

## **Real Prospects for Early Childhood Intervention: Family aspirations and professional implications**

### **ABSTRACT**

The political climate in which to develop a nationally cohesive programme of Early Childhood Intervention is ripe. Initiatives such as the Early Support Programme, Sure Start and the National Service Framework are examples of this. Early Childhood Intervention is one of the four major platforms of the recently launched Government strategy on special educational needs, *Removing Barriers to Achievement* (Department for Education and Skills (DfES), 2004c). This strategy articulates a major imperative to translate aspirations into reality. Yet high quality service delivery can be achieved only through skilled, reflective practitioners in the context of a society that truly recognises the changing pattern of childhood disability.

The lessons learnt internationally about Early Childhood Intervention (Guralnick, 2005) also have much to teach us about service development and delivery to our most vulnerable children and their families. At the heart of this process must be the voice of the family – guiding, informing, sharing, engaging. The key to successful Early Childhood Intervention is responsiveness – to society, to its families, but, most of all, to its children.

## **INTRODUCTION**

*Worldwide, 780 million young children are affected by biological, environmental and psychosocial conditions that can limit their cognitive development. (Guralnick, 2004a,b)*

The Office of National Statistics (Melzer et al., 2000) confirms that now, in the UK, one in five children has special educational needs. Today, disability is manifested in different ways to those that we have traditionally known; therefore, as professionals, we need to modify and adapt our practices to be able to cope with different family patterns of caring associated with different patterns of disability. In order to meet families at more unfamiliar points of need, it is important that we identify additional circumstances in which professionals may need to offer Early Childhood Intervention services.

## **CHANGING FAMILY PATTERNS**

In order to plan for providing relevant and effective Early Childhood Intervention services at these points of need, we have first to identify the context and circumstances in which these needs arise.

### **The context for Early Childhood Intervention**

Since the mid-1960s, parents and professionals have campaigned relentlessly for child- and family-centred planning in Early Childhood Intervention service provision (cf. Odom et al., 2003). The approach has gained credibility as the

weight of evidence supporting its success grows (Gallagher, 1993; Leskinen, 1994). In increasingly family-centred models (e.g. Developmental Systems Model (Guralnick, 2001); Ecological Approach (Mäki, 1994)), the relationships between the families and the professionals supporting them offer the following 'key reciprocal functions' (Carpenter, 2004):

- support
- education
- liaison
- communication
- provision of information
- collaboration
- resources
- advice.

Services increasingly encourage families to define their own membership to take account of different family support networks.

Approaches which have contributed, and continue to contribute, to the development of service provision may no longer be addressing the full spectrum of need. We must be mindful that our approaches need to be responsive, changing as the needs profile of our children, and their families, changes. Demographic research (Odom et al., 2003; Peterander, 1996; Soriano, 2005) has increased our understanding of the factors leading to disengagement of children and families from societal systems (e.g. education, employment, etc.), a fact strongly endorsed by the new report from the Prime Minister's Strategy Unit (2005):

*Poverty can increase the risk of a child having an impairment... Having a disabled child can also mean that parents find it harder to maintain full-time employment, their housing can be inadequate for their child's needs, and expenditure on basic needs is increased. (p. 86)*

Thus Early Childhood Intervention services can no longer focus solely upon children with traditionally recognised disabilities (e.g. visual or hearing impairment, Down's syndrome, etc.), but need also to offer support to families of children with special educational needs in emerging categories associated with factors such as low birth weight, genetic abnormalities and prenatal abuse (e.g. those born with substance or alcohol addictions). Some of these children may have obvious disabilities. While others might not, they may have characteristics that predispose them to developing special educational needs (Marlow et al., 2005; Woodward et al., 2004). Early Childhood Intervention services need to

intervene at the point at which their interventions can pre-empt, or lessen the impact of, emerging difficulties.

## **EVOLVING CONTEXTS OF NEED**

The UK Government, in *Every Child Matters* (DfES, 2003), notes that:

*...overall, this country is still one where life chances are unequal. This damages not only those children born into disadvantage but our society as a whole.*

The same report notes that family patterns are changing. There are more uncertainties and risks, and more single parents without supportive family networks. There is clear evidence that negative outcomes for children are frequently associated with a number of key factors, including:

- low income and parental unemployment
- homelessness
- poor parenting
- poor education opportunities
- substance misuse
- low birth weight
- community factors, such as living in a disadvantaged neighbourhood.

In the case of a disabled child, these factors will all exacerbate any problems experienced by parents with regard to their child's individual needs.

## **Social exclusion**

### ***Vulnerable, 'at risk' children***

Social exclusion starts very early, long before a child is born. It is rooted in poverty, inadequate housing, chronic ill health and long-term unemployment. Children born into poverty are denied the resources and opportunities available to other children. Although most grow up in loving families who care passionately about wanting a better life for their children, too many children living in poverty begin and end their childhood in a state of social exclusion and educational underfunctioning, and continue to experience unemployment, poverty and ill health throughout their adult lives. Mittler (2000) states that:

*The challenge to our society is to loosen and break the stranglehold of poverty on the development of our children.*

The gap between rich and poor has grown in Britain at a rate faster than in any other country in Europe and second only to New Zealand in the whole world. UNICEF (2000) reported that 19.8% of children in the UK were living below the poverty line, as were 22.4% in the United States. These figures were compared with 7.9% in France, 10.7% in Germany and 2.6% in Sweden. The children at greatest risk of poverty were those in lone-parent households or families with one or more disabled persons.

Poverty in childhood increases the likelihood of low income in adulthood. A teenage mother with a childhood spent in poverty has six times the risk of

remaining unqualified at age 33 compared with other mothers (Horton, 2003). There are clear links between child poverty and children living in care and its negative impact. Children in care face more challenges to their emotional well-being as a result of frequent moves, high levels of bullying and separation from their families (*op. cit.*).

In the UK today and every day:

- parents of over 400 children will divorce
- 300 children will be accepted as homeless and be found accommodation
- 81 children will be taken into care
- 87 children will be added to Child Protection Registers
- 150 children will be born to teenage mothers.

(Mittler, 2000)

In the UK, there have been growing concerns about the association between families with a disabled child and poverty. Emerson (2003) deduces, from an extensive review of literature, that the association between poverty and intellectual disability suggests the importance of targeted interventions to increase 'the personal and social capital' available to children with intellectual disabilities and their families. The UK Government has committed itself to ending child poverty within 15 years, but Gordon et al. (2000) note that 55% of families with a disabled child live, or have lived, in poverty. Dobson and Middleton (1998)

estimate that the cost of bringing up a disabled child is three times that for a non-disabled child.

The five priority outcomes articulated in *Every Child Matters: Change for children* (DfES, 2004b) – to be healthy, to stay safe, to enjoy and achieve, to achieve economic well-being and to make a positive contribution – seek to encourage action to reduce deprivation and child poverty within a context of positive experience for children in all aspects of their daily lives. The Belgium educationalist, Dirk Mombaerts (2004) reminds us of the undercurrent of change in our society, against which all children’s development must be set, and he argues that we live in an age of individuality. Since the beginning of the 20<sup>th</sup> Century, we have begun to focus far less on group identity, with a shift to individual rather than group values – from the ‘we’ to the ‘I’ identity. Consequently, Early Childhood Intervention will have to adapt to the new challenges of society (with the inherent implications for practice) and the new developmental state of the human condition.

### **Prenatal abuse**

For babies exposed to prenatal abuse, there is a high risk of abnormality leading to disability. It has been reported that, in the developing world, iodine deficiency is the greatest cause of intellectual disability (Fujiura, 2004; Maberly, 1994; World Health Organisation (WHO), 2004a).

### ***Drug abuse***

Ball (1995) reported in a national survey in the United States that 375,000 newborn babies a year had been exposed in the womb to cocaine, heroin, marijuana, methadone and amphetamines. One in every nine women, in the maternity wards of the private and public hospitals studied, had used illegal drugs in pregnancy. (The study revealed that the problem transcended the class barrier, and was as great, if not greater, among the middle classes.) It illustrated that exposure in the womb to cocaine could cause prenatal strokes and lasting brain damage, seizures after birth, premature birth, retarded foetal growth, breathing lapses, absence of part of the gut, and structure abnormalities in the genital and urinary organs.

The *Guardian* (June 1998) reported Slotkin's studies showing that smoking by pregnant mothers was consistently causing low-birth-weight babies, long-term damage to unborn babies, or even death in 50% of cases.

The emergence of children with intrauterine drug exposure has necessitated the creation of a spectrum of Early Childhood Intervention services to meet their needs. Belcher et al. (2005) write about three promising intervention programmes designed to improve the well-being of parents with drug dependence and their children. These programmes – Project STRIVE, the Early Infant Transition Center and Home-U-Go Safely – all aim to reduce the adverse neurobehavioural and neurodevelopmental outcomes which are the impact of maternal substance abuse on the developing foetus. To work with parents in these programmes is

vital if we are to prevent the deaths of children such as Ashley (aged 2), who drank a 40 ml dose of methadone while his mother was smoking heroin in another room (Wainwright, 2004).

### ***Alcohol abuse***

Alcohol abuse in pregnancy is an even greater problem than illegal drugs. The advice given in the United States, displayed in many public places, is:

*According the Surgeon General women should not drink alcoholic beverages during pregnancy because of the risk of birth defects.*

Recent work in Australia and New Zealand has shown how alcohol is a teratogen, a poison. Within 15 minutes of consuming alcohol, there is an impact on the unborn foetus in the pregnant mother: the umbilicus becomes white and flaccid (instead of red and taut), thus reducing the flow of oxygen to the unborn child (Craft & Tindle, 2002). This same study reports significant rises in the numbers of newborn infants diagnosed with foetal alcohol syndrome (FAS), particularly in Maori and Aboriginal populations.

Studies in the United States, South Africa and Scandinavia suggest that one in 300 infants is affected by what is now termed Foetal Alcohol Syndrome Disorder (FASD), a pervasive disorder, with affected children suffering problems with memory, attention span, hyperactivity, growth deficiencies, physical and craniofacial abnormalities and a diminished IQ (Boseley, 2004). What are the

implications of FASD for teaching and learning? For example, babies with FASD are born with underdeveloped parietal lobes. As the parietal lobe is critical for numeracy, these babies develop into children with specific problems in number processing and mathematical cognition (Kopera-Frye et al., 1996).

With the high profile publicity campaigns given over to promoting alcoholic beverages in the western world (Grainger, 2004), there are issues, in relation to FASD, worthy of explanation in the European context (Carpenter, 2004). The Australasian study (op. cit.) particularly has suggested that excessive binge drinking can affect the quality of sperm in males. One estimate by Plant (2004; reported in Grainger, 2004) is that one in 300 children is affected by FASD in some way, compared with the Down's Syndrome prevalence of one in 666. In Britain, this suggests that between 600 and 1,200 babies with FASD are being born every year. The United States estimate that it costs them \$1.5 million to care for each FASD-affected child.

In the UK, 23% of girls under the age of 14 were admitted to hospital with alcohol-related mental health problems; 5% of all 11-year-olds consume alcohol on a weekly basis (Borcham & McManus, 2002). We have a cyclical problem, rooted in childhood, with profoundly damaging effects on the next generation of children.

### **Low-birth-weight infants**

With technological progress and developments in medical practice, the survival rates of neonates are increasing (Emsley et al., 1998; Woodward et al., 2004). A significant proportion of these children will be born with major disabilities and will require the lifelong support of professional services (Carpenter, 1999).

*Improved diagnosis, better survival rates, and a growing incidence of complex disabilities such as autism have resulted in a 62% increase in the number of disabled children living in the UK. (Community Care, 2005)*

Professionals will need to plan ahead, to address the challenges to family life, to explore new ways of intervening in order to improve life for the next generation of children with learning difficulties and their families, and to work with them to achieve their aspirations.

### ***Survival rates of neonates***

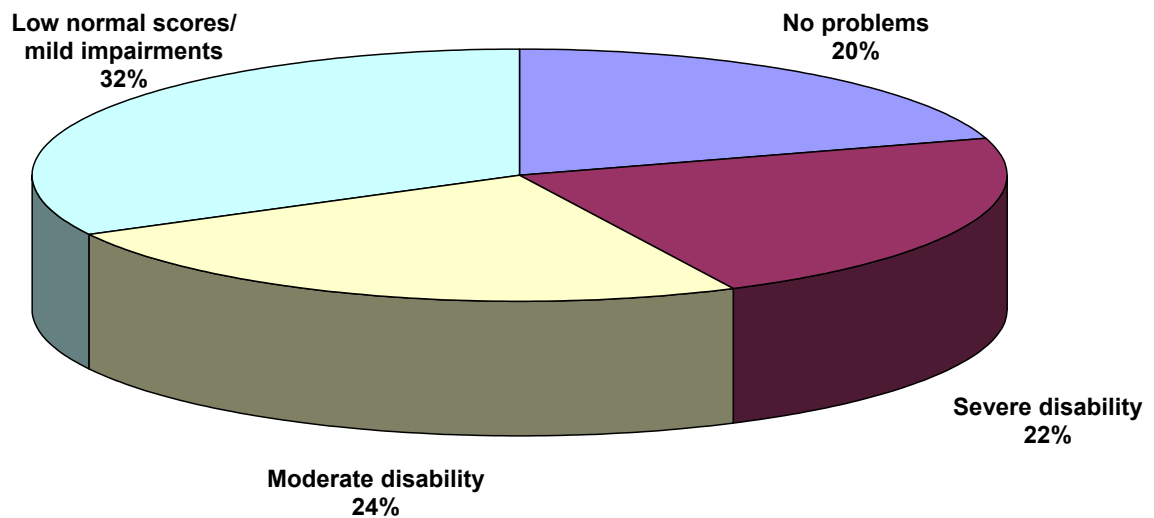
Emsley et al. (1998) have particularly focused on the survival rates of premature/very low-birth-weight infants as an upward trend reported in many Western countries. Their study showed that during 1984–89 and 1990–94, the survival of preterm babies had improved from 27% to 42%. These figures pale into insignificance when compared with the outcomes of the EPICure study (Marlow et al., 2005). The population of the study, established in 1995, were infants born in the UK and Ireland at less than 26 weeks gestational age, of which 80% now survive. (Woodward et al. (2004) in New Zealand gave a survival figure of 90% for the same population.)

The impact of premature birth is explained in Table 1 below.

**Table 1: The percentage of children with different degrees of disability with examples of the types of problem in each classification under each category (from the EPICure study; Marlow et al., 2005)**

<b>Gestation at birth:</b>	<b>23 weeks or less</b>	<b>24 weeks</b>	<b>25 weeks</b>
<b>No disability</b>	<b>12%</b>	<b>14%</b>	<b>24%</b>
<b>Mild disability</b> <ul style="list-style-type: none"> <li>• Low normal IQ scores</li> <li>• Wear glasses/have squint</li> <li>• Mild hearing loss</li> <li>• Minor neurological abnormalities</li> </ul>	<b>25%</b>	<b>36%</b>	<b>35%</b>
<b>Moderate disability</b> <ul style="list-style-type: none"> <li>• Moderate learning problems</li> <li>• Cerebral palsy, but walking</li> <li>• Hearing aids</li> <li>• Some vision deficit</li> </ul>	<b>38%</b>	<b>22%</b>	<b>22%</b>
<b>Severe disability</b> <ul style="list-style-type: none"> <li>• Severe learning problems</li> <li>• Cerebral palsy, not walking</li> <li>• Profound deafness</li> <li>• Blindness</li> </ul>	<b>25%</b>	<b>29%</b>	<b>18%</b>

A follow-up study, when the EPICure group were 6 years' old, saw assessment taking place on 80% of the original cohort. These assessments yielded the outcomes depicted in the diagram below (see Figure 2).



**Figure 2: Proportion of children with disability out of 241 children seen at 6 years by comparison with their classmates (Marlow et al., 2005)**

Boys seemed to fare much less well than girls, being more prone to disability and having lower scores in all major developmental test areas. This difference cannot be explained but it has been found throughout the study from its first results in the period after birth.

Perry and Pollard (1998) vividly describe, through their research, the impact of traumatic birth and early care processes on the infant, and how such experiences will shape the brain and its perceptions and reactions for years to come. The 'emotional security' described by Robinson (2003) as being a crucial component of a baby's psychological development is severely disrupted through a birth which requires intensive and invasive medical treatment.

A disturbing piece of research (Fitzgerald, 1998) from University College, London, discovered that babies' sensory systems have a unique, pain-signalling mechanism which disappears as they grow older and that newborn children feel pain longer and more sensitively. In premature babies, the mechanism that 'dampens down' the pain messages does not work properly. It is therefore essential to consider whether the impact on the sensory pathways subsequently compromises their effectiveness as learning channels for these children.

Intense ethical debates arise around these babies' fragile lives. The High Court case of Charlotte Wyatt highlighted the diverging opinions between medical judgments and parental opinion, leading one commentator to claim, 'Keeping "miracle" babies alive is a disaster for all' (Marrin, 2004). Traynor (2004) has reported that mercy killings are a regular feature of medical practice in Holland. Clear guidance is needed to end these dilemmas for the medical and legal professions. Charlotte Wyatt's survival into 2005 has called into ethical debate the original 'Do not resuscitate' order from the High Court (Templeton, 2005).

At the heart of this complex maze of medical activity lies a family, traumatised by the birth of one of its children. This mother's words describe the human pain and anguish:

*...on the first visit they gave me too much information... It's great there's so much out there, but it can be too much to absorb. Even if your child*

*doesn't have a disability, you're adjusting to your life with a baby – you've just given birth, your lifestyle has changed, you're exhausted and, on top of that, you have to come to terms with something you hadn't anticipated. There is a danger of being bombarded.* A Mother (Foundation for People with Learning Disabilities, 2005)

### ***Assisted conception***

Throughout the world there is an upward trend in the rate of multiple births, particularly in countries where the treatment of infertility is available (Mitchell, 1998). Russell (1998), reporting the preliminary findings of a Medical Research Council study, noted that 70% of multiple births due to *in vitro* fertilisation, resulted in some form of disability. Hence, some families may have one, two or more children with disabilities. In a similar domain, the role of genetic information (Barr & Millar, 2003) is influencing the coping strategies of parents who have a child with disabilities. They state:

*When a child has a disability parents often seek answers as to the origins and nature of the condition as part of the adaptation process. For some parents this will result in genetic investigation and could lead to the provision of personal genetic information about the child and parents.*

(p. 2)

Ironically, some disabled children may themselves be victims of improvements in neonatal and medical care. A review of 25 studies of babies born after assisted

conception (Helmerhorst et al., 2004) notes the greater risk of perinatal morbidity (and thereby possible later ill health, disability or special educational needs). This study found the risk to be greatest in singleton pregnancies rather than in the multiple (twin) pregnancies most commonly associated with post-natal difficulties.

Helmerhorst et al. note that:

*25 years after the birth of the first baby conceived by in vitro fertilisation, our data draws attention to a number of challenges. Firstly, emphasis needs to shift, more than it has already, from achieving a successful pregnancy to achieving a successful outcome [for the child].*

(Helmerhorst et al., 2004)

In effect, the increase in assisted conception raises new challenges for neonatal and other child health services. As Helmerhorst et al. observe, there is a need to narrow the gap in positive outcomes for children between assisted and other pregnancies. There are also implications for neonatal and Early Childhood Intervention services if we are likely to continue to see the survival of very small and sometimes very vulnerable babies.

### **Needs in families of premature babies**

Champion (1998a,b) demonstrates how the mother (or caregiver) is the facilitator of brainstem maturation. She emphasises the importance of the first year of life in which the organisational pattern enabling the infant to cope with external stimuli is established. Those babies born prematurely, who spend their early weeks in

an incubator separated from their mother for much of the time, may suffer consequences not yet understood.

In her more recent work, Champion (2003) has shown that 55% of mothers of preterm babies attending the Early Childhood Intervention programme at the Champion Centre were diagnosed with clinical depression. Post-traumatic stress disorder was also prevalent displayed through irritability, outbursts, crying, numbed responses, traumatisation and experiencing flashbacks.

It is increasingly recognised that fathers' emotional needs in relation to a disabled child often go unmet (Carpenter, 2002). Fathers, too, are an integral part of the difficult complexities that co-exist as families redefine themselves as parents of a vulnerable, low-birth-weight infant. Emotions experienced by both parents were:

- terror
- grief
- anger
- guilt
- impotence
- jealousy
- depression
- intense fatigue
- frustration.

The family system is also challenged by the birth of a preterm infant. The euphoria and atmosphere of congratulation is replaced by worry and anxiety for the health and survival of this vulnerable baby. Expectations will be derailed; concepts of 'parenting' may be restructured; wider family attitudes and perceptions may not be as expected; beliefs and cultural expectations may be challenged. There is a process of family adaptation over time, building a pattern

around the child and its difficulties. Families have to devise new routines, and identify the parts that assist, sustain or hinder them.

Of course, these feelings may be part of the lifelong journey that these families will tread. The extent of cerebral injury may not be fully realised until the child realises certain developmental milestones. The child, and its long-suffering family, may be subject to years of intense scrutiny as Woodward et al. (2004) report.

## **THE MENTAL HEALTH OF YOUNG CHILDREN**

Increasing numbers of children are experiencing mental health problems. In the UK, a recent survey (DfES, 2001) showed that 10% of children aged between 5 and 15 years experience clinically defined mental health problems. This same study conjectured that the roots of these problems could have begun earlier for many of the children concerned, and defined the problems that young children and their families could face as follows:

- emotional disorders, e.g. anxiety states, phobias, and depression
- conduct disorders, e.g. aggression, defiance, anti-social behaviour
- hyperkinetic disorders, e.g. disturbance of activity and attention
- developmental disorders, e.g. delay in acquiring certain skills such as speech, social ability or bladder control

- attachment disorders, e.g. children who are markedly distressed or socially impaired as a result of an extremely abnormal pattern of attachment to parents or major caregivers
- eating disorders, e.g. pre-school eating problems
- habit disorders, e.g. sleeping problems, soiling, spontaneous urination.

In a study by Melzer et al. (2000), it was noted that poverty was an indicator of a stressful life from which often 'unhealthy' patterns of family functioning emerged that could give rise to mental health difficulties. In the United States, Guralnick (2004a,b) has estimated that up to 65% of children exhibit peer interaction problems which, long term, raise quality of life issues. There is limited research in this area, and priority is needed. The World Health Organisation predicts a 50% rise in the level of child mental health disorders by 2020. This would put them in the top five most common causes of childhood disability, sickness and health. Early Childhood Intervention is one of the most effective ways to tackle mental health problems, with positive benefits for parents as well as children, and yet the families who most need it often shun it (Napier, 2002).

Children with special educational needs are three times more likely than the general child population to have mental health problems. In *Count Us In*, the report from the National Committee of Inquiry into the mental health needs of children and young people with learning disabilities, the need for high quality Early Childhood Intervention, as a means of averting later mental health and

psychiatric problems, is strongly advocated (Carpenter & Morgan, 2003, 2004; Foundation for People with Learning Disabilities, 2001).

This is the backcloth of need among very young disabled children in this 21<sup>st</sup> century; a different scenario to that of 50 years ago when disabilities such as visual and auditory impairments, cerebral palsy and Down's syndrome were the dominant conditions. The causal base of our present day profile of disability would appear to be attributable to either advances in research around causation (e.g. Fragile X syndrome) or medical science (e.g. premature infants) or behaviour changes in society (e.g. drug abuse).

### **NEED FOR EARLY(ER) INTERVENTION**

Early Childhood Intervention services will have to extend their criteria of need to allow them to take account of family circumstances which place children at risk of negative educational and life outcomes. By providing very early support, services can increase the likelihood of the family being able to engage or re-engage with mainstream societal services (e.g. education, health), thus reducing the long-term costs to society (Barnett & Hustedt, 2005; Guralnick, 2001). Studies by researchers such as Champion (2003) and Perry and Pollard (1998) indicate that the disabling side-effects of birth accidents, such as multiple birth and premature birth, can be ameliorated with very Early Childhood Intervention and prenatal intervention.

In any individual family context, there is a unique pattern of need. Early Childhood Intervention services have to be prepared to meet the spectrum of need and be equipped to recognise and respond to it. Aware professionals will need to work with families collaboratively and sensitively to allow them to identify their needs and to pre-empt negative effects.

### **EARLY CHILDHOOD INTERVENTION PROGRAMMES**

Many families, when reaching out to professionals during traumatic periods of their lives, have found that the intrinsically supportive process of Early Childhood Intervention (in its appropriate form) has sustained them. This is very much the experience of families who, for example, have been involved in the National Autistic Society's EarlyBird programme (Morris, 2002), which bridges the gap between diagnosis and the start of formal schooling, and empowers parents with the skills and knowledge specific to autistic spectrum disorders (ASD). Recently, Wylie and Foster-Cohen (2004) have reported an early intervention approach through music, which encourages early communication and social interaction. The mother of India, born at 24 weeks, said of this programme:

*My husband and I felt as if we were on a different planet where everyone but us knew what to do for our baby. Music seemed the only way of creating a safe, intimate environment where I could truly become connected with my little girl. (p. 37)*

For almost 40 years, in the United States, the Head Start programme has served disadvantaged children in low-income families throughout the nation, with the overall goal of increasing children's readiness for school. The programme has been critically examined over those 40 years. Despite mixed reviews, often dependent on the political and economic climate, the latest longitudinal analysis by Barnett and Hustedt (2005) indicates generally positive evidence regarding Head Start's long-term benefits. Every \$1 spent on children in the early years saved the state \$7 later by reducing the interventions necessary on crime, welfare, mental health and job prospects.

The Head Start programme was the inspiration for our Sure Start programme in the UK. Similar universal childcare programmes helped the Nordic nations abolish child poverty by catching potential problems early. The World Health Organisation is reported to have said, in 2004;

*Poverty, violence and stress will condemn an increasing number of children and young people to life with a troubled mind.*

Within the Head Start programme, Webster-Stratton and Reid (2004) have recently reported their work into early childhood conduct disorders. They state:

*This sample of socio-economically disadvantaged preschoolers is at higher risk of developing oppositional behaviour disorders and attentional*

*hyperactivity disorders, as well as experiencing language and learning delays.* (Webster-Stratton & Reid, 2004, p. 2)

Their programme has developed a range of interventions targeted at training teachers and parents to enhance children's social competence, reduce aggression and strengthen early literacy. In so doing, they aim to prevent some of the secondary risk factors such as school failure, peer rejection and conduct disorders. There is a particular emphasis on 'emotional literacy' and helping children to learn words to express their feelings and understand other people's feelings. Such skills as effective problem-solving, anger management, making and keeping friends, and communicating with others are taught during 'circle time' through child-sized puppets.

## **THE NATIONAL POLICY CONTEXT**

Sohns (2004) reported that an earlier Helios II study of European Union countries found that the UK was the only country without a national policy or infrastructure in relation to Early Intervention. We await the outcomes of the European Agency Pan-European Project on Early Childhood Intervention (Soriano, 2005), in the anticipation that a different picture will be reported.

Our practice in the UK, until very recently, has been based on individual initiatives responding to local need. In the late 1980s, my wife, Susan, and I reported the Blythe Home-Liaison Playgroup, an early intervention scheme run

on a voluntary basis for mothers and children under 3 years with disabilities in rural North Warwickshire (Carpenter & Carpenter, 1989). In the late 1990s, we pleaded for a nationally co-ordinated strategy to bring together these local initiatives to offer families, wherever they live, a better quality of service (Carpenter & Carpenter, 1997).

So what are some of the 'real prospects' that lead me to believe that, at long last, we have a platform upon which we can build cohesive, nationally co-ordinated Early Childhood Intervention? Why are things so different?

Now, at the start of this 21<sup>st</sup> Century, there is a raft of policy and service initiatives.

***Every Child Matters (DfES, 2003)***

Early Childhood Intervention – to both address social exclusion and maximise children's development (and thereby their life chances) – is a key theme within the Government's Green Paper, *Every Child Matters* (2003). It sets out a range of proposals to 'reform children's services for the 21<sup>st</sup> century' and gives Early Childhood Intervention a new urgency and a high priority across all children's services.

The Government, in *Every Child Matters* (DfES, 2003), notes that:

*Overall this country is still one where life chances are unequal. This damages not only those children born into disadvantage but our society as a whole.*

The same report notes that family patterns are changing. There are more uncertainties and risks, more single parents without supportive family networks, and clear evidence that negative outcomes for children are frequently associated with a number of key factors, e.g. homelessness, unemployment, poor parenting, etc.

Russell (2003) also outlines the considerable financial and social disadvantage because of the additional costs associated with disability. She comments that:

*We need to review the circumstances [of families with disabled children] to ensure that they have the quality of life they deserve. Investment in families with a disabled child and avoiding family breakdown will have direct benefits for the community and the economy as well as for parents and children. They can 'pay back' the cost of enhanced family support through tax and pension contributions. Importantly and additionally, we cannot improve the efficacy of any interventions unless we address the context within which they are to be delivered. (Russell, 2003)*

***Together from the Start (Department of Health (DoH)/DfES, 2003)***

The Government established a multi-agency working party to produce *Together from the Start*, which is the first practical guidance for professionals working with disabled children (from birth to three years) and their families. The guidance was launched in 2003, simultaneously with guidance on the development of Early Childhood Intervention/support services for deaf children and their families. This parallel guidance addresses the particular issues for early-identified deaf children and their families in the context of the introduction of universal newborn hearing screening.

*Together from the Start* begins from the premise that:

*Effective early intervention and support can produce improvements in children's health, social and cognitive development and help tackle some of the many social and physical barriers families of disabled children face to full participation in society.*

It also has a strong family focus, recognising that:

*It is not only disabled children's impairments which determine the quality of life but also disabling attitudes and a disabling environment which can result in unequal access to community services and facilities. Effective intervention strengthens the ability of families to provide effective support to their children and improves outcomes for the whole family.*

*Together from the Start* also acknowledges the challenge of a rapidly changing population of young disabled children, including those with very complex multiple disabilities (in part because of the increased survival of very preterm babies, due to improvements in neonatal care) and a significant reported increase in the prevalence of ASD and attention deficit hyperactivity disorder (ADHD).

The implementation of *Together from the Start* is being rolled out in the Early Support Programme, a set of resources which aims to help families and professionals move away from crisis intervention to planned, sustained Early Childhood Intervention (Ford, 2004). Early Support is the central Government mechanism to achieve better co-ordinated, multi-agency assessment and service delivery for disabled children under three years and their families.

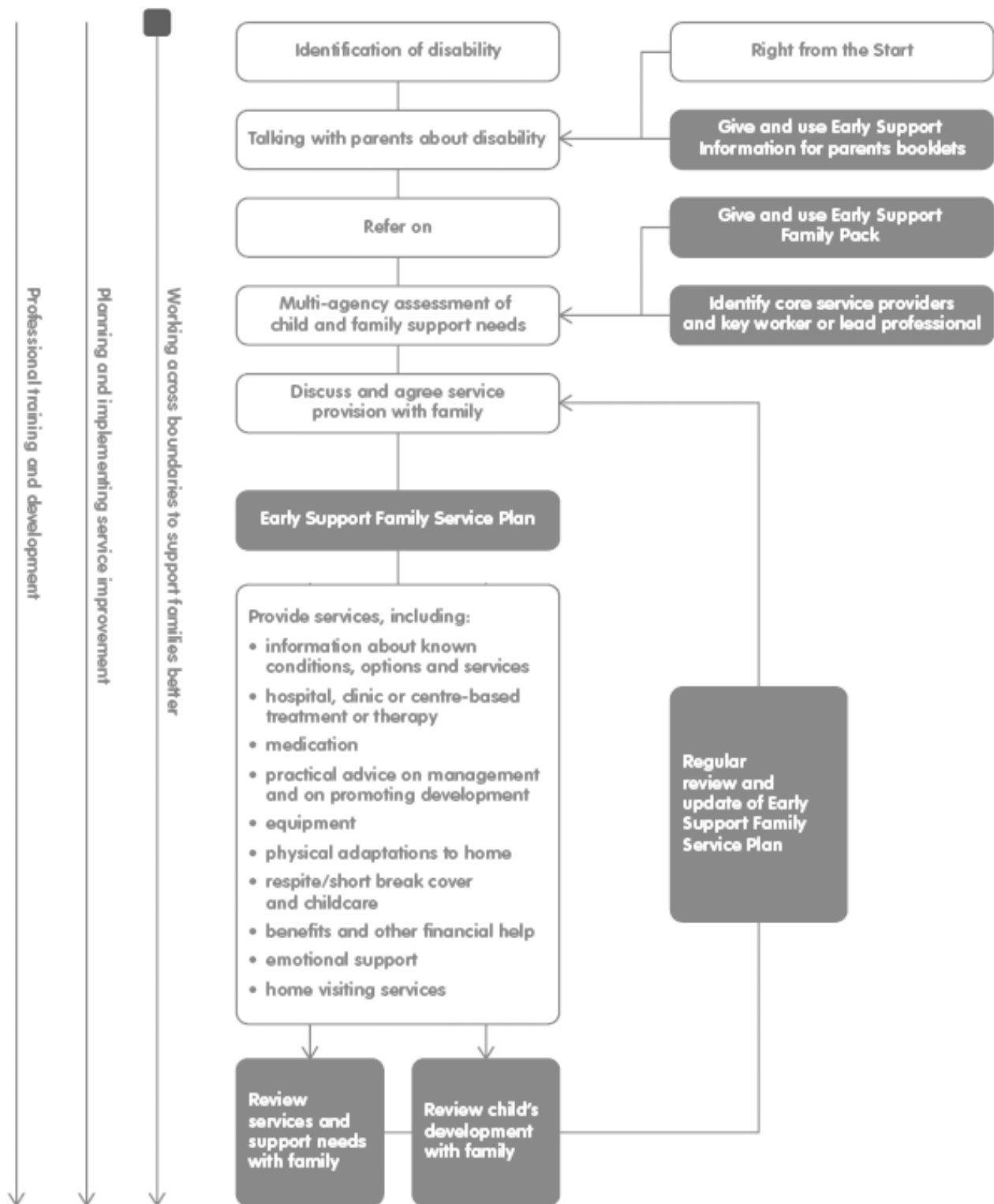
Its greatest strengths are the family-owned Family Service Plan – which is central to the liaison with a keyworker in the context of a transdisciplinary approach (Carpenter and Russell, 2005) – the excellent information resources and the Early Support Family Pack. The information resources, written by parents and the respective national disability organisations, are high quality, and tackle some of the more sensitive areas of ‘Rare syndromes’ and ‘When your child does not have a diagnosis’. The Early Support Family Pack and accompanying professional guidance (DfES, 2004a) are set in a clear framework of service delivery and family interaction (see Figure 3 below).

***The Child Poverty Review (HM Treasury, 2004)***

The Early Support Programme permeates early childhood initiatives across Government departments. For example, *Child Poverty Review*, the Chancellor of the Exchequer said:

*The Government's Early Support Pilot Programme was introduced in 2002 to take practical action to improve service outcomes for very young disabled children and their families, focused on better integration of services, improved information and support for parents and modelling effective multi-agency working, including simple co-ordinated assessment and support from key workers... Over the long term, the Government will extend early support for disabled children and their families through building on the experiences of the Pilot Programme and spreading these tools and effective strategies to all Local Authorities and Children's Trusts.*

(HM Treasury, 2004)



**Figure 3: Right from the start: talking to families about disability (DfES, 2004a)**

***The National Service Framework for Children, Young People and Maternity Services (DoH, 2004)***

Similarly, in the recently published *National Service Framework* (NSF; DoH, 2004), there is clear direction to all agencies that Early Support is key to their work with families.

*Local Authorities, Primary Care Trusts, NHS Trusts, early years and day care providers use the Early Support professional and family materials to improve the services in consultation with local parents of disabled children.*

Standard 8 of the NSF is very specific about this:

*The Early Support programme has developed materials for professionals and families to improve services and the Government has committed to spreading these tools and best practice to all Local Authorities and Children's Trusts.*

Such direction will hopefully inform the structures of Health Authorities, leading them to use the materials in common with professionals from other disciplines. Indeed, the imperative to use the materials from Early Support is made explicit for Education in *Removing Barriers to Achievement*, which states:

*Through the...National Service Framework for Children and the implementation of Every Child Matters, we will ensure that the principles established by the Early Support Pilot Programme become integral to practice nationally. (DfES, 2004c)*

It is heartening to see parents of disabled children so central to these developments for, as Professor Kathy Sylva and her colleagues have asserted through the EPPE study:

*For all children, the quality of the home learning environment is more important for intellectual and social development than parental occupation, education or income. What parents do is more important than who parents are. (Sylva et al., 2004)*

### **Sure Start**

Sure Start is a 'flagship' Government programme (Carpenter and Russell, 2005), creating multi-agency, universal support systems for families with young children in disadvantaged communities. The programme provides a range of support services for families and children, with a strong focus upon developing the capacity of local professionals and parents and improving the life chances of potentially vulnerable children.

Sure Start-funded Children's Centres must be located in and serve families in disadvantaged areas. They bring together locally available services and integrate

management and staffing structures (not necessarily on one site). All Children's Centres must offer:

- early education integrated with child care
- family support (including outreach services for parents)
- child and family health services.

The Sure Start Children's Centres are intended to act as a hub for local community services for parents and providers of childcare services for children of all ages. Their services can include:

- Early Childhood Intervention integrated with day care for babies and children until they reach school age
- day care suitable for working parents (i.e. 5 days a week, 48 weeks a year, if required)
- early identification of children with special needs and disabilities with inclusive services and support for their families.

Active parental involvement is a key theme within Sure Start. Schemes are expected to develop specific strategies to include fathers and families from minority ethnic groups in planning local services. Family support and health advice must be available at times suitable for working parents, and all services are expected to be accessible to disabled children and their families.

The Sure Start programme is being considerably extended. Early messages from its evaluation suggest that the provision of flexible early education and intervention services, linked to active community development and parent education support, can have impressive outcomes for otherwise disadvantaged and socially excluded communities. All Sure Start Programmes offer Portage Home Teaching Programmes (White, 1996) for young children with special educational needs or disabilities. It is expected that Portage will be more widely available in the near future, with the Government considering requiring that Portage or similar home teaching schemes be available in all areas.

### ***Removing Barriers to Achievement (DfES, 2004c)***

The Government's Special Needs Action Programme, *Removing Barriers to Achievement* (DoH/DfES, 2004) probably provides the most favourable environment for many years with regard to the development of Early Childhood Intervention services within the UK. The programme sets out a strategy which has a clear focus on improving service outcomes for the very youngest disabled children and their families, and comments that 'early intervention is the corner stone of our strategy'. Key goals are:

- better integration of services
- improved information and support for parents
- new ways of working for professionals.

Recognising the need for families to lead 'ordinary lives', the strategy also promotes better co-ordination of child care and early education, and the creation of local networks to provide specialist advice and support to professionals. Importantly, the current evaluations of Sure Start Early Excellence Centres and the Early Support Pilot Projects demonstrate a commitment to creating an evidence base for Early Childhood Intervention – with the prospect of a National Centre underlining the need for an ongoing agenda of development, training and research in this area.

The National Centre for Early Childhood Intervention is a DfES-commissioned feasibility study being carried out by Mencap (Campbell, 2004). If the Centre comes into existence, it will serve as the definitive source of advice, information, research and training related to Early Childhood Intervention for disabled children from birth to five years. The recently published report from the Prime Minister's Strategy Unit (2005), *Improving the Life Chances of Disabled People*, has welcomed the feasibility study for a National Centre for Early Childhood Intervention, specifically stating:

*If implemented, such a Centre could be an important hub of training and evaluation of early interventions to help guide service provision for young disabled children and those with special educational needs.*

This report goes on to call for a better deal for families and professionals working in Early Childhood Intervention, through improved family support, better childcare, early education groups, advice and information, work force development and a national database. Indeed, the report states:

*The early years are a critical period for disabled children. Child development and future life chances – as well as those of siblings – are critically affected by the support and services received by young disabled children and their families. Targeting support at these families will also play a major role in helping to eradicate child poverty. (p. 85)*

All of this is in stark contrast to 10 years ago, when the Helios II European Study (1994–96) (Peterander, 1996) reported no national system of Early Childhood Intervention across the UK!

## **PROFESSIONAL PRACTICE**

*The professionalism on which you stand is not a different road to the one on which we tread... It's also the road that's cushioned and softened by the laughter and the smiles of love, and tears of our children. That road is the same road, and, when we relate to each other, we have the partnership that dreams are made of. From the educational psychologist who sits with you and tries to translate the vision you have for your child in the way his or her report is written, to the occupational therapist who'll make a separate attachment to your child's wheelchair so the cat can curl*

*up next to your child, to the midwife who finds a lovely position you can feed your child in even though it's completely against her textbook knowledge... These are professionals who are working in the spirit of the term 'partnership'. (Manuel, 1996)*

Professionals are being faced with children with increasingly complex learning disabilities. Their families require services to devise new strategies for sustaining and upholding them. These self-defining families will require Early Childhood Intervention that can enable them to work with professionals towards meeting the needs of their children; for example, through a Family Service Plan (DfES, 2004a). All family members – brothers, sisters, grandparents, significant others – need to feel acknowledged and valued through this process. Inclusivity is the key to work with families in this millennium.

## **NEW PATTERNS OF WORKING TOGETHER**

If these needs are to be met in families, a co-ordinated and coherent approach is necessary. This approach demands new patterns of working that are neither multi-professional nor interdisciplinary, but are transdisciplinary. The Australian researcher, Pagliano (1999) defines this approach:

*...in a transdisciplinary team the roles are not fixed. Decisions are made by professionals collaborating at a primary level (rather than at a secondary level as in a multi-disciplinary team). The boundaries between*

*disciplines are deliberately blurred to employ a 'targeted eclectic flexibility'.*

(Pagliano, 1999, p. 2)

Bruder (1997) has discussed the importance of transdisciplinary service delivery in the context of curricula for children with disabilities:

*Intervention from specific therapeutic disciplines can result in a child learning isolated skills that have minimal relevance to the remainder of the intervention program... As second-generation research on early childhood intervention expands, individual therapeutic interventions must be encompassed within a larger curriculum framework that identifies all teaching (including therapy) episodes. (p. 538)*

In home-based services especially, professionals' willingness to engage in role release and role acceptance, and to use a transdisciplinary model to plan and deliver interventions, can result in several fundamental shifts in the way Early Childhood Intervention is carried out. It is more 'in tune' with the family life pattern; more naturalistic and responsive to the child's context.

In Early Childhood Intervention, an adult is needed to support a child's knowledge and skill transfer because young children learn in context – not in isolation from the context (Dunst et al., 2000). In no way does this diminish the importance of each of the individual disciplines; in fact the functional basis of the transdisciplinary model recognises that professionals from a variety of disciplines

have expertise that is very much needed by family caregivers. It offers professionals 'role release' that is the cornerstone of the transdisciplinary team, (Kaczmarck et al., 2000). This is fundamental to the keyworker role advocated in the Early Support Programme, and accords with Limbrick's (2004) notion of the 'team around the child', with the keyworker being pivotal to the delivery of, and liaison with, services for families.

Guralnick's (2001) Developmental Systems Model for Early Childhood Intervention (see above) is possible only if we can cut through the rhetoric and jargon of our various professions and truly embrace partnership. This does not come automatically; it has to be worked for. Fialka and Mikus (1999) speak of the 'dance towards partnership' and state that:

*the only magic to forming partnerships is to slowly, tenderly and persistently share our dreams with each other, for it is our children who give us the reason and opportunity to strengthen our partnerships with others.*

Skilled professionals will no longer be concerned solely with their own disciplinary boundaries, but with their capabilities as empathetic human beings and their disciplinary skill base in order to enhance the lives of the families that they support. They will need to use an Empowerment Approach (Appleton & Minchcom, 1991) that recognises the family as a system, with its own social network and the right to a choice of services and levels of engagement.

Negotiation (Dale, 1996) will be a key feature of their practice and, where there are differences between professionals and families, there will be joint decision-making based upon shared perspectives. Families will be provided with high quality support and information based on the latest research, specific to their child's needs/disabilities (e.g. the Early Development Group model promoted by the Down Syndrome Educational Trust (Bird & Wood, 2003)). Partnership with families thus becomes a dynamic, not a static concept, which is multi-level, rather than linear, in its approach.

## **CONCLUSION**

The political climate in which to develop a nationally cohesive programme of Early Childhood Intervention is ripe. Through the many policy initiatives mentioned – Sure Start, Early Support, *Removing Barriers to Achievement*, the *National Service Framework*, etc. – there is a major imperative to translate the articulated aspirations into reality.

So there are 'real prospects' for Early Childhood Intervention: the policy framework exists, but it will only become a reality in the lives of families and children with disabilities through the commitment of skilled professionals. At the point of diagnosis of a child's disability, a parent's first question is hardly likely to be about the local Early Childhood Intervention services. These families are frightened, disturbed, upset, grieving and constantly vulnerable. The role of the professionals involved with them is to catch them when they fall, listen to their

sorrow, dry their tears of pain and anguish, and, when the time is right, plan the pathway forward.

In the days following their child's diagnosis, families will begin to regain some equilibrium – but it is never the same. Then the professional's role is to nurture the family, restoring for and with them their aspirations for their child. For many families to date, appropriate Early Childhood Intervention services have been something of a postcode lottery. It is hoped that the new frameworks and national imperative will bring about greater demographic equality.

Much emphasis lies on the skills, indeed the availability, of experienced, empathetic professionals. Where are the professionals trained to achieve this sensitive transdisciplinary role? How many professionals can plan for atypical developmental needs across major skills areas such as cognition, communication, motor, emotional and social (Porter, 2002)? If our broad goal of inclusion is to become a reality, we have to acquire some of the special pedagogies and strategies required by this ever-diversifying group of children (Lewis & Norwich, 2005). The role of the keyworker, much debated and exalted in the last decade, has found itself suddenly catapulted into 'requirement status'.

There are a plethora of one-day courses designed to brief professionals on these new initiatives in policy, but, in practice, are there enough professionals on the ground? Are service structures in place to facilitate delivery? Keyworking is a

time-consuming approach: do we have the capacity in services to deliver this much-exhorted style of service delivery, family-friendly as it is?

What we lack in the UK is any rigorous, accredited training in Early Childhood Intervention – courses which offer focused study and which draw together the best in early childhood education, together with our knowledge of the development of very young children with disability. These need to be courses which address the specificity of learning and developmental patterns in disabled children, as Guralnick (2004a,b) has rightly indicated in his challenge for second generation research in Early Childhood Intervention which builds upon the knowledge base which already exists across childhood disability.

Internationally, there are models which we can refer to in order to guide course development. Twiss, Stewart and Corby (1997) report the Diploma in Early Childhood Intervention Course in New Zealand for teachers. This course, offered as a one-year secondment, promotes in-depth study of a Systems Approach to involvement with families and early childhood development, specifically related to Early Childhood Intervention principles and practices. Similar courses exist in Australia.

In Austria, Kurz, Mosler and Kirschlager (2003) describe an 18-month course to train Early Childhood Interventionists. These are professionals from any appropriate disciplinary background (e.g. social work, therapies, education, etc.)

who wish to engage in postgraduate study and supervised practice to acquire the requisite and relevant skills to deliver high quality Early Childhood Intervention to families. Furthermore, Pretis (2005; in press) reports a current Leonardo da Vinci project which is trying to combine individual and national training idiosyncrasies with the idea of a European passport on professional training in Early Childhood Intervention using the idea of flexible modules.

University College Worcester has a long and proud history training exceptional early years teachers; it has a proven track record of successful courses for professionals in the field of special educational needs. There is commitment in current developments to multi-agency training to address the emerging needs from the National Childcare Strategy. With this background, I would commend the University to consider the development of appropriate training in Early Childhood Intervention.

Yet high quality service delivery to our most vulnerable families can only be achieved through skilled professionals in the context of society's response. The lessons learnt internationally about Early Childhood Intervention (Guralnick, 2005) also have much to teach us, and need to be set against the changing pattern of childhood disability (Goswami, 2004). The key to successful Early Childhood Intervention is responsivity – to society, to its families, but, most of all, to its children.

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