

When looking at reviews of Early Development Groups (EDGs) and Early Intervention (EI) studies three key issues present:

- a) a conflict in terminology and course content
- b) paucity of details of intervention programmes
- c) lack of recent studies (i.e. in the last 10 years) of studies focussing on more than one area

There is a wide variety of meanings of Early Intervention, some studies pertain to a wide ranging intervention covering a number of skills areas, whereas some papers are focussed on one skill, for example requesting behaviours or gross motor skills. The length of study varies widely from a few weeks to many years, and where intervention has taken place is a further variable, usually in a clinical setting, in a specialised centre, at home or a combination. For the most part I have looked for examples closest to the Early Development Groups which my research will be observing, that is: intervention which covers a number of different skills areas, takes place over the first four years of a child's life and is delivered at a specialist centre or at home. However this begins to severely limit the amount of studies available, so it is essential that information is drawn from as wide a source as possible without losing sight of the key questions: 'Do the Early Development Groups/Early Intervention programs help children to make more progress than without this intervention?' and 'Is family support an essential part of this?'

The validity of comparing outcomes of this variety of programs, all using different methodology, various cohort sizes and a range of data reporting, is somewhat limited. As such there is no attempt here to compare programs or to suggest a hierarchy of effectiveness. For detailed comparative papers see Gibson & Harris (1988) Spiker & Hopmann (1997) and Nilholm (1996).

A further challenge when looking at the research on the effect of EDGs and EI for children with Down syndrome is the lack of detail in papers about what each EI program actually consisted of. Program details in Fewell and Oelwein's 1991 description of the 'Washington Model Pre-school Program' consist of the programs objectives, the first of which was to "increase the children's rate of development in six skill areas: gross and fine motor, cognition, receptive and expressive communication and social/self help. A test-teach-test model using curriculum-based assessment tool served as the core of this systematic and individualized instruction." (pg 57). Hanson (2003) describes the program content in her study as "home-based early intervention services implemented by the children's parents. Educational goals and programs were developed during weekly or bi-weekly visits to the family's home by a home visitor who, together with the parents, designed, implemented, and evaluated the strategies." (pg 354/5).

Many other papers report that the research described will impact on Early Intervention and should be taken into consideration by educators when devising EI programs (Dykens et al 2007, Fidler et al 2008, Paterson 2001). They do not often suggest details of how this might be implemented, a concern expressed by Cebula, Moore and Wishart (2010): "A strategic attempt to fill these knowledge gaps is

required, along with a drive towards developing studies that are aimed at testing competing theoretical accounts rather than simply providing behavioural descriptions” (page 123) and by Fidler & Nadal (2007), “ Amid these advances [...] there remains a wide gap between these research findings and the development of innovative practice.” (pg 262).

The most detailed paper comes from Bird and Wood (2003), which describes precisely the content of Early Development Groups run at The Sarah Duffen Centre in Portsmouth in the early 2000’s (which is similar to the model to be studied in this research). However, I have as yet found no follow up data reported to suggest the efficacy or limitations of these groups, leaving an obvious area for investigation which my research will contribute to in detail.

Consideration also needs to be given to the age of the more detailed literature; most programs, with the exception of the EDGs at The Sarah Duffen Centre, were run and reported on 20 plus years ago. The Washington Model Pre-school Program in 1971, Hanson’s study in 1974, and Cunningham’s research at the Hester Adrian Research Centre in 1973 (Cunningham 1986). Since much of this data is very much ‘of it’s time’ it must be read with its social, cultural and historical context in mind; throughout the 1970s there was a growing movement toward the belief that no child was uneducable and that babies born with Down syndrome were able to be raised at home by their families. The increase in children with Down syndrome being raised in the home gave opportunity for educators and researchers to challenge public perception and enable infants with Down syndrome to achieve much more than had previously been thought possible. On looking back at these studies however, the methodologies and therefore some results have been challenged. Gibson and Harris (1988), in their review of 21 studies, dated from 1967 to 1986 and covering a vast range of interventions, find that “the results have been mixed and sometimes confusing, in large measure because the EI programme accountability literature for the biologically handicapped abounds with methodological problems, and appeals often to ideology rather than to empirical process in the generation and interpretation of findings.” (pg 1).

Much of the more recent literature on Early Intervention has been concerned with parental participation in programs and the effect of the intervention on families. Although not a new concept (Bronfenbrenner 1977 & 1986), and one which early interventionists and researchers were mindful of (Sloper et al 1983, Cunningham & Glenn 1985, Treloar & Cairns 2002, Fewell and Oelwein 1991, Hanson 2003), there is still much concern over how EI can serve to increase parental anxiety and engender an over reliance on professional help and advice (Sloper 1983, Rix 2008, Hanson 2003). However many conclude that the positive effect on parents is one of the most valuable long term outcomes of EI programs, “The positive effects of these parents’ growth as advocates and teachers of their children are evident when examining the children as young adults.” (Hanson, pg 364). The widest interpretation of ‘worth’ should considering the longer lasting effects of a program are not to be overlooked in the qualitative assessment of EI.

Rix's conclusion in 'Until the Cows Came Home' sums up this conflict in parent response to EI,

"The parents in this study often welcomed professional advice [...]. All parents felt glad to be doing something for their children [...].

For all but one of the families in this study the early intervention process has, at times, been counterproductive, generating conflict and guilt."

Although a wide range of studies have commented on the complex nature of the parent-instructor role, there is still much to be derived from investigating this area further. Questions remain as to what influences this role for parents; does social class have an impact on how parents perceive professionals, the advice they give and the instructor role they are expected to take on?, is the teacher/instructor role confined to the main caregiver?, what impact may this have on their relationship with their child and other family members (do they become the family teacher too)? Mahoney et al (2006), Cruic (1990), Hauser-Cram et al (1999) and Head & Abbeduto (2007) have produced some interesting studies on the parent – instructor dichotomy and how family and social influences may affect the development of the child with Down syndrome. Although these wider questions are not within the remit of this study, they will impact on the design and methodology and it may be prudent to lay the groundwork for a future, more detailed project examining these aspects of the development of the child with Down syndrome and their families.

Two further issues which arise from the current and earlier literature are the types of intervention which appear to be available now, and the longer-term impact of EI on children's development. In the UK the development of Portage services (a pre-school home visitor service) has perhaps, in some areas, superseded other EI programs. The aim of Portage is to support families of children with additional needs and develop a program which helps *"parents to identify what is important to them and their child and plan goals for learning and participation"* (NPA website; <http://www.portage.org.uk/about/values>). This service is, however, patchy and inconsistent across the country and covers children who are disadvantaged in a variety of ways: physically, developmentally or socially, for example. The Portage visitors can come from a variety of sources: trained Portage visitors, the voluntary sector, seconded from teaching or similar professions and they may see a child regularly every fortnight for 2/3 years, or in a group session, or for a limited number of sessions, all depending on the Local Authority they are working under (Russell 2011). Portage should be supported by the Early Support Materials (<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/ES54>) a detailed checklist of development and accompanying information on how children with Down syndrome may develop (<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/ESPP13>), however much of this material has been archived or is no longer available, and the Early Support website no longer in existence. It has proved difficult to find examples, thus far, of how well portage is serving the needs of children with Down syndrome; it is doubtful that even the best service is able to provide the specific, long term intervention which focuses on the particular learning profile of children who have Down syndrome. Although not the main focus of this study, during the course of the

research I will hope to review a small proportion of the Portage service and determine its value for the families included in this study.

A key hope in providing Early Intervention is that it will improve developmental outcomes for the children involved; improved developmental outcomes should mean better engagement in school, more effective adaptive and social skills and ultimately more independence as an adult. It is widely debated however, and for some, whatever the hopes in the first Early Intervention schemes, long term effects appear to be limited and in some cases improved development arrests on the cessation of the intervention:

“Studies which monitor post-programme IQ scores, [...], support a tendency for gains to decline with time to increasingly approximate test levels of control subjects or of population test norms for at-home DS children in general.” (Gibson & Harris, 1988, pg 10)

Cunningham, in his 1986 assessment of the Hester Adrian Centre study, found a similar pattern; whilst the children in his study made developmental gains whilst receiving intervention, ‘...no support was found for the hypothesis that the early intervention would have long-term benefits reflected in measures of child development...’ (pg 178)

It appears essential from these conclusions that we must continue to look further at the implications of Early Intervention and what longer-term outcomes involvement in a program could bring. It is possible that we need to look past traditional IQ and DQ tests and seek to find a more ecologically based assessment of ‘value’ for the child and parent. If a child learns the skills of perseverance, independence and motivation during his first years, and the parent learns how to teach these skills, is it then possible to measure the worth of these skills as they are used, replicated and built upon in later life? As a parent reports in Hanson 2003, “I found it very helpful to me. And I have done it again and again over the years with him...to break things down. To teach him.” (pg 361)

Many studies do show that children make progress whilst involved with the project (Hanson 2003, Fewell & Oelwein 1991, Cunningham 1986) but the measurements used are not necessarily standardised (Fewell & Oelwein 1991), an issue which is further compounded by recent research suggesting that children with Down syndrome respond poorly and inconsistently in cognitive tests (Wishart & Duffy 1990). In my research I will respond to these gaps in methodology and aim to put in place a rigorous enough procedure that will enable replication to assess the longer term stability of the Early Intervention outcomes. Whilst the timeframe of this study is too short to follow the children and families involved longitudinally, I aim to make the methodology and theoretical frameworks robust enough for this to be possible in follow-on studies.

Throughout the 1970s and ‘80s the inception and development of Early Intervention had a profound effect on the lives of people with Down syndrome, their families and communities; high expectations and a determination to improve quality of life for people with Down syndrome drove a range of

professionals to develop innovative and progressive programs. Through the 1990s and into this century a greater understanding of the dynamic nature of development, the emergence of the behavioural phenotype associated with Down syndrome and a clear drive in research to 'unlock' the mechanisms of how people with Down syndrome learn has forged a pathway from which a range of hypotheses can be tested and evaluated.

"Without evaluation studies, and further more detailed knowledge of socio-cognitive development, it will remain difficult to identify the intervention routes which are most appropriate for children with Down's syndrome and their families" (Cebula, et al, 2009, pg 122)

This study aims to contribute to this testing of theories in practice and to be part of the next generation of research which moves forward the education, inclusion and independence of people with Down syndrome.

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