficulties with phonology will continue for longer with children who stammer (*Louko et al 1990*) which can compound the difficulties that these children face.

This would imply that early intervention with the aim of monitoring and modifying the child's developing phonological system, alongside their stammering, would be appropriate.

It may be that there are links between the development of language and stammering. Some children who stammer appear to have a delayed ability to understand and use language (*Yairi et al 1996*).

There has been some speculation that children who have a slower language development have a better chance of recovery because they are less concerned about their language and keener to utilise their capacity to be fluent (*Watkins et al 1999, Paden et al 1999*). This would imply that the early intervention programmes that are designed to monitor and modify language are appropriately targeting this area.

4 EFFECTS OF FAILURE TO INTERVENE

The research base clearly demonstrates the consequences of failing to provide early

intervention for young children who stammer.

When stammering is not brought under control with treatment soon after onset, the disorder can seriously disrupt the ability of the child to communicate throughout their entire life (*Packmann & Kuhn 2009*). Indeed, research has shown that pre-schoolers who wait for treatment are at risk of negative psychological, emotional and social effects (*Langevin et al 2007a, b*). Additionally, stammering is likely to impact negatively on the social-emotional, educational and vocational development of the child (*Lattermann et al 2007, Gabel 2006*).

Children who stammer develop negative attitudes towards their speech and communicative ability from as early as three years of age (*Vanryckeghem et al 2005, Bajaj et al 2005, Jelcic-Jaksic et al 2000*) and this becomes increasingly negative with age (*Vanryckeghem & Brutten 1997*).

Persistent stammering impacts on self-esteem and self-image (*Klompas & Ross 2004*) and the greatest adverse effect occurs during formative school years where stammering negatively impacts on children's academic performance and their relationships with their peers and with teachers (*Crichton-Smith 2002, Hayhow et al 2002*).

An added dimension is the occurrence of bullying. Children who stammer are more susceptible to bullying (*Langevin & Hagler 2004*) and tend to experience significantly more teasing and bullying than their fluent peers (*Langevin et al 1998, Langevin 2000*). Children who stammer are significantly rejected more often in social settings and have even rated as less popular than their peers: a trend that appears to continue despite the implementation of recent integration and anti-bullying policies (*Davis, Howell & Cook 2002*). A growing body of evidence has established a link between being bullied and the occurrence of emotional, academic and even physical difficulties (*Murphy et al 2007*).

Given the above, researchers recommend treatment early in the pre-school years (*Lattermann et al 2007*) and state that it is not acceptable to delay treatment for an extended period of time (*Lattermann et al 2007*).

5 THE ONGOING EFFECT OF FAILURE TO PROVIDE EARLY INTERVENTION

Research suggests that as an individual grows older the continued negative effects of stammering can be socially and psychologically debilitating (*Langevin et al 2007 a, b, Lattermann et al 2007, Gabel 2006, Klompas & Ross 2004*). Davis, Shisca & Howell (2006) have identified elevated levels of state anxiety in those who persisted with stammering.

The social stereotyping of people who stammer is predominantly negative: they are seen as excessively nervous, anxious and reserved (*Mackinnon et al 2007*), and there appears to be a correlation between the severity of the stammer and the lack of positive regard in others (*Gabel 2006*). These attitudes towards those who stammer can have many negative consequences including limiting occupational, educational, and social opportunities (*Crocker et al 1998*).

Longitudinal research following children with speech and language disorders (including stammering) from the age of five has consistently found that in early adulthood there are increased rates of anxiety disorders (*Craig & Tran 2006*), and around 50 per cent of adults who stammer meet the criteria for social phobia (*Stein, Baird & Walker 1996*).

Stammering is a significant vocational handicap (*Hurst & Cooper 1983*). It has been found that many employers hold negative attitudes towards people who stammer (*Hurst & Cooper 1983a, b*) and this can impact on the likelihood of successful recruitment or promotion (*Klein & Hood, 2004*).

At least 60 per cent of young people in custody have difficulties with speech, language and communication (*Bryan & Mackenzie 2008, Bryan et al 2007, Bryan 2004*) and the incidence of stammering among offenders in prison is twice as high as among the general population (*Hamilton 1999*).

Ultimately, stammering can prevent a person achieving their potential in society (*Packmann & Kuhn 2009*).

6 GOVERNMENT SUPPORT FOR EARLY INTERVENTION

The Government has recognised the importance of the early years to all children, and the necessity of identifying problems as early as possible. The Government also recognises its responsibility to provide prompt support to tackle such problems (*Every Child Matters agenda (2003), Sure Start, Children's Plan (Bercow 2008)*). Stammering impacts on all of the five aims of the Every Child Matters agenda:

- be healthy
- stay safe
- make a positive contribution
- enjoy and achieve
- achieve economic well-being.

In March 2008, the Department of Health published an update of the Child Health Promotion Programme. This programme lies at the heart of all universal services for children and families and highlights a child's speech and language development – including stammering – as one of eight priority topics for the health and development reviews of children.

As of September 2008, the Early Years Foundation Stage set out a single framework for learning, development and care for children in all registered early years settings and schools from birth to the end of the reception class. This includes communication, language and literacy as one of the six, equally important areas of learning and development.

The Bercow report, also published in 2008, drew five major conclusions:

- Communication is crucial.
- Early identification and intervention is essential.
- A continuum of services, designed around the family, is needed.
- Joint working is critical; and
- The current system is characterised by high variability and lack of equity.

Early identification implies recognising a child's difficulty in a timely manner and providing an appropriate response. Early intervention includes prompt and

relevant support for the child and the family. In addressing Speech, Language and Communication Needs, there is a strong clinical agreement on the value of early intervention and the risks associated with any lack of provision. If a child receives appropriate help early on, he or she has a better chance of managing their difficulties, developing effective communication skills and achieving their potential. The risks to a child of lack of timely intervention are lower educational attainment, limited career prospects, challenges to mental health and, in some cases, descent into criminality (Bercow 2008, p7).

The Better Communication Action Plan arose as a direct result of the Bercow Report. This puts early intervention at the heart of the government agenda culminating in the National Year of Speech, Language and Communication in 2011/12. The Government will form a Communication Council and appoint a Communications Champion early in 2009.

The NHS Constitution (2009) also sets out a series of rights which are protected by law, including:

You have the right to be given information about your proposed treatment in advance, including any significant risks and any alternative treatments which may be available, and the risks involved in doing nothing (NHS Constitution 2009, Section 2a)

The risks of doing nothing with young children who stammer have been outlined above and are well documented in Bercow (2008).

It goes on to say that

You have the right to compensation where you feel you have been harmed by negligent treatment (NHS Constitution 2009, Section 2a)

The NHS Constitution (2009) also sets out a series of pledges which relate to the supporting of initiatives which will enhance staff development and therefore the provision of early intervention for young children who stammer:

The NHS commits to provide all staff with personal development, access to appropriate training for their jobs and line management support to succeed ... all staff will be empowered to put forward ways to deliver better and safer services for patients and their families. (Section 3a)

All the evidence, from clinical opinion to a large body of research to the Government's own health and educational policy indicates that the best and safest course of action for young children who stammer is to provide early intervention.

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