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The Progression of Early Intervention Disability Services in Ireland

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ABSTRACT

The Republic of Ireland is an island situated in North West Europe inhabited by 4.6 million people with 2.8% aged between 0-4 years with a disability (Central Statistics Office, 2012).

The Irish Government funds the Irish health services, which in turn directly and indirectly funds disability services. Education and Disability legislation have developed in parallel with an apparent increasing congruence with both moving towards a rights based approach. Today, Early Intervention disability services are delivered by both statutory and non-government agencies with wide variation and no national consistency in service provision. Some

components of the Developmental Systems Approach can be discerned in Irish service provision and these include: screening, access, comprehensive interdisciplinary assessment and early childhood programs. However, assessment of families, development and implementation, monitoring and outcome evaluation, and transition planning are not as identifiable. Guided by legislation and organisational restructuring, Early Intervention provision in Ireland is in a state of flux with an emphasis on developing national uniformity of family centred Early Intervention services.

Key Words: Ireland, children, disability, early intervention services.

Introduction

This paper presents the historical context of the development of the Irish health services, focusing on disability services for children to provide the background to the structure and activities of Early Intervention Services as they are configured today in the Republic of Ireland. Current legislation underpinning service provision is reported from both a health and education perspective with reference to the current status of services for children with disabilities under the age of 5 years. The applicability of components of the Developmental Systems Approach

(Guralnick, 2001) to Irish service provision is explored and finally future recommendations for service improvements in Ireland are made.

1. History of early childhood services.

The industrial revolution in the early to mid-nineteenth century is often cited as a pivotal time for people with disabilities in western societies. Prior to this they were not segregated from the rest of society (Quinn & Redmond, 2005). In Ireland in the 18th century developing health and welfare provision was directed at the ‘sick poor’ on a charitable basis with philanthropic and voluntary funding and support (Harvey, 2007). Overtime, the sick poor were divided into those poor perceived as worthy of support, the so called ‘deserving poor’ which included orphaned children and people with disabilities, and the ‘undeserving poor’. Service provision in terms of health, welfare and education developed, albeit slowly, with an increasing role played by religious orders and the State gradually emerging as a service provider (Considine & Dukelow, 2009). In Ireland, from the mid-nineteenth century, people with disabilities outside the home environment were supported under the Poor Law, predominantly in workhouses. This is in contrast to many other western countries. It was not until the early twentieth century that particular provision was made for people with disabilities in specific residential institutions (Quinn & Redmond, 2005). In the 1920s, with the founding of the Irish State, funding was limited and health services were not a financial priority (Harvey, 2007). There was continued

reliance on religious orders and voluntary bodies for the provision of disability services for children through residential homes and special schools (Sweeney & Mitchell, 2009).

In parallel, the concept of a universal national health service first emerged in the 1940's (Harvey, 2007). The afore mentioned financial constraints coupled with opposition from the medical profession, Catholic Church and Department of Finance resulted in the incremental development of a universal health service over the later half of the twentieth century (Harvey, 2007). In 1966, the Public Health Nursing service was introduced. This amalgamated the domiciliary nursing service, midwifery and district nursing services provided by local authorities and non government agencies (National Council for the Professional Development of Nursing and Midwifery, 2005). A universal child public health service was offered with Public Health Nurses (PHN) attending "to the public health care of children from infancy to the end of the school going period" (Department of Health and Children, Circular No. 27/66, para 7).

In the 1970s, services for children with disabilities were transformed by the organisational reconfiguration in both public health and disability services. Public and political disquiet and a belief that community care was more cost effective, resulted in a shift from large institutional care to smaller community settings (Quinn & Redmond, 2005). Over the latter half of the 20th

century secular non-government agencies, such as, Enable Ireland (originally Cerebral Palsy Ireland), were established in response to expressed need. The Health Act (1970) changed the organisation of statutory services from local government at county level to grouping counties into eight administrative Health Board areas. In the early 1990's, The Needs and Abilities Report (Government of Ireland, 1990) made a number of recommendations for the development of disability services and public health services nationally. It highlighted the need for community healthcare personnel, such as Public Health Nurses to receive training in the screening and detection of developmental disabilities. Furthermore, it asserted that regional multi-disciplinary Early Intervention teams should be available to provide specialist services for infants and young children with developmental delay.

In 2000, the National Children's Strategy outlined six operational principles to guide services for children, which to some extent mirror aspects of Guralnick (2001) and Blackman's (2003) conceptualization of Early Intervention service delivery. The need to establish a whole-system approach to delivering health care in Ireland was highlighted by the Health Strategy (Department of Health and Children (DoHC, 2001a). This strategy is based on four principles: equity, people-centeredness, quality and accountability. In 2001, the Primary Health Care Strategy was also launched (Department of Health and Children, 2001b). This strategy was based on a population approach to healthcare with the aim of meeting 90-95% of the needs of

the Irish population within the primary healthcare setting. As a result of the Primary Health Care Strategy the development of multidisciplinary primary health care teams commenced.

On foot of the Health Strategy (DoHC, 2001a) and the Primary Health Care Strategy (DoHC, 2001b), the Prospectus Report (DoHC, 2003) outlined the reconfiguration of the health boards into four administrative units under the control of the Health Service Executive (HSE) (Harvey, 2007). This organisational framework is again under review with a move towards clinical directorates, which will encompass a wide range of services, including personal and social services for people with disabilities (O'Shea, 2009). The uncoordinated and unstructured historical evolution of disability services coupled with the influences of a number of different organisations, with different philosophies of care, will influence the unified vision for the national health service.

2. Current legislation of early childhood intervention birth to 5 and early childhood special education.

In Ireland, the education and health sectors for children with disabilities under 5 years have developed along separate traditions (European Agency for Development in Special Needs Education, 2010). Education for children with disabilities has been described as a 'neglected area' until the 1990s (Considine & Dukelow, 2009). At an international level, Ireland is a

signatory to both The UN Convention on the Rights of the Child (1989) and the UN Convention on the Rights of Persons with Disabilities (2007) which affirm the right of all children to equal education without discrimination within the mainstream educational system. At a national level, the report of the Special Education Review Committee (SERC) (Department of Education and Science (DES), 1993) brought the concept of integrated education into the Irish context and set out the rationale for early education for children with special needs. The notion of inclusion of children with disabilities into mainstream education was supported by the 1998 Education Act. The White Paper on Early Childhood Education ‘Ready to Learn’ (DES, 1999) outlined the necessity of a preschool placement as a priority prerequisite, particularly for children with special needs. The Education for Persons with Special Educational Needs (EPSEN) Act (2004) provides the legislative framework for the provision of education for children with disabilities aged between 4 -18 years. It is intended to ensure that persons with special educational needs can be educated where possible in an inclusive environment. Special Education needs are defined as a person who has a restriction in their capacity to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability (EPSEN, 2004). The current focus is to find every possible means by which a child with a disability can participate fully in mainstream education and in social and leisure activities. Nevertheless, models of disability in education policy are

considered to have fallen short of a rights based approach for all persons with a disability (Considine & Dukelow, 2009).

Issues of health and education policy for children and adults with disabilities were addressed in the Disability Act (2005). The Disability Act (2005) protects the rights of people with disabilities and provides for an assessment of their health and educational needs, and assures appropriate planning will be undertaken on their behalf. In 2006, the Centre of Early Childhood Development (CECDE) made recommendations for practice and policy. They indicated that the National Council for Special Education (NCSE) in collaboration with the Department of Health and Children (DoHC) should ensure that children aged between birth and 4 years have appropriate multidisciplinary team support with the inclusion of an early educational expert to support the child in early childhood settings.

In 2007, Part 2 of the Disability Act (2005) was implemented providing a statutory assessment system for children less than five years of age. It provided the statutory right for children to have an independent assessment of needs within a specified time frame and a Service Statement outlining the required services. The process is co-ordinated by an Assessment Officer who is employed by the HSE. The Disability Federation of Ireland (DFI) asserted that they are 'deeply concerned that the operation of the Act is not nearly as effective as it could be'

(DFI, 2010, p. 1). Disability policy has progressed, and while it appears more coherent with a rights based approach than education policy, some have considered it not as robust in this regard as it could be (De Wispelaere & Walsh, 2007).

3. Current status of services

Contemporary services are in a state of change. In 2006, the Office of the Minister for Children was created. This provided national leadership to integrate equality and health and childcare functions in the State. On the 2nd June 2011, a diverse range of services for children, which were the responsibility of a number of government departments were consolidated into the Department of Children and Youth Affairs (DCYA). This brought together a number of key areas of policy and provision for children and young people including the Office of the Minister for Children and Youth Affairs (OMCYA), the National Educational Welfare Board (NEWB), the Family Support Agency (FSA) and the Irish Youth Justice Service (IYJS). The purpose of this extensive merger was to direct the effort to improve outcomes for children and young people in Ireland (DCYA, 2012). There is currently no national policy for universal or specialist Early Intervention services in Ireland. However, a National Early Year's Strategy is currently being developed by the Department of Children and Youth Affairs focussing on universal Early Intervention service provision.

To address the ad hoc development of children's disability services, the Health Service Executive highlighted the need to reconfigure services for children with disabilities (HSE, 2010b) and initiated a national programme 'Progressing Disability Services for Children and Young People', in joint partnership with non-government agencies, the Department of Health and Children and the Department of Education and Skills. This Programme, which was

launched in 2011, aims to implement the new structures for disability services within the context of the primary care model as directed by the Health Service Executive Reference Group Report (2009). The Health Service Executive Corporate Plan 2011-2014 (HSE, 2011) asserts that the aim of these services is twofold. Firstly, to provide geographically based services, which are timely and accessible for children with disabilities and their families. Secondly, to provide a singular clear pathway for assessment and intervention, with health and education working in partnership, to support children to reach their full potential.

The Standards Framework for the Delivery of Early Intervention Disability Services (HSE, 2010c) was developed in consultation with 100 stakeholders (professionals and families) in Early Intervention. Standard 1.1 of the Framework, it states that the team's ethos is child and family centered and underpins the primacy of the role of parents and carers in their child's development (HSE, 2010c). In 2011, the Health Service Executive set out principles to guide services: Bio Psychosocial Model, Equitable, Accessible, Family Centered, Integrated Team Approach, Accountability, Inclusion, Early Detection and Referral, Evidence Based, Evaluation of Outcomes, and Cultural Competence. Hence, the bio psychosocial model is currently the guiding framework for Irish Early Intervention services. The focus of intervention is on the child in the context of their family and considers the influence of the family on the child's development (Dunst, Trivette & Hamby, 2007).

4. Components of the developmental systems approaches and their applicability to current services in Ireland

a) Screening/Referral

Best Health for Children Revisited (HSE, 2005) identifies Public Health Nursing as one of the key professionals in the delivery of child public health and therefore, ideally placed to identify children with developmental disabilities. Public Health Nurses, with support from other primary care team members, provide the National Child Health Surveillance and Screening

Programme to all children under six years of age (Health Act, 1970). The current approach employed by Public Health Nurses to identify developmental delay is through developmental surveillance. This is a longitudinal process, which includes obtaining a comprehensive history, observation of the infant and the elicitation of parental concerns (Rydz, Shevell, Majnemer & Oskoui, 2005). However, this professional subjective assessment of a child's development has limitations (Rydz et al., 2005). Most Health Service Executive areas include a developmental checklist in the child health record to support the Public Health Nurses in practice. However, Best Health for Children Revisited (HSE, 2005) cautions against the use of such checklists in the determination of the developmental status of the child, as it is not a standardised assessment. The American Academy of Pediatrics (2006) recommends any developmental concerns identified during child health surveillance should be followed-up with a standardised developmental screening tool. A recent national survey of the current practices, in the 32 Public Health Nursing areas, suggests that only 30%, of the 23 areas that responded are using the Ages and Stages Questionnaire (Squires, Twombly, Bricker & Potter, 2009) as an adjunct to developmental surveillance (Institute of Community Health Nursing, 2011).

Children who are identified as at risk of having a delay and/or disability may receive intervention at a primary care level through preventative and health promotion services, for example, Triple P (Sanders, Mazzucchelli & Studman (2003) and local support groups, such as, Community Mothers (Molloy, 2002). Children presenting with more complex needs are

referred to Early Intervention teams in the primary care network (DoHC, 2001b) for more specialist interventions. More specialist parenting programmes may then offered to support parents; for example, the Hanen Parent Programmes such as ‘More Than Words’ (Sussman, 1999) and ‘The Incredible Years’ (Sutton, Utting & Farrington, 2004). Some children are referred for Early Intervention Teams through the Disability Act Assessment of Needs Process. For children who have a diagnosable disability the referral pathway to these specialist Early Intervention services may be more direct. However, the identification of children with global developmental delay continues to be problematic (Marks, Glascoe & Macias, 2011) with many remaining undetected until school-going age (Hall & Elliman, 2003).

b) Access

Variations in access to services exist across Ireland (National Disability Authority, 2011). Access is dependent on the geographic area, the age of the child and types of disabilities or developmental concerns. Regional and county variations in referral/access criteria currently exist. For example, in the Mid West Region, children are accepted who have complex developmental needs requiring input from two or more therapy disciplines within a specialist team (Mid West Disability Services, 2011). In County Meath, a child must present with physical, sensory and/or learning disabilities, developmental delay or be on the autism spectrum and must require ongoing team-based interventions (Early Services Meath, 2008). In counties Longford and Westmeath, children must present with significant delay in two or more

areas of development on a standardised tool (Sharif, n.d.). Consequently, accessing specialist Early Intervention services has been identified as a stressful, fraught with questions and challenges for caregivers (Foran & Sweeney, 2010; O'Loughlin, Carroll & Caulfield, 2010/2011). In relation to access, the Health Service Executive (2010c) highlighted that consideration should be given to: (a) the needs (that is specialized versus general) and strengths of the child, (b) the needs and strengths of the family, that is: ability to travel, access to public transport and geographical location of the family, and (c) services should not be less if the location is more remote.

When a team receives a referral, there are again variations in pathways of care. There may be a multi-agency forum, for example, Kerry Early Intervention Intake Forum (Enable Ireland Kerry, n.d.) where professionals come together to discuss a child's needs and design a pathway of care. Alternatively, services may have an intake multi-disciplinary meeting (Limerick Children's Services, 2009) where referrals are discussed by the team and accepted if the child meets their criteria. To address the variations in access a national working group is working together to develop a single national system with no regional variations.

c) Comprehensive interdisciplinary assessment

As with other aspects of Early Intervention in Ireland the application of comprehensive interdisciplinary assessment varies with long waiting lists for service delivery and disparity in

speed of service delivery across the country (Central Statistics Office (CSO), 2010). Although, most geographical areas have Early Intervention teams there is no standardised model of practice for team-based assessment. A comprehensive assessment is the norm in established teams, with coordinated input from the various disciplines as appropriate. A variety of models of team working are used. For example, Enable Ireland North East (n.d.) use an inter/trans disciplinary model of service and Cederman (2006) found that transdisciplinary team based assessment is carried out in some areas. Teams may work closely in one location or across different locations. Team composition varies and may include all or some of the following disciplines: physiotherapist, speech and language therapist, nurse, paediatrician, medical doctor, occupational therapist, social worker, psychologist, early childhood educator, family support worker, administrator and dietician. A consultant geneticist and genetic counsellors are available as a national service. Location of assessments may vary between centres, homes, or pre-schools. Following assessment professionals are guided by national best practice guidelines for informing families of their child's disability (National Federation of Voluntary Bodies, 2007).

The Assessment of Needs Process is working well in areas where Early Intervention services are integrated and where the process is aligned with team assessment and intervention (National Disability Authority, 2011). However, the process has shown that divorcing

assessment from intervention can mitigate against providing responsive, family-centered Early Intervention services and supports (NDA, 2011). The requirement of a diagnosis to enter the resource allocation system for school supports and for entry to some discipline specific services, has led to the Assessment of Needs being accessed in order to obtain a diagnosis.

Payne and Coughlan (2010) explored staff perspectives of the Assessment of Need process and found that there were inconsistencies in Assessment Officers expectations and requirements; the process was time-consuming and created pressure; and assessment of need applicants were being prioritised over children on intervention lists. However, children did receive a comprehensive assessment, a Statement of Need and there was consistency in report writing.

The National Disability Authority (2011) state statutory guidelines need to be developed to add clarity to the Assessment of needs process and should include any developments from the disability working groups and take account of the views of parents of children with disabilities.

d) Early Childhood Intervention Programme

The Health Service Executive (2010c) state that service provision should be individualised as one size does not fit all and that the needs of each individual and family should be considered.

Following comprehensive team assessment, some teams formulate an Individual Family

Service Plan (IFSP) (Limerick Children's Services, 2009; Brothers of Charity Southern

Services, n.d.). The plan aims to be directed by the assessment findings, the family's concerns,

priorities, and resources. Ward (2009) found that parents were not involved in goal setting for their child during the initial stages of attending a service. Evidence of inter-disciplinary collaboration and a will to work in an integrated manner with families does exist in Ireland (Carroll, 2011). Whyte and Kelly (2009) found many indicators of international best practice, in the Mid Leinster area, notably the practice of working in partnership with families at every stage of the intervention. Interventions aim to follow a comprehensive plan to meet the needs of the child and the family. Interventions can include building family support, empowering the family, facilitating coping strategies, carrying out specific interventions, and/or teaching techniques and strategies. Interventions may be provided in an interdisciplinary way or as a single discipline, based on different priority/waiting list management criteria. A variety of intervention methodologies are used, for example, individualized or group. Interventions can be home based or centre based. Some services offer a key worker service. For example, Enable Ireland Cork Children's Services (n.d) highlight that the key worker is a member of the team who supports and helps the parents and is the direct team contact for the family. Following multi-agency partnerships, managers and parents reported improvements in the provision of responsive, team-based and family-centered services (Jacob, 2011). In other studies, parents reported satisfaction with gaining knowledge, skills and receiving support (O'Loughlin et al., 2010/2011) and when professionals acknowledged their attributes as parents (Ward, 2009). While there was evidence of good practice in Ireland, there were parents who expressed

significant levels of dissatisfaction with information and continuity of care (Harnett, Dolan, Guerin, Tierney & Walls, 2007). Carroll (2011) found that parents were unaware of the management of their child's records which was a source of concern for parents.

e) Assessment of Families

In some teams, there is a tradition of both health and personal social services working together. Where these services exist a nurse or a social worker commence the initial interactions with families and provide an assessment of family strengths and needs. Quin and Redmond (2003) highlight that while the practice of joint health and social services structures provides for a holistic approach to the child and family's needs, there may be a tendency to subsume all support into a medical model. Assessment of family strengths and needs are intertwined with the assessment of the child's needs, with intervention and with the use of Individual Family Service Plans. The Health Service Executive Reference Group Report (2009, p. 15) recognizes that 'having a child with a developmental delay or disability puts significant additional stressors (emotional, practical and financial) on the parents and family. Their needs arising from these stressors must be factored into all interventions and care planning'. The Central Statistics Office (2010) highlighted that families had a mixed awareness of entitlements. However, in another Irish Study, caregivers were found to be aware of and actively using extra

community and ancillary services to the Early Intervention team, such as respite care and home help support (Foran & Sweeney, 2010).

f) Development and Implementation of a Comprehensive Programme

Education and health provision for children with disabilities continues to develop in parallel (European Agency for Development in Special Needs Education, 2010). In 2010, the government commenced one year of free pre-school education for every child in Ireland. This initiative has enhanced the availability of education services for all pre-school children in Ireland. However, there is little or no provision for children with disabilities who need individual support to access pre-school education. Children with disabilities may be able to access special pre-schools for children with disabilities run by disability organisations or privately run mainstream pre-schools. Interdisciplinary intervention for these children is mainly centre based with sessional interventions within the child's education setting.

g) Monitoring and Outcome Evaluation

In Ireland, there is no standardized way to assess the quality of early childhood intervention. Although there is no universal team approach, there are numerous documents available to health professionals to facilitate monitoring, self-audit, evaluation and to identify areas for improvement. For example, Checklist for Assessing Adherence to Family-Centred Practices

(Wilson & Dunst, 2005), Guidelines for local implementation groups on developing a governance structure and policies for children's disability services (HSE, 2010a), and the Standards Framework (HSE, 2010c). The Health Service Executive guidelines suggest that to achieve best possible outcomes for children and families: explicit goals and objectives need to be set, responsive to each family's priorities, regular evaluations and feedback from both team members and families, formal and informal evaluation of functional, clinical and personal outcomes. However, it is important to note that existence of a framework and guidelines does not ensure their implementation (Carroll, 2011). It is deemed best practice that Early Intervention programs must allocate resources and time to evaluation as an essential way of determining the quality of the services that they provide (Fallon, 2000). A national group is working to develop a draft performance reporting framework that supports partnership-based programme accountability and performance reporting, with a focus on outcomes for children with disabilities and their families.

h) Transition Planning

Children are discharged from Early Intervention services at 5 or 6 years of age, when they enter formal education. Their developmental and therapeutic services may be transferred to school aged disability teams where they exist. For many children they are referred to the primary care system. Foran and Sweeney (2010) highlighted that the transition from an Early

Intervention service to primary education was a major source of anxiety for caregivers. This recent study indicates that the development of standards is required to enhance the smooth transfer for children and their families.

6. Future Recommendations for the expansion and improvement of services in Ireland.

The provision of Early Intervention services in Ireland is inconsistent across the country as a consequence of the historical influences and the ad hoc development of service provision.

Ireland is in the process of addressing these inconsistencies. The Health Service Executive is the unifying body directing the vision of geographically based Early Intervention teams across Ireland. The EPSEN Act and the Disability Act provide the legal framework to support this vision. Interdisciplinary working is promoted by government strategies and policies, however the fidelity of the implementation of policy and legislation remains unclear. There is a need to focus on consistency of development through monitoring and evaluating child and family outcomes as well as system outcomes.

At the time of writing, no national Early Intervention policy exists in Ireland and the Health Service Executive organisational structure is in a state of flux. Paradoxically, almost three-quarters of a century after the concept of a universal health service first emerged, the vision of current Irish healthcare policy is to provide a single-tier health service supported by Universal Health Insurance (Department of Health, 2012). Guided by legislation and organisational

restructuring, the developing Early Intervention system in Ireland is undergoing radical change.

Early Intervention needs to be at the forefront of health and education services, facilitating

seamless transitions between universal and specialist services for every child with special

needs. The development of services needs to be supported by a national Early Intervention

policy which will ensure uniformity of service provision for each child with a disability in the

Republic of Ireland. The future of Early Intervention in Ireland lies in the hands of working

groups, implementation groups, researchers, teams and families.

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