Building Blocks to Best Practice

Introducing an “Integrated Holistic Model” of Early Intervention with Children and Families

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Introducing the “Integrated Holistic Model”

Introduction

On the arrival of their newborn baby for whom they have so many hopes and dreams, some parents face the news, then or soon after, that their child has a disability. This usually raises many complex and perplexing questions for the future. This paper is concerned with the support services with which the families, who have a child with a disability, subsequently engage to support all family members to live full and active lives. This presentation weaves legislation, research, theory and practice in the provision of services to children and families, where the child has an identified disability.

The essential message of the paper is that the future of early intervention services is founded on core principles and this requires substantial paradigm shifts in the way in which early intervention services are provided in Ireland today. These core principles are substantiated in international literature and are now being supported by local research on the “Integrated Holistic Model” in its application in an Irish context. We enter this debate as experienced early intervention practitioners with a strong conviction that if services “get it right” in these early years, it can make a significant difference for the rest of people’s lives. We wanted to know how a family could cope with the different and sometimes contradictory goals that were being set from different disciplines.

We begin with reviewing the legislative context, in particular the health and education dimensions, for disability services. We then review the principles of Good Practice in Early Intervention Services through a brief overview of the “Integrated Holistic Model” and describe the changes in St Michael’s House Services in redeveloping their model of early intervention. We conclude with some comments on the training context. It is useful to focus on the objectives of early intervention for young children (birth to 6 years) with or at risk of developing disabilities. Early intervention aims to:

- Minimise the impairment effect of disability;
- Ensure people reach their potential;
- Support families.
As stated in the British Government guidelines consultation document for birth-to-three year olds (2002), early intervention is defined as supporting the child in all aspects of development, including:

- Health Care;
- Educational and therapeutic input;
- Supporting the family as needed to maximise emotional development;
- Providing support that respects cultural and religious views.

It is clear from the paper by Glennane et al. (2005) that there is high level of agreement on some of the core principles. Sloper (1999) and Carpenter (1998) identify the following common features of successful services:

- An holistic approach to assessing and meeting family need;
- An emphasis on the importance of collaborative relationships with professionals;
- A consistent, single point of contact;
- A flexible, individualised needs-led approach;
- A focus on parent perception of need;
- The empowerment of parents.

Research
This paper incorporates the learning from two pieces of research conducted in Ireland by the two presenters in voluntary organisations providing services to children and adults; one to people with a physical disability, the other a learning disability. This research sets out to explore how to implement new models of early intervention services to children and families with a disability. Both methodologies employed qualitative methods with aspects of the action research paradigm, to directly influence the implementation of service provision.

The Disability Context
This development in early intervention services within disability services is set within a wider context of change in the disability sector. There are currently a number of major developments in policy and legislation:

- The landmark document, Strategy for Equality (Commission on the Status of People with Disabilities, 1996), signalled the beginning of change and the requirement for partnership and consultation with people with disability;
- The establishment of the National Disability Authority in 2000;
- The Government Health Strategy, Quality and Fairness (Department of Health and Children [DHC], 2001), introduced the principle of person centred services and sought
the development of standards in disability services;

- *The Education for Persons with Special Educational Needs Act* was signed into life in July 2004;
- The *Disability Bill* launched September 2004 presents the opportunity for the most radical changes to date - however it is still unclear as to the potential impact of this legislation;
- The *Strategic Review of Disability Services* established in 2004 by the DHC following a commitment sanctioned in Sustaining Progress 2003-2005;
- The Reform of the Health Services currently underway.

Consequently, disability awareness has moved from being a health issue to a matter of importance for all Government Departments, crossing education, employment, social welfare, housing, transport etc. The government has committed to a mainstreaming agenda.

*The Education for Persons with Special Educational Needs Act (2004)* impacts specifically by providing for Individual Education Plans for children with special education needs. It is possible to interpret the Act as including all birth to 6 year olds. The National Intellectual Disability Database Report (Barron and Mulvany, 2003) identifies 1,044 children in the birth to 4 age category and 1,878 in the 5 to 9 age group. *The Disability Bill (2004)* will provide for a health needs assessment. It is anticipated that these assessments and plans will be incorporated into one plan for each child. For many years, confusion has existed in the provision of services to young children with disability and their families, arising from the split responsibility between health and education. The question remains as to whether the aforementioned Bill and Act will resolve these issues.

**The “Integrated Holistic Model”**

The “Integrated Holistic Model” describes the key building blocks of effective early intervention, based on best practice as reflected in international research.

Developing from the work of Bronfenbrenner (1979), a theme that will emerge within the conceptual framework is the “rings to change”. These are eight interconnected rings containing the key elements of the model. The framework links what happens within the microcosm of the family who has a young child with a physical disability with the mesocosm of the organisation and the macrocosm of society at large.

The “Integrated Holistic Model” is founded on the following core values:
• Rights based perspective;
• Social model;
• Inclusive environments.

Rights Based Perspective  
The rights based perspective takes seriously the assertion that all persons are born equal with inalienable rights (Quinn, 2001:2). In the Irish context Baker (1998) quotes the Irish constitution: “The Republic guarantees ... equal rights and equal opportunities to all its citizens... cherishing all the citizens of the nation equally.” Yet rights of Irish children and adults with disabilities are weak (Quinn, 2001). However, Ireland has legal obligations in international law and policy.

Social Model  
A significant shift in thinking in the implementation of the Integrated Holistic Approach is the move from the medical to the social model of disability. Quinn (2001:3) states:

“According to the social construct idea, people are not born different. Difference is not inherent in a human being. It is socially constructed.”

The change from a medical to a social model moves from individual responsibility to societal responsibility. Put simply, if I break my leg, it is not my leg which prevents me getting up a step, but the absence of a ramp to facilitate me. Oliver (1993:63) defines the medical definition of disability “…as individual problem ...” The medical model supported segregation; the social model focuses on inclusion. The World Health Organisation (WHO) recently revised the international classification of disability (ICIDH) to acknowledge inclusion in activity and participation as set out in Table 1 below.

| Table 1 - ICIDH |
|-----------------|-----------------|
| Original ICIDH  | Revised ICIDH2  |
| impairment      | to              | impairment |
| disability      | to              | activity   |
| handicap        | to              | participation |

Inclusive Environments  
Inclusive settings are the least restrictive environments of choice, in its fullest sense. They include full access to buildings, support to participate in activities or welcoming and open attitudes.
Implementation of the “Integrated Holistic Model” challenges the provision of centre-based services. Inclusion reduces stigma and provides the opportunity for the community to act as a resource for the family to support child development.

**Eight Building Blocks of the “Integrated Holistic Model”**

On embarking on an exploration of the eight main building blocks of the model, it is important to set out their reliance on the essential role of the two cornerstones of Child and Family Centred and the beneficial structure of the Individual Family Service Plan. See Figure 1.

![Figure 1 - Eight Building Blocks of the Integrated Holistic Model](image)

The key elements (building blocks) of the “Integrated Holistic Model” are:

1. Child and Family centred approach;
2. Partnership;
3. Collaboration;
4. Interdisciplinary/transdisciplinary approach;
5. Individual family service plans;
6. Bringing services closer to families;
7. Implementing, reviewing and evaluation;
8. Outcomes focused approach.

**1. Child and Family Centred Approach**

Since the 1970s, the importance of working with families as well as the child with disability, has been acknowledged. Rosin et al. (1996) defines Family Centred Care as a service delivery system with families as the focal point, serving as partners and decision-makers in the early intervention process. This requires an understanding of family systems. Begun (1996) defines this approach as transforming, by placing the family at the centre and viewing the service provider as a collaborator. Families are not just a collection of individuals but a complex system; it is not just about receiving information for assessment purposes and for parents to provide therapy, but rather the inclusion of the whole family in the process.
Brinker et al. (1994) argue that the simultaneous goals of early intervention are to facilitate the development of the infant with disabilities and to assist the parents in their adaptation to their child. Adaptation refers to a process of grieving that helps a family achieve a comfortable balance and to promote the growth and development of individual members and the system as a whole in adjusting to a member having a disability. Rainforth and York-Barr (1997) suggest that it is important for therapists to understand the implications of grieving. Beresford (1995) suggests:

“…a good service would involve a holistic, interagency approach ...in which the needs of the child as opposed to the impairment are considered...”

DePompeii and Williams (1994) advocate the need to develop the capacity within the family throughout its life cycle.

Evidence

In the research within the physical disability organisation all stakeholders were asked how would they know that such services were present in Ireland and their replies suggested:

- Provision for siblings;
- Home visits;
- Involvement in all parts of assessment process in defining the issues, and devising solutions;
- Meeting parents together;
- Timing of visits;
- Video of intervention for father;
- Key worker.

2. Partnership

“(Partnership) ....requires abdication of paternalistic approaches to helping relationships and adoption of empowerment, participatory involvement and competency enhancement approaches to help giving.” (Dunst et al., 1994:211)

Rosin et al. (1996) propose that family centred early intervention creates the need to change how parents and service providers work together. Partnership involves a movement away from the expert model of professionals gathering information and making decisions about service provision. Dale (1996) proposes the adoption of the negotiating model whose premise is that parents and professionals have separate but potentially highly valuable contributions to make.
In organising programmes and consulting on the design of services with families, parents report that they feel more equal in these environments. For example if I attend my GP, I am unlikely to raise many questions about my service. However, if I were to attend a consultation on GP services, I may have strong suggestions to make. Consulting with parents needs to take place at an individual, family level and service level.

3. Collaboration
Jesien (1996:186) defines collaboration as:

“...the sharing of power, information, and resources between at least two persons, programs or agencies to facilitate a mutually beneficial activity to further the achievement of a mutually beneficial goal.”

Crais (1993) suggests that the key issues in making collaboration successful are to focus on process versus outcome and the extent to which the service is family directed or professional directed. The essence of collaboration is choice, involving parity among participants, based on mutual goals, dependent on shared responsibility for participation and decision making, sharing resources and accountability for outcomes. Rainforth and York-Barr (1997) suggest that collaboration may be described as not directive, authoritarian or prescriptive.

Evidence
In the research all stakeholders were asked how would they know that such services were present in Ireland and their replies suggested:

- Asking parents about the level and nature of their involvement, and where the involvement should take place;
- Using a problem solving format;
- Committing resources to enable parent involvement in advisory programmes;
- Facilitating parent to parent contact;
- Using evaluation and parent satisfaction surveys;
- Consulting on the planning and development of services;
- Family directed service.

4. Interdisciplinary / Transdisciplinary Teams
Tuchman (1996:120) states that:

“The team is the mechanism which makes the heart of the intervention work. The team approach recognises that young children with disabilities typically have multifaceted needs that can be addressed more effectively by a team rather than by a single service provider.”
Models of Teaming
Tuchman (1996) describes multidisciplinary, interdisciplinary and transdisciplinary teams. Teams develop by establishing a shared vision and philosophy, and learning how to work together effectively to make decisions, solve problems and carry out responsibilities.

Multidisciplinary teams
Multidisciplinary teams share common goals but work independently of one another. Each member represents his/her own discipline and uses discipline specific skills. Parents receive information related to a specific area of development and a plan is drawn up which relates to the particular discipline.

Interdisciplinary teams
Interdisciplinary teams share common goals and are committed to communicating with each other and with families with whom they work. There is planned interaction and formal arrangements for communication, for assessments, planning, and intervention. However, there is also increased parental involvement.

Transdisciplinary teams
Transdisciplinary teams share common goals and plan together using a systematic process for sharing roles and crossing disciplinary boundaries to maximise communication, interaction and co-operation among members. Decisions are made by consensus and family participation is crucial.

Tuchman (1996) identified this model as providing the best service to families as they integrate the principles of co-ordination and family centred service to a greater extent than do the others. The most common form of teaming in the Irish disability sector remains multi disciplinary teams, with some movement towards interdisciplinary working.

Integrated Therapy and Natural Environments
Rainforth and York-Barr (1997) argue that transdisciplinary models are best placed to support natural environment work. Integrated Therapy emphasises the provision of services within contexts which are considered meaningful or functional for an individual. Discussion is needed in Ireland to develop natural environment work by using key people and environments in the person’s life.

5. Individual Family Service Plan (IFSP)
“The guidelines, mandating an Individual Family Service Plan (IFSP) for each child and family, the identification of the parents’ concerns, priorities, and resources (CPRs), and the focus on increased decision making by parents have prompted early
intervention professionals to discover new and creative ways to engage parents and other caregivers in the early intervention process.” (Crais and Wilson, 1996:125-126).

The core focus of US IDEA legislation is on parental involvement and the mechanism for ensuring parent-professional collaboration in implementing the IFSP process. Rosin et al. (1996) portray the IFSP process as a promise to families, a way to build trusting relationships and a vehicle for empowerment. In the UK, a system of “statementing” or legally obliging educational needs is in use. The Education for Persons with Special Educational Needs Act introduces the Individual Education Plan process in Ireland.

6. Bringing Services Closer to Families
Services Closer to Families involves changes in the way services are provided. They build on the principle of inclusive communities. They involve the setting up of outreach services and increasing home and community visits.

7. Implementing, Reviewing, and Evaluation
Bauman et al. (1997) state that inadequate levels of programme evaluation are evident. Within the past ten years, there has been a substantial increase in the move to service evaluation. Intellectual disability service providers in Ireland have made a significant commitment to a range of quality assurance models, some with external accreditation.

8. Outcomes Focused Approach
The Outcomes Focused Approach requires a paradigm shift from looking at the services people receive to looking at what goals are achieved. The Council on Quality & Leadership, Personal Outcomes Measures (1995) model has specific outcomes for early intervention services.

Paradigm Shift
The “Integrated Holistic Model” requires paradigm changes in practice. This change is summarised in the following table of the Paradigm Shift Summary. I propose that for a team to work successfully, they must aim to cross all elements of the paradigm.
Table 2 - Paradigm Shift Summary

<table>
<thead>
<tr>
<th>From</th>
<th>To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charity</td>
<td>Rights</td>
</tr>
<tr>
<td>Paternal</td>
<td>Empowering</td>
</tr>
<tr>
<td>Medical Model</td>
<td>Social model</td>
</tr>
<tr>
<td>Disability focus</td>
<td>Child and family centred</td>
</tr>
<tr>
<td>Expert</td>
<td>Partnership</td>
</tr>
<tr>
<td>Prescriptive</td>
<td>Collaborative consultation</td>
</tr>
<tr>
<td>Professional driven</td>
<td>Consumer driven</td>
</tr>
<tr>
<td>Segregated</td>
<td>Mainstream/Inclusive</td>
</tr>
<tr>
<td>Group</td>
<td>Individual</td>
</tr>
<tr>
<td>Education/Therapy</td>
<td>Whole life</td>
</tr>
<tr>
<td>Multidisciplinary</td>
<td>Inter/transdisciplinary</td>
</tr>
<tr>
<td>Discipline focused</td>
<td>Age group programme based</td>
</tr>
<tr>
<td>Standards</td>
<td>Outcomes</td>
</tr>
<tr>
<td>Centre based Assess.</td>
<td>Integrated real environment Assess.</td>
</tr>
<tr>
<td>Deficit</td>
<td>Strengths based</td>
</tr>
</tbody>
</table>

From Theory to Practice

In considering the implementation of this model in Ireland, the following recommendations were made:

- Dedicated structure;
- Leadership and Co-ordination;
- Understanding Change;
- Teamwork and Time;
- Getting Parents involved;
- Move from uni-dimensional to multi-dimensional approach.

To make this complex change effective, it is essential to understand that the “Integrated Holistic Model” is a better way of providing services to children and families. The Model pulls together different threads that have existed in many services in Ireland, some of which are more developed in the U.S. It is presenting a more complete picture of the intervention which requires the marrying of Irish, and International practice. St Michael House Services show that this is possible, that a service has made significant steps to move into the model.
Moving from Child Centred to Child and Family Centred Services in Early Intervention

St. Michaels’s House

In St Michael’s House, the journey of change began for us at the end of the 1990s. A multidisciplinary team provided a range of services to young children with intellectual disability. We knew that there were gaps in the services due to resource deficits. We knew that some of the families who used our service were not always happy with us. We believed that this was because of resource deficits, but we also had an underlying feeling that there was something else going on. So we set out to discover what the staff and the families who used the service thought of the current services, and what they thought should be different. At the same time, we researched the literature for examples of models of service in Ireland and in other countries.

Through a two-year process of research and consultation, we arrived at the point where we understood that, in order to meet the needs of the children and families we serve, we had to make some radical changes to our model of service. It is fair to say that the change we faced was transformational. We will describe the theoretical basis of the change in the model of service and describe how our new model of service operates.

Who is the User of the Service?

Wasik (1990) conceptualises the user of services in the following way:

<table>
<thead>
<tr>
<th>Older models</th>
<th>Newer models</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>Family</td>
</tr>
<tr>
<td>Individual</td>
<td>Family System</td>
</tr>
<tr>
<td>Encapsulated</td>
<td>Ecological</td>
</tr>
<tr>
<td>Handicapped</td>
<td>Universal</td>
</tr>
</tbody>
</table>

This shift from older models of service to newer models reflects our changing understanding of children, of families and of disability. Ecological theories of human development highlight the inadvisability of viewing children’s development in context that is divorced from the child’s family and wider environment. Our understanding of disability has shifted from a deficit-oriented model to a model that identifies the strengths and needs of all children. The family becomes the focus of intervention, not because the family is *per se* in need of help because they have a disabled child, but because families are where children grow and learn and because childhood disability may place additional strain on families.
The Role of the Helper in Newer Services

Just as our view of the people who use the service changed, our view of ourselves as service providers also has to shift.

Table 4 · The Role of the Helper

<table>
<thead>
<tr>
<th>Older models</th>
<th>Newer models</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expert</td>
<td>Collaborator</td>
</tr>
<tr>
<td>Problem solver</td>
<td>Facilitator</td>
</tr>
<tr>
<td>Decision maker</td>
<td>Negotiator</td>
</tr>
</tbody>
</table>

In older models of service the professionals were seen as having all the expertise and all the solutions to any difficulties that might face families. Professionals were considered to know what was best for children and for families. In newer models of service, families are seen as the experts in relation to their own child. Certainly, professionals have expertise in particular areas and that expertise, taken together with the family’s knowledge of their own child, can be shared so that everyone can work collaboratively with families to support them to make decisions that are right for them. Newer models of working are essentially about empowering families. Families who have a child with a disability face many years of decision-making. Early intervention services that do not empower families create dependencies that inevitably cause difficulties for the family and child when those services change, as they surely will, as the child grows.

Individual Planning

In newer models of early intervention services, supports are provided based on identified need for both child and family. Parents are more likely to identify “playing with toys” as a goal for their child than to identify that their child needs to be optimally positioned to use their hands, develop increased range of motion, acquire the concept of means-end and develop hand-eye co-ordination. Plans to support development need to centre on the realities of children’s lives, not on developmental domains and deficit models.

Families may have needs arising from their child’s disability. Assisting a family to retain or reinforce the family’s connection to a natural support network of family or friends is a legitimate goal of early intervention.

Using Outcomes

A framework such as Outcomes for Families with Young Children (The Council on Quality & Leadership, 1995) supports services to make the transition from old to new ways of working. Instead of focusing on inputs (number or type of staff, number of assessments carried out, number of treatment sessions) or processes (the way the work is organised), the service focuses on Outcomes.
Some Outcomes for families with young children are:

- Families are informed;
- Families choose child development goals;
- Families choose their goals;
- Families choose services and supports;
- Children attain developmental milestones.

Services organised to support Outcomes emphasise information giving, key-working and the co-ordination of services, services based on family identified need and collaborative/transdisciplinary work.

**Key Working**

Sloper (1999), reviewing services in the United Kingdom, states that the absence of key workers causes provision that is “…piecemeal and service- rather than needs-led.” Families incur additional stress when they have to deal with multiple unconnected, or worse, contradictory interventions from different professionals. A keyworker or service co-ordinator, who knows the family well, assists the family to pull all the pieces of service provision together into a connected whole that fits with their individual family needs.

**Transdisciplinary Work**

How professionals work together is a major factor affecting the co-ordination of services to families. In the past, multidisciplinary teams of specialists – doctors, social workers, speech and language therapists, occupational therapists, physiotherapists, teachers and psychologists all worked separately, causing the problems of fragmentation described above. With the advent of interdisciplinary teams, where information is shared, all team members can facilitate goals.

There is growing interest in transdisciplinary teams. In this type of team the roles of the team members are less differentiated. Members share skills with each other and one or two members work primarily with the family, calling on the more expert skills of their colleagues as required. The concept is particularly applicable to Early Intervention teams precisely because it is a powerful tool for dealing with fragmentation.

Guralnick (1997) whose book “The Effectiveness of Early Intervention” is the seminal work summarising the ‘state of the art’ of Early Intervention describes the hallmarks of effective Early Intervention services as follows. Effective services should:

- Centre on the needs of families;
- Be based in the community;
• Be able to thoroughly and efficiently integrate the contributions of multiple disciplines;

• Have the capacity to plan and co-ordinate supports and services from multiple disciplines.

This statement does not ignore the need for appropriate models of curriculum and service content. It takes for granted that effective services must have an effective content component (while acknowledging that we still face many challenges in developing our knowledge base about what really works in Early Intervention). Rather, it prompts us to understand that many of the challenges we face lie in the “how” not in the “what”.

**Training for Professionals**

In Ireland there is no specific training for professionals to work with young children with disability and their families. Many courses (therapy professions, learning disability nursing, some childcare and education courses) contain short modules focused on the needs of children with disability in specific areas. However, there is a need for training for all professionals that clearly articulates models of early intervention and equips staff from a range of disciplines to work effectively with families with young children with a disability.

In terms of how professionals work together there is a need for training courses to encompass within them specific approaches to teamwork and to skill sharing transdisciplinary work. There is a need for the relevant undergraduate courses to focus on the importance of co-ordination and integration. Common training inputs are one way of achieving this. It might also be useful to look at establishing a post-graduate diploma type course that supports professionals from a variety of backgrounds to learn the additional skills they require to become skilled early interventionists.

We in St. Michaels’ House feel at this stage we have made significant progress, but the work is not without its challenges. Shonkoff and Meisels (1990) state:

"The progressive and inevitable ambiguity of disciplinary boundaries represents one of the central challenges facing the field of early childhood intervention"

This is as true in 2004 as it was in 1990.
References


