European Developments in Early Childhood Intervention

Edited by

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EUROPEAN DEVELOPMENTS IN
EARLY CHILDHOOD INTERVENTION (ECI)

Introduction

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We are looking at the foundations of the human soul, those developments which are as essential as the foundation of a house, and as invisible when all is well.

(Krystal, 1998)

Foundations of childhood

The way that society views childhood is currently undergoing a paradigm shift or evolution of ideas and theories, leading to a new understanding of children's educational development (social and emotional as well as academic), mental health, well being and general state of happiness. The recently phrased 'ecologic-systemic' perspective of child development, for example, provides a 'systemic way of analysing, understanding and recording what is happening to children and young people with their families and the wider context in which they live' (Howarth, 2000). This has an impact on the future development of early childhood curriculum models and 'shifts the educational emphasis away from telling children what they should know, towards listening and responding to the richness of their present lives' (Porter, 2002).

This understanding, which owes much to the collaboration between the disciplines of education and neuroscience, as well as to advances in genetics and neuroscience, leads to increased awareness of those children and families whose foundations may require extra support in the form of Early Childhood Intervention (ECI) [4] to ensure successful long term outcomes. A UK project looking at the Mental Capital and Wellbeing for children with learning difficulties found that:

> *Scientific advances in genetics and neuroimaging offer a potential opportunity within the next 20 years to identify children with learning difficulties in infancy... Cognitive neuroscience is already uncovering neural markers or biomarkers for detecting the different learning difficulties measurable in*

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[4] Actions within the framework of Early Childhood Intervention are focussed upon children (and families) with needs from birth until a maximum of six years of age. This is distinct from Early Intervention which refers to necessary action and intervention being used to support any child and his/her family as early as possible during any time in his/her education.

infancy. Such advances will eventually enable environmental interventions from infancy which would alter developmental learning trajectories for these children with consequent benefits throughout the life course. (Goshwami, 2008)

It is to be hoped that the number and range of children being identified and provided with the opportunity for access to ECI services would increase in parallel with such important developments. Other medical developments and societal factors would indicate an increase in the number of children and families requiring intervention.

In our schools, we are educating 'a new breed' of children with complex learning needs (Carpenter, 2009). The causal base of the difficulties in learning presented by these children is different from that we have traditionally known. Who are these children, and what are their numbers?

McClusky and McNamara (2005) state that the latest Government figures indicate that there are as many as 700,000 disabled children in Great Britain, among which are 'more than 100,000 severely disabled children in the UK [whose] numbers are known to be rising as a result of medical advances' (p.151). This statement directly relates to children whose disabilities, often profound, multiple and complex, are due to prematurity of birth. The EPICure UK study (Marlow et al., 2005) reports that 80% of children born at less than 26 weeks' gestation now survive. A comparable New Zealand study (Woodward et al., 2004) suggests a 90% survival rate for pre-term infants weighing less than 1,500 grams at birth, with a 63% disability factor.

The need for intensive, very early intervention with these children is crucial (Carpenter and Egerton, 2005), but, again, do we actually have the intervention strategies that will truly maximise the learning of these vulnerable infants and minimise the impact of their traumatic birth and subsequent fragile health status? Champion (2005) details the brain development of these very-low-birth-weight, pre-term infants and the neurological compromise they face. Many will have complex health needs requiring invasive procedures such as supported nutrition, assisted ventilation, rescue medication for complex epilepsy (Brown, 2009). Where these children have severe and complex disabilities (and the EPICure study (Marlow et al., 2005) suggests this is so far well in excess of 50% of surviving infants), their patterns of learning may be different to those which can be accommodated by existing teaching and learning strategies. For example, the sensory approaches many teachers have found effective for delivering a relevant curriculum may not engage children whose severe/profound and multiple learning disabilities (S/PMLD) emanate from pre-term birth because their sensory pathways may not only be damaged, but also incomplete and compromised (Champion, 2005).

Children with Foetal Alcohol Spectrum Disorder (FASD) are also a cause of concern (Carpenter, 2009 (in press)). International estimates suggest that the prevalence

could be as many as 1:100 children (Autti-Ramo, 2002; British Medical Association, 2007; May and Gossage, 2001; Sampson et al., 1997), and the disabling effects range across the learning difficulty spectrum from mild to profound (www.fasaware.co.uk). Their emotional well-being is particularly fragile, leading to high rates of suicide in later life. Early diagnosis and directed ECI is key for this group of children if the effects of secondary disabilities (exclusion from school, poor mental health, low self esteem, exposure to bullying and criminality) are to be ameliorated.

A recent analysis of ECI situations in Europe indicates that 'an increasing number of children present psychological and socio-emotional problems', whether this is due to increased incidence and prevalence, more frequent diagnosis or a change in parental awareness. The analysis also highlights an 'increasing focus upon the population at risk in its broadest sense' as being subject to ECI (European Agency for Development in Special Needs Education, 2005).
In their chapter on the Early-Aid-System in Germany in the present publication, Armin Sohns and Olaf Kraus de Camargo point to the fact that children with physical, mental and multiple disabilities comprise only 20% of all children attending Early Aid centres. The majority are children without clear-cut diagnoses. As they write, 'Nonetheless, these children and their families are without doubt in need of support and care.'

Current and future approaches to ECI, therefore, clearly need to be dynamic, evolutionary, well informed and reflective.

Foundations of ECI
Developments in ECI are currently receiving pan-European attention at policy and professional levels. In 1996, the European Agency for Development in Special Needs Education was formed to act as an independent and self-governing organisation, providing a collaborative platform for member countries regarding the development of provision for learners with special educational needs. The Agency is maintained by the Ministries of Education in the participating countries (member states of the European Union as well as Iceland, Norway and Switzerland), and is supported by the European Union Institutions via the Jean Monnet programme under the EU Lifelong Learning Programme.

The United Nations Convention on Rights of People with Disabilities (2006) is a major international directive that informs the work of the Agency. The main international documents and statements guiding the Agency's work are:

- The Salamanca Statement
- The UNESCO Dakar Framework for Action Education for All: Meeting our Collective Commitments

- The Charter of Luxembourg
- The Madrid Declaration
- The United Nations Standard Rules.

The establishment of the agency was seen by its founders as a reflection of the increasing collaboration that had evolved between the various European countries in the area of special needs education, which was valued and productive. Indeed, the collaboration led to the implementation of a number of specific programmes for learners with special educational needs as well as for the professionals involved in their education. These programmes contributed considerably to the development of special needs education across Europe. They also demonstrated, however, that there was a continuing need for a more permanent and systematic structure for pan-European collaboration in this field, facilitating extended exchange of information and experience among and within countries with a view to promoting quality of provision (http://www.european-agency.org/).

ECI in the context of pan-European initiatives is seen as 'the right of very young children and their families to receive the support they might need'. The aims are 'to support and empower the child, the family and the services involved' in order to build 'an inclusive and cohesive society that is aware of the rights of children and their families' (European Agency for Development in Special Needs Education, 2005). At a European level, the Agency points out, a new concept of ECI is evolving, 'in which health, education and social sciences (particularly psychology) are directly involved, focussing on child development and the impact of social interaction on human development in general and the child specifically'. It is felt that this reflects a shift from the type of intervention that focuses mainly upon the child to a more family and environment focussed approach in response to a move in the wider disability field from a 'medical model' to a 'social model'. [5]

Foundations of families

If ECI is to be family focussed, service providers will need to be aware of the changing patterns of families and the potential uniqueness that each family will require in the delivery of an 'Individual Family Service Plan' [6] due to differences in family structure, in order to meet their needs effectively. The UK Government notes that family patterns are changing . There are more uncertainties and risks, and more

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[5] Under the **medical model**, individuals with disabilities are defined by their illness or medical condition. Medical diagnoses are used to regulate and control access to social benefits, housing, education, leisure and employment. While this can provide access to much needed services, the medical model promotes the view of a person with a disability as dependent and needing to be cured or cared for, and it justifies the way in which disabled people have been systematically excluded from society and discriminated against. Under the **social model,** disability is seen as the product of the physical, organisational and attitudinal barriers present within the society in which we live and not as the 'fault' of an individual disabled person, or an inevitable consequence of their impairments. The removal of discrimination requires a change of approach and thinking in the way in which society is organised.

[6] The Individual Family Service Plan (IFSP) evolves from a meeting where families and professionals talk together about current concerns as well as recent progress and map future targets for intervention. The plan is reviewed at agreed intervals. When a child enters compulsory education, this is usually replaced by an Individual Education Plan (IEP).

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; and community factors, such as living in a disadvantaged neighbourhood (DfES, 2003). The skills, knowledge and flexibility to meet the needs of a range of families in complex and often (particularly in the case of children under the protection of Social Services) changing environments is key to ECI in the 21st Century, as 'the ecology of the family is first and foremost the family's domain'.

> *[W]e all have different family maps, it is important for that map to be shared with key workers and other professionals working closely with families so that professionals can take this into account when planning early interventions.* (Carpenter, 2007).

It is also crucial that ECI programmes embrace the cultural and socio-economic diversity of families accessing their services. Moreover, professionals from a range of backgrounds and disciplines employed in the delivery of ECI programmes must unite in the attitude they project to families, which should necessarily be empathetic, supportive and above all empowering. Assumptions about families' needs, particularly in regard to parental response to their child's diagnosis, are dangerous and can be alienating, resulting in parents feeling that their views and opinions should not be voiced lest they are met with judgement and prejudice. As Carpenterpoints out:

> *Families describe differing reactions to the birth of their child with a disability. These can affect family dynamics and determine the ways in which professionals can offer optimum support. It is important that professionals discover and respect these responses, so their intervention programmes are appropriate instead of a result of their own assumptions about the family.* (Carpenter, 2007)

In addition, jargon free terminology for service delivery is needed in order for a common language between professionals and parents to emerge, which puts parents firmly at the centre of a Family Service Plan rather than on the receiving end of what professionals may deem best or most suitable. For example, the range of terms used to describe ECI approaches include: ecological; family-centred; trans-disciplinary; multi-disciplinary; interdisciplinary; inter-agency; multi-professional; child-centred; family centred; family focussed; service focussed; resources focussed; community based, to name but a few. If families move from one geographical area to another resulting in a different 'approach' to ECI, such differences in terminology could be confusing.

Foundations of Good Practice

The European Agency for Development in Special Needs Education (2005) proposes five recommendations from its recent analysis of situations in Europe based on the principle that ECI is a right for all children and families in need of support:

1. ECI availability for children and families should be a matter for policy measures with clearly defined target groups and eligibility criteria as well as service/ provision information readily available for parents
2. ECI provision should be as geographically close as possible to families and should be family focussed
3. Cost free services/provision should be available for all families in need
4. Interdisciplinary working requires co-operation with families as the main partners of professionals, a team building approach to ensure cohesion and holistic provision and stability of team members for as long as possible
5. Health, education and social sectors should share responsibilities for ECI provision which can be achieved through co-ordination of sectors and provision across disciplines.

In 2003, Robin McWilliam developed a model for ECI that emphasises five components:

- Understanding the family ecology through co-maps
- Functional needs assessment through a routines-based interview
- Transdisciplinary service delivery through the use of a primary service provider
- Support-based home visits through the Valdberbilt Home Visit Script [7] http://www.siskin.org/resources/pdf/Vanderbilt_Home_Visit_Script.pdf [online 29.07.09]
- Collaborative consultation to child care through individualised intervention with routines.

Such services should be delivered in the child's natural setting, preferably at a local level, with a family-oriented and multi-dimensional team approach (European Agency for Development in Special Needs, 2005).

The need to respond to changes within the population of services users was recognised by Carpenter and Campbell in 2008, who warned us that:

> *Within the changing landscape of services for young children there is a growing recognition that the needs of young disabled children and their families should be taken into account in all national strategies and local*

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[7] The purpose of the Home Visit Script is to give home visitors in early intervention a structure for providing support-based home visits, attending to functional needs of families and the children in those families. It supports professionals in using an alternative to a hands-on, activity-based approach (i.e., 'the toy bag approach') that implies that the visitor is directly helping the child's development. The script instead gives the home visitor a guide for talking to the family about the many dimensions of child and family life that are part of early intervention in natural environments. R. A. McWilliam © 2004

initiatives. The population of disabled children and children with special educational needs has changed and is still changing. There is a need for early childhood intervention services to respond positively to these changes.' (Carpenter and Campbell, 2008)

Examples of thoughtful evidence-based ECI practice are found abundantly in the pages of this book, many of which are driven by policy measures within individual countries. Chapters cover a range of topics within ECI, from the diversity of children and families in need of support to the need for professionals to be in receipt of the very highest quality of emerging qualifications and training programmes, the writers contributing to this publication share a common passion and driving ambition – to provide ECI which 'helps families to provide as warm and developmentally supportive an environment as possible for their child' (Guralnick, 2005), which can be achieved by:

...working with families to help them address all of their information needs, to arrange agreed upon supports and services, to help minimise interpersonal stress, to reduce the need for families to deplete their own financial and related resource that can disrupt family functioning, and to convey to the family that they can feel confident in their ability to parent. (Ibid.)

When this occurs, 'ECI has its finest moments' (Ibid.).

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CHAPTER 2

Supporting parents with intellectual disabilities and their children – reflections on elements of a planning concept

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Introduction

A major result of the de-institutionalisation and normalisation processes in the disability service system over the past decades was that people with intellectual disabilities gained more control over all areas of their lives, including partnerships, sexuality and parenthood. In many European and other Western countries, this process of emancipation was accompanied and supported by a more general, partly successful struggle for more citizenship rights for people with intellectual disabilities – for full participation and equal opportunities to realise their personal potentials[6]. In this context of new service models and gradually strengthening citizenship rights, the number of people with intellectual disabilities who have become parents and need additional support has been steadily increasing (Pixa-Kettner et al., 2006; Tarleton et al., 2006). In consequence, the professional service system is being challenged to find effective ways to cope with this. Therefore, the appropriate question from a professional point of view is how these 'effective ways' should look.

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[6] A remarkable reference for this fact can be seen in the 'European Disability Strategy' reflected in the title of a European Commission communication of May 2002, 'Towards a barrier free Europe for people with disabilities'. Its principles have become the basis for European disability policies: equal treatment in employment and occupation; mainstreaming disability issues in relevant Community policies; improving accessibility for all.

In this context, the European perspective is extremely interesting[7]. In many respects, contrasts and inequalities in European welfare state arrangements and service systems for people with intellectual disabilities are evident. Some European countries are in the process of modernising their institution-orientated care systems, which tend to segregate and isolate people with intellectual disabilities from mainstream society and, in addition, which are seen as inflexible and costly. Other countries have implemented more individualised and integrated services, but face specific problems of integrating generic and special policies in to meet anti-discrimination requirements. Yet others are establishing new service structures for people with intellectual disabilities, because there were none before. However, having a positive concept of diversity, and thus following an individualised approach, the European perspective productively advances the need to develop supportive arrangements that are tailored to the practical needs and specific situations of parents with intellectual disabilities.

In recent years, a variety of person-centred planning instruments have been developed in the field of intellectual disability[8] (Sanderson 2007). Even though they differ in theoretical background and explicit objectives, they represent important progress in providing professionals with new tools to work with. There are good reasons to claim that existing planning instruments are not really adequate for the predominantly very complex situation of parents with intellectual disabilities and their children. Planning support for these parents is a task which touches many organisational boundaries and which requires extensive collaboration and joint working between the different players in this arena. Besides informal networks, professionals from service providers, social

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[7] This text is based on a series of European seminars funded by the EU–Grundtvig partnership programme. The 'European Network of Parenting Support' (ENOPS) was initiated by the University of Ghent. Other partners are the Institute of Child Studies (University of Minho), the Centre for Planning and Evaluation of Social Services (University of Siegen) and a service provider in the Netherlands, Arduin.

[8] e.g. person-centred planning instruments like 'MAPS', 'PATHS', life-style planning, future planning (in the tradition of O'Brien), but also instruments for 'individual service planning' – for example, the American Association on Intellectual and Developmental Disabilities (previously the American Association on Mental Retardation) 'Support Intensity Scales' (SIS) (for an overview see Sanderson (2007).

departments, health departments, youth welfare departments, the justice system, etc., are involved at some level, bringing with them their conceptual orientations and service models. At the same time, professional intervention is happening within the 'family' – a 'social space' that is normally respected as 'private' and protected from public or statutory interventions, but which, in some cases, is under close social control. From this background, the following questions are of interest:

- What does systematic planning of individually supportive arrangements for parents with intellectual disabilities and their children look like?
- What are the theoretical implications that have to be reflected upon when one is working on such planning concepts?
- What can we learn from existing person-orientated planning instruments?

To find answers, it is necessary to have a closer look at a variety of general aspects related to the situation when people with intellectual disabilities become parents. Theoretical elements of planning concepts are described below, as well as examples of practice.

Theoretical elements of planning concepts

The concept of disability and inclusive environments

During the second half of the last century, the concept of disability developed from the so-called 'medical model' into the 'relational model', often called the 'social model' of disability (Oliver and Barnes, 1998). The medical model considered disability as a defect or a shortcoming of the individual, a deficiency or an absence of something that was considered important. The medical model aimed to protect people with disabilities from a society in which it was thought they would become lost by consigning them to

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segregated placements. However, this often meant lives spent in large, traditional institutions, where partnership, sexuality and parenting were almost impossible.

When people with disabilities gained more power, often supported by their own organisations, they soon began fighting isolation and tutelage. Such a development has probably taken place in all countries where people with disabilities have gained sufficient influence and a stronger citizen status (Bengtsson 2000). The relational or social model considers the person with a disability as an individual with the same rights of participation and life experience as others. Disability is seen as a problem not within the person, but in the relationship between the person and the physical and social environments. It should not be accepted that disabilities result in exclusion; instead energy must be devoted to the removal of barriers in the excluding environments so that they become accessible for people with disabilities. Individually tailored arrangements should create solutions that allow for difference, including disabilities. In this sense, the relational model aims to realise 'inclusive environments' that contribute to neutralising the effects of disability so that the person affected gets the same opportunities as others, obtains equal conditions and thus achieves real participation in society. 'Inclusive environments' can be seen as a term that corresponds to the guiding principle of participation in the International Classification of Functioning (ICF), which promotes barrier-free public infrastructure and mainstream services. Furthermore, in the United Nations Convention on the Rights for Persons with Disabilities (2008), Article 23 clearly states the right to start a family.

For parents with intellectual disabilities, this means that their higher social dependency should not create a momentum of exclusion by consigning them to a segregated system of support. On the service level, the same strategies that are valid for other parents in critical life situations should be valid when parents are labelled as 'intellectually disabled'. In the first place, all possible support should be organised to

enable the parents to live with their child in a responsible way. If this is not or no longer possible, the second step should be to try to find a place for the child from among their informal network of relatives, friends and neighbours as close to the natural parents as possible. The third level of intervention should be to develop foster care arrangements with adequate ties to the natural parents.

In the structure of social services in many European countries, it is often unclear which sector is primarily responsible for parents with disabilities and their children. There are various complementary institutional systems that could be involved in such a situation:

- The **youth welfare system** will focus on the children's wellbeing and might tend towards developing intervention strategies to manage or, if necessary, provide a substitute for the parents
- The **disability system** might focus on the mother's situation and the challenges for her in caring for her child
- The **medical system** will orientate itself to its traditions of medical diagnosis and treatment, and is likely to resort to psychiatric models or support approaches to control parents
- The **judicial system** will emphasise parents' rights and the well-being of their child. However, although having the family's best interests in mind, it may tend to orientate itself towards the medical approach to be on the safe side.

In this situation, parents with intellectual disabilities – being dependent on agency support – are vulnerable not only because of their disability, but also because of the paternalistic systems that may disregard their rights as citizens. To a certain extent, the agency which becomes involved and then dominates the further proceedings depends on the incident which initially led to the family's referral. However, although inter-agency cooperation tends to be problematic, a model should be fostered where joint

responsibility is taken by the different agencies. In this situation, it would become very important that these parents could rely on a 'case manager' or 'facilitator' who would be their 'friend in the system' and coordinate the planning process to create an advantageous and supportive arrangement that enables the parents with disabilities to have a good quality of life.

Family concepts and parenting with intellectual disabilities

Another theoretical concept that has to be reflected upon when we refer to parents with intellectual disabilities is the more fundamental understanding of how families have to 'be' and how they have to function. In general, an increasing variety of family arrangements can be observed. Besides the nuclear family, consisting of a married couple and their children living together in a household, a remarkable number of other forms of family life have become reality: long-term relationships outside marriage; single fathers and mothers; 'patchwork' families; or families, who are 'living apart together'. Still, this construct of an ideal family with a working father and a nurturing mother, who raise and educate their children relatively autonomously, influences thoughts and attitudes even today.[9] It becomes obvious that these concepts of 'normality' and divergence have to be reviewed. They seem even more inappropriate when one is dealing with parents with intellectual disabilities. These parents also conform to many different models of family life. There are married couples and unmarried couples, single mothers, fathers with a new partner or parents in residential care.

However, additionally, parents with intellectual disabilities find themselves confronted with high moral standards and prejudice. It is discussed whether they can be 'good enough parents' and what this actually means. Furthermore, these parents are often

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[9] More and more parents find themselves confronted with high expectations to fulfill their parenthood roles. In this context, it should be realised that hardly any family can fulfill their roles as parents without support – it is just the extent of the support which varies.

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under pressure from stressful living conditions, such as low financial resources, social isolation, bad housing conditions and an enduring ambivalence from professional agencies in their contact with them. From this point of view also, they can be considered as families with special needs. Concepts of support have to handle the contradiction that on the one hand people with intellectual disabilities now have more control over their own lives and can lay claim to their citizenship rights, including the right to have a family, while, on the other hand, society has to ensure their children's wellbeing. It is becoming more and more difficult for parents with intellectual disabilities to meet these requirements.

Systematic planning of individually tailored support arrangements for parents with intellectual disabilities and their children has to take into consideration the diversity of family systems. They should focus on the relationship and interaction between parents and children. Professionals putting interventions into practice have to reflect on their own attitudes to family systems when they set goals for their work, analyse family situations and plan supportive arrangements.

It is important to look for new model approaches to help parents with intellectual disabilities – models that shift away from a deficit model of service delivery (Heighway, 1992) to an approach that is based on strengthening and empowerment, as well as on a family-centred, as opposed to a professionally driven, philosophy of support. Professionals and communities should collaborate to support this group of citizens, so that they can exert their rights, particularly the right to be a parent, in a fully inclusive society.

New service models and parents with intellectual disabilities
Experiences with parents with intellectual disabilities have shown that the main problem with their ability to fulfil their parental roles rests with the overwhelming

environmental pressure that they experience, rather than a lack of any major 'parenting skill' (Guinea, 2001). Research within this area revealed that parents' IQ alone did not predict parental ability (Espe-Sherwindt,1990; Tymchuck, 1992; Guinea , 2001). According to Espe-Sherwindt (1990), other factors seem to be better indicators in predicting adequate care for their child by parents with intellectual disabilities. In addition to having an IQ greater than 50, these included having: a partner; fewer children; adequate financial support; and adequate, acceptable support from formal and informal sources. As Booth (2003) stated in an editorial of the *Journal of Learning Disabilities*:

> *We know that adequate supports protect against parenting breakdown, and we know a great deal about the kind of support that is most effective* (Booth and Booth, 1996; McGaw, 200X). *We know that training works* (Feldman, 1994; Tymchuck and Feldman, 1999)…*and we know, importantly, that the state can more easily provide the supports a family lacks than it can replace the love between a child and a parent.* (p. 207).

Therefore, when supporting these parents, professionals should take a wider perspective and include an ecological framework to address the family's needs and expectations in order to help them gain the necessary balance, energy and competencies to fulfil their roles as parents.

Despite this knowledge, one tends to forget these aspects when supporting parents with intellectual disabilities. According to Goodingue (2000, in Booth, 2003), a report from the Social Services Inspectorate in the United Kingdom illustrates how parents are destabilised by a 'professional knows best' culture, which is characterised by poor professional knowledge, weak assessments, an over-zealous attitude towards risk, a lack of awareness of disability equality issues, unarticulated services and a seriously

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limited service provision. These facts are acknowledged in the United Kingdom's White Paper, *Valuing People* (Department of Health, 2001). According to Booth (2003), this document was the first official policy statement in the United Kingdom to recognise that there are people with intellectual disabilities who are parents too, and to support their right to marry and have a family.

As already mentioned above, this right could not be realised for a long time. For example, in Germany, only few cases of people with intellectual disabilities becoming parents were known of until 1992 when the Law on Guardianship was changed after a long debate. This gave people with (intellectual) disabilities more citizenship rights and ended the enforced sterilisation, which had been partly illegal but still common practice due to society's poor understanding of this group of people. The few parents with intellectual disabilities who existed before that passage of Law had had to face many problems and were mostly discriminated against.

In 1996, Pixa-Kettner published a study in which she pointed out the stagnant, poor situation that parents with intellectual disabilities were in even four years after the legal situation had been changed. This study had quite an impact on the policy of state and service providers. It focused attention on the special problems of these people and their children and so, in the past 10 years, many ideas and some models have been developed and made available. Parents with intellectual disabilities have profited from the gradual change in the paradigms of the German disability service system. They were moved away from special institutions into supported living in regular flats. Similar developments, as research shows, can be found in other European and Western countries (Prangenberg, 2006).

Examples of support arrangements for parents with intellectual disabilities

Stichting Arduin in the Netherlands – from care to support

One service provider involved in the European network described above was Stichting Arduin in the Netherlands. Their example is used here to describe local service structures and new models of support.

In the Netherlands, as well as in many other countries, the parenthood of people with intellectual disabilities is still a controversial issue, and the Dutch government is rather reticent on this topic. Nevertheless, a research study on behalf of the Dutch Ministry of Health, Welfare and Sports by Willems, de Vries, Isarin and Reinders (2007), shows that 0.5 to 1% of people with intellectual disabilities in the Netherlands have children. For most service providers, supporting them is still a rather new venture. But the example of Arduin shows how traditional service structures can be changed and how parents with intellectual disabilities can be supported in the community.

Arduin is an organisation providing services for people with intellectual disabilities in the Netherlands. Within Arduin, inclusion, emancipation and self-determination are considered to be fundamental to securing the best possible quality of life for people with intellectual disabilities. As a consequence of adopting this quality of life (QOL) perspective, Arduin was transformed from an institution into a new community-based organisation, which focuses on supporting each individual based on their own opinion of their needs. The 360 former residents were resettled over a wide area in Zeeland, and now live in more than 125 houses in 25 different villages and towns.

The differentiation between the three life spheres – accommodation, work/daily activities, and leisure – is fundamentally important in the process of deinstitutionalisation and promotion of QOL. The concept of QOL was operationally defined and implemented through the eight core QOL domains identified in international literature (Schalock and Verdugo, 2002). From a large action research

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project, it was concluded that from these eight domains, those of inclusion, self-determination and personal development were especially influential in the shift from 'total care' – as conceived within the traditional institutional – to 'support' (Van Loon, 2005; Van Loon and Van Hove, 2001).

Nowadays, Arduin supports some 660 clients. Of these, 435 clients live in houses belonging to the organisation, and, of these 435 clients, five have children placed in foster families. Arduin supports nine parents/families who have 18 children living with them, and 13 who have 15 children not living with them. Arduin's ideas on QOL, inclusion, self-determination, empowerment and the support paradigm are widely accepted as guiding principles in supporting parents with disabilities.

Individual plans

Working with individualised support means that the people themselves decide what services they want and need. It is common in the Netherlands to have a Care Plan that determines the provision of care. This Care Plan is written by professionals, has a Quality of Care focus, and its requirements are mainly instrumental. It is therefore not suitable for provision of support from a QOL perspective.

Communication with the person with intellectual disabilities should be based on their equal status with professionals. This is why, in Arduin, professionals developed the Personal Plan, in which an ongoing dialogue between the individual and their personal assistant is the key, to replace the Care Plan. In contributing to their Personal Plan, the person with intellectual disabilities works with a personal assistant, who helps them to express what they want, identify their own support needs and determine how support should be organised to enable them to have a good QOL. This document is reviewed in the same way on an ongoing basis. The person with intellectual disabilities and their personal assistant also work together to evaluate the support received.

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Recently, Arduin developed a system of support based on the domains of QOL (Schalock, 1996). In the manual of the Supports Intensity Scale (SIS) (American Association on Mental Retardation (AAMR), 2004), Thompson et al. describe the support needs assessment, planning and monitoring process as a dynamic process with individualised support plans, based on a person's desired life experiences and support needs. To improve the quality of their service, Arduin transformed its support procedures accordingly, and the description of the required supports in the Personal Plan is based on this alignment between input (goals/perspectives of a person and their support needs), and throughput (the individual support plan). This alignment between SIS, individual support plan and QOL, creates an excellent opportunity to support people methodically in improving their QOL. An important advantage is that the person themself and their quality of life are at the centre of the support services.

Practical steps in planning helpful arrangements for parents with intellectual disabilities and their children

Several clients of Arduin are parents or future parents. The starting point for support always has to be that where Arduin has responsibility for the support of a person with intellectual disabilities, this responsibility also encompasses the person's child or children. The nature of this responsibility, however, can vary depending upon the situation. There are several possible scenarios:

1. <u>The parent lives in a house run by Arduin. The child or the children live with them.</u> Arduin's responsibility here also extends to the education of the child, and thus to supporting the parent in managing this education. The ultimate responsibility for the child's education can be transferred to an external agency (e.g. a child custody agency).

2. <u>The parent lives in a house of their own, and receives support from Arduin. The child or children live with them.</u>

   The responsibility of Arduin concerns the support of the parent in managing the education of their child. The ultimate responsibility for the child's education can be with an external agency (e.g. a child custody agency).

3. <u>The parent lives in a house run by Arduin. Their child or children live with a foster family</u>.

   Arduin is responsible for supporting the parent in their contact with their child, and with any external agencies, such as the family social worker and foster family.

4. <u>The parent lives in a house run by Arduin. The child or children are adopted by another family.</u>

   Arduin is responsible for supporting the person in their contact with their child and with any external agencies, such as the family social worker and adoptive family.

5. <u>The person lives in a house run by Arduin and is pregnant.</u>

   Arduin has a responsibility to ensure that their client has a sound, thorough preparation concerning the arrival and upbringing of their child, from a practical as well as an emotional and pedagogical perspective.

6. <u>The person lives in a house of Arduin and would like to have a child.</u>

   Arduin is responsible for providing information for their client, making them aware of the implications of parenthood, and what the impact on their life of having a child will be.

In practice, parents (and prospective parents) are supported by Arduin in various ways:

- Pre-pregnancy and parenting courses are run in Arduin's education centre

- Practical support for parents in bringing up their child is arranged by various professionals

- 'Friendship circles' are organised

- Experienced support workers are available for parents at any time, whether their child lives with them or in a foster family

- Wherever possible, access to mainstream services and agencies is arranged.

Special attention is drawn to situations where, for example, the safety of the child is at risk, where the financing of support is not clear or where questions of case management are raised.

Early Intervention in Coimbra and Montemor-o-Novo, Portugal

The Early Intervention Service

A second example is that of the Early Intervention Service in Portugal. In Portugal, the situation for parents with intellectual disabilities tends to be particularly difficult due to traditional service structures and prejudices. Nevertheless, there are some positive examples of initiatives undertaken in different parts of the country that make a difference in the lives of these parents.

Support is provided to parents with intellectual disabilities through early intervention services developed according to the Despacho 891/99 of Portuguese legislation. This law defines the target populations, which are children from birth to six years old, at high risk of or with special needs and their families. It defines early intervention as community-based services which involve health, education and social services, as well as private institutions and informal resources. It clearly states that the field of early intervention is multidisciplinary and interagency, and recognises the need for:

- Team work, with teams being structured according to local need on a transdisciplinary basis, with a case coordinator that has primary responsibility for liaising with each family

- Special training in developmental and early intervention related issues (e.g. family-centered practice)

- An Individualised Intervention Plan to be developed and implemented according to a family-centered philosophy

- Identification of the family as the locus for planning and delivering early intervention services, rather than focusing only on the child

- A defined intervention structure, taking into consideration flexibility, coordination and available resources.

Within this scenario, Coimbra and Montemor-o-Novo have experience of supporting parents with intellectual disabilities who are eligible for the programme on the basis of identified risk factors for child development. These programmes are home-based, and they provide home visits on a weekly basis, as well as community support, according to the different needs of the families. The teams typically include nurses, doctors, therapists, psychologists, social workers and special educators. After the referral and the initial contact, the teams define with the family who will be the case coordinator, and where and when they will meet to support the family. Good communication between the different partners in communities where the teams work, has contributed to an increase in the number of families being identified for support and subsequently followed up by these services.

The experiences of these two programmes indicate that, so far, they have had a positive impact on the lives of the families with intellectual disabilities that they serve. Furthermore, the case coordinators were able to follow closely the court proceedings in which some of these families were involved and to function as the families' rights

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advocate. Despite these efforts, more research needs to be done to follow up more specifically the support provided to these families, as well as their satisfaction with services and the impact on their children.

Teams of professionals support these families based on a set of principles of empowerment described by Dunst (1988). The first one is that, in supportive relationships, we believe that people are competent or that they have the capacity to become competent. The second principle states that the failure in demonstrating competences is not due to deficits within the person but rather the failure of social systems to create opportunities for competencies to be displayed. The third principle is that the individual being helped should attribute the change in their behaviour to their own actions, in order to acquire a sense of control over their life. These principles require professional preparation and supervision of practice as essential aspects to ensure quality work with these families.

Unfortunately, there are still an unknown number of parents with intellectual disabilities in Portugal who are not receiving these early intervention services, as these are scattered and few in number. Another important consideration is the fact that early intervention only serves children until the age of six years old, which often leaves these families without support when the early intervention programs come to an end.

Planning instruments

In these early intervention programmes, a Family Individualised Intervention Plan (IFSP) is developed together with the family. The IFSP is intended to form the basis of services provided to children at risk of or with special needs and their families. It is a written document, mandated by law, which should involve collaborative team work between the family and professionals in its development. As such, it should be responsive to the unique needs of each child and family (Espe-Sherwindt, 1996). Thus,

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it is intended to be both a planning process and a document that supports the capacity of families to care for and nurture their infant or toddler. The instrument requires a family and child needs assessment, as well as written outcomes for the intervention plan. The intervention plan should evolve around finding the necessary supports to answer family identified needs within the community. Consequently, it is important to help the family develop a network of informal and formal support in order to manage family affairs and needs.

Conclusion: the need for empirical research on the effects of supportive early intervention practices

Taking a European perspective, it has become clear that in several European countries, the parenthood of people with intellectual disabilities has been taboo until recently. Traditional service structures, and the lack of opportunity for self-determination, made it almost impossible for this group of citizens to realise their dream of establishing their own family.

Nowadays, as service structures are changing, more and more people with intellectual disabilities are becoming parents. However, this leads to new challenges in the support system. Examples of good practice prove that people with intellectual disabilities can be successful parents despite all doubts. Stichting Arduin and the early intervention services in Portugal show that, from different starting points, parents can be supported innovatively and strengthened in their ability to parent.

To improve the quality of life of these families, several aspects need to be considered. First, it is necessary to raise public awareness of the situation of parents with intellectual disabilities and their children. In this context, it is fundamental to sensitising

policy makers, relevant stakeholders and service providers – and also for increasing the diversity of family models. In the context of disability, mainstreaming and full inclusion into the society, the parenthood of people with intellectual disabilities has to be considered as a relevant issue.

Currently, there is still a lack of research in this area. To ensure that service providers offer personalised support and cooperate within the different sectors of the social welfare systems, it is necessary to promote research concerning the parenthood of people with intellectual disabilities. The more professionals know about how to arrange support for these families, the more people with intellectual disabilities will succeed in achieving full citizenship, including the right to marry and have a family.

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CHAPTER 3

Croatian perspectives on early childhood intervention: being a parent

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The historical background of early childhood intervention in Croatia was understood as a primarily health-care area of work taking place in health-care institutions. Such connection to medicine has had good and bad consequences which will be discussed in the chapter. Changes have been initiated in the past ten years or so in both parent associations and university circles. Changes are connected with practice (sociocognitive approach and improvement of parent-child communication), with the training of experts through post-graduate university courses and with legislation and social inclusion. The goal of numerous initiatives has been to create conditions that will enable the parent to let go of his role of a co-therapist and become a parent again. The next step is seen in the creation of a generally available network of services open to all parents and their young children regardless of their type of developmental problem.

Historical roots

Early childhood intervention is a socioculturally based activity that, in every country, reflects a range of particularities according to its social and historical development. As inhabitants of a country of Mediterranean and Central European tradition, Croatian people have always given a high priority to parenthood, education and the healthy development of children, which probably explains the high interest in early childhood intervention that has been present from its very beginning in the early 1970s.

However, this interest is not reflected in the way services have evolved for young children whose development has been clearly compromised or threatened by environmental or biological circumstances. Although we have no studies that provide a precise description of present early childhood intervention characteristics in Croatia, I shall briefly describe the social circumstances from which early childhood intervention has emerged and continues to develop here. These circumstances are linked to social development, especially in the area of education and health care for children, but they also relate to history and geopolitics since, after World War Two, Croatia remained in the so-called Eastern, communist block.

Among historical data which tell of a long tradition of caring for very young children, there is a reference to one of the first privately run shelters for orphaned children. First mentioned in

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late 13th century, it was officially opened in Dubrovnik in 1432 under the name of *Ospedalle della Misericordia*. The history of health care for the youngest in our society is also evident in the development of paediatrics. In the course of its 100 years of existence, Croatian paediatrics developed a way of integrating curative and preventive care. It also has a strong social component, and adjusts itself to the needs of children (Grguruć, 2005). In this way, the therapeutic procedures concerning young children, including early support, are even now closely linked to a medical setting.

The connection to medicine has had good and bad consequences. The good ones include: sound neonatal and postnatal medical diagnostics and care available to all; the introduction of the obligatory newborn hearing screening programme into maternity clinics (Marn, 2005) and the possibility of early cochlear implantation; and certain social rights (e.g. extended maternity leave) resulting from the medical diagnosis. Undesirable consequences include a medical understanding of early childhood intervention focusing on the child and their deficit.

Education enjoys a traditionally high reputation – parents wish for their children to have an easier and better life than theirs, and therefore they think their children will benefit from learning. Knowledge is something that people can take with them wherever they emigrate to, and it increases their potential for coping in new circumstances. Since, during past centuries, Croatians, for economical or political reasons, have moved to the better developed Western countries, the value of education as 'transferable property' has been recognised.

Compulsory elementary education for all children has been in place since 1874, but it did not encompass children with developmental disorders. Organised care for children with developmental difficulties began with the opening of a private boarding school (1885) in Zagreb, which first became the state school (1891) for deaf children and then for blind children (Tonković, 1960). The creation of an inclusive setting for the education of children with developmental disorders alongside children of typical development was made possible by a special law almost a century later in 1980. However, inclusive education was slow to permeate our educational system, and the problems of removing structural (Zovko, 1982) as well as psychological (Levandovski, 1982) barriers have been systematically documented in the research.

Lack of money has always been stated as the main reason, although widespread knowledge and attitudes based on the still present medical model of childhood disabilities presents a bigger problem. Mainstream schools do not have specialist teachers and other necessary support for children with additional educational needs. This means that this problem has still

not been solved in a practical sense, and a mainstream school or a preschool can refuse to admit a child on the grounds of not having adequate prerequisites for the child's inclusion.

In some cases, parents themselves give up on mainstream schools or preschools, fearing their child will not make any progress due to a lack of quality educational support. Thus, in the field of education, on one hand we have legislation permitting educational inclusion, and on the other we have inadequate conditions for its quality implementation. In the area of early development, however, the situation is even one step further behind as there is no appropriate legislation for family-centred and developmentally supportive programmes, and no relevant documents that could provide guiding principles to help clinicians offer services that respond to these changes in contemporary practice. However, there are many initiatives (mostly coming from parents' organisations and from the university) to change this.

What is most needed in order that initiatives can be taken is better coordination and a stable financial support for intervention services in family environments. Most newly conceptualised programmes which are implemented outside medical institutions do not have stable funding, and those within the framework of biomedicine follow the old model. The lack of coordination is probably linked to a lack of trust among professionals and a shortage of team coordination skills in the area of early development.

Initiatives for change

Changes have been initiated in the past 15 years or so by both non-governmental organisations in the civil sector (i.e. parents' associations) and university circles – not only as a result of their own scientific research, but also thanks to the close ties between Croatian academics and their foreign counterparts, which has led to awareness of more recent international research and calls for evidence-based practice.

The parent movement started to demand new programmes for their young children that focused on the development of their communication and ability to learn based within the home environment, as well as on the possibility of their inclusion into infant nurseries and preschools. The goal of numerous initiatives has been to create conditions that enable the parent to let go of their role of 'co-therapist' and become a parent again.

Croatia has a well developed system of pre-school settings, and the vast majority of mothers are employed, so the mothers of young children with special needs have begun to look for opportunities to include their children in mainstream nursery or preschool programmes so

their children can socialise and grow together with mainstream children. In their efforts to do so, parents have obtained specialist support from university institutions. Parents now have an improving understanding that although each child is born with a unique biology, this does not mean the child's future is predetermined. 'Nature and nurture thus appear to act together seamlessly, in developmental duet' (Brazelton and Greenspan, 2000, p. 34). Parents are a force that permanently influences the improvement of the early childhood intervention system in Croatia.

On the other hand, university professors have a good insight into the importance of providing early childhood intervention and the new trends therein, and are well aware of their responsibility to speed up the transfer of research results into practice. In 2002, a big pilot project on models of early support was thus launched under the title of 'Being a Parent' (Ljubešić, 2003). Multidisciplinary research at the University (Croatian Institute for Brain Research) focusing on brain plasticity and repair after perinatal hypoxic/ischemic lesions in infants also brought academics into contact with families of young patients and made them aware of the psychological pressure on these families and its effect on the parent–child relationship and pre-linguistic communication. The research also brought academics' attention to the development of social cognition, a domain that determines the quality of cooperation and of communication development in a child, and which is also crucial for the child's learning and psychological development. This is how the sociocognitive approach in early childhood intervention came to life. There are efforts, through various procedures aimed at the child's family members, but also at the child itself, to raise the understanding of the interacting social partners' intention and to increase the frequency and duration of joint attention episodes.

The current state of early childhood intervention
When describing the contemporary state of early childhood intervention in Croatia, it must be emphasised that the picture is very erratic, depending upon the region in which a family lives, and the kind of developmental disorder their child has (Ljubešić, 2008). Families from the Zagreb region are in a far better position than those living elsewhere, as the majority of both traditional treatment settings (i.e. medically based programmes) and new programmes in family environment settings are concentrated in this area. The further east or south one goes, the less favourable the situation becomes (Ivšac, 2008).

Regarding the type of developmental disorder, families of children with sensory impairments are in a better position than others. Reasons for this lie in the medically clear diagnosis and the great efforts made by individuals who are making advances in this area, but also in the

decades of specialised training of medical doctors regarding the importance of prevention. For example, universal neonatal hearing screening (Marn, 2005, 2008) started in early 2002 at one maternity unit in Zagreb with about 3,000 neonates per year. (In Croatia, there are about 40,000 neonates annually.) Only 10 months later, screening was implemented at all 34 maternity units in Croatia, and, at the end of 2006, it became mandatory throughout Croatia. Statistical analysis shows that between 85% and 90% of all neonates are now screened before discharge. Croatia thus became the sixth country in Europe to introduce neonatal screening at the state level.

In hospital, parents are given a booklet about the typical development of speech and hearing in children. The purpose is to motivate parents to come to a second stage of hearing assessment when required, and to help early detection of retrocochlear, progressive or acquired hearing impairment. The data showed that the second stage is needed in 1.5% of all neonates. The average age of diagnosis is six months, when the intervention starts (Marn et al., 2008).

The worst situation is faced by young children with complex health and developmental difficulties, and by children who display only behavioural indicators of developmental atypicality, but who are otherwise healthy (e.g. autism spectrum disorders, developmental delay, intellectual impairments). The reasons for this are tied to the very fact that the medically based philosophy of early childhood intervention still prevails. More specifically in the approach to a young child, which still predominantly takes place in a medical setting, we recognise two very different treatment approaches. Children with high neurological risks or problems established at birth (e.g. Down syndrome, brain malformations or lesions) are included in medical follow-up with many different check-ups and therapeutic programmes taking place in specialised centres under the name of early multidisciplinary approach (Afric at al., 2008). Although parents are listed as team members in name, in effect they are not. Many experts regularly see the child, but multiple professionals do not work together, and services are not team based. As parents come to the centre, the child enters clinical or medically based programmes instead of procedures that are developmentally supportive and that promote children's participation in their family environment.

Treatments focus on the child and their deficit, resulting in the routine implementation of intensive, mostly motor, exercises involving a parent as a co-therapist. Doctors are often insufficiently selective in the application of therapeutic procedures. This means that, from an early age, all children are included in baby exercises that are implemented by parents on a daily basis, and also in physiotherapy and occupational therapy programmes and, later, in

sensory integration therapy. As parents do not have the proper psychological support and are convinced of the truth of the tenet, 'the more exercise, the better', they often take the initiative of hiring therapists to exercise their young children. However, this overexposure to various therapeutic procedures destroys daily routine and a normal family life, and requires additional financial outlay by parents. At the same time, this approach has undesirable psychological consequences for children, often leading to negative or passive attitudes and learned helplessness. One of the most frequent questions posed by parents of young children at neurodevelopmental risk is 'How do I motivate my child to exercise?' The understanding that children can learn through participating in their everyday activities and meaningful, fun experiences with their family and caregivers is slowly getting to be a familiar concept. Its full implications have not yet been accepted – this is unfortunately even more true of service providers in medical settings than of parents.

The research (Bulić, 2008), which focused on studying the time spent by family members in daily activities involving their baby with multiple difficulties in comparison with families without young children with special needs, showed very high strain put on mothers by all activities; fathers were statistically less involved than fathers of typically developing children, whereas the involvement of relatives and possible caretakers was almost insignificant (Bulić, 2008).

Data from one other study (Martinac-Dorčić, 2007) involving families of pre-school and school children with cerebral palsy also showed that, in the long run, mothers bore the brunt of the strain. According to this research, conducted with 77 families who had a child with cerebral palsy and 118 families with typical children from different regions, it was revealed that mothers of children with cerebral palsy experienced more intense parental stress, had more pronounced neuroticism and pessimism, perceived a poorer quality of marriage relationship and less family cohesion and adaptability. They also had fewer available social networks and had a greater need for social support in comparison with mothers of typically developing children.

Another approach is seen with children who are born physically healthy and who show no clear signs of atypical development in their first year of life. In other words, since doctors primarily focus on checking neuromotor milestones, and if motor development is normal, everything is considered to be fine. However, during the second year, parents perceive more clearly that the child does not cooperate in an age-appropriate manner, and, in particular, that language development is missing. This makes them alarmed, and they turn to paediatricians for help. Unfortunately, paediatricians often disregard parental observations and concern.

We carried out an analysis on 480 clients who contacted the Early Communication Unit of the University Rehabilitation Centre in Zagreb for the first time between 1999 and 2006. This showed that 44.8% of children were still in the pre-linguistic stage of development, although their average chronological age was 3.5 years. The families had generally postponed their trip to see a professional, having had other members of their family who had talked late but who, in the end, had caught up developmentally. All these children were in well organised paediatric care, and since there was no known biological basis for a developmental disorder, parents had been advised to wait until the problem became clear (Ivšac at al., 2006). Metaphorically, in such cases, development was being treated as a disease: paediatricians were waiting for full-blown symptoms of developmental disorder and for a diagnosis in order to even begin therapy. However, for the majority of children, the lack of speech was just an outward manifestation of much more complex difficulties such as autism spectrum disorder or profound learning disabilities. A particularly strong source of frustration for parents, and also for professionals in this situation, is that although assessment and early diagnosis of developmental difficulties have improved, there is no state-of-the-art system of early childhood intervention that can provide educational support to such a child. There is also inadequate information provided to parents and a lack of psychosocial support to the family.

However, it must be emphasised that through the efforts of some individuals, certain programmes with young children and families, based on international evidence, are more and more regularly implemented (Cvetko, 2004; Hrgovan, 2007; Joković Oreb et al., 2008). Parents have accepted these programmes exceptionally well, and there is a reason to believe that in the near future the programmes will be able to meet the needs of all families with young children who have developmental difficulties, and will also become a part of the early childhood intervention system in Croatia.

How the current situation is perceived by professionals in their actual work
It is interesting to observe how practitioners working in the field of early childhood intervention in various Croatian towns feel about the current situation. In spring 2008, I collected anonymised data from 20 professionals in the early childhood intervention field by asking them to complete two unfinished sentences (see below). Through this simple method, I wanted to find out what they perceived as their major professional concerns and what they would change if they had the power. All responded. Their replies were relatively lengthy, which spoke in favour of their motivation, and they were surprisingly uniform, showing that, although of different ages and from different regions, they all experienced similar problems. Interestingly enough, although their personal incomes are not high, this was not mentioned in

any of the replies. The shortened answers are listed by order of their frequency (from the most frequent to the least):

1. 'In my work with small children and their families, the hardest thing for me up to now has been...'
   - Facing up to the parents' difficulties in accepting their child is different:
     i. 'When I cannot reach the parents'
     ii. 'When I see they do not accept their child'
   - Organisational problems and work conditions
     i. Poor coordination among professionals
     ii. Work that is not team based
     iii. No time allocated for work preparation
     iv. Too great a case load for each professional
     v. Too many uncoordinated therapists involved with one child
     vi. No professional supervision support
   - Dealing with difficult diagnoses, and with the uncertainty of the prognosis
   - Securing the funds necessary to provide services
   - Organising the child's transfer to a mainstream pre-school programme.

2. 'If I had a magic wand, I would…'
   - Secure more support for parents
   - Enlarge the number of services, especially home visits…
   - Organise more educational programmes for professionals
   - Improve legislation
   - Create a team and strengthen it
   - Change attitudes of parents, politicians
   - Give free specialist toys to all children, and financial aid to families
   - Improve inclusion in mainstream preschools.

In 2006, I had an opportunity to get a glimpse of how professionals perceived the early childhood intervention situation in Croatia, when a specialist discussion group 'Early Diagnostics and Rehabilitation – Early Intervention' was organised within the framework of a colloquium. Some 30 specialists from different parts of Croatia sat around the table together with representatives of parents' associations. The main conclusion was that a system sensitive to needs of every family should be established, while individual conclusions were as follows:

1. Include parents as active members of their children's early childhood intervention teams and as participants in specialist assemblies and training
2. Create a specialist qualification jn early childhood intervention and permanent advanced training courses for early childhood education specialists
3. Introduce professional supervision for early childhood interventionists
4. Encourage cooperation between specialists in the field of biomedicine and behavioural sciences, early childhood intervention programme users and the community
5. Initiate the creation of legislation and secure funds for early childhood intervention from various sources in the Ministry of Health and Social Care, Ministry of Science, Education and Sports, from sponsors, etc.

The need to strengthen the early childhood intervention system in Croatia, and the ever improving cooperation of professionals in this area, resulted in the setting up of a national, multiprofessional organisation – the Croatian Association for Early Intervention – in late 2007.

Current situation in the education of professionals

Various factors have influenced the education of professionals, especially formal and informal contacts between Croatian and foreign specialists. An important role has been played by international conferences, such as the Second International Society on Early Intervention Conference in Zagreb in 2007 which provided a strong impetus to Croatian practitioners who participated in large numbers. This conference was attended by many members of the European Society on Early Intervention – EURLYAID.

The current situation has also been strengthened by the large number of training courses that have taken place in the past 15 years, involving many visiting foreign early childhood intervention specialists under the auspices of the Organisation of Croatian Academy of Developmental Habilitation, and by the recently launched university postgraduate course in early childhood intervention at the University of Zagreb. The latter programme is offered by the Faculty of Education and Rehabilitation Sciences, and is officially accredited by the National Council of Higher Education of the Republic of Croatia. It is delivered across three semesters and carries 90 ECTS[2] credit points. In order to enrol on the programme, students

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[2] European Credit Transfer and Accumulation System: a student-centred system of transferable credit points awarded on the basis of the student workload required to achieve the objectives of a programme, objectives

are required to have completed a university degree programme in a related area of social science and/or humanities (e.g. speech and language pathology, special education, psychology, pedagogy, social pedagogy, social work), and are required to have a minimum of one year's practical experience of working in their respective discipline. Applicants are also required to take an entrance examination which tests their commitment to working with at-risk families and young children.

Croatia did not have a degree programme in early childhood intervention until 2006. This was the first time that such a programme had been developed, and the first generation of students are due to complete it in 2009. In creating this programme, specifics of its implementation in Croatia were taken into account. The greatest problem was the students' need for practical training, since there are no centres offering modern early childhood intervention services where they can complete their internship. Instead, each student, under the supervision of their professor, creates and implements an early childhood intervention programme for a given family.

In accordance with the sociocognitive approach, emphasis is put on deepening the parents' knowledge about their child. The family is given an explanation for why their child behaves differently from its peers (i.e. about how their child learns and understands what happens around them). Now, instead of feeling helpless and rejected when their child does not want something or refuses to cooperate, parents are able, with professional support, to realise that their child often does not understand what is expected of them and that their child's reaction is a natural response to a breach of their personal boundaries. A better insight into their child's understanding of the social world and the child's need for self-sufficiency changes parental behaviour, and parents themselves start to devise strategies for creating episodes of joint attention during play and interaction with their child which advance their cooperation. The hands-on work with the child, which builds on their interests but is also structured in a simple and understandable way, directs the child's attention toward the adult partner in the play so they learn how to recognise what is expected of them and how to cooperate better. Thanks to student activities, the number of services intended for young children with developmental difficulties and their families has risen.

In the first period, the programme enrolled a smaller number of students than needed, but in proportion to practical teaching capacities. The Faculty of Education and Rehabilitation Sciences has been conducting the research directed at prevention, early development and

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preferably specified in terms of the learning outcomes and competences to be acquired. More information about this system is available online at http://ec.europa.eu./education/programmes/socrates/ects/index_en.html

treatment of early forms of disorders for many years within the framework of various expert and scientific projects, and has also been developing family-oriented programmes. Together with the research, clinical activity within the University Centre for Rehabilitation of the Faculty of Education and Rehabilitation Sciences has been developing, and it is constantly being improved. The teaching staff in the early childhood intervention programme has participated in numerous early childhood intervention training programmes abroad, in this way improving their level of competence for implementing such a programme both practically and theoretically. Since on-the-job training is the weakest link of the Croatian system, experienced practitioners from some foreign centres of early childhood intervention took part as guest lecturers in the programme, while an especially strong relationship was developed with the Phoenix Children's Resource Centre from the UK.

Some of the institutions implementing habilitation and rehabilitation programmes in early childhood have financed tuition fees for their employees, taking into consideration the need for permanent training of their specialists working with young children. Also, in cooperation with some teachers and the degree programme supervisor, these institutions have created the conditions (both objective and subjective) necessary for a high-quality implementation of the acquired skills and competences by future specialists; and as a result of the launching of the programme we expect a significant modernisation of (re)habilitation practices for young children in Croatia.

Conclusion

If we take a look at the situation and the perspectives of the early childhood intervention development in Croatia, we see that the pace of change is accelerating and that the system is being established in the regions where it has not previously existed and is being modernised in those where it does exist. Changes in the area of legislation have been the slowest, as they require the coordination among various state bodies that are ponderous and autarchic, which is the result of our political past. Efforts to join the European Union will definitely yield results in this area. Strong instigators of change are the higher education and civil sectors (parent and professional associations), which cooperate well together. Both have realised that if a parent plays a role of a therapist, the child does not have a parent. This is why, in Croatia, 'Being a Parent' is such an evocative name for the ongoing early childhood intervention movement.

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CHAPTER 4

Early Childhood Intervention in Portugal: Interplay of family centered, community based and interdisciplinary factors

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Abstract

The 1990s were the most productive years in Portugal for the field of early childhood intervention. In a little more than a decade, it evolved from an emerging service, provided within a child-centred perspective in ways similar to special education with older children, to a rapidly growing field with a totally different conceptual framework. Part of this evolution was triggered by the implementation of a community-based programme of early childhood intervention in Coimbra, located in the central region of the country. The intent of the Coimbra Project was to develop a system to provide individualised, comprehensive services to children and families by using formal and informal resources already available in the community, and by creating a collaborative effort involving Health, Education and Social Service agencies.

The problems confronting the target children and families were so diverse that an array of service providers cutting across different disciplines, agencies and theoretical orientations was needed. Teamwork skills and collaborative approaches had to be developed. Training played an essential role in the Project development, and this, without a doubt, was the single most important factor associated with the programme's effectiveness.

The passage of early childhood intervention legislation in October 1999, grounded in the conceptual framework and structure of the Coimbra Project, started a paradigm shift of early childhood intervention in Portugal. A family-centred, inclusive, ecological and comprehensive early childhood intervention approach grew to be widely accepted throughout the country among practitioners, researchers and parents. However, since 2006, a new political climate and an emphasis on cost-cutting have led to

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proposed legislation that reduces early childhood intervention services for children with disabilities, excluding at-risk situations and emphasising services based on a therapeutic and child-centred model. After a two-decade evolution towards an evidence-based approach, practitioners' greatest challenge will be to maintain quality early childhood intervention services despite legislative and budgetary obstacles.

Key features of early childhood intervention in Portugal

Until the beginning of this century, free and appropriate education for children with disabilities in Portugal was regulated only after the age of three years. Beginning in the early 1990s, a wide array of programmes and services, all calling themselves 'early intervention', had developed across the country: some child-centred, some professional-centred, some resulting from the work of a single professional or a group of professionals or even teams. Some depended on the Departments of Education or Health; others depended on the Department of Social Security, or were the result of an articulation of public and private agencies (Almeida, 2000; Bairrão and Almeida, 2002). Conceptual framework, delivery models, target populations, goals, outcome measures, level of parental involvement, type, intensity or duration of services were extremely variable from programme to programme, and even within the same programme.

The passage of early childhood intervention legislation (Joint Executive Regulation nr. 891/99) in October 1999 was a landmark. The legislation contained an important change: rather than focusing only on the education of the child, it clearly identified the family as the locus for planning and delivering community-based early childhood intervention supports and services. The legislation also provided a reminder that the field of early childhood intervention is multidisciplinary and interagency, made up of professionals from Education, Health and Social Services, which should provide comprehensive developmental services to children with special needs aged from birth to six years and their families. The need for an individualised intervention plan was also a central feature of the Portuguese legislation. This plan was to be developed and implemented according to a family-focused philosophy.

The legislation defined a structure which included local community teams, coordinated by a coordinating

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team in every district. Professionals from different Education, Health and Social Service public agencies, as well as from private institutions, were to be included in these teams. Supervision and evaluation of the process of implementation of the law were to be provided by five regional groups in each of the regions of the country, and at the national level by an interdepartmental group with representatives from the three departments involved: Health, Education and Social Services.

The legislation has been very successful in providing early childhood intervention services in vast areas of the country, especially the central region and Alentejo (north of the Algarve and south of Lisbon) (Franco and Apolónio, 2008; Tegethof, 2007). In some other regions, the legislation has not been not fully implemented because of a lack of involvement from regional political authorities.

The Coimbra Early Child Intervention Project: a precursor of the national model

Coimbra is Portugal's third city. It is the capital of the Central Region, one of the five regions that constitute the country. The Central Region has six districts. Coimbra District has an area of 1,600 square miles and a population of about 450,000. Like the whole country, the Coimbra District comprises different social and geographical contexts, ranging from very isolated communities in the mountains to touristy, coastal villages, or from families living in extreme poverty where alcoholism is a serious problem to professional families who are financially comfortable.

The city of Coimbra itself is of moderate size, with a population of 150,000. The University, one of the four oldest in Europe, was founded in 1290 by King Dinis, and is situated on a hill overlooking the oldest part of the city and dominating its skyline. All year long, University students are often seen walking the narrow streets in their traditional black capes, bringing to Coimbra, 'fados' and ballads, books and poems, dreams and nostalgia.

Coimbra Project goals

The Coimbra Project began in the Coimbra District in 1989, with the articulation of five regional agencies representing Health, Education and Social Services. At the time, unlike other areas of Portugal, the Coimbra District had some of the finest health and education services, as well as a long tradition of

collaboration among different agencies. The comparative abundance of not only services, but also people, committed to working together on behalf of children and families may help to account for the development of this Project in Coimbra at this particular time in the country's history.

Five years later, in 1994, a working party was created at the national level, to develop national legislation on the provision of early childhood intervention services. A member of the Coimbra Project was invited to participate in this group. In 1999, 10 years after the beginning of early childhood intervention in Coimbra, despite interruptions due to changes in the government, the efforts of the working party came to fruition: the legislation was passed. Most of the goals, assumptions and even the structure that constituted the basis of the Coimbra Project were included within it.

Six main goals have guided the development of the Coimbra Project (Boavida and Borges, 1994; Boavida, Espe-Sherwindt and Borges, 2000):

1. To be district-wide and community-based, with an early childhood intervention team in each of the 17 councils of the district
2. To develop an interagency, multidisciplinary system of early childhood intervention, using resources already existing in the community (both human and material) and involving Health, Education and Social Services, as well as other formal and informal resources
3. To provide individualised, comprehensive services to children aged under three years at high risk of or with disabilities and their families
4. To develop and provide training to all the professionals involved in the Project
5. To promote collaboration with other programmes in Portugal and abroad
6. To contribute to the development of legislation in Portugal.

Project assumptions

The Coimbra Project was based on six philosophical assumptions:

1. Early childhood intervention helps the family as they adapt to accommodate the needs of their child
2. Early childhood intervention optimises the environment, thereby helping the child reach their potential

and preventing secondary disabilities (Bennet and Guralnick, 1991)

3. Every family, regardless of socioeconomic status, has strengths and resources that should be used to enhance the development of the child (McGonigel, Kaufmann and Johnson, 1991)

4. No professionals can substitute for the caregiving role of the family

5. Enabling and helping families increase their parenting skills will have a persisting effect, beneficial beyond early childhood intervention years (Dunst and Trivette, 1987; Dunst, Trivette and Deal, 1988; Simeonsson and Bailey, 1990)

6. Early childhood intervention will also have a positive impact on society, increasing its awareness of the need for early support to young children and families (Moor, Van Waesberghe, Hosman, Jaeken and Miedema, 1993).

Project structure

Choosing an ecological and transactional framework (Bronfenbrenner, 1977, 1979; Sameroff and Fiese, 1990, 2000), the Project team believed that early childhood intervention services should involve the family and should be community-based, with the family as a whole being the target for service delivery. Rather than promoting a standard setting or single location for early childhood intervention, the Project focused on those settings identified as natural environments: a child care setting, the home or elsewhere in the community according to family preferences and the needs of the child (Boavida, 1993). Whenever possible and appropriate, services were to be provided within the context of the family's daily routines, using resources available within the family and the community.

A local intervention community team was created in every council of the Coimbra District. Team members are professionals from different agencies operating in the community. Only a small number of professionals work full time in the Project. In most cases, early childhood intervention is only part of their job. They still perform their regular work in their employing agency. Since the beginning, all 17 teams have included a core set of professionals: a primary care physician and a nurse from the local health centre; one or more special educators from the public school system; and a social worker and a psychologist, either from a private institution, health centre or any other local agency. Due to a shortage of specialised professionals in small communities, the Project makes available an occupational therapist

and a speech therapist on a consultancy basis; therapists are available only in the biggest councils. The diagnostic and therapeutic services of Coimbra Children's Hospital and its Child Development Centre, as well as the Cerebral Palsy Centre, are also available to any community team (Boavida and Borges, 1994; Boavida, Espe-Sherwindt and Borges, 2000).

Each team has a fully equipped space that is provided by one of the agencies involved; here assessments, meetings and sometimes parent support groups take place. The team uses a transdisciplinary approach that attempts to transcend the boundaries of the individual disciplines, maximising parental involvement as well as sharing skills among professionals and families. The team member from the discipline most closely related to the needs of the child and family is, in most cases, designated as the primary service provider and service coordinator.

At the district level, there exists a coordinating team with one representative from each of the signing agencies: Coimbra Children's Hospital; the Regional Primary Care Administration, which coordinates local health centres; the Regional Education Department; Coimbra's Social Services Centre; and the National Association of Early Intervention (ANIP). The coordinating team provides coordination among the different services and, even more importantly, all the organisational support to the Project, including planning, supervision, training, regular meetings with community teams, project development and implementation.

This coordinating team as a whole is also responsible for the development of the activity report and the negotiation of the budget on a yearly basis. Based on written agreements regarding roles and responsibilities that have been developed between the Project and the service-providing agencies, each participating agency is asked to allocate specific resources, either professionals, funding or facilities (Boavida and Borges, 1990).

In addition, the Coimbra Project has created a supervision team, which functions at an intermediate level between the coordinating team and the 17 early childhood intervention community teams (Boavida and Violante, 1993). This supervision team supports the professionals in the field, and ensures that the adopted philosophical and conceptual framework is respected (Boavida and Carvalho, 2003).

Children and families

The Project currently serves approximately 350 children and families each year. The total number of children supported up to the current year (2007/2008) was 3,450. Within this population, 33% had established developmental problems, 47% belonged to high-risk groups and also presented delay in at least two areas of development, and 20% have received intervention on a preventive basis. Tables 1 and 2 describe the major developmental problems and environmental risk factors found among the population served.

Table 1. Prevalence of developmental problems among the children supported by the Coimbra Project from the beginning of the Project until 2007/2008 (n=3,450)

Developmental problems	80%
Language and communication disorders	10%
Fetal alcohol syndrome and effects	8%
Chromosomal abnormalities	7.5%
Hearing impairment	5.8%
Cerebral palsy	3.8%
Visual impairment	2%

Table 2. Environmental risk factors among the children supported by the Coimbra Project from the beginning of the Project until 2007/2008 (n=3,450)

Environmental risk	67%
Poverty	61%
Alcoholism	19%
Social isolation	12%

Illiteracy	9%
Parents with learning difficulties	9%
Neglect	8%

From the beginning, children at environmental risk have been the focus of special attention within the Project. Families living in deprived environments in substandard housing and overcrowded conditions can frequently be rejected by the community, and, as a result, become distrustful of services. In an atmosphere of depression, discouragement and helplessness, parents may struggle to make the child's development a priority. Psychological and physical energies are usually spent in tasks of mere survival. Professionals often tend to attribute any delay only to poor living and environmental conditions, and clinic staff can become frustrated by the high rates of absenteeism presented by these families.

With these concerns in mind, in 1998, Coimbra Children's Hospital and the Coimbra Project started a 'Developmental Clinic in the Community' (Boavida, Carvalho and Carvalho, 1998) designed exclusively for children and families at environmental risk. If agreed to by the family, a team including a developmental pediatrician, a psychologist and a clinical special educator meets the family and child in the most convenient place for them, which, if possible, is the home. The case coordinator or any other local team members chosen and desired by the family are present during the evaluation. The evaluation includes (1) a pediatric and neurodevelopmental assessment of the child and (2) family-identified strengths, priorities, needs and risk factors, with the help of instruments developed for this purpose. Finally, family members and professionals from the clinic and the local team gather to develop a plan. Their discussion covers the formal and informal resources available, strategies, outcomes and activities, as well as other issues to be included in the plan (Boavida and Carvalho, 2003).

When children with mild developmental delay live in poverty, professionals can tend to focus on the environment as the sole underlying cause of delay; this is in itself an extra risk factor as it might mean a medical explanation being overlooked, and the child being deprived of the necessary medical investigations and interventions. This proved to be the case in the area where the 'Developmental

Clinical in the Community' was operating: most of the children were considered 'normal' by local professionals, and had been labelled as 'at-risk' children. However, mild developmental delays were identified in 60% of the children seen at the 'Developmental Clinic in the Community'. In some cases, a visit to Children's Hospital for laboratory investigations or imaging studies became part of the plan. Some non-specific brain malformations were identified, as well as Fragile-X syndrome. The 'Developmental Clinic in the Community' is an illustration of how (a) the evaluation of the child in their natural environment, in the context of the family and community, and (b) the opportunity to have an extended discussion involving family, local professionals and developmental specialists, have proven to be very helpful in planning and implementing intervention (Meisels and Fenichel, 1996).

The role of families

Dunst, Johanson, Trivette and Hamby (1991) described professional practices as falling along a continuum, from a professionally centred model at one end to a family-centred model at the other:

- *Professionally-centred model*: Professionals are the experts; families are expected to rely upon the professional, who is the primary decision-maker
- *Family-allied model*: Professionals continue to identify the needs of the child and family and define intervention, but view families as being able to implement intervention
- *Family-focused model*: Professionals view families as consumers who, with assistance, can choose between the various options identified and presented to the family by the professionals
- *Family-centred model*: Professionals view families as equal partners, and families are viewed as the ultimate decision-makers. Intervention is individualised, flexible and responsive to the family-identified needs of each child and family.

In spite of being aware of the importance of families, and considering families the target for service delivery, the level of parental involvement in the Coimbra Project was comparatively low in the early years. Now, the Project has moved steadily from family-allied and family-focused approaches towards an approach that is truly family-centred (Carvalho, 2004; Cruz, Fontes and Carvalho, 2003). Two factors have contributed to this progress towards a totally different level of parent participation in the early childhood intervention process: (1) the adoption of a transdisciplinary team model and (2) the use of a

Portuguese version of the Individualised Family Service Plan, the PIAF (Plano Individualizado de Apoio à Família), as a process to be developed and implemented in a way that supports families' goals and objectives (Espe-Sherwindt and Boavida, 1997).

By its very nature, a transdisciplinary approach creates opportunities for families and professionals to work together (McGonigel, Woodruff and Roszmann-Millican, 1994). In such an approach, families are viewed as team members. Their role of sharing information in their own 'discipline' – being a parent of a child with special needs, and being aware of their own priorities, strengths and needs – makes them an important and priceless resource in the intervention process. The perception of families as team members is integral to the process of developing and implementing the PIAF in a way that is flexible and functional, and that enables, empowers and strengthens families (Deal, Dunst and Trivette, 1994). In a recent study, the results of an analysis of the Coimbra Project PIAF demonstrated a widespread shift from traditional practices to a more family-centred approach, although some individual variations were evident (Campelo, 2007).

Training and professional preparation

The delivery of early childhood intervention services is a complex task that requires a combination of knowledge, skills and experience that enables practitioners to select and use the best intervention techniques (Gallacher, 1997). The change from traditional family–professional roles and relationships to a family-centred approach is not easy to implement (Espe-Sherwindt, 2008). From the beginning, professional preparation was considered the cornerstone of the Coimbra Project development (Espe-Sherwindt and Boavida, 1995).

The task of preparing professionals in Portugal in 1989 came with many challenges. We were faced with: (a) professional training that was primarily child-focused; (b) no regulations on how services were to be provided; (c) a lack of pre-service preparation in early childhood intervention attitudes, knowledge and skills; (d) a shortage of trained and experienced professionals and faculty in the field; and (e) the continuing evolution of concepts and recommended practices. As a result, the Project's emphasis on creating a common conceptual and philosophical framework among professionals from different

agencies and disciplines was one of the major goals of training and, in retrospect, played a critical role in bringing about an openness and ability to adopt a new approach.

To address these challenges, a variety of strategies for continued professional development had to be considered. Consultations with visiting specialists (especially from the USA), interaction with programmes in Europe and in the USA, short-term conferences and workshops, course work and supervision were all utilised as strategies to build and refine early childhood intervention skills and encourage continued professional support and growth (Boavida and Borges, 1994).

Professional training programme design

Since pre-service preparation of the different professionals involved in the Coimbra Project did not include family-centred collaborative approaches to service delivery, the teams were not prepared to function in a system that challenged practitioners to work with the child and the family in the context of their daily routines and environments. We had extensive discussions about such questions as:

- What did professionals in our community need to know to be able to serve children and families effectively?

- How could in-service training enhance the awareness, knowledge and skills of professional who had limited or no experience in the field, and facilitate a shift from a definition of intervention as a set of activities for eligible children with disabilities to a broader view of intervention influencing the child's development and the family's ability to care for the child?

- In addition, how difficult and possible would it be to create a system of in-service training and ongoing support that would be appropriate across disciplines and practices?

- How could we define local needs and, whenever possible, local solutions to those needs?

Programme content and process

Knowledge and skills in a wide range of critical areas are important for professionals to be appropriately qualified to provide early childhood intervention services (Thorp and McCollum, 1994). We identified four

broad categories (conceptual framework and evidence-based practices) for training purposes: (1) children, (2) families, (3) team functioning and (4) philosophy and values.

Sub-categories included in the training curriculum were:

1. Child development and behavior (typical and atypical)

2. Specific developmental problems (vision impairments, hearing impairments, motor impairments, autism, Down syndrome, Fragile-X syndrome)

3. Developmental screening and assessment

4. Portage curriculum and model (Shearer and Shearer, 1972)

5. Growing: Birth to Three (Copa, Lucinski, Olsen and Wollenburg, 1999a)

6. Working with families

7. Home visiting

8. Family-centred early childhood intervention

9. Transdisciplinary team work

10. Developing and implementing the PIAF (IFSP)

11. Philosophical and conceptual framework of early childhood intervention

12. Supervision.

Certain characteristics have been identified as key to training programme development and implementation (Bailey, McWilliam and Winton, 1995; Gallacher, 1997; Malone, Straka and Logan, 2000; McCollum and Catlett, 1997; Stayton and Bruder, 1999; Winton and McCollum, 1997):

1. Team-based training

2. Values and philosophy, in addition to bodies of knowledge and skills

3. An interdisciplinary or transdisciplinary programme

4. A common core of content across disciplines

5. A shared vision and a common philosophy of service delivery

6. Involvement of family members in the delivery of training

7. Production of meaningful and enduring change in professional skills and attitudes

8. Responsiveness to team decisions and identified needs

9. Opportunities for practice and reflection within the context of training

10. Participants as active learners

11. Relevant to everyday practice

12. Opportunities for direct observation of eligible children and families

13. Ongoing support through appropriate individualised supervision.

In the last 10 years, given our significant training needs, we have had to design a professional development system that is comprehensive, yet creative, flexible and adaptable to local needs and resources. During the first year, we were able to visit and establish contacts with early childhood intervention programmes and professionals in the USA. It was the beginning of an extensive exchange of materials and ideas and a very high traffic of consultants in and out of Coimbra, each contributing anything from a one-time involvement to a more continuous participation in the training programme. The collaboration with specialists from the USA was absolutely critical in areas like family involvement, working with families, development of the PIAF, family-centred services, transdisciplinary teamwork and supervision. European specialists also participated in training activities in Coimbra, but on a smaller scale. This collaboration, together with all the experience gathered in the provision of services, has been important for the development of our own training team. As a result, most of the in-service training curriculum of professionals working in the Project is planned and provided nowadays by our own professionals. In addition, the Project is frequently called to train professionals around the country (Boavida and Carvalho, 2003).

All professionals involved in the Project, are required to attend training as part of their agency's agreement with the Project. The overall structure of the general in-service training programme includes courses, experience in the field, workshops, small conferences, inter-team meetings (quarterly meetings of all the teams for case study presentations or discussion of relevant theoretical topics) and a two-day, annual, national conference. We have developed a three-day, intensive initial training package, which covers the philosophical framework and PIAF development and implementation. All professionals attend a two-day developmental assessment course and a four-day 'Growing – Birth to Three Curriculum' workshop (Doan-Sampon, Wollenburg and Campbell, 1993). Professionals also attend quarterly inter-

team meetings, additional to the ongoing support provided through supervision. Usually another four to six days of training are provided on issues related to specific disabilities or intervention techniques. Other training activities, provided throughout the year, are organised in response to professionally identified needs. This adds up to a total of 18 to 20 training days each year. Training for and by the Project is now typically characterised by the provision of team-based training, the involvement of family members in the delivery of training, the involvement of participants as active learners, and responsiveness to team decisions and needs.

From the beginning, the involvement of health care providers and the collaboration between Health, Educational and Social Services (a specific feature of the Coimbra Project) were considered extremely important for the success of its implementation. However, as the Project began to unfold, we recognised the late identification of at-risk children as a major concern. Early referral is considered critical to the intervention success. Health professionals are usually the best situated to identify very young children with disabling conditions or with risk factors (Boavida and Borges, 1994). The delay in the referral process was related to a lack of awareness among primary care physicians and nurses, who often were more concerned in the child's first months of life with their growth than with their development (Boavida Espe-Sherwindt and Borges, 2000). As a result, health professionals became a particularly important target for training above and beyond our community teams. In order to increase the participation of primary care physicians and nurses, an extensive training programme was developed.

The main issues included were:

1. The identification of biomedical and environmental risk factors for developmental disabilities
2. The systematic use of developmental screening techniques in the regular follow-up of children
3. The importance of good health care in family functioning
4. The importance of early identification in eligible children and families
5. The need to change traditional medical attitudes towards developmental problems and early childhood intervention.

Given our purpose (to increase identification by health care providers), we decided that this specific

content, with a breadth and depth tailored to physicians and nurses, would be essential to create a strong knowledge base and clinical skills in these two disciplines. This training for health professionals consisted of theoretical and practical courses and workshops in each and every one of the 17 health centres in the Coimbra District, with a standardised package of developmental screening and assessment materials being distributed to all physicians and nurses involved in the local teams. In addition, all the healthcare providers involved participated in a two-week, observation training in the developmental clinic of the Child Development Centre, where they were able to have contact with different developmental disorders and the interdisciplinary evaluation process. The discipline-specific process for delivering this component of the training programme differed from subsequent professional preparation, which was consistently transdisciplinary and team-based. Physicians and nurses were also included in all the later transdisciplinary training.

Supervision

Effective supervision is an ongoing process that goes far beyond training opportunities, and can facilitate the integration of knowledge, skills and attitudes gained from training events into the daily work with children and families. As a result, it is also an important means of supporting the complex task of professional change and the new roles and new visions of service delivery (Bertacchi, 1991; Copa, Lucinski, Olsen and Wollenburg, 1999b; Gallacher, 1997; Shanok, 1991). From the beginning, we recognised that one of the major goals of the professional training process needed to be the development of a common conceptual and philosophical framework among professionals.

In the Coimbra Project's particular structure, the supervision team, made up of five professionals, is located at an intermediate level between the coordinating team and local teams. Supervisors are selected from those professionals with recognised knowledge and experience in providing direct services to children and families. Like any other Project professional, they come from different agencies; some work for the Project on a part-time basis. Besides being supervisors, they all perform other tasks to support the Project development. Each supervisor is assigned a certain number of local teams and meets regularly with them, usually every other week. These meetings can take place more frequently based on the specific needs of teams: for example, helping them with new complex cases or helping the

team absorb new and inexperienced professionals.

Supervision is essentially the process of guiding professionals to accomplish the Project goals, always remembering the quality of services provided to families and children. It helps professionals build and refine their early childhood intervention skills, encouraging their development through ongoing reflection. Believing that learning occurs in a relationship context (Fenichel, 1991; Shanok, 1991), we understand and highlight supervision as a privileged place to build relationships and, therefore, a privileged place to promote learning.

Revisiting the last 20 years of early childhood intervention in Coimbra and Portugal

The evolving face of early childhood intervention in Coimbra and Portugal

As discussed earlier, when the Project started its activities in 1989, no legislation or any kind of recommendations for the provision of services existed in Portugal. In most cases, services were child-centered, using the same methods as special education programmes for older children (Boavida and Borges, 1994). Similarly, throughout the country, there existed no specific early childhood intervention professional training, either pre-service or in-service. Any early childhood intervention content being included within pre-service or in-service training programmes was typically incompatible with what was considered best practice internationally. Our decision to move towards a family-centered, community-based, interagency, transdisciplinary model, inspired by American legislation, but adjusted to fit our own reality and creativity, created significant changes in early childhood intervention in Coimbra and in Portugal. The implementation of the Coimbra Project constituted the starting point of a *no return* process in the development of early childhood intervention in Portugal.

Target populations and goals of early childhood intervention

Making decisions about the target population and focus for early childhood intervention has had a significant impact throughout the country. Besides serving children with disabilities, early childhood intervention started providing services for children at high risk of delays and disabilities; that is, those children and families with multiple, environmental risk factors, with poverty often being the common denominator. In addition, providing support and instruction to families in order to contribute to their

autonomy, independence and empowerment was considered a goal as important as enhancing child development, minimising developmental delays, remediating existing problems or providing therapeutic services to children (Guralnick, 2005). Identifying the family as the target for delivering services and supports has proved to be a paradigm shift for providers.

Level of family involvement

Early childhood intervention in Portugal has moved steadily towards a family-centred approach. The changing point from a family-allied philosophy to an increasingly family-centred one was represented by the introduction of the PIAF (Plano Individualizado de Apoio á Familia), a Portuguese version of the American Individualised Family Service Plan (IFSP) (Espe-Sherwindt and Boavida, 1996). The PIAF was viewed as a planning process and document developed and implemented by the team of the family and professionals, and was based on conversations about family priorities, concerns, strengths and needs (McGonigel, Kaufman and Johnson, 1991). Services were organised and coordinated from the perspectives of families, who are the constant in child's life and the primary unit for service delivery. In addition, professionals were required to work with the family as an integral part of the team, abandoning traditional prescriptive models. This model of collaboration and partnership between family and professionals at all levels of the intervention process was the key to the successful implementation of family-centred services. However, this particular philosophical change has proved to be the most challenging for some conservative, child-focused, trained professionals (Carvalho, 2003), not only in Portugal, but also in other countries (Campbell and Halbert, 2002).

Location in which intervention occurs

Since we view every child as having unique needs, and living in a unique family within a unique community, we do not prescribe a standard setting for early childhood intervention. Instead, the location depends on the everyday routines and activities of the child and family. Locations may include the family's home, a childcare setting, the health centre or elsewhere in the community, provided those settings are identified as natural environments (Stayton and Bruder, 1999).

Collaboration among agencies

A transdisciplinary interagency team model, by its very, nature creates a structure for professionals from

different disciplines and agencies to work together to provide integrated and comprehensive services to children and families (McGonigel, Woodruff and Roszmann-Millican, 1994). The need for such a model is particular important for families with complex, intense service and support needs, as the absence of such coordination would make support to families and their infants and toddlers with special needs an unfulfilled promise. First the Coimba Project and then the Portuguese legislation promoted such a model by specifying that teams are to include professionals from different Health, Education and Social Security agencies, as well as professionals from private institutions. However, this model creates the need to build a shared philosophy and common language and goals among the professionals on the team. Such a need must be constantly addressed as professionals enter and leave the early childhood intervention system (Boavida, Espe-Sherwindt and Borges, 2000).

New values and roles in early childhood intervention

The Project model required a dramatic reconceptualisation of the traditional role of service providers: from decision-makers to facilitators, from multidisciplinary to transdisciplinary, from direct services provided to children to indirect, consultative services to children and family (Stayton and Bruder, 1999). Throughout the last 20 years, we have continued to view the child's developmental needs as integrated across the major developmental domains, and the child's and family's services and supports as preferably implemented by a single professional with assistance from other team members on a consultancy basis. All these shifts in service provision are possible only if a new set of attitudes, skills and competencies necessary for professionals to work with families are present (Roberts and Innocenti, 1998).

Future challenges and considerations

Portugal, like any other country with limited resources, is forced to make creative and wise decisions on how to use resources. From the beginning, we have believed that the most realistic way to provide early childhood intervention services is by building on existing human and material resources, articulating relationships between agencies and professionals, and using whatever is available in the community.

The 1990s were productive years in Portugal for the field of early childhood intervention. In a little more

than a decade, early childhood intervention evolved from an emerging service, provided within a child-centred perspective, to a rapidly growing field with a totally different conceptual framework. Part of this evolution was triggered by the implementation of a community-based programme of early childhood intervention in Coimbra, located in the central region of the country. The Coimbra Project successfully addressed the challenges of this new field of early childhood intervention: how to support families and the parent–child relationship at a very vulnerable time; how to help families become equal members of the team; how to choose evidence-based practices; how to organise services; and how to help practitioners adopt this new model (Healy, Keesee and Smith, 1989).The Coimbra Project developed a system to provide individualised comprehensive services to children and families by using formal and informal resources already available in the community, and by creating a collaborative approach involving Health, Education and Social Services. Since the problems confronting the target children and families were so diverse, an array of collaborative teams that cut across different disciplines, agencies and theoretical orientations was needed. Training played an essential role in the Project development, and without a doubt was the single most important factor associated with the programme's effectiveness.

Since the beginning of the new millennium, early childhood intervention has acquired a growing audience, and professionals, agencies and families are fully aware of the significant paradigm shift that occurred in Portugal. A family-centred, inclusive, ecological and comprehensive early childhood intervention approach has been widely accepted in many locations throughout the country. *Generally*, families and professionals report that they value practices embodying this approach, although some specific variations in early childhood intervention implementation can be seen in specific regions of the country (Tegethof, 2007).

The Portuguese political climate has now shifted, and, with it, new directions have emerged especially from the Ministries of Education and Social Security. Emphasis is currently being put on immediate cost-cutting, without any consideration of the impact on future costs of special education or institutionalisation. These changes have also meant that Portugal is now in the process of revising early childhood intervention legislation. The proposed legislation appears to exclude at-risk situations, either environmental or biological, and to emphasise services directed at children with disabilities, based on a therapeutic and child-centred model. It also intends to select children for services according to the

International Classification of Functionality (ICF), from the World Health Organisation, as well as reduce the level of articulation and involvement of Public Institutions.

These numerous societal and legislative changes on the horizon pose new challenges to families, early childhood intervention practitioners, trainers and planners. Twenty years ago, Healy, Keesee and Smith (1989) predicted that there would always be a conflict between the 'system' and the intimate, flexible, relationship-focused process of early childhood intervention. They pointed out that this model of early childhood intervention is indeed revolutionary, and that we would need to be creative, visionary and vigilant to promote this revolution. The major priorities in Portugal for the next decades will be to develop ways to increase the involvement of families, to redefine professional training according to desired outcomes and to maintain good quality early childhood intervention services despite political and legislative constraints. With such big challenges facing us, we still hope that with the help of so many committed families and professionals, and after a two-decade evolution towards an evidence-based approach, the field of early childhood intervention will continue to be an exciting one in Portugal.

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CHAPTER 5

Language Intervention in Daily Life: The Karlstad Model of Language Learning

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Background

The Karlstad Model is a language intervention programme for individuals with language disorders, developed in the late 1970s by Iréne Johansson who is a professor in both phonetics and special education. The model was developed in collaboration with parents, professionals and researchers at the University of Umeå and the University of Karlstad, Sweden for individuals who needed language training. It is a theoretical model combining key ideas about speech and language learning, and also a model of practice. It is still evolving as a result of input from new experiences, working partners and research.

The model may be used with all language learners, and has been adapted for children, adolescents and adults with different types of language disorder. Many of them have had mental or perceptual difficulties in additional to a speech and language disorders; others have had only a language problem. This model has also been used with children who have hearing difficulties and/or a cochlea implant and those who are from a multilingual background.

The first aim of the model is communication and to prepare the child for the social use of spoken and written language, so that they become socially competent to live independent adult lives. Language competence is an obligatory requirement for the child in their social adaptive and cognitive development, and thus a prerequisite for an independent adult life.

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The second aim is to prepare the child for the cognitive use of language in order to facilitate problem-solving, and improve memory and thought processes. The third aim is to teach those around the child the specific way to communicate with them, and to facilitate inclusion of the child into the environment.

Philosophic and theoretical introduction

The model's main aim is to work for a better quality of life for all individuals with speech and language disorders. It regards communication, speech and language learning as of utmost importance to achieve this goal. The Karlstad Model is based upon the relationship between language, the individual and society. Empowerment is a key principle of the model. The theory of empowerment is about giving knowledge to those who need it when they need it. This knowledge can enable a person to gain power over their own life and themself. Another strong influence is the ecological theory of human social development (Bronfenbrenner, 1979). According to this theory, people behave and perceive other people's behaviour as a consequence of cultural, religious, ethical, political and social factors as well factors based upon their own experiences. That the individual is influenced by those around them, and has the power of influence is the foundation of democracy. Language in this way can be seen both as a prerequisite condition for and as a ticket allowing contribution to democracy.

The Karlstad Model has been inspired by the social constructive theories of Vygotsky (1962). A basic principle of learning is that the child is regarded as a subject, in need of emotional and psychological energy and guidance. Engaging in problem-solving, the child is guided by adults or other children who are further on in their development. The adults in the environment have to be in front of the child, so they can use manual signs, and they should provide the child with developmentally appropriate challenges. The child is engaged in an unceasing process, always working towards new goals. Nobody can actually teach the child anything, the child is the 'architect and the director' of his own development.

Content, form and use

The model is based upon normal language development, and looks at language development as a life-long, creative process which is included in other activities, and governed by social, cultural and historic factors. The people around the child have to show the way and support the child in becoming competent in spoken language. In the professional literature, language development and language problems in young children are approached from a number of different perspectives. This model describes language development based upon the language milestones and progression that characterize the developmental stages. Bloom and Lahey's (1978) theoretical model of language and communication is another framework in the model. This takes a holistic perspective based upon the integration of three fundamental components; form, content and use. A child's early communication and later linguistic communication is seen as a mutually dependent unit consisting of these three components. As the child acquires their language, they must develop the capacity to function according to these components. The balance between the components is upset if there is a problem which means that one or more of the three components is lacking.

The use of language belongs to the field of pragmatics. It appears to be an area of particular difficulty for many children with developmental language disorders. It is a challenge to know how to take part in conversation or any other speech event. The use means that words and language should function in accordance with the social rules that are relevant in different situations with different conversation partners and about different subjects. To know what correct and incorrect behaviour is, the child must have experienced how to behave in different settings. It is important to have an understanding and sense of the use of language, to make the content accessible to others, and to take pleasure in using it. Pragmatic

functions provide meaning beyond the syntactic information, such as linking new information with old information or using various speech acts (e.g. questions, exclamations, etc.). The *content* concerns the meaning of words, phrases and sentences, and has to do with knowledge about objects and events in the real world. Gaining knowledge from language content is a continuous process. The content is influenced and determined by the child's cognitive and emotional ability, and closely connected to memory.

The child's system of communication needs to become appropriate and to be in a *form* which can be shared with other people. Speech is the most common expressive form of communication in our society, but is only one of many possible forms. Conventional signs which are used in everyday life as alternatives to speech include pointing, gestures, mimicry, manual signs, written words and other graphic symbols.

Partnership

Focus on the child

The language training programme has a holistic perspective, and is constructed around the child's initiative and their own activities. The child is never a passive recipient or an onlooker, but is active and learns through their own experiences. The child's motivation is important for learning, and therefore learning through play is the main focus. The training has to be attractive for the child. Very often the child with language disorders needs other forms for adaption than children without a disability. The model emphasises the importance of individualisation. It is always the child's capabilities, needs and interest which are central to the adaptation. Children are unique, and grow up in different environments. Therefore, the whole process – from initiation to practice, involves adaptation to the tempo of the individual child, their progress and structuring of the environment and materials. The programme places an emphasis on language training which supports the child in their daily activities at home, in the nursery or at school, and new exercises are devised to take account of this.

Networking groups

The traditional way of treating a child with speech and language problems was to call in the 'experts' and leave the problems in their hands. The intervention was often clinically based, and what happened was known only to the child and the therapist. The Karlstad Model is the antithesis of this way of thinking. It introduces another kind of working model based upon a networking group for language intervention. The networking group is an educational instrument for implementing speech and language training in daily life (Johansson, 1997). It is family-centred – its key focus being the child and the family – and built upon partnership. The fundamental idea from which the group operates is that the child develops their language based on their own needs in their environment. Life is lived through relationships, activities, socialising and working with others, and language learning is carried out in the same social context and cultural framework.

A networking group may consist of the parents, relatives, language therapist, staff at the local day nursery or the school, and other people who may belong to the child's network, all working in close cooperation and partnership. Membership of the group is voluntary, and based on democratic principles – all the members are equal, and their different knowledge about the child has equal status. The group has a long-term perspective, and meets on a regular basis to discuss the speech and language training, and how to put their common goals into practice.

Members have different roles, and each is responsible for their individual part of the training. The group can be a powerful tool for initiating changes in the child's communication skills. All

networking groups are different from each other depending on their members and the child. Networking starts when the parents make the decision that they want this form of intervention planning. The parents invite key people who are directly involved in the child's daily life to participate in the group. These may include relatives, neighbours, professionals and significant others. When these people have a shared insight into how children learn language, and into the specific difficulties that are delaying the process for their child, they can give vital support and mediate processes as effective pedagogues in everyday settings. The parents and the relatives in the networking group are the stable people in the child's life, and are there for the long-term; the specialists may often change.

The regular meetings generate a forum where all can communicate constructively, and the professional knowledge of the specialists can be combined with the latent knowledge of those in the child's everyday life. (It is important to realise that knowledge about the child's communication skills is often held by those close to the child, and rather than by professionals and specialists.) Fundamental to the Karlstad model are the networking group members' collective understanding and knowledge of the child and the child's language. An absolute prerequisite of its success is the group's awareness of speech and language and the development of children.

Using the Karlstad Model, the networking group assesses how the child learns through interaction with others and how meaning is formed by them in their social context. Through the group's creative problem-solving based upon the knowledge of child, they then evolve an intentional system of communication relevant to the child and plan the intervention.
The structure of the intervention programme is individualised, which means that the child leads intervention. The child should never be a passive receiver or observer, but should be allowed to make their own experiences. Language learning should be fun and enjoyable for all. The intervention programme is also holistic; the development of communication is seen

as an integrated part of the child's total development – motor, perceptual, cognitive, emotional and social.

The ability to set goals, and agree how best to achieve them, is an important challenge for the members of the group. A common view of the child's challenges and needs is generated through discussion among the networking group, and together they carefully determine programme goals, identify primary goals, split them into targets small enough to be attainable for the child, and propose exercises and procedures. Information from preliminary assessments and evaluations are considered key to planning for the child's optimal progress. The intervention is planned so it can be carried out in a structured way to help the child to cope with the tasks, and is summarised using a 'Language Training Form' (see Figure 1 below). The networking group also aims to facilitate smooth transitions for the child into new environments. This is supported by members within the group who know the child well.

Language Training Form for XX				
Period:				
Overall goal:				
Evaluation date:	**Partial goal**	**Resources/ method**	**Responsibility for training**	**Responsibility for generalisation**
Pragmatics				
Lexicon				
Grammar				
Phonology				
Prosody				

Figure 1: Example of a network group intervention planning document

Goals are defined not only for the children, but also for the adults. The adults share the responsibility for language training by taking different roles, discussing what approaches to use, how the training is to be done and how to generalise the new knowledge into daily life. All members of the group follow the same strategies, but each of them gives the child opportunities to acquire knowledge and skills in different ways, and in different environments. Most importantly, everybody aims to be an effective communication partner for the child.

The model of practice

The Karlstad Model presents a comprehensive proposal for practical intervention planning supported by sound theory. Through this model, practitioners can promote language development from pre-linguistic, 'performative communication', through 'primitive grammar', 'simple grammar ', 'complex grammar' to 'reading – and writing' at school age (see Figure 2). Through working with and developing the model, resource materials and methods have been designed. Some of these have been published in books and reports, which have been translated into different languages. The books contain a description of the theoretical background, ideas for developing materials and how to implement the language training.
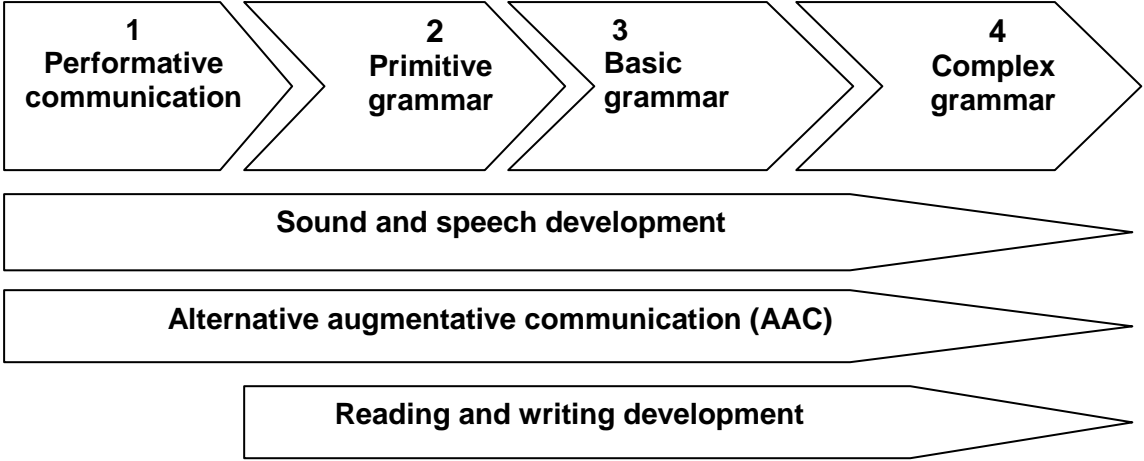
Figure 2. An illustration of the different phases of language development

The different phases of language development

Performative communication (Johansson, 1988)

Performative communication is the basic building block of more conscious communication and is intentional, deliberate and goal-directed. There is an understanding that the child can use other people as tools to achieve a specific objective, but also that other people may be the objective. The actions build upon different modalities, involving different signals from the visual, audio, motor channels which complement each other. The child engages other people using gaze, facial expression, sounds and body movements well adapted to its purpose. Performative communication is seen as a process with growing complexities of expression, and symbolic contents. The members of the child's community network need training to allow them to identify, accept, interpret and use this expressive, performative communication. The principal aim in this phase is priming and training the child's listening and attention skills. Young children are particularly sensitive to speech sounds, but the ability to perceive and discriminate between small differences in the properties and qualities of speech sounds is difficult for many of the children with language disorders. They need to learn to notice the differences and similarities between speech sounds and to group them into different categories. To facilitate this, the child is presented with speech sound sequences which are differently organised and structured from their mother tongue.

Through interacting with others while playing, listening, looking, imitating and touching, the child learns how to enjoy communicating. The written materials (Johansson, 1988)[2] consist of 12 programmes along with proposals for activities and materials. Some of the special areas focused upon are turn-taking, speech/sound listening patterns, baby massage as tactile communication, mirroring and alternative and augmentative communication (AAC).

Primitive grammar (Johansson, 1990)

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[2] A list of different language translations of Karlstad Model publications can be found following the 'References' section of this chapter.

During this phase, the aim for the child is to develop a large, receptive vocabulary of about 250 words, and expressive use of about 30–50 words (AAC-mediated[3] and/or spoken) and to master some speech acts. In early lexical development, words are the building blocks of language. The child needs to develop a large vocabulary associated with their needs, feelings, thoughts and words specific to situations which they meet in their everyday life. By working with sounds, pictures, sight-words and manual signs, through sorting and categorising, the child learns the meaning and the form of words. Some speech sounds (phonemes) can be difficult to distinguish on the basis of sound alone, so they are made visual to help the child derive meaning from what they hear. On this basis, tangible speech sounds (see photo, right) are introduced in the Karlstad Model to support the acquisition of aural discrimination.
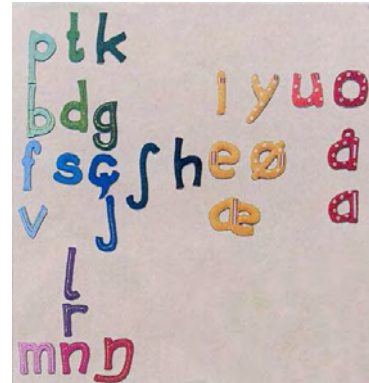
The tangible speech sounds are based on 'IPA letters', and are made from different materials. The varied colours, weights, textiles and markings represent the distinctive features of the sounds. In the beginning the child plays with these figures. In cooperation with the child, the adult names the sounds. This enables cognitive feedback in terms of phonological representation of the sound.
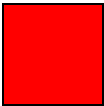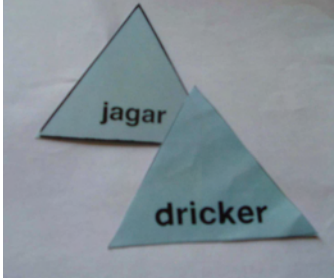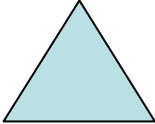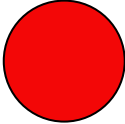
In addition to being manipulable, these speech units can be used in other tasks (e.g. the synthesis and analysis of phonemes and syllables in words, or the segmenting of phonemes in a word to analyse units for spelling). In different ways, they will be used in all the following phases. The written materials (Johansson, 1990) contain 31 programmes which consist of listening, imitation of sounds and movements, books, songs and rhyme. Some of the special areas focused on here are listening and imitation of sound combinations, books with pictures of manual signs and sight-words.

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[3] e.g. manual signs, symbol, pictographic, electronic, etc.

Basic grammar (Johansson, 1996)

At this stage the child is learning basic, 3-word sentences, and uses three categories of words – nouns, objects and verbs. To acquire syntactic structures, the child must discover and use the grammar of their language to determine 'who did what to whom' in each sentence. The aim at this stage is for the child to be able to ask questions, refer to something, use several types of language, and engage in proto-reading and writing, and discriminate between and segment words/sounds.

	A red, square denotes a word that influences something.
	A blue triangle denotes a word describing action.
	A red circle denotes a word describing what is under the influence of the action.

Figure 3. Illustration of sentence elements

Learning grammar involves the processing of sentences rather than just single words, and this will be difficult for most children with language disorders. In the development of grammatical structure, they will probably be reliant upon visual facilitation (see Figure 3). Cards of different shapes and colours are used to make this concept visual – the picture is on one side and the word printed on the other. The subject of the sentence is illustrated by a red square and the object by a red circle. Action words are represented by a blue triangle with only the printed word. The child is supported to put the chosen words into the correct order. When the child has mastered the simple rules of grammar, is able to categorise words and demonstrate their use, has an extended vocabulary and has mastered basic language skills, they can move on to the next phase.

The written materials for this phase (Johansson, 1996) contain 12 programmes which include ideas for working with lexicon, grammar, phonology and picture books with simple text. Examples of resource materials associated with them are: shapes and coloured cards with pictures and printed words (illustrated in Figure 3 above), templates, and training ideas for listening to sounds in combination with visual phonemes. The shape and colouring system represent the major linguistic features.

Complex grammar (Johansson, 2006)

In this phase, activities focus upon the use of pragmatic skills as well as extending and varying the vocabulary used. This is achieved through telling stories, reporting, referring and planning. Children with language disorders often struggle to learn to use complex grammar. To support the abstract, grammatical structures, new parts of speech are introduced and made visual. The child's progress in learning new grammatical structures is linked to the size of their vocabulary. To be able to use complex and long sentences, they need to have a large vocabulary – about 2,000 words. It is a challenge for them to be able to use different inflections, to determine grammatical endings and order the words correctly.

The written materials (Johansson, 2006) contain different training ideas for pragmatics, lexicon, syntax, semantics, morphology, phonology, prosody, awareness of speech and language and proto-reading and writing. Examples of associated materials are; different coloured shapes representing the different parts of speech, plates illustrating different types of sentences, scenes with paper figures, games and books.

Sound, speech and listening

Listening is the receptive form of spoken language, and starts early in this intervention. Most babies learn language by listening; many children with language disorders have problems with listening due to their difficulties with perceiving, processing and interpreting speech. To listen effectively, it is important to be able to keep sounds in the auditory memory. Auditory attention skills are essential for speech and language processing, and poor auditory attention can compromise listening. The child needs to learn strategies to direct their attention towards sounds which are important at the moment of utterance, and not to be disturbed by other sounds. Many children with language disorders have unclear speech for various reasons from motor planning to phonology and articulation. All speech training starts with listening exercises. Phonological representations are cognitive manifestations of speech sounds, and in optimal circumstances, these representations are developed on the basis of auditory speech input and on the articulation of the speech output.

Prosody

Prosody refers to variations in pitch, loudness, duration and pause/silence in speech. Prosody plays an important role in a range of communicative functions, and is used to enhance or change the meaning of what is said. Infants are highly sensitive to prosody, showing a preference for child-orientated speech (e.g. 'motherese') and demonstrate an ability to remember prosodic patterns specific to their native language. This early sensitivity to prosody suggests that it may be of primary importance in language acquisition. There has

been considerable research investigating the role that prosody might play in the acquisition of language in typically developing children.

As a result of working with children with hearing impairment, a visible system for the acquisition of prosody was designed. The section in the written materials, entitled 'Speech training' (Johansson 2006, 2007), contains ideas of how to work with prosody during sound, listening, voice, breath and articulation activities (see photo below). The material can also be used for other children in need of speech training.

One resource used in the speech training is a palatal plate (see photo below). It is used pedagogically to focus the child's attention on, and to increase their awareness of, articulation. Use of this plate gives the child extra sensory and motor stimulation in addition to visual and auditory stimulation.

Each plate is made to fit an individual. It is removable and manufactured from acrylic and covered with small nuts (see photograph). The therapist can screw various stimulants at different places on the palate, to encourage the child to become aware of a

particular area in order to produce, for example, dental, velar or palatal sounds. The plate is very flexible, hence its commercial name, 'Flexi Plate'. It was inspired by the Castillo-Morales

concept of orofaciale regulation therapy, but the design of the Flexi Plate differs from that pioneered by Castillo-Morales.

For older children, the palatal plate is used as a cognitive instrument – a 'map of the mouth' – in speech training. Awareness and attention about 'where and how' a sound forms is the key to successful training. The child, supported by an adult, uses the plate for approximately 20 minutes twice a day in the context of a structured speech and language programme. For the youngest children (i.e. approximately 6 months of age) a more simple plate is made. The aim here is to focus attention on increasing their oral activity. As part of a developing educational application, a visual system for the acquisition of sounds is created for use in combination with the plate. The written materials (Johansson 2002) include a programme which takes account of the different areas important for the speech therapy; voice, articulation, phonology, prosody, perception, memory and oral motor.

Alternative and Augmentative Communication (AAC)

On the way to spoken language, the Karlstad Model calls for the use of alternative and augmentative communication (AAC) methods. For some children, expression and comprehension of spoken language is problematic. For children who have difficulties with spoken language, it is necessary to find an alternative and augmentative way to communicate. Some children will need AAC for both expression and comprehension of language. Supporting language with manual signs and written words is important and is integrated into all exercises in the intervention. This is seen as a means to encourage communication and develop speech and language. There are two main aims in using AAC in the model: support for communication in daily life, and as an instrument in language learning. Manual signs are designed to reflect spoken language. Signs are borrowed from sign language and combined using spoken/written language syntax (not sign language syntax). Manual signing is always used simultaneously with spoken language.

Manual signs are easier for the child to 'articulate' than speech, and when combined with spoken language, the signs and gestures give multimodal (i.e. visual, kinaesthetic and auditory) feedback and support. Speech is the goal, but AAC gives the child a tool to communicate with as a precursor to talking. All kinds of AAC – gestures, tactile symbols, manual signs, pictures, pictograms, rebus (e.g. Bliss, Widgit) and written words can be used. The choice depends on the needs and ability of the individual child. The principle behind this type of intervention is to use as many alternatives and modalities as possible to facilitate spoken and written language for those unable to produce speech. The supporting adults must be competent in using signs, and take the lead by being one step ahead of the child's developmental level. It is important to be a good language model by using AAC consistently with everyone around the child as well as with the child themselves.

Reading and writing *(Johansson, 1993)*

The prerequisites of reading and writing – the ability to recognise graphical symbols (including words, graphemes and rebuses – sight-words) can be transformed into speech or signs, and to perceive oneself as a reader – are founded during the earlier phases of the Karlstad Model right back in the primitive grammar phase. The basic methodology used during the reading and writing phase aims to strengthen the child's self-identity as a reader, encourage the child to attempt to decode graphical symbols, to review their interpretations critically, and to self-correct when necessary. The resource material is organised into 12 reading programmes, each of which ends with a book. The structure of each programme focuses on: (a) form, and the recognition of sight-words, syllables and letters; (b) teaching the child to shift attention between form and content; (c) constructing new sentences with sight- words, syllables and letters (analysis – synthesis (See Figure 5 below), creating meaning); and (d) making a story book. The training areas in this phase are the lexicon, syntax, morphology, phoneme grapheme connection and articulation of sounds.

Figure 5. From gestalt to parts

Pedagogical principles

There are some basic principles relevant to the methodology used in the Karlstad Model.

1. Language training is a life-long journey; it will never come to an end. The best results are seen when intervention is early and individualised. It is never too late to start. The pedagogic focus is on slow progression, structured and systematic daily training in different environments, programme continuity based on experience, and practice with multiple repetitions. The structured programme enables all involved to maintain an overview of the intervention and remain on task. It ensures predictability of the material which enables the child to achieve, while allowing variation and creativity which maintains interest.

2. The purpose of breaking down the overall intervention aim into shorter-term, small-step targets and exercises is important for maintaining motivation – both for the child and those facilitating and supporting the exercises. Motivation leads to curiosity and exploration, and is an important driving force for the child's development.

3. Experience with the Karlstad Model shows that printed word seems easier for these children to remember than spoken words; visual processing and visual memory skills in people with developmental language disorders are often less impaired than their other cognitive skills. The Karlstad Model therefore capitalises upon children's learning strengths by using visual resource materials. Print makes the language visual, and clear

and accurate concrete representations of abstract concepts and effective modelling of language use are crucial in facilitating language learning.

Conclusion

The steps in the Karlstad Model follow each other in a developmental progression. The level, order and the relationship between the steps contribute to giving the child the basic building blocks for learning language, reading and writing. In this way, the model offers them the opportunity to become a more independent communicator and contributor within their family and community. The model provides practical guidelines and ideas that can be absorbed into the daily life and activities of those around the child, but, most importantly, it lets the child guide us.

We have to remember that no two children are alike, including their rates of progress; their developmental profiles are uneven and vary greatly. Language training may differ from one child to the next; the resource materials and methods have to be individualized to facilitate each child's learning; but, nevertheless, they can follow one common model. The model involves the child in joyful discovery of their own potential through the programme's motor, perceptual, language and cognitive activities. There is no single approach to language training, no single method. Practitioners have to gain insight into many different methods, so that they, with the child's family, can make the choices which will unlock language learning for that child.

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CHAPTER 6

Quality and Innovation in Early Childhood Intervention

Based on the Level of Communication between Professionals and Families

Irena Samaria[1]

Introduction

In the last decade, many countries have shown great interest in early childhood intervention,[2] and new methods, models and ideas are emerging from all over the world. Most of the attention has focused on the *child,* and a great number of professionals are urged to help the family fit into the models or methods applied – in other words, to fit into the 'system'. Is this the real purpose of early childhood intervention*,* or should professionals be the ones to fit into the child's and the family's world?

How can *families* be sure that they have chosen the most appropriate early childhood intervention model or method for themselves and their child? How do professionals assess the families' needs and wishes, and how can they help them receive the most appropriate services? How can families and professionals communicate best in order to build a good relationship and approach based on each individual and each family? These are the questions addressed by this chapter.

Where do quality, innovation and communication meet?

Quality

It is not living or dying that defines who we are because this is the same for us all. We are all born, we all live for a while or longer, and we all die. It is ***how*** that distinguishes us – how we live; how we die.

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[1] Psychopathologist- Clinical Psychologist (freelance)
[2] Early childhood intervention refers to children under six years of age – pre-school age – and their families. The child may present developmental disabilities or be at risk because of the environment they are living in, the fact of being born prematurely, etc.

How we live is strictly related to luck and choices: luck, because we do not choose where we are born, and we cannot always choose how to live – how we live is related to our society, the opportunities we are given, the education we receive, the financial level of our family and other circumstances; choices, because there are always choices, even if sometimes choices and opportunities can be very restricted – like living or dying, having to enough to eat or not, fighting or letting go. And then there's how we *want* to live and how we want to die.

Some families choose to have children, and some choose not to. Even when families choose to have children, they do not know *how* their children will be. Usually, the birth of a child is a tremendous joy, a promise. When a child is born with a disability, it is as though all the joy has been taken away from the family, leaving in its place mourning – saying goodbye to the desired child who was never born.

From the time this unexpected child is born, there will be love, but there will also be suffering. This child is often associated with pain, disappointment and guilt. For some families, the suffering goes away with time, entirely or partly, but, for others, sometimes suffering remains for ever. Accepting and loving the unexpected baby is not enough; taking care of the child becomes a full time and lifetime job.

Quality of life

Quality is such a personal and pragmatic affair! What is quality to one person is not to another. Quality is related to a person's background, likes and dislikes, tastes and personal convictions. Some like caviar, and others like French fries; some like camping holidays, and others like staying in five-star hotels; some like reading, and others like watching television; some like listening to music, and others like playing games; some like going to work, and others enjoy leisure; some like being with people, and others being alone. And so it goes on. There is no possible way to keep everyone satisfied by offering the same things.

From the time a child with developmental disabilities is born, different professionals such as doctors, psychologists, therapists, etc., surround the family to help them give their child the 'best

possible education', prevent the child from getting worse, and help them develop to the best of their ability. Some professionals and educators are just trying to promote their preferred method, programme or their personal ideas, but is this really what early childhood intervention is about?

Nowadays, we live in a modern society surrounded by new ideas, methods and equipment. Books, media, the internet, etc. are all different sources of information, which give families the opportunity to investigate different methods and approaches, but how can they really know if these are good or bad, reputable or dangerous? How do we, as professionals, meet the family's needs? How do we meet the family's needs in the best interest of the child? How can we make a decision for someone else?

For families, it is more than having choices. It is a bucket full of battles from which they have to choose the right battles to fight for their child and, in the end, for the child's right to have *rights* – the right to go to school, the right to have a job, the right to live a fulfilling life. Ultimately, it is the right to be unique and different.

Times are changing and, with times, we are changing too. There are currently no universally recognized standards for early childhood intervention, since the available services are different from one country to another. Early childhood intervention services and their quality depend a lot on the health, social, legal and educational systems of individual countries. In other words, they depend on the priorities and ideologies of each society regarding developmental disabilities.

There are no miraculous therapies in developmental disabilities. Early childhood intervention becomes quality intervention when it is based on customizing the existing services, models and methods to meet the child's and family's lives and needs. It is based, not on imposing upon them what professionals imagine is right, but on encouraging them to build their own road towards their personal idea of quality and accompanying them as they do so. Offering quality services in early childhood intervention could mean rigidity to one person, but flexibility or complete freedom to others. One thing is certain: the quality of the services provided influences the holistic development of the child, and has an impact on the family's life.

In order to help the child develop, adapt and make the best of this fast-moving society, we should first consider 'quality'. Quality in early childhood intervention means:

1. *Providing structured early childhood intervention programmes adapted to the child's and family's abilities and disabilities.*

   This includes: deciding if the services provided will be child- or family- oriented; acknowledging the present situation of the family/child ('Where we are'), the future plans ('Where we are going') and the possible interventions ('How to get there').

   A family interview is necessary to identify their current situation, needs and expectations. Other requirements are: an assessment of the child; a study of existing services in their community; and provision of the best possible services through the society's financial support structures, social security services, etc. It is important to put support in place for 'at risk' children and families as soon as possible.

2. *Equal status in interaction/communication between families and professionals.*

   This is essential. Professionals may have knowledge and diplomas, but they also need the ability to listen and not impose their ideas, and to build a real team based on positive and equal exchanges between everyone involved.

   Pediatricians and other specialist doctors play an essential role since they usually break the news of the child's diagnosis of developmental disabilities to the family. Doing so in the right way is crucial.

   It is also important for professionals who offer early identification, early guidance and referral to services to use simple, jargon-free language if they want the level of communication between themselves and the child's family to be good. They need to acquire the skills to convey respect for and adapt their practice to the family's needs, abilities, difficulties and aspirations.

3. *Working as a transdisciplinary professional team*

    This includes: helping families as part of a coherent programme with shared short and long term goals, not as individual professionals each with their own aims; having a well-trained and stable staff team (this requires management investment in continuing professional development, well-organised systems and competitive salaries for staff); building a good support system without creating dependency so that families know when and how to reach for help when they need it; establishing stability and routine, well-defined roles, ongoing communication and trust; and recognizing the importance of the family structure, and the role of their extended family and friends as well.

    The coordinator or head of an early childhood intervention program has an important role because they are the person liaising between professionals, families and the staff. The coordinator should, above all, be capable and very understanding. When the coordinator respects, encourages, rewards, supports psychologically, guides when needed, is close and has an open communication with the staff, they foster resilience in the team.

4. *Ensuring the progress, well-being and emotional stability of the child and the family's satisfaction*

    This includes: being able to establish goals, taking into consideration the child's progress, communication, behaviour level and well-being).

5. *Collecting data, assessing and re-evaluating the progress of the child*

    This includes: understanding the importance of identifying the baseline situation and intervention objectives; keeping data, videos, documents as evidence of programme effectiveness; moving towards increasing the child's independence; being optimistic and positive.

Innovation

Change is inevitable in life since the circle of life itself changes all the time. Innovation is closely related to change. Innovation in Early Intervention is not more than changing the way we think, the things we do and how we do them; an introduction of something new. 'Innovation' is thinking creatively about an already existing situation and making significant changes. Let us take the example of 'impairment', 'disability' and 'handicap'. These concepts have not fundamentally changed through the years, it is just the way we apply them that changes.

- *Impairment*

  This is a psychological, physiological or structural loss or weakening resulting from damage. Example: A person breaks a leg as a result of an accident and is unable to walk.

- *Disability*

  The word, 'disability', describes the result of a functional limitation – the consequences of the 'impairment'. Example: The person with the broken leg (impairment) has restrictions in walking (functional limitation) and needs a wheelchair to move around.

- **'Handicap'**

  The 'handicap' is the degree to which the disability limits or prevents the person from engaging in an activity which can be accessed by those without a disability. Example: The person with a broken leg arrives at a theatre, but finds that, while people without a disability can get in via a flight of steps, there is no access for the wheelchair leading to their exclusion from an activity open to others. Disability has thus led to a disadvantage in fulfilling an opportunity in life in relation to their peer group.

To summarize: *impairment* refers to a damage of a part or organ of the body; *disability* is a functional limitation with regard to a particular activity; and *handicap* refers to a disadvantage in fulfilling an opportunity in life in relation to a peer group.

Quality means that every citizen should have *access* and *choices* in society.

Communication

First it is important to define communication because often people imagine they are communicating, but are not.

For an interaction to be classed as 'communication', it needs to be able to fulfil certain criteria. Simply, it occurs when someone ('A') transmits information with the intention that another person ('B') intentionally receives, interprets and responds to it meaningfully. Communication is sometimes misunderstood as being expressed only with words. However, the message from A (the person sending a communication) to B (the person receiving that communication) may include not only words, but also facial expressions, body orientation, gestures, signs, images, sounds, etc. Sometimes a person will communicate by taking someone by the hand and leading them to a place or an object they wish for.

For communication to be successful, the following conditions have to be met:

- The message is transmitted from A (the sender) to B (the receiver).
- B receives the message.
- B wants and is able to communicate, understand the context (common language), interpret the message correctly and respond appropriately within a viable time period.

When 'B' responds to 'A', their roles are reversed.

Communication between professionals and families

If communication is considered to be the basis of any social interaction, inclusion and achievement, then, in the context of Early Childhood Intervention, who communicates with whom and for what reasons?

1. *Professionals and families*

For many years, communication between professionals and families was often a one-way transmission, something like a monologue. Professionals directed and families were supposed to follow the prescribed method, always 'for the child's sake'. Sometimes, even today, this happens. For example, in hospitals, while there are many caring professionals, we may meet some who never have time for a dialogue, are always in a hurry, quite often look annoyed by different questions, and think parents should 'do what they are told', since the professionals are those who have 'the knowledge'.

No matter how socially adept, educated, positive or persistent families are, they are ultimately those receiving assistance, support and guidance from professionals who are supposed to have the answers, and are supposed to be able to help them and their children have a better life. Or is this really true? Are families the only ones receiving a service? Aren't professionals receiving one too?

What, then, are professionals in receipt of? In answer to this question, we need to consider: what use is knowledge if one cannot pass it on, if one cannot share it?; what use is there in studying for years if one cannot put knowledge in practice?; what would professionals do if they didn't have this job? How would they live? Do all professionals choose to do this job because they like it or like helping other people, or do some of them do this job because they just need a job, need to be needed or to have power over other people? To help them do their job, are they not reliant on expert information and co-operation from the family?

Professionals who work with the families – home visitors, doctors, trainers, psychologists, therapists, etc. – need to be able to communicate with them in order to be able to help them help their children or themselves. For the families, getting support is more than buying services. It is most of all about buying choices and freedom for themselves and their children.

Real communication is essential between families and professionals. Communication can help them all exchange ideas and knowledge, discuss possibilities and impossibilities, set priorities, set targets and create a future plan, meet the abilities and the disabilities of the child as well as

the needs and the disabilities of the family. The same words can sometimes mean different things. So it is essential to explore in depth what families understand by the words used by the professional team and therefore whether the 'common' expectations and vision for the child are understood in the same way by both?

In doing this, professionals need to be honest with the families, to respect them whoever they are, and not to be aggressive or rude. For those educators, home visitors, special therapists, etc. who favor a specific approach, it is important to help the family and those around them understand that there is no miracle cure. On the other hand, a good approach is also one which recognizes that every child, whether they have mild or severe disabilities, can really improve and progress, however long it takes.

2. *Professionals and children with developmental disabilities*

Professionals who work with children with developmental disabilities – special educators, home visitors, therapists, doctors, psychologists, etc. – need to communicate with them in order to be able to help them. Often, communication can be the most difficult part of their work because the children need to have a personal reason, a motive and a need in order to want to communicate. For example, a person with autism spectrum disorder hears and sees the human beings close to them, but has difficulty analyzing their audio and visual perceptions in order to give them a meaning.

Professionals must always keep in mind that communication can be verbal or non-verbal with children with developmental disabilities and it can include: body language, body orientation, eye contact, sign language, computer writing, pointing, use of pictograms, etc. If the child's chosen means of communication are consistently ignored, then it may develop behaviour problems.

Example: Imagine you are in China. You do not understand what is going on around you. Someone appears, takes your hand and begins to lead you somewhere else. They are explaining very well in Chinese what is going to happen, where you are going and what you will be doing, but you don't understand Chinese, and you say so in your own language. This has no

effect, as they do not understand, and they take no notice and continue walking. At first, you keep on trying to make them understand. As time goes on, you start to become tired, bored or anxious. Your attempts to communicate become more insistent, as you try to make your Chinese guide realise you want out, you wish to stop, you are hungry, tired, thirsty and want to go to the bathroom. However, still your guide does not respond to you. As time goes by and your anxiety or tiredness increases, you have to make the other person understand what you are feeling or wishing to say. Their non-communication persists, and you get angry, frustrated and even react aggressively by pulling your hand or pushing the other person away. It's as simple as that: many behaviour problems are caused by difficulties in communication.

3. *Families and children with developmental disabilities*

Families cannot escape from the reality that their child will be dependent on them for a long time, and the hardest thing for the family to do is to keep themselves together and for them to find their own peace and happiness. Children with developmental disabilities can be tiring: tiring, because they need to be taken care of 24 hours a day; tiring, because parents have to think constantly about making a choice between this or that programme, about their child's future and their inclusion in society.

Families can sometimes be very aggressive too, fuelled by their anger at the birth of a child who is different from others and who will always be dependent, anger at a society unable to bring relief and specific help, anger caused by a prejudiced society or incompetent professionals, anger caused by their pain. Most families adore their child, and worry continually about the child's future and well-being, sacrificing their time and personal aspirations to meet their child's needs. Nevertheless, there are also families who mistreat their child with developmental disabilities because they consider that this child does not understand or deserve attention or just because they are angry. Some parents have no room for this imperfect, unexpected child; they spend nothing on them (time or money) and deny their right to have a voice or a fulfilling existence, as if their child does not understand anything or as if families 'know best'. They

sometimes even spend their life disliking any other child for being healthy or having no developmental disabilities or other families for having no such cares and battles.

Communication between families and people with developmental disabilities mostly depends upon the quality of the relationship between them. If the families want and take care of their child, then they will treat them well, and their child will want to communicate with them; if they do not, their child then has no reason to communicate positively. Some children presenting with developmental disabilities are unable to communicate well, and some have the incentive to communicate only when they wish to express a question, a need or demand, a piece of information, frustration or pain – something related mostly to themselves. Others have difficulty decoding a message conveyed to them or are unable to answer appropriately and within a viable period of time. Communication is not only a matter of *intention* but also a matter of *ability.* People who do not communicate or who do not communicate well can exhibit unpredictable and inappropriate behaviour, crises, aggression, self-injurious behaviour, depression and can be very difficult to support.

4. Children with developmental disabilities and their peers
The communication between children with developmental disabilities and their peers, as is the case with all other communicating partnerships, is based both on verbal and non-verbal communication. We first have to understand that children with developmental disabilities are not all alike and have different characters, and different kinds and degrees of disability (intellectual, physical, behavioural, communication, sensory and/or emotional). The relationships between these children seem honest and simple, and the context is often based on useful and functional communication such as expression of needs – the need to talk, need to eat or drink, need to go somewhere together, need to share, etc.

Some commonly occurring problems related to communication and speech can involve:

- *Pronunciation*

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- E*ffective use of language*,

- Use of *words and sentences, grammar, rhythm, meaning, context, intonation*

- Repetition of words and sentences previously heard (*immediate or delayed echolalia)*.

Nevertheless, some children can also present with psychological problems: depression and lack of interest in interaction with other children, aggressive and challenging behaviours, stress and panic attacks. These problems can get worse if (a) these difficulties remain unidentified, or are identified but ignored, or (b) the child's communication with those around them is poor or non-existent.

5. Families and children with developmental disabilities and society

Families and their children with developmental disabilities are often considered to be different, and as such are at risk of being excluded by society. This causes families additional stress related to their child's integration and future in society, the choices they have to make daily, and how other people see their child and themselves as a family. It is not only *what* the society communicates to the families, but also *how* they communicate their ideas, beliefs and values through verbal and non-verbal communication.

Are all families able – educationally, socially, psychologically and financially – to help their children? Do all families have free access to services if they need guidance on how they can help their children? No. Fortunately, some countries have a free social and health service which is able to take care of the child's health and education, but, even in these countries, not all families have equal opportunities, not all families have the ability to speak out*,* research all the possible choices, and reach a decision on what is best for their child.

The psychological state of the children with developmental disabilities and their families can make a big difference to their:

- Progress

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- Adjustment to society

- Development of self-esteem.

The environment in which the family is living and the support – social, psychological, educational – they receive will contribute to the well-being and peace of the child and the family. Feeling left out is a horrible and lonely feeling bringing despair and depression to so many families and children. Families can feel this way for many different reasons. Not only when they have no support group to help them or no specific guidance, but also when their children follow a specific programme, but the families are excluded and their needs are not taken into consideration.

Professionals often overlook the importance of:

- Including families in decisions about their child's developmental plan

- Explaining to parents what and why they are carrying out specific activities with their children and how each activity can help the child's development

- Giving quality time to families too.

If we remind ourselves when and why we communicate, we realise that it is surely because we have a need and intention to:

- Express feelings and wishes

- Express thoughts and share knowledge and information

- Express demands and desires

- Control our environment

- Describe a situation related to ourselves

- Relate to others, etc.

Our sense of self is created, developed and changed through our interpersonal relations and our level of communication within our immediate environment. The role of professionals is not only

to provide the most effective services adapted to the child's and family's lives; it is also to give the child and the family the desire and means to communicate with them.

What steps can professionals take towards ensuring quality in early childhood intervention?

1. Interview families and pre-evaluate the needs, difficulties and abilities of the child and the family. This can be done at the child's home.

2. Forster equal exchange/communication and common decision-making and goal-setting between early childhood interventionists, professionals and families.

3. Invest in a well-trained, satisfied and stable staff team (home visitor, special educator, etc.) with access to continuing professional development opportunities to work with the child.

4. Give specific attention to the progress, well-being and emotional stability of the child along with the family's needs.

5. Ensure the collection of data by each therapist and educator, ongoing and annual assessment of the progress of the child by a psychologist and continual re-evaluation of the child's needs, abilities and disabilities by the interdisciplinary team.

Early childhood intervention guide

Every country has its own policy on early childhood intervention based on its history, laws, past activities, educational and social system. A well-structured and organised guide could help families receive the proper services earlier, reduce stress and save time and energy. Such a guide could include two types of information:

1. *General information on early childhood intervention*

- Some written information could be available in the guide, and further verbal information could be offered via a free telephone helpline routed through an early childhood intervention centre.

- Information on the country's existing services, statistics, opportunities, laws and rights of the persons with developmental disabilities. A map of services and specialists could be presented on the back cover of the guide.

- Answers to frequently asked questions.

- Details of how to contact an early childhood interventionist and what may be discussed during an initial meeting?

- Detailed information about existing models and methods.

2. ***Personal information on the child and the family to completed by the early childhood interventionist***

- Personal information on the child/family

- Pre-evaluation of the child's and family's general situation

- Information of any previous or existing interventions

- Information on the professionals involved as well as on the six-monthly goals and nature of the proposed intervention

- Timetable of all meetings/appointments related to the child (specialists, therapists, etc)

- Weekly timetable of the child.

Conclusion

Early childhood intervention is not a miracle! It is about helping the child and the family to get the best they can from their community and existing methods so that they can reach their personal level of well-being and satisfaction. Nevertheless, we must keep in mind that all the existing methods and models are not useful. Information given by professionals is not always right or important. Not all families are willing to support and help their children personally, or have expectations of them.

The bridge between the needs of the child and their family, and the professionals and their existing services is communication. The deeper the communication and collaboration of the families, children and professionals is, the faster the child will develop.

CHAPTER 7

Drug-addicted Mothers and their Babies in Early Intervention: Diagnostic Features, Interactional Patterns and Maternal Attitudes

Alexander Trost[1]

Introduction

In Germany, during the past few years, we have had to take notice of a dreadful series of child maltreatment and even infanticide cases. These events seem to mark the tip of an iceberg of misery, structural and value problems in families, mostly at the lower end of the socio-economic scale, and point to failings in the organisation of Germany's public social service system. Ideas for solutions have ranged from rigid control to offering preventive courses for all young parents.

In the face of a growing number of maladapted and mentally distressed children, it is time to reflect on the conditions of origin of these disorders and to generate ideas for effective prevention. In-depth information is provided by research into infant development, attachment theory, neurobiological research and systemic-psychoanalytic approaches to family dynamics. German social paediatricians talk of the phenomenon of a 'new morbidity', meaning the shift from organic diseases to psychosocially determined, developmental impairments that derive from early sensory deprivation, disorders of self-regulation, interactional difficulties with primary caregivers and attachment problems.

The German nationwide Child and Adolescent Health Survey (KiGGS), a representative study by the Robert Koch Institute for the federal government, reported that 13.7% of all children (16.0% of boys; 11.4% of girls) were in special medical care due to their need for functional therapies or other medical, pedagogical or psychosocial action as a result of disabilities and conduct or emotional disorders (Schlack, 2008). They also found that almost 15% of 3–17-year-old children showed manifest or marginal disturbances of conduct and/or emotions. Children from lower socio-economic groups displayed these problems three times more

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frequently than those from higher groups. Since most of these problems tend to become chronic and set the courses of these children's futures, prevention strategies are very much needed, and will definitely be less costly than the medical and institutional, as well as the sociological, consequences of maladaptive development.

The Adverse Childhood Experiences (ACE) Study, a collaboration between the Centres for Disease Control and Prevention (CDC) and Kaiser Permanente's Health Appraisal Clinic in San Diego, California, used a retrospective approach to examine the link between childhood stressors and adult health. Over 17,000 adults participated in the research, making it one of the largest studies of its kind. The ACE Study findings have been published in more than 30 scientific articles. The following are some of the general findings of the study:

- Childhood abuse, neglect and exposure to other adverse experiences are common
- Almost two-thirds of study participants reported at least one ACE, and more than one in five reported three or more
- The ACE score had a strong positive association with the risk of drug initiation from early adolescence into adulthood and problems with drug use, drug addiction and parental drug use.

Moreover, the ACE study demonstrated a positive correlation between (1) specific violence-related stressors, including child abuse, neglect and repeated exposure to intimate partner violence, (2) specific risky behaviours and health problems in adulthood, and (3) adverse childhood experiences and the severity of the depression (Dube et al., 2003).

Infants of drug-addicted mothers

Today, we know that a secure attachment to a primary caregiver is a crucial factor in fostering resilience in children as they grow up. Recent results from neuroscientjfjc research prove the relevance of emotional, preverbal processes for the proper development of the brain. In this context, it is necessary to look at the earliest phase of relationship between an infant and their primary carer.

The first months of life provide multiple opportunities for babies to develop interactional patterns with their primary caregivers, but, at this time, they are also very vulnerable to disadvantageous interaction. If the first phase of this relationship is severely disturbed – which is very likely if the parents are drug addicted – the risk to the child of unfavourable psychosocial development, including severe mental problems as well as drug-addiction, will rise rapidly.

As early as 1900, there were 100,000 women in the USA who were reported to be addicted to opiates,[2] most of them having children. (Opium played a significant role in gynaecology and obstetrics at that time.) However, for a long period of time, these children have been a neglected group in research and early childhood intervention worldwide. Today, about 46% of German opiate-abusing women have at least one child, and 50% of these children live with their mother.

In Germany, we have 40–50,000 children of illegal drug-abusing parents. These children, compared to others, are exposed to higher biological and psychosocial risks, including:

- Discontinuity in basic care, lack of family structure, neglect, repeated out-of-family placements
- Chronic stress exposure due to the emotional instability of the primary caregiver
- Insecure attachment patterns and dysfunctional coping strategies passed on to them by the primary caregiver
- Developmental impairment: physical, cognitive, linguistic, emotional and social
- Behavioural disorders, such as attention deficit hyperactivity disorder (ADHD), aggressiveness, learning difficulties
- Poverty and social isolation of the family
- Depressive and antisocial traits in parents
- Low educational and professional achievement
- Becoming drug abusers themselves (50% risk), mostly due to psychosocial problems.

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[2] Drugs derived from opium such as heroine, methadone, morphine.

These findings suggest the need for extensive research efforts and implementation of effective support services as a means of primary prevention. However, currently there is very little research into the postnatal development of children of opiate-abusing mothers (Hogan, 1998). In addition, only about 10% of the drug counselling services provide any support for these children, and there are very few progressive programmes (e.g. "Comprehensive Care Programs" – http://www.dshs.state.tx.us/THSteps/services_ccp.shtm) for this target group.

During their pre- and postnatal development the children of opiate-addicted mothers are exposed to a number of biological risks, with a wide range of very different possible outcomes:

- Compromised brain development due to transplacentar exposure to nicotine, alcohol and cocaine
- Malnourishment and growth problems
- Preterm birth
- A high prevalence of infectious diseases (e.g. HIV, Hepatitis)
- Perinatal complications (e.g. Sudden Infant Death)
- Neonatal Abstinence Syndrome by intrauterine-acquired physical dependence, hyperexcitability, hypotonus, reflex anomalies. (These problems usually normalise during the first year of life.)

Compared to babies of alcohol-addicted mothers, the biological risks are not as severe because opioids are neither cytotoxic nor teratogenic. This is the reason that we do not see abnormalities and enduring cerebral damage. More recent studies emphasise that an opioid substitute, along with participation in standardised care programmes, can improve the health status of mother and foetus enormously (Finnegan and Ehrlich, 1990; Fischer et al., 1999).

We can therefore act on the assumption that the risks of intrauterine drug contact are far less dangerous than the psychosocial risks (Ornoy, Michailevskaya and Lukashov, 1995). Psychosocial factors form the

main cause of the cumulated incidence of mental disorders in these children during toddler, preschool and school age. They can include:

- Problems in the establishment of a nurturing and trusting mother–child relationship due to emotional instability and inconstant or inhibited parenting
- Discontinuity in basic care, which is the main reason for Social Services taking the baby into care immediately after birth (30%) or during the first years of life (20%)
- Co-morbid conditions (e.g. borderline personality disorder, depression, antisocial behaviour disorder) in up to 70% of opiate-dependent mothers
- Poor developmental stimulation, resulting in language, motor, cognitive or emotional developmental delays.

Until now, there has been very little government agency support for the drug-addicted mother-to-be or during the first months after the birth of her child.

What does a baby need? – opportunities and risks in early interaction

The newborn baby has to cope with a number of developmental adjustments right from the very beginning of their life. They have to take in and process information from an outside world, which is very different from the womb environment. Their motor system has to adapt to the earth's gravitation, their metabolism to oral food and breathing, and they have to decode social signals and respond to them. All these changes are accommodated almost perfectly by babies who have a good self-regulatory capacity and are within a sensitive mother–child relationship.

Papoušek and Papoušek (2001) invented the concept of Intuitive Parental Competences. These are unconscious, typical patterns of conduct shown by parents with their babies. They are biologically based, but psychosocially modified, and are matched intuitively to the abilities of the child at their stage of development. For example, the typical, intuitive distance for making eye-contact with a six-week-old baby is approximately 30 centimetres, and that is exactly the distance at which the baby can focus sharply. At that

age, any other dialogic distance gives an observer the impression that the mother–infant dyad is not well attuned. Adjustments made to accommodate interactions during the first postpartal months can be expected only of caregivers, due to the developmental constraints in infant vision and head control.

The Intuitive Parental Competences include:

- General dialogic skills such as the dialogue distance mentioned above

- Greeting responses

- A higher-than-usual pitch in speech directed towards the infant

- A prototypical, 'baby' language

- Imitation

- Simple, interactive games

- Other communicative elements that help to establish synchrony, rhythm and reciprocity in interactional sequences, thus establishing a 'mutual dance' or 'affective reciprocity' (Tronick, Als and Brazelton, 1980).

These patterns are the foundation of the baby's interactional knowledge and form the basis for a growing self-regulation and empathy. They enable the child to pay attention to the parent and to learn by dialogical didactics. Thus, the caregiver:

> *…is biologically predisposed to lead the infant toward a fundamental sociocultural integration and, for this purpose, toward the acquisition of a proper cultural communication… Intuitive caregiving aims not only at hygienic, autonomic and emotional needs of infants, but also at the need to be together with someone, to share experience, to acquire adequate means of communication, and to create novel symbols.* (Papoušek and Papoušek, 2002)
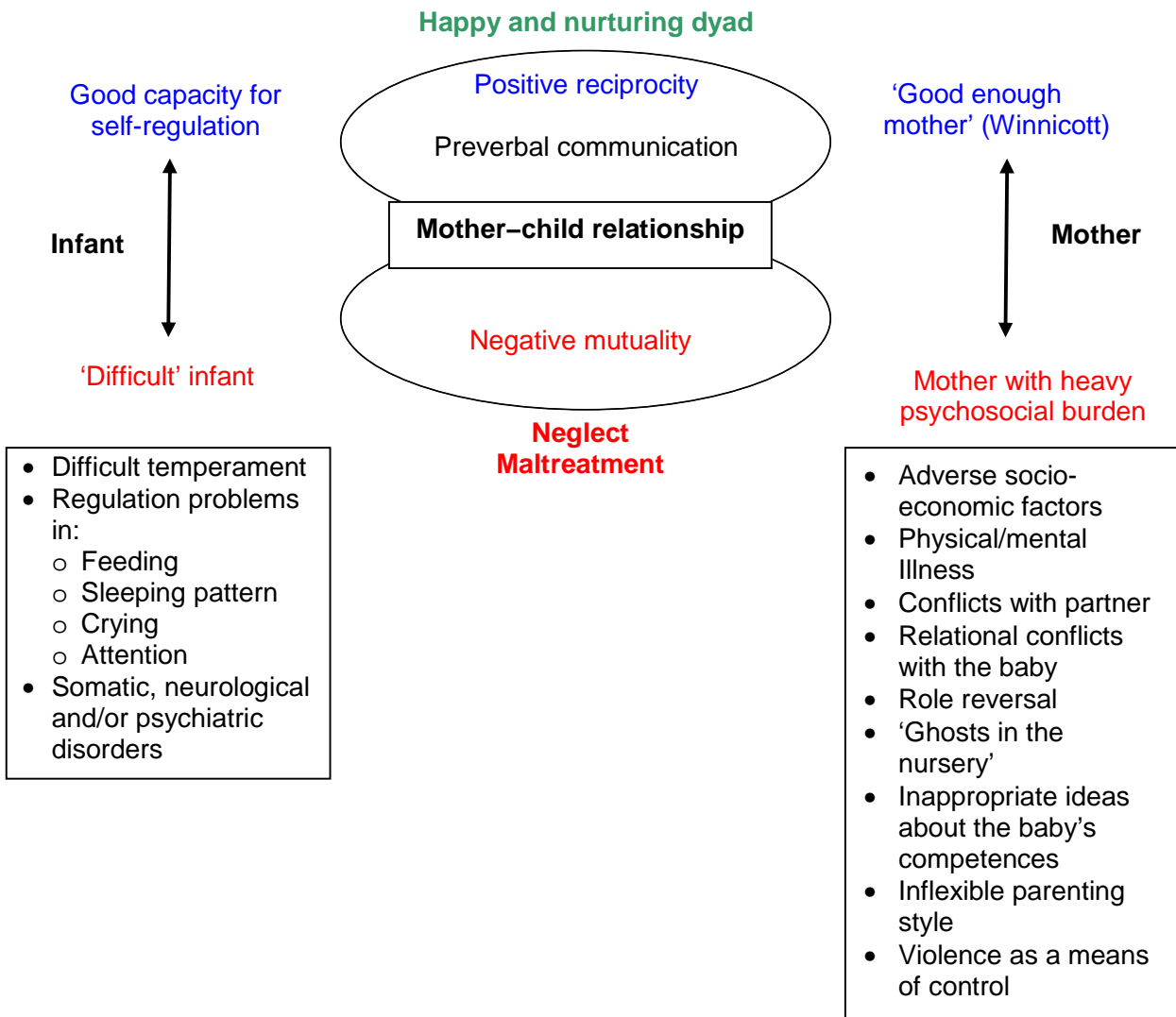
If the Intuitive Parenting Skills are sufficiently accessible, and the child possesses a basic ability of self-regulation, the mother–child relationship should show a flowing reciprocity. If, on the other hand, the infant

shows a difficult temperament or major difficulties in self-regulation such as feeding disorder, sleeping disorder or prolonged crying, the risk of a negative reciprocity developing between mother and child rises. In babies of drug-addicted mothers (who often also abuse tobacco), we find these regulation problems more frequently due to the babies' hyperexcitability after drug withdrawal. We often also find a – transitory – retardation of development. All this undermines their ability to respond properly to the mothers' interactional signals.

Even more pivotal are maternal stresses and strains and the social impact of drug addiction (see Figure 1). The most significant risks form two categories: socio-economic risks – poverty, unemployment, etc.; and health risks – physical and, even more importantly, psychiatric illness. Conflicts in partnership and post-traumatic flashes often destabilise the mother's psyche. 'Ghosts in the nursery' – cf. Selma Fraiberg's (1975) observations concerning the re-emergence of childhood conflicts at early stages of childbearing and after birth – and role reversal may lead to inappropriate developmental ideas and insecure attachment (Fonagy et al.,1993).

Recent neurobiological research showed that maternal stress will raise the fetus's cortisol level by transplacentar diffusion or epigenetic mechanisms. The stressed baby with regulation problems and insecure attachment will show a chronically elevated Cortisol level (Francis and Meaney, 1999). Cortisol has a negative effect on the development of brain structures like the hippocampus and the prefrontal cortex, which organize attention, impulse control, regulation of emotions, motivation and the self-concept. Thus chronic stress or even early trauma will most likely lead to behavioural and personality problems (Brisch, 2004).

Happy and nurturing dyad

Good capacity for
self-regulation

Positive reciprocity

Preverbal communication

'Good enough
mother' (Winnicott)

Infant

Mother–child relationship

Mother

'Difficult' infant

Negative mutuality

Mother with heavy
psychosocial burden

**Neglect
Maltreatment**

- Difficult temperament
- Regulation problems in:
  - Feeding
  - Sleeping pattern
  - Crying
  - Attention
- Somatic, neurological and/or psychiatric disorders

- Adverse socio-economic factors
- Physical/mental Illness
- Conflicts with partner
- Relational conflicts with the baby
- Role reversal
- 'Ghosts in the nursery'
- Inappropriate ideas about the baby's competences
- Inflexible parenting style
- Violence as a means of control

Figure 1. Possible outcomes for a mother–child dyadic relationship

All these stresses are likely to induce insensitive behaviour by the mother toward her infant, which means that the preverbal dialogue is frequently disrupted, and the child may be unable to establish the amount of self-regulation that could normally be expected at their age. Moreover, drug-addicted mothers tend to overstimulate the baby at times when they are alert and not using drugs. On the other hand, when they are using drugs, they are likely to understimulate or even neglect the baby. Thus, in both situations, the infant experiences a lack of self-effectiveness in making the mother respond to their communicative offers. This lack of affective tuning-in may, in the worst case, lead to depression in the child, or, at least, to an insecure attachment pattern. The child feels either dependent on the mother's actions, which are mostly unpredictable, or they derive their security only from self-stimulating activities. Thus, it is difficult for the

infant to feel safe – to perceive the mother as the secure base they need to begin exploration, to learn. Adequate maternal support and an increasingly differentiated, preverbal dialogue are essential prerequisites for the baby to learn self-regulation in many situations, beginning with the early adaptations, such as establishing day–night rhythms, regulation of crying, digestive adaptation to food, and subsequent progression to understanding and regulating emotions, regulation of attention and the emergence of capacities for executive functioning (Shonkoff and Phillips, 2000).

How can we detect disorders of preverbal communication? There are various warning signs in child behaviour (e.g. passivity, avoidance of human contact, feeding and sleep problems, as well as high levels of irritability). Warning signs in parental behaviour could be a pragmatic or rigid handling of the baby, few relaxed dialogues with the baby when he or she is open to communication, or inadequate stimulation of the baby (in general, too much or too little) as mentioned above.

Interactions within mother–child dyads: a controlled study

As part of a controlled study (2001–2005), I (as Professor of the Catholic University of Aachen and Child Psychiatrist in ECI Moenchengladbach) and two assistants (final year students and experienced mothers themselvses) investigated the interactions within 30 illegal drug-addicted mother–child dyads[3] (patients of various drug clinics, birth clinics, drug ambulances, community drug user support centres, etc.) compared with 31 control dyads who were not drug-addicted. Eighteen of the drug-addicted mothers were taking part in methadone programmes; 12 reported that they were clean of opiates. The control group consisted of two sub-groups: 15 dyads without any diagnosis, but with mothers who were taking part in a special parenting programme (PEKIP) on their own initiative; and 16 dyads with babies who were patients of an Early Intervention Centre (Kinderzentrum Mönchengladbach), mainly due to motor regulation problems. Mothers

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[3] In order to keep the complexity of the study design manageable, we investigated only the mother–child dyadic relationship. Of course, fathers also possess these skills, although in a slightly different way. In the very first months of life, they often contribute more indirectly by protecting, encouraging and supporting the mother–child dyad if present; later, they contribute strongly to the child's ability to explore through engaging with them sensitively through play.

with major problems in following a daily structure could not, understandably, be recruited for this study, and therefore there was a sample bias towards more positive dyadic interactions among the drug-addicted group than might have been expected if it the group was proportionally representative of the drug-addicted mother population. The babies were 6 weeks to 14 months old.

The following questions were investigated:

1. How does the baby cope with developmental adaptations?
2. How well do mother and child succeed in matching their interactions?
3. Are there typical interactional patterns in drug-addicted mother–baby dyads? Which attitudes do mothers show towards their child?
4. What is needed to prevent interactional vicious circles, developmental impairment and intergenerational transmission of the addiction-related patterns?

Methodology

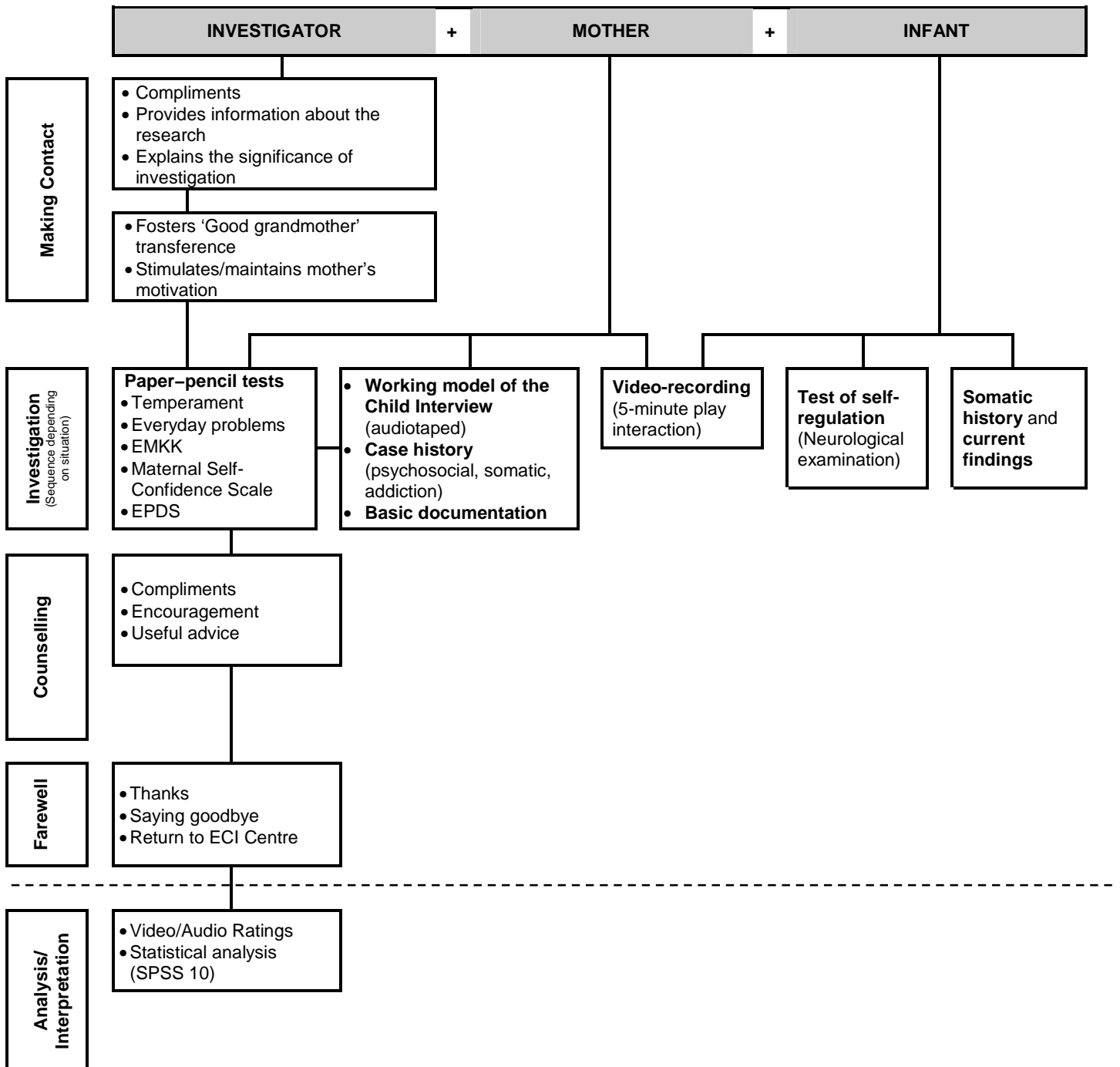We followed the procedure represented by the diagram below.

INVESTIGATOR	+	MOTHER	+	INFANT

Making Contact

- Compliments
- Provides information about the research
- Explains the significance of investigation

- Fosters 'Good grandmother' transference
- Stimulates/maintains mother's motivation

Investigation (Sequence depending on situation)

Paper–pencil tests
- Temperament
- Everyday problems
- EMKK
- Maternal Self-Confidence Scale
- EPDS

- **Working model of the Child Interview** (audiotaped)
- **Case history** (psychosocial, somatic, addiction)
- **Basic documentation**

Video-recording (5-minute play interaction)

Test of self-regulation (Neurological examination)

Somatic history and **current findings**

Counselling

- Compliments
- Encouragement
- Useful advice

Farewell

- Thanks
- Saying goodbye
- Return to ECI Centre

Analysis/ Interpretation

- Video/Audio Ratings
- Statistical analysis (SPSS 10)

Figure 2. Diagrammatic representation of research methodology

Results

Drug-use status of mothers

As can be seen from Table 1 below, drug use among those addicted had diminished dramatically during pregnancy, although the use of tobacco and methadone (probably as substitutes) had risen equally dramatically. Almost all the women in this group had stopped drinking during pregnancy, but only a very few had stopped smoking, which is alarming considering the developmental risks to the baby from tobacco use.

Table 1. Present and historical drug use/abuse by mothers in the drug-addicted and control mother–child dyads

Addiction/abuse	Drug-addicted client group (n=30)		Control group (n=31)	
	Historical use/abuse (n)	Present use/abuse (n)	Historical use/abuse (n)	Present use/abuse (n)
Alcohol	14	1	1	0
Tobacco	4	**24 ***	5	2
Cannabis	18	6	1	0
Heroine	24	0	0	0
Methadone	6	18	0	0
Cocaine	27	0	0	0
Pharmaceuticals	13	0	0	0
Designer drugs	12	0	0	0
Other	13	0	0	0

*This value is in bold to emphasise the high incidence of tobacco abuse as an additional health risk for the child.

Life circumstances

Most mothers who used drugs lived in a problematic socio-economic situation: 83% were on welfare; 50% had no occupation; and 60% had delinquency problems. At the time of the research, 60% suffered from severe physical illnesses, such as Hepatitis C, cardiac or intestinal problems. 63% of the drug-addicted mothers had suffered physical or psychological maltreatment or sexual abuse, compared with only 6% of the control mothers. These experiences correlated with depression as measured by the Edinburgh Postnatal

Depression Scale (EPDS; Cox et al., 1987) (Spearman's rho (r_s)=.486) and 'insensitivity to the infant's needs' (trs: 'Unempfänglichkeit für kindliche Bedürfnisse') (r_s=.530).

Pregnancy, birth and first postnatal months

There were no significant differences between the groups, except for breastfeeding: only a very few drug-addicted mothers breastfed their babies, even for a very short time. In Germany, mothers who use methadone are still frequently advised not to breastfeed, although the perceived risk of doing so does not have a solid, scientific basis today. Indeed, there are more specialists who think that the disadvantage of the opiate transferring to the baby is less important than the positive effect on attachment-fostering interaction during breastfeeding (Kästner et al., 2007). Most of the babies of drug-addicted mothers had to stay in the paediatric hospital for several weeks following birth while they were going through opiate withdrawal, which put an additional strain on the mother–child relationship.

Making contact with mother and child – the 'motherhood constellation'

This study took place in the field of early intervention and social work, and therefore had to meet the conditions of this environment. This also meant that clients did not differentiate between the research relationship and a typical client–professional relationship. A neutral or detached research stance would not have been appropriate. Even during these comparatively short contacts between mother and researcher (about two hours) transference and counter-transference processes took place. Inevitably, co-regulative sequences between mother and researcher occurred, which had to be noted and reported right from the beginning. In many cases, we found confirmation of Daniel Stern's hypothesis of the 'good grandmother' transference from the mother to the researcher. This translates well to the circumstances of a young mother who finds herself in a triadic situation with her own mother. In this scenario, there are two maternal perspectives: one where both women adopt a maternal attitude towards the baby, and a second where the grandmother looks upon both the baby and her daughter as her children. Daniel Stern (1995) calls this the 'motherhood constellation'.

Soon after a woman becomes a mother, her focus on her baby and her baby's needs has several related themes:

- A life-growth theme – her concern for the growth and development of her baby
- A primary relatedness theme – her emotional engagement with her baby
- A supportive matrix theme – ensuring the development of support systems for her baby
- An identity reorganisation theme – a transformation of her self-identity to permit and facilitate these functions.

Stern stresses how a mother 'desires to be valued, supported, aided, taught and appreciated by a maternal figure'. She wants a 'good grandmother' to help her, to take care of her and to validate her new status as a mother herself. Like all transferences, when the transferring person has unresolved conflicts, traumatic experiences and unsatisfied longings in this area, this is expressed through a dramatic and intense dynamic.

Table 2: Physical, mental and sexual abuse

	1. Physical abuse in family	2. Child maltreament	3. Mental abuse	4. Neglect	5. Sexual abuse	None
Controls	1	0	2	1	0	29
Drug Clients	14	11	14	8	11	11

For this reason (as evidenced by the research), the drug-addicted mothers solicited the researchers more frequently than the control mothers for concrete advice on parenting, feeding, handling, etc. Such a situation could provide an important opportunity for professionals in early childhood intervention to establish a supportive relationship with their clients, as will be shown later in this chapter.

After the first encounter between researchers and participants, we made video recordings of the mother–child dyads engaging in interactive play. At this early stage, it was perhaps easier for the mothers to be task-oriented than later when their relationship with the researcher had become more important.

We answered the initially posed questions as follows:

1. How does the baby cope with developmental tasks? [4]

The following conclusions are drawn from the anamnestic interviews, basic documentation, the temperament questionnaire Infant Characteristics Questionnaire (ICQ), Form A (Bates, 1979, 1987), the form 'Everyday problems' (Papoušek, 2001) and the findings from the test of self-regulation.

The babies of drug-addicted mothers were much more 'difficult' than the babies in the control group. Their mothers mentioned symptoms of a tactile-kinaesthetic disorder significantly more frequently, notwithstanding that the babies from the control subgroup 'Kinderzentrum' commonly received physiotherapy for these disorders. In addition, the babies of drug-addicted mothers were more irritable and were less able to modulate arousal (as evidenced by their anamnesis). This can partly be explained by the foetal drug exposure, but, as shown later, this may also be a question of maternal responsiveness, which is an additional risk factor for disturbance in the development of these children's self-regulation and attachment.

2. How do mother and child succeed in matching their interaction?

To evaluate this aspect, we decided to video a five-minute play interaction. The mother was instructed to amuse herself and her baby by playing together as they usually would on a play-mat either on the floor or on a physiotherapy table in the early childhood intervention centre. The researcher used a hand-held camera, positioning it so that the baby's face was in focus and the mother's face was reflected in a mirror behind the baby. Thus, the facial expressions of both mother and baby could be watched simultaneously without having to use two cameras and a split screen display. Any initial unease or shyness on the part of the mother was soon resolved by the baby's unselfconscious presence – as confirmed by the mothers' responses when asked if this play situation was typical of their everyday experience with their baby.

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[4] Developmental tasks are well defined by R.J. Havighurst (e.g. *Developmental Tasks and Education* (McKay, 1972)).

After rigorous training, the video-based, interactional diagnostics turned out to be an uncomplicated instrument for collecting data which was easily analysable, and provided useful information for resource-oriented counselling and developmental support. We used two different scales during analysis: the Munich Communication Diagnostics (Papoušek and Papoušek, 2002) and the mother–infant playing scale (Chatoor et al., 1997, trs. Pal, 1998).

The Intuitive Parenting Skills (Papoušek and Papoušek, 2002) were highly negatively correlated with irritability of the baby ($r_s=.427$) and with an unhappy childhood of the mother ($r_s=.405$). They were also significantly less apparent in the dyads where the mother was drug-addicted ($p<.000$). In this group, we found much more intrusive behaviour and inappropriate, dysregulating activities from the mother ($p<.000$). The responsiveness (dialogische Abstimmung) was much lower than in the control group ($p<.000$).

The Chatoor/Pal scale consists of four sections, each describing a major aspect of mother–infant interaction:

- Reciprocity (Wechselseitige Bezogenheit)
- Insensitivity to the baby's needs (Unempfänglichkeit der Mutter für die Bedürfnisse des Kindes)
- Conflicts in the relationship (Konflikte in der Mutter-Kind-Beziehung)
- Intrusiveness (Aufdringlichkeit der Mutter).

Again, the differences between the dyads with drug-addicted mothers and the control dyads were highly significant (between $p=.000$ and $p=.002$). The mothers who were using methadone were more intrusive and less responsive compared with mothers who were former drug users but currently clean; the results for the 'Kinderzentrum' (EIC) control mothers showed they had more dyadic conflicts with their babies than the non-Kinderzentrum control mothers (Mann-Whitney *U* test: $p=.033$), which can easily be explained by the normal stress associated with early childhood interventions: having a more 'difficult baby'; the need for physiotherapy whether the baby is amenable or not; feelings of guilt, etc.

Figure 3. EPDS depression scores for drug-addicted and control group mothers
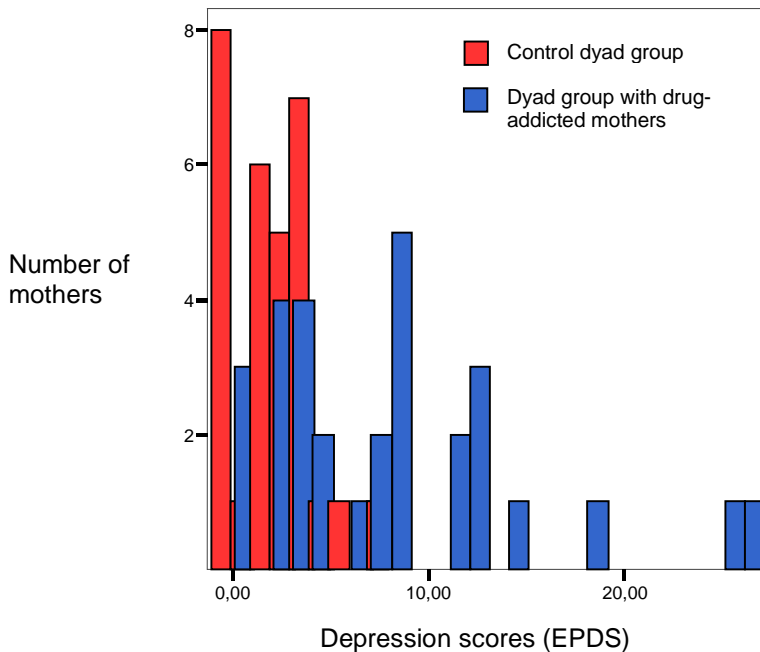
The graph shows the EPDS depression scores within the two groups. This may give one explanation for the reduced emotional availability of the drug-addicted mothers compared to those in the control group. EPDS scores of 12 and above indicate increasing severity of depression, which means that 23.3% of the drug-addicted mothers were currently suffering from clinical depression. The same number scored a subclinical depression.

Since none of the mothers were noticeably intoxicated at the time of the investigation, and had tried their best with their babies, we can assume that during times of negative emotion, or if they were using drugs, their emotional availability for and responsiveness to their infant might be even poorer.

3. <u>Are there typical interactional patterns in drug-addicted mother–baby dyads? Which attitudes do</u>
   <u>mothers show towards their child?</u>

The exploration of maternal attitudes was carried out using various diagnostic instruments. The 'Working Model of the Child Interview' (Zeanah et al., 2000) allows assessment of the relational quality between a

mother and her baby through analysis of the mother's narrative, generated during a semi-structured interview (45–60 minutes). The results demonstrated clear differences between the groups in several dimensions. Especially important was the dimension of 'coherence', which indicated the level of ambivalence and contradiction during the narration both in content and in non-verbal communication. In attachment research, 'coherence' is an important indicator of the quality of attachment. For example, a poor narration which lacked detail would indicate an insecure–avoidant attachment.

Both criteria – differences in attitudes and coherence of the narrative – applied to the drug-addicted mothers (p=,000). They worried much more about their children, felt less joy when they were with them, and proved to be less sensitive and involved. On the other hand, they showed a greater sense of guilt than mothers in the control group. Overall, the mother–child relationship described by the drug-addicted mothers seemed insecure and unbalanced. Their preoccupation with their own burdened life situation, combined with probable insecure attachment representations, make these attitudes understandable. These mothers were less emotionally available for their babies, but, at the same time, they put their greatest hope in their child as a precursor of a new life. Almost all drug-addicted mothers, but very few of those from the control group, answered the question, 'How did your baby change your life perspective as a woman?', in the following ways:

- 'A significant change in my life perspective'
- '[I knew I had] to become adult, to take responsibility'
- '[My baby brought] new meaning and new aims for my life…[he is] "the pure hope", almost as an analogy for the newborn Jesus: "the redeemer is born, he will save me from misery, take away guilt and give [me back my] future…"'

To a certain extent, this applies to any new beginning – the chance to enhance life, to have loving relationships – but, on the other hand, for these mothers the danger of failure was especially close if there was a lack of support or a negative social context. Obviously, pregnancy and the first year of life with a

baby are particularly vulnerable periods, especially for the drug-addicted group of mothers, and sensitivity was needed in the implementation of support and assistance for these mothers.

The Questionnaire for the Investigation of Maternal Attitudes for Mothers of Infants and Toddlers (EMKK) (Codreanu and Engfer, 1984) captures important attitudes of the interviewed mothers in nine subscales, among which are 'Rigidity', 'Tendency to punish', 'Unhappy childhood', 'Excessive demands' and 'Frustration tolerance'. In most of these subscales, we found highly significant differences between the two research groups, proving that the drug-addicted mothers were substantially more exhausted, full of self-doubt, and that they experienced feelings of helplessness with their child which were also reflected in their actions. Their interactions with their child tended to more inflexible and non-responsive, and they had a much higher tendency to punish their child than mothers from the comparison group. These tendencies correlated with the experience of an unhappy childhood.

Compensating for their insecurity in relationships and education, they tended to be overprotective and intrusive towards their baby, while expecting at the same time to receive consolation, love and care from the baby to counterbalance their feelings of loneliness and unsatisfied emotional needs. Murray et al. (2003) found in their study that the self-perception of the drug-addicted mothers was significantly more depressive, which contributed considerably to an insecure attachment. They also found that if drug-addicted mothers had received any psychotherapy, their children were much less disturbed at the age of 5 years than those children of mothers who had not received psychotherapy.

The last domain assessed was the global function of the dyad. Two scales were used:

- Mary Ainsworth's Maternal Sensitivity Scale (Ainsworth, MD 1973, 1971): a five-stepped assessment of the mother's ability to respond to her baby's needs (9 = highly sensitive, 1 = highly insensitive)

- The Parent–Infant Relationship Global Assessment Scale (PIR-GAS; Zeanah et al., 2000): a supplement to the Zero to Three Classification, Axis II (personality disorder/mental retardation) (National Center for

Infants, Toddlers, and Families, 1994) which measures the relationship between the infant or toddler and its primary caregivers from 'well adapted' (90 +) to 'grossly impaired' (10).

Table 2. Global function of the dyad and maternal sensitivity

t test		N	Mean	SD	p=
PIR-GAS	Control dyad group	31	83,97	6,457	
	Dyads with drug-addicted mothers	30	67,00	12,006	**.000**
Ainsworth Maternal Sensitivity Scale	Control dyad group	31	7,65	,915	
	Dyads with drug-addicted mothers	30	5,60	1,545	**.000**

Both parameters show that the efficiency of the dyad in respect of a free and secure development of the mother–infant relationship is severely disturbed in the drug-addicted mothers.

Conclusion

The results of this study show how endangered the infants of drug-addicted mothers are right from the beginning of their life. Not only are they at risk of transplacentar damage from the drugs absorbed by the mother, especially from concomitant use, but also, in particular, from stress hormones such as cortisol which have a negative, long-term effect on the baby's brain structure. There are strong indications that maternal stress during pregnancy results in a poor capacity for self-regulation in the baby, as well as non-responsive, intrusive or neglectful behaviour of the mother postpartum (Wurmser, 2007).

Following the birth, the effects of the mother's oscillation between behavioural extremes may be an additional factor leading to impairment in the child: as mentioned above, without drugs or during opiate withdrawal, mothers tend to be overactive, maybe intrusively handling the baby, whereas fully drugged they tend to be unresponsive and insensitive. Thus, the baby cannot build up a consistent framework of expectations, which is essential for establishing any attachment strategy. This also leads to a higher cortisol

level. All these risks are predictive of a disorganised attachment pattern which itself heightens the risk of later 'self-medication' with cannabis and/or opiates in order to self-calm and self-stimulate simultaneously.

4. What is needed to prevent interactional vicious circles, developmental impairment and intergenerational transmission of the addiction-related patterns?

Many studies have shown that sensitive or insensitive parenting during the first months of life plays a key role in the emergence of secure or insecure mother–baby attachments at the end of the infant's first year. Parental sensitivity is the ability to perceive and interpret children's non-verbal and verbal expressions correctly and respond to these signals promptly and appropriately. Attachment to a protective caregiver helps infants to regulate their negative emotions in times of stress and distress, and to explore the environment, even if it contains somewhat frightening stimuli. As is shown in this study, there is a high risk of mismatch or even failure in the early interactions of an opiate-affected mother and her baby child, compared to non-drug using mothers. Early preverbal interaction is the precursor of a secure or insecure attachment pattern and the end of the first year of life.

Right from the beginning, attachment relationships are the predominant and most influential relationships in a child's life. They set the stage for emotional and cognitive interpretations of social and non-social experiences, for language development and for acquiring knowledge of oneself and others. Attachment relationships continue to influence thoughts, feelings, motives and close relationships throughout life.

> *If, during interactions with parents, the child experiences acceptance, sensitive responsiveness to distress and appropriate challenges during exploration and cooperation, a secure model of a relationship is carried forward to other relationships in childhood, adolescence and young adulthood.*
> (Grossmann and Grossmann, 2007)

The mother–child relationship develops in a dynamic adaptive process as a functional unit. As Winnicott (1957) famously said, 'There's no such thing as a baby,' meaning that the baby's existence at this stage can only be thought about, observed and nurtured in association with a primary caregiver, in a dyad. The dyad is

supported by effective feedback signals released by both the infant and the adult. On the baby's side, their appearance, eye-contact and their social smile are stabilising factors. On the mother's side, her self-confidence, self-esteem and ability to give unconditional emotional exchange and care are key factors in the appropriate regulation of her own thinking, feeling and behaviour. This suggests that any intervention has to target primarily the mother.

The drug-addicted mothers are special in two additional aspects: First, there might be a genetic predisposition for arousal regulation dysfunction rendering it likely that they will turn to illegal drugs as calming and/or stimulating agents. Second, if parents are poorly regulated themselves, they hardly can be expected to be a good role model for their babies in that matter, so they might themselves need help and education in controlling arousal.

Given the pivotal role of attachment in children's development, various types of intervention are used to help parents develop secure affective bonds with their children. Many interventions focus on improving parent/caregiver sensitivity. Daniel Stern's 'Good grandmother' transference can be an appropriate and effective model for developing a supportive relationship in early intervention settings for drug-addicted mothers. These women need support from direct, emotionally close relationships formed with professionals who can provide the structure and education they need, and who are sufficiently able to control their countertransference. Ideally, such a relationship should begin during pregnancy and last as long as possible. This is a very different model to the relationship paradigm more common in drug rehabilitation that emphasises the need to maintain professional detachment and boundaries. This stance was originally established as a consequence of the intrusive, demanding and sometimes clinging behaviour of drug-addicted clients. Berger et al. (2003) showed that an interdisciplinary, comprehensive care programme for young drug-addicted mothers could improve the psychosocial development of their infants, especially those whose mothers managed to stabilise their life situation within a social network which included relatives, partnership and employment. These women also benefited more from sensitivity training with their babies. Once again, the age-old adage, 'It takes a village to raise a child,' proves to be true. However, about 50% of

the children from Berger et al.'s study were found to be placed out-of-home at the end of their first year of life. This number is comparable to figures from most other studies.

Since most babies of drug-addicted mothers are presented to an Early Childhood Intervention Centre for the treatment of irritability, tonus problems or coordination problems, there might be opportunities not only to provide functional therapy, but also to strengthen the dyad and enhance the mother's sensitivity. Professionals should try to understand the mother's situation and assist her towards competent parenting. This will help the infant more than if a professional fixates on their somatic issues and sees the possibly 'difficult' mother as a mere obstacle to the infant's development.

Bakermans-Kranenburg et al. (2003) investigated the effectiveness of preventive or therapeutic interventions which aimed at enhancing parental sensitivity and children's attachment security. Seventy studies were traced, producing 88 intervention effects on sensitivity (n=7,636) and/or attachment (n=1,503). Randomised interventions appear to have been fairly effective in changing insensitive parenting and infant attachment insecurity. The most effective interventions used a moderate number of sessions and a clear-cut behavioral focus when working with families with, as well as without, multiple problems. Interventions that were more effective in enhancing parental sensitivity were also more effective in enhancing attachment security, which supports the notion of a causal role for sensitivity in shaping attachment. It is encouraging that therapeutic interventions really help and that insecure attachment patterns can be changed into secure ones.

How can early childhood intervention services support the drug-affected mother–child dyads?
The fostering of responsive parenting and secure attachment must be a focal issue. To accomplish this, mothers (and, of course, also fathers if available) may need help in six areas:

- Understanding child development in general: what babies can do at different ages
- Understanding the individual child's specific signals of emotional well-being and distress, especially if the child has special needs

- Training in responsive parenting and adequate arousal regulation

- Organising sufficient time for sensitive interactions

- Finding an adequate, substitute caregiver for times when the mother cannot care for the young child themselves, and encouraging her to recognise when this help is needed

- Understanding their own personal history, including attachment problems resulting from their own childhood, as well as integrating traumatic experiences. This will include, in most cases, psychotherapy or counselling from a different person to the early childhood intervention professional.

Inadequately handled babies often react very positively to responsive and sensitive contact from the therapist. Professionals should respect the mother's feelings of shame. They often need relief, not higher demands. It is important to strengthen the mother's competences, not to demonstrate that the professional can do better. Therapeutic actions should therefore include the mother.

All this is impossible without rigorous training of the early childhood intervention worker. There is a need to train service providers in the use of proven attachment-based techniques and in recognising atypical behaviours linked to disorganised attachment. Some programmes are already well evaluated. Being developed for high-risk populations in general, they can also be successfully implemented in early childhood intervention with drug-addicted mothers and their infants. In Germany, Ziegenhain et al. (2004) presented the 'Entwicklungspsychologische Beratung für junge Eltern', a comprehensive, video-based programme to raise maternal sensitivity and counsel young parents. Keywords of this programme are: 'To see, to understand, to act…'. In the Anglo-American sphere, the STEEP programme (Erickson and Egeland, 2002) is the most widespread approach. It evolved from the high-risk population Minnesota Parent–Child Project, a longitudinal study that started in 1975 and is now already investigating the second generation. A newer, also successful, approach is Marvin's (2002) 'Circle of Security', an excellently conceived programme, based on easily understandable metaphors, and designed as a group intervention.

The large and increasing number of impaired parent–child relationships proves the necessity of new approaches in early childhood intervention. Exemplified in this study of drug-addicted mothers and their

babies, we demonstrated that professional relationships and interventions should take into consideration that it is primarily the mother who needs support and education in order that the baby can develop into a fully capable child, adolescent and adult, who can competently self-regulate and is capable of forming empathic, loving relationships with others.

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CHAPTER 8

An inclusive early intervention programme: the case of two pre-schoolers

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Introduction

In the culturally diverse inclusive settings of contemporary Western societies, typically developing children and children with or at risk of developmental disorders, either native-born or of minority origin (i.e. from a language, social or ethnic minority background) can be found learning together. However, although the inclusive education movement represents the emergence of empowered voices advocating for disability rights and better educational services for this population, the same movement has been rather silent about the plight of children from minority backgrounds (Artiles, 2000).

The literature and practices on inclusion tend to ignore sociocultural issues, and focus instead on diversity of ability between students (Bos and Fletcher, 1997; Pai, 1990). However, the marginalisation of ethnic, social, linguistic and gender differences is deeply troubling, given the obvious presence nowadays of ethnic and linguistic minorities in the special education system. It is also troubling given the 'cumulative risks' (Vernon-Feagans et al., 2006) that children from minority backgrounds face. The risk factors for them involve not merely the difficulty of acquiring the mainstream language of the society they live in, but also the complex dimension of sociocultural status, which comprises variables such as parental education, occupation, income and attitude towards knowledge acquisition, and consistently correlates with developmental disorders emerging in preschool years. Such factors significantly reduce school readiness and increase the risk of poor academic achievement later in school years (Anderson-Brantlinger and Guskin, 1987; Diaz, Padilla and Weathersby, 1999; Sameroff et al.,1987; Skiba et al., 2005).

In order to compensate for this 'double disadvantage' (Mir, Nocon, Ahmad and Jones, 2001) emphasis has lately been placed on early childhood intervention – that is, a remedial process which operates from a holistic perspective of the child within

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their family, school and sociocultural environments from an early age (0–5 years), and involves relevant professionals and the family in transdisciplinary evaluation, assessment and interventions which unfold, support and empower the child, the family and the service providers within the child's life context (Soriano, 2005). We now know with virtual certainty that the quality of the environment in which young children spend their early years has a critical influence on their capacity to develop an adequate foundation for later learning, as well as for emotional regulation (Zigler, 2000). This is why early intervention for young children at risk of developing a special need is nowadays considered to be necessary, as it can remediate existing developmental disorders or even prevent their occurrence. An important implication of the above observations is the pressing need to bring to the fore – through empirical research – the issue of sociocultural diversities in special education, in order to better inform future analysis of inclusive education and early childhood intervention (Gay, 2002).

The training and education of children with special needs is a complicated process both in terms of educational setting and educational content. As far as the educational setting is concerned, it is clear that the inclusion approach has prevailed. This means that mainstream classrooms are consistently 'opening up' to include all children irrespective of their differences and diversities. As far as the educational content is concerned, there have been several attempts to deal with the curricula-related problems that these children face through individualised programmes, which however are often incompatible with the educational setting.

Initial discussions about the 'inclusion' initiative began in the USA and Europe as early as the 1980s (Ferguson, 2008). A central argument has been that education for children with disabilities ought to be as close to mainstream education as possible. A primary rationale behind the implementation of the inclusive approach in special education can be found first of all in the 'rights and ethics' stance which supports the view that individuals with disabilities have the fundamental human right to be educated, ideally alongside non-disabled peers (Dyson, 1999). This basic right is grounded in the ethical principles of fairness and social justice (Lipsky and Gartner, 1999; Skrtic, 1991). A more practically oriented rationale, still closely aligned with rights and ethics, behind the need to adopt the inclusive approach has been that it provides greater opportunities for the development of cognitive and other developmental abilities, as well as social skills, than would occur in traditional special education settings (Odom, 2000). This is because the inclusive approach entails

global diagnostic evaluation and the implementation of an educational programme that takes into account not only factors regarded as necessary by the curricula but also existing sociocultural differences and diversities.

The main idea behind inclusive education has been encapsulated in the Salamanca Framework of Action, which states that all children should learn together, wherever possible, regardless of any difficulties or differences they may have (United Nations Educational, Scientific and Cultural Organisation (UNESCO), 1994). Nowadays, there are several initiatives to expand the mainstream classroom, in order to place all children in one inclusive setting.

Inclusive education can provide greater opportunities for learning and development when it is provided from early years. Given the cumulative nature of the educational system, what happens at the very beginning of elementary school sets the stage for everything that comes later (Crosnoe, 2006). If global evaluation is carried out and underlying developmental disorders are screened at an early age, then it is possible to regulate them with appropriate intervention before children start formal schooling. This explains why placement of young children with or at risk of developmental disorders in inclusive settings is today a major aspect of recommended practice in early childhood intervention (Sandall, McLean, Santos and Smith, 2000). Although many debates over the years have revolved around the benefits and challenges of inclusive early childhood intervention educational programmes (Fox and Hanline, 1993; McLean and Odom, 1993; Peterson and Beloin, 1998), an inclusive setting for preschoolers at risk of developmental disabilities is no longer a rarity.

Despite the acceptance and expansion of inclusive services provided in early childhood, questions remain regarding how those services should be provided to allow sufficient learning opportunities for young children with or at risk of developmental disorders and to ensure the development of important cognitive and social skills in these children (Hauser-Cram, Bronson and Upshur, 1993). These questions become more pressing when preschoolers from minority backgrounds with or at risk of developmental disorders are involved.

Sociocultural issues in inclusive education should be given due attention as they should be considered neither statically (as far as time is concerned) nor uni-dimensionally (as far as space is concerned). The inclusion approach has focused primarily on *spatial practice* and *physical/perceived space* (i.e. the mainstream

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education classrooms and the activities and behaviours occurring within them) and has used mainly *single time scales* (i.e. certain ages or grade levels) when examining the impact that placement in the physical contexts of mainstream education classrooms can have on the learning and development of children with disabilities (Artiles, 2000). Although it is important to study the physical spaces in which students are placed, and the academic and social outcomes deriving from this placement, it is also necessary to obtain detailed accounts of the organisational *practices* (e.g. school funding, staffing) and instructional *processes* (e.g. level of teacher expectations, teacher–student interaction patterns), which construct these outcomes (Harry and Klingner, 2006). Therefore, such outcomes should be examined from a *holistic perspective* – that is, by taking into account the history of the cultural group the child being studied belongs to, the history across their individual lifespan and the history of their moment-to-moment lived experiences – by looking at how all these time-levels intertwine and contribute to certain academic and social outcomes. In this way, it is possible not only to see how an individual child develops, but also whether they reproduce or transform cultural patterns that are believed to be transferred from one generation to the next (Wong and Johnson-Kowley, 2001). In general, by looking at sociocultural issues in early childhood inclusive education through a more contextual and continuous lens, researchers and practitioners will become more aware of the difficulties that children from minority backgrounds experience from a very early age, and will feel compelled to help overcome them in order that all children – majority and minority, typically developing and those with disabilities – are able to derive maximum benefit from an early intervention inclusive programme.

Methodology

The aim of the present research study was to examine how cognitive and sociocultural factors interacted and influenced the progress of two children in an early intervention inclusive educational setting. The study not only took into consideration the diversity of the children's abilities, but also brought sociocultural issues to the fore, since the children participating in the research originated from two different sociocultural backgrounds and, according to the nursery school teachers, had not managed to achieve school readiness in the course of the year.

The research consisted of three phases: (1) the diagnostic procedure comprising (a) the history of each child, which gave information about their psychosocial traits and global development, (b) an evaluation of their cognitive and verbal abilities, and (c) a

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dynamic assessment; (2) the early childhood intervention educational programme (inclusive and specialised); and (3) the evaluation of the programme. In all three phases, *transdisciplinary research teamwork* was implemented, during which several professionals of different disciplines assessed the child from their own professional perspective (e.g. educational, psychosocial) and then through collaborative teamwork. In all three phases, parents became truly equal partners of the transdisciplinary team, contributing to the comprehensive diagnosis and to the design of a specialised inclusive curriculum for the child (McCormick and Goldman, 1988; Orelove and Sobsey, 1991; Rainforth, York and McDonald, 1992).

The two boys involved in the research attended the kindergarten class at the Children's Centre of the Aristotle University of Thessaloniki. Every year this Centre accepts approximately 150–170 children, aged 2.5 to 6.5 years, whose parents are University students or members of the academic or administrative staff. The Centre, which has been operating for approximately 20 years, is supervised by the School of Preschool Education Sciences. During the past years, the Centre has also accepted children with developmental disorders, providing them with intermittent, individualised support from postgraduate students in Special Education under the supervision of specialists from the Department of Psychology and Special Education.

During the school year, 2007–2008, the Children's Centre launched an Early Intervention Service involving the early childhood intervention teachers, a clinical psychologist employed at the Centre and other specialists from the Department of Psychology and Special Education. The Early Intervention Service is run by the Centre's President, who is a professor of school psychology in the Department.

During this time, 12 children with developmental disorders have joined the Centre's Early Intervention Programme. The research team carried out a thorough evaluation of this group, and selected two boys for the purpose of the research. The boys were aged 4.5 and 5.5 years respectively, with mild intellectual disabilities, yet with different individual profiles. The boys differed in terms of the language and achievement difficulties they manifested in the class. They also came from different sociocultural backgrounds: the older boy, named D., was a minority, non-native speaker of Greek, and originated from a low sociocultural context (his mother had suspended her studies at the University and his father had secondary-level education); on the other hand, the younger boy, G., was a native speaker and originated from a high sociocultural context (both parents were University

professors). Despite the age difference, both boys were attending the same class because, according to Greek educational legislation, children from minority ethnic backgrounds may prolong their stay in kindergarten in order to ensure psychosocial readiness before they enter formal schooling, even if they are at no risk of developmental disorders.

Diagnostic procedure

During the pre-kindergarten year, erroneous perceptions had been formed among the boys' teachers as to the reasons underlying their emerging language and achievement problems. More particularly, the teachers had attributed all the problems D. had started manifesting in class (i.e. language difficulties and limited attention span) to his 'foreignness' and especially to his mother-tongue. At the same time, they had attributed the speech and achievement problems of G. either to a personality disorder or an underlying autistic spectrum disorder. His teachers had assumed that the child was unlikely to have developed any type of intellectual disability, since his parents were both university professors, and therefore the boy had been raised in a highly intellectual context. This could explain why, while trying to understand his symptoms, the teachers had focused on any other factor apart from a developmental disorder.

Towards the end of the pre-kindergarten year, the teachers had been faced with the dilemma of either allowing the children to advance to the kindergarten level or suggesting that they repeat the pre-kindergarten class. Ultimately, they decided to initiate *pre-referral procedures* – that is, to meet with the research team of the academic board of the Children's Centre to discuss the nature of the children's problems so as either to modify instruction and the mainstream curriculum or to place the children in a special educational inclusive setting.

The pre-referral process recognises that many variables affect behaviour and learning, rather than first assuming that the difficulty lies within the student. The research team and the teacher look specifically at what single or combined variables (e.g. classroom, teacher, student characteristics) might be affecting a particular student. Examining student records and work samples, and conducting interviews and observations, contribute to the research team's investigation. These data gathering approaches are intended to specify the manifested problem more precisely and to document its severity. Modifications to the teacher's approach, the classroom,

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or the student's activities may then be suggested, attempted and documented. It is important for teachers to keep track of the specific modifications they attempt with a child who is having trouble learning or interacting because these can provide valuable information to the research team (Shin, 1998).

- **Interviewing**

Initially, the research team conducted interviews with parents, teachers and the Director of the Children's Centre to get the developmental and psychosocial history of the children.

The child named G. lived with his parents and two siblings – his elder sister and his twin sister (the twins had been conceived by *in vitro* fertilisation). At the age of 2 years, G. had been able to say very little, so the parents had first consulted a child psychiatrist who had diagnosed the child as being at risk of autistic spectrum disorder (a diagnosis which the parents had not initially disclosed to the Children's Centre), and had referred them to a speech and language therapist to address the child's emerging language difficulties. As academics, the parents had high expectations of their son, and, on their own initiative, they also carried out various cognitive exercises and curriculum activities at home with him in addition to the speech therapy sessions.

The child named D. lived in a more extended family which comprised his parents, his two brothers (D. being the eldest of the three) and his grandparents on his father's side. These grandparents lived nearby, and had very frequent contact with the children and an active involvement in the family's decisions – a traditional family structure still common among this cultural group. The mother, a Russian, had suspended her studies at the Greek university by the time the present research began. The father had been born in Russia of Greek minority parents and spoke a particular ancient Greek dialect. The family had been living in Greece since the early 1990s, and all three children had been born in Greece. The child's father had acquired his secondary education in Russia.

Both parents had high expectations of the boy, not so much in terms of school performance and academic achievement, as in the case of G., but in terms of bilingual attainment, which means they anticipated that the boy would easily become fluent in both Russian and Greek. When, at the age of 3 years, the child's difference became obvious, his mother appointed a speech and language therapist of the same

ethnic origin as the father, and who could speak both Russian and Greek, to work with the child in the Greek language for approximately one year. The speech and language therapy did not bring about any notable changes, which is why the child's mother decided to suspend the sessions. Almost two years later, he took up drawing lessons and also started receiving an alternative form of speech and language therapy – the so-called Padovan therapy, which includes two methods of neurofunctional reorganisation: one for speech and the other 'corporal' (Padovan, 1995). It is worth mentioning that D.'s younger brother, who was also exposed to this diverse language context and attended the same Children's Centre as D., had not manifested any language difficulties at all.

- **Cognitive-psycholinguistic testing**

Apart from the interviews with the parents and teachers, two tests were used to assess the boys' cognitive and language levels: the Illinois Test of Psycholinguistic Abilities (ITPA) and the Test of Language Development (TOLD-P:3).

The ITPA (Kirk and McCarthy, 1961) is a test which measures cognitive-psycholinguistic abilities in children aged from 2 to 13 years old. The test, which includes 12 subtests, is based on the information processing approach and covers three major areas: (1) channels of communication (auditory-vocal and visual-motor); (2) psycholinguistic processes (reception, association and expression) and (3) levels of organisation (representational and automatic-sequential). This test was selected first because it had been standardised in Greek, and therefore it could be reliably administered, and second because it is relatively culture-free, since it examines everyday knowledge and basic skills. Another reason for selecting this test was that it could provide the basis for the design of remedial programmes according to the strengths and weaknesses of each assessed child.

The average quotients scored by the two boys in the test indicated 'mild intellectual disabilities' in both cases. Their scores did not reveal evident discrepancies between the representational and automatic-sequential levels. Since they scored lowest in the auditory-vocal channel, they were also assessed using another psychometric test, the TOLD-P:3 (Newcomer and Hammill,1982), which, through eleven subtests, assesses semantics, phonology and morphology-syntax at the receptive and expressive levels. This test showed that G.'s difficulties were in semantics, while D.'s were primarily in morphology and syntax – difficulties which emerged at both levels of reception and expression. Based on the above information, the research team

assumed that G.'s communication abilities were inhibited by his low verbal abilities and by psychosocial factors, such as parental high expectations and pressure to achieve. In the case of D., his difficulties in morphology and syntax were attributed to his low verbal abilities as well as to the fact that he was semi-bilingual, which made him unaware of his language problems and consequently more communicative in comparison to G. (Cummins, J.,1984).

When the diagnostic procedure was completed, the President and the Director of the Children's Centre announced the results to the children's families (and in particular to D.'s mother and to G.'s parents) and discussed with them the next phase of the intervention programme. At this stage of the research, which coincided with the beginning of the school year, the children did join the kindergarten class, in which there were 22 children, the teacher, an assistant teacher and an early intervention special educator. The teachers, the special educator and the research team decided that G. and D. would undergo individualised dynamic assessment for approximately one month before the goals and the content of the intervention programme were designed.

- **Dynamic assessment**

Dynamic assessment refers to several different, but similar approaches to evaluating student learning. The goal of this type of assessment is:

> *…to explore the nature of learning, with the objective of collecting information to bring about cognitive change and to enhance instruction.* (Sewell, 1987, p. 436)

One of the main characteristics of dynamic assessment is that it can initiate *dialogue* or *interaction* between the assessor and the student. The interaction allows the assessor to draw conclusions about the student's thinking processes, their response to a learning situation and also the means of instruction that can bring about positive change in their cognitive functioning (Hoy and Gregg, 1994). Because it incorporates an interactive component, and also looks at students' achievement over time, this type of assessment has been suggested as more useful than standardised tests which statically assess skills and deficits. Dynamic assessment has also been considered to be very useful with students from minority backgrounds because it can help overcome the typical problems that arise when tests are used with this

population (e.g. literal translations of standardised tests may not render concepts understandable, and thus such tests remain invalid for certain cultural groups (Omark and Watson, 1983)).

In the present research study, the outcomes from the developmental and psychosocial record of the children along with their cognitive-psycholinguistic assessment helped the researchers to design the activities included in the individualised dynamic assessment procedures. These activities focused primarily on the children's cognitive and language abilities and unfolded both in the inclusive setting and the resource room. The activities that took place in the inclusive setting followed the kindergarten curriculum, which was based on the thematic approach and project methodology.

To monitor the boys' progress during the dynamic assessment, *ecobehavioural analysis* was used. This is an approach that assesses learning environments by analysing instructional problems and the development of effective interventions, especially in classroom environments in which there are minority-language students (Arreaga-Mayer and Perdomo-Rivera, 1996). The application of ecobehavioural analysis allows the researchers to determine which combination of specific ecological, teacher and student variables result in higher levels of language usage and academic achievement. This type of analysis stems from earlier 'transactional' (Holiday, 1985) and 'ecological' (Davis and Stiffman, 1990) perspectives, which emphasise the need to go beyond intrapsychological issues to consider the ethnic, social and cultural contexts in which individuals find themselves.

The rationale for applying ecobehavioural analysis is that a student's language usage and behaviours within an instructional programme are determined to a large extent by the types of interactions the student has with learning environments and with the people in these environments (Arreaga-Mayer, 1993; Cummins, 1989; Ellis, 1986). In ecobehavioural analysis, each classroom is viewed as a single ecosystem in which the physical environment of the room, available materials, instructional grouping, language of instruction, individual students and teachers interact continuously to form a unique learning environment (Arreaga-Mayer, Carta and Tapia, 1994, 1995; Carta, Sainato and Greenwood, 1988).

Indeed, in this study, the teacher, her assistant and the early childhood intervention special educator continuously interacted with the children and systematically

observed them as they undertook several individual tasks, collaborated with their classmates on group tasks, interacted with their teachers and played with their peers in and out of the inclusive and specialised setting. The application of this technique during dynamic assessment was necessary in order to identify the individual needs, strengths and weaknesses of each child.

Launching the intervention programme

Approximately one month after implementing the activities in the context of dynamic assessment, it was possible to define the children's needs for the inclusive and specialised intervention programme. It was decided that the children would attend the specialised intervention programme twice per week, while, in the inclusive setting, they would receive learning support from the teacher, her assistant and the special educator, who would encourage the children to participate as much as possible in the mainstream curriculum.

One important outcome deriving from the dynamic assessment was that G. and D. seemed to compensate for each other. The two boys had similar language problems, but they differed in the area that was most affected (G. had difficulties in semantics, while D.'s difficulties were primarily in morphology and syntax), and they also differed in their behavioural characteristics. More particularly, G. seemed to be very shy when he interacted with his teacher, and rather withdrawn in both the inclusive and specialised settings. At the same time, he could concentrate well on any given individual task. On the other hand, D. was much more sociable and communicative at the teacher–student level and in the specialised class, but he would get easily distracted during in-class activities that required concentration. This finding played an important role in the formulation of the specialised intervention programme that followed the individualised dynamic assessment procedures because it highlighted the need for the two children to attend the programme *together*, in order for them to function better as a small team and benefit from the intervention. In addition to the two boys, the teacher also selected two or three of their classmates, after having acquired their parents' consent, to attend each session of the specialised intervention programme.

The specialised intervention programme followed the content of the mainstream curriculum, but placed particular emphasis on the enhancement of cognitive strategies, narratives and verbal interaction. This is why the research team decided

to cultivate strategies of problem-solving through narratives and through activities of discrimination, classification and analogical reasoning, integrated within the content of the curriculum.

The intervention programme aimed to help the children ultimately: (1) to reach a performance level that would match that of their classmates; and (2) to attain better social interaction with their peers. The short-term goals were defined gradually and were often modified as the programme unfolded. Nevertheless, it was important to encourage G. consistently to participate more actively in the assigned tasks in both settings and, at the same time, to regulate the unrestrained behaviour that D. displayed, especially during play time.

It is expected that the more complex are the needs that children have, the more professionals are likely to be involved in the practice and assessment of the applied programme (Lacey, 1999). Indeed the teacher, her assistant and the early childhood intervention special educator all held responsibility for the day-to-day management of the inclusive and speacialised programme, as well as for any necessary modifications. It should be noted that the special educator communicated with the speech and language therapists who were working with the children during out-of-school hours, yet this attempt to communicate and collaborate did not yield any positive outcomes.

The teacher, her assistant and the early childhood intervention special educator had frequent meetings with the President of the Children's Centre, the children's parents and the research team that carried out the study. In particular, the teacher was in close contact with the President who was supervising the intervention programme, and had to submit regular progress reports on both children. The research team and the parents met three times in all in the course of the year, when the parents were informed about their children's progress and how to deal with their difficulties.

In order to see how the specialised intervention programme helped G. to become more involved in assigned activities and play, and D. to regulate his behaviour in and out of the classroom, it is important to describe specific activities that unfolded during the programme's sessions. Thus, it will become obvious how the two boys' differences compensated for one another so that both children eventually benefited from the specialised intervention programme.

One exercise the teacher selected for improving the children's arithmetic skills was naming all weekdays and ranking them in chronological order with the use of small cards. For D. it was rather confusing to find out which day corresponded to the concepts of 'today', 'yesterday' and so on. With the teacher's encouragement, however. he patiently tried to find the right answers. On the other hand, G., who had consistently seemed confident with arithmetic-related exercises, would rush to provide the correct answer before any other child could, and clearly seemed to appreciate the teacher's praise. Yet, in the next attempt, he would prompt D. to answer by discreetly pointing out to him the card that depicted the required weekday.

Another task that the teacher introduced aimed at familiarising the children with the concept of 'height'. G. easily grasped this concept, while D. kept confusing 'taller' with 'older'. The teacher suggested that they first observe one another, in order to distinguish who seemed taller/shorter. Then each child lay on a large piece of paper laid on the floor, and the other children attempted to measure his height by placing felt pens in parallel to his body. All children were happy to collaborate in this task, and, while they were interacting in order to carry it out, they also playfully teased each other. G. initially remained detached, hesitated to become actively involved and preferred to observe the others from a short distance. D. encouraged him by letting him start the measurement first and helped by passing the felt pens to him. Indeed, G. eventually participated in the task and interacted with his classmates, which certainly suggested progress in relation to his social skills.

In another activity which involved the dramatisation of a story they had been working on (i.e. pretending to be a journalist who was either reading the news or conducting an interview), the teacher prompted the children to form groups of three in which one child would take the role of the journalist, and another the role of the interviewee, while the third child would record the interview session – roles which they would then alternate. In this activity, G. was initially hesitant, especially when he had to be the 'journalist'. In contrast, D. was eager to grab the 'microphone' and start the session. However, D. used a limited range of themes and very short phrases while posing the 'interview questions', but then G. came up with a few more ideas, so that a short dialogue between the two boys was eventually produced.

Evaluating the specialised intervention programme

Overall, throughout the implementation of the specialised intervention programme, D. seemed eager to become an active member of the group he worked with in each session. He also learned to regulate his impulsive behaviour, collaborate with his peers during structured activities, and interact with them during play time instead of merely teasing them as he had been doing at the beginning of the year. In the course of the year, his vocabulary improved significantly and, even though he had not learned several basic words and was still making syntactical errors, he could nevertheless describe his experiences orally and construct short, simple narratives in an adequate way.

The overall analysis for G. revealed that he had gradually adopted a more active attitude in the specialised programme, since he had become more receptive to the teacher's affection and had started asking for her help when he could not carry out a task or for her support when he felt his classmates were not treating him fairly. This observation signified some progress for G., who had initially almost never taken the initiative to talk and had passively accepted the teacher's remarks. As far as his interaction with his classmates went, there was also evident improvement: at the beginning of the school year he consistently refused his classmates' assistance in completing a task and would not invite others to play along with him. Through the specialised programme, he gradually learned to break his isolation during structured activities (e.g. looking carefully at what his classmates were drawing and trying to copy their sketches), but also during play time (e.g. teasing his peers in an attempt to communicate with them). On the whole, successful inclusion in the classroom was attained for both children, not only because their verbal abilities and cognitive skills improved, but also because, through their ability to express themselves better, they started interacting with their peers more closely.

The positive outcomes of the intervention programme rendered the process of accepting the children's problems easier for their parents. This was especially difficult to achieve because the parents used to hold certain perceptions of their children's problems, which, in the course of the programme, had to be altered as a different diagnosis emerged. D.'s mother was especially satisfied with her son's progress and came to accept his problems. An additional factor which perhaps made the process of acceptance easier for her was that there were no high achievement-related expectations of the child from the rest of the family. G.'s parents said they were satisfied with the programme, their collaboration with all the professionals involved and their child's progress, although they seemed not to have come in terms with his

problems. Whereas, after the programme, D.'s mother decided to send her son to a special educational inclusive setting for the coming school year and quickly made all the necessary arrangements for the transfer, G.'s parents remained undecided on whether their son should repeat the kindergarten class and receive intensive home-based training at the same time or start formal schooling in an inclusive educational setting.

Conclusion

If a comprehensive and accurate diagnosis had been carried out when the children were younger (as early as 2 years of age), and both children and their parents had received adequate specialised support, then the parents would have more easily accepted their children's problems and both boys' progress would have been better overall. Unfortunately the majority of the so-called transdisciplinary teams in Greece, as is the case in several other countries, do not operate systemically, and this can lead to serious misdiagnoses and consequent misplacements. It is quite common for professionals in special education to focus on behaviour problems when dealing with preschoolers and achievement problems when working with school-age children. Moreover, most professionals who participate in a transdisciplinary team do not acknowledge boundaries to their expertise, and end up providing advice even on topics that are beyond their knowledge and practical experience. Thus erroneous representations and consequently false expectations are created.

According to the literature, most disorders that children from minority groups develop are likely to be attributed to language difficulties and cultural adaptation-related problems. It is also wrongly assumed that children originating from a high sociocultural context will not develop mild intellectual disabilities (Kavale and Forness, 1985). By adopting a transdisciplinary approach where global evaluations are carried out and every child is supported both in terms of educational setting and educational content, it is possible to avoid the mistakes and the ensuing false representations described above, and to ensure that all children and their families gain maximum benefit from intervention programmes.

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CHAPTER 9

The Early-Aid-System in Germany

Armin Sohns[1] and Olaf Kraus de Camargo[2]

The development of the legislative and institutional structure

Today, Germany is covered by a system of early childhood intervention or 'early aid' centres (Frühfördereinrichtungen). These centres offer family-centred support for children with developmental risks and their social environment. The law distinguishes two separate types of services within this system: the interdisciplinary early aid centres and the social-paediatric centres.

It was in the early 1970s when the systematic development of early aid services was started. The creation of the social-paediatric centres is very often linked to the name, Hellbrügge. Under his leadership, the first social-paediatric centre was founded in Munich in 1968 (Hellbrügge, 1981). The social-paediatric centres were planned to be supra-regional, interdisciplinary, perpatetic services of the health care system. In these centres, teams of physicians, psychologists, educators and therapists worked within a hierarchical structure with a medical leadership. The recognition of this kind of health care service in German legislation took more time, and occurred at the end of the 1980s in the Fifth Book of Social Laws (SGB V). The care delivered at the social-paediatric centres is therefore a service paid for by the public and private health insurance companies.

The first early aid centres were also founded in the early 1970s (Sohns, 2000). The legislative establishment of these centres occurred following the 'Recommendations of the German Council on Education' (Speck, 1973) that influenced the modification of the third law within the Federal Law for Social Services (BSHG) in 1974. This law launched the foundation of numerous regional early aid centres in Germany. Although they were based upon different

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professional concepts and approaches, they tried to reflect and satisfy the recommendations of the Council as interpreted by Speck (1966):

> *The intention of these recommendations was to create more possibilities for joint learning of children with and without disabilities to achieve integration inside and outside of schools and, beyond this, to deliver aid in the early stages of development during which disabilities are first manifested, trying to prevent a later segregation at school. Early aid was therefore understood as a service for social integration.*

In the following decades, over 1,000 early aid centres were founded in Germany, and literally covered the country with an early childhood intervention network. The professionals employed within the centres were mainly pedagogues that delivered support to the children with disabilities and their families by giving advice about how to manage the daily living activities and special pre-school education of their children (psychopedagogic approach). Following the recommendations of the Council on Education, the support delivered was mostly home-based within the families' natural environment.

The further development of the early aid centres was accompanied by conflict at the professional and political levels. The Federal Law for Social Services established in paragraph 40 that early aid should be delivered through 'remedial pedagogy'. In consequence, the financial resources for these measures had to be provided by the counties. Due to these circumstances, the early aid centres were urged by many counties to employ pedagogical professionals. This development was criticised, especially in the medical community. Even the 'Deutsche Ärztetag', as the most influential professional organisation of physicians in Germany, formulated a resolution in 1976 against the establishment of the early aid centres:

> *Contrary to the recommendation of the 'German Council of Education' to establish new centres with a pedagogical focus, the "Deutsche Ärztetag" recommends the*

expansion of existing medical institutions. This way the tendency towards unilateral orientation of Early Aid measures can be avoided. Concomitantly higher effects could be obtained with less costs' (Der Kinderarzt 7, 1976, 846).

On the other hand, the pedagogical early aid centres opposed the imposition of medical hierarchical structures and direction as established in the social-paediatric centres.

It seems obvious that these discussions, characterised as they were by professional distrust and mutual rejection, were not conducive to developing interdisciplinary cooperation. In regions where such cooperation did occur, this was based on personal relationships and mutual respect between individuals from different professional groups, especially community physicians.

After the legal recognition of the pedagogical early aid centres in 1974, it took until 1988 for the legislation to recognise the social-paediatric centres (Gesundheitsreformgesetz, 1988). Following this long period of independent, parallel existence, the relationship between both these systems was structured in 1992. It was ordained that the treatment in social-paediatric centres:

> *…should be focussed on those children who cannot be cared for adequately by physicians or early aid centres because of the severity or the chronic nature of their illness or impending illness. The social-paediatric centres shall co-operate closely with the physicians and early aid centres involved.* (GStruktG Art.1, paragraph 119 SGB V and ' 4 FrühV).

For the first time, an interdisciplinary approach in early aid was required by the 'Law of Rehabilitation' (Rehabilitationsgesetz, 9th Book of Social Laws, SGB IX) of 2001 and the 'Ordinance of Early Aid' (Frühförderungsverordnung FrühV) of 2003. By law, interdisciplinary

early aid centres and social-paediatric centres are the only services who can offer early interventions. On an organisational level, the social-paediatric centres are seen as supra-regional institutions (tertiary care), and the interdisciplinary early aid centres as local/regional institutions (secondary care). Both must employ an interdisciplinary team.

Today, the home- and centre-based systems of early aid delivery are composed of approximately 130 social-paediatric centres and 1,000 early aid centres, both of which services are financed by public health insurance. In the social-paediatric centres, the interdisciplinary teams have a mainly diagnostic focus, but are able to offer long-term, centre-based care. Some of them also offer in-patient care in social-paediatric hospitals, but they are unable to offer home-based care. This situation is far from ideal. First, it means that parents are obliged to take their children to the centres, and sometimes endure long trips to receive adequate support. Second, the professionals at these centres do not have the opportunity to evaluate the impact of day-to-day environmental factors upon the functional well-being of their patients.

In contrast with the social-paediatric centres, the work of the regional early aid centres can be both centre-based and home-based. In most cases, 'home-based' means providing support for the child within their actual home, but, in many centres (especially in East Germany), it also means working with the child in kindergartens. Traditionally in East Germany before 1990, kindergartens were considered the main social environment for children. While the share of home-based care reached about 80% in 2000, the ongoing financial cuts have reduced it to about 50% in 2007 (ISG-Studie). This means, in consequence, that parents are increasingly obliged to take their children to the centres. In spite of the contra-indication of the social needs of children with disabilities and their families and of scientific evidence, the environmentally based approach is being continuously sacrificed by the financing institutions. This is the case in early aid centres across the counties.

Early aid centres are traditionally responsible for the pedagogical professionals. Accordingly, the early aid centres have hired mainly pedagogues. However, due to differences in federal law between the states in Germany, one can also find early aid centres with interdisciplinary teams. In those centres, the medical and therapeutic professionals are mostly financed through public health insurance. In two of the 16 German states, early aid centres are integrated with social-paediatric centres, and therefore do not offer home-based care. In one state, the early aid centres are mostly associated with remedial schools. Despite the federal character of the law of rehabilitation (2001), it has not been possible to harmonise the regional differences.

The development of professional standards in early aid

Accompanying the legislative development and the establishment of a financial basis for early aid services, the last decades have been marked by an intensive development of professional standards leading to important paradigmatic changes in professional approaches to children with disabilities and their families.

While in the early 1960s and 1970s, the prevailing approach was based on the belief that disabilities could be compensated for by intensive therapeutic interventions aimed at 'curing' or 'healing' the disability (bio-medical concept), this view underwent major changes during the 1980s (Rauh, 1985; Schlack, 1989). Whereas the former view was characterised by 'technocratic and function-oriented therapeutic approaches' (Weiß, Neuhäuser and Sohns, 2004), professionals as well as parents felt uncomfortable with the strict delineation between 'experts' on one side and 'lay' parents on the other that the approach implied. This allocation of roles presumed that parents had to follow the expert advice, and they were reduced to being mere 'co-therapists' for their children (Holthaus, 1989). The technocratic approach was further challenged by the results of academic research into the effects of therapeutic

interventions on children with developmental disorders. In summary, the research found that there was very little benefit for the child and family from strict, unidimensional, functional approaches, but more promising results from approaches that were environmentally based and individualised (Weiß, Neuhäuser and Sohns, 2004). Following this philosophy, the professional standards of former 'early interventions' were developed to take account of approaches that can better be described as 'early aid'. These are characterised by a strong commitment to interdisciplinary and transdisciplinary working and to the promotion of an ecologic-systemic approach. Following the German Council of Education's original, legislative aim of 'social integration' (Speck, 1973), a social-environment-focused system of early aid which was family- and kindergarten-centred could be established.

The core principle of this approach is the recognition of the advantage of holistic procedures over uni- or multi-disciplinary, therapeutic 'interventions' that do not take into account the family system and the environment of the child. Especially in the first phase of coming to terms with their child's disability, parents are insecure, often shocked, and experience feelings of being offended, blamed and ashamed. Associated with that emotional stress is the burden of the intensive daily routine of special care for the child, additional administrative issues and the many appointments filled with therapies or diagnostic procedures. The social context in many cases also suffers transformations. Fewer family members and friends tend to be available for help and support (Sohns, 2000), and the traumatised parents often hesitate to request professional help to deal with the many problems they are facing (Sohns, 2000). In such a situation, it is in the interests of the child that the whole family – and in certain cases even other professionals involved with the child – receives support from professionals who can address the many emotional aspects of the special situation the family finds themselves in and offer appropriate information and advice.

In contrast with the historic approach, based on the role of parents as co-therapists receiving 'orders' from experts and having to 'comply', this new approach respects the autonomy of the

child and the family. The responsibility for the actions to be taken remains within the family. Thus the family members and the child have become the 'initiators', based on the principle that self-initiated actions tend to be more productive and show longer lasting effects than externally imposed actions. In early aid, the action taken by professionals therefore always aims to support the initiative of the child and the family. This principle has been enshrined in the expression, 'Aiding for Self-Aid', coined by Montessori.

New demands resulting from social transformations

The necessity for such a review of professional standards derives also from a reassessment of the kind of disabilities eligible for early aid and the associated criteria for granting it. In the beginning, the majority of children receiving 'early Intervention' had 'classic disabilities' in the sense of structural (World Health Organisation, 2007) or functional impairments (Sohns, 2000). The percentage of children attending with these disabilities has shrunk continuously over the last decades. The last epidemiological survey regarding early aid in Germany in 2001 analysed all institutions offering early aid in the state of Mecklenburg-Vorpommern, and can be considered representative of the German federation. Figure 1 below summarises this information.
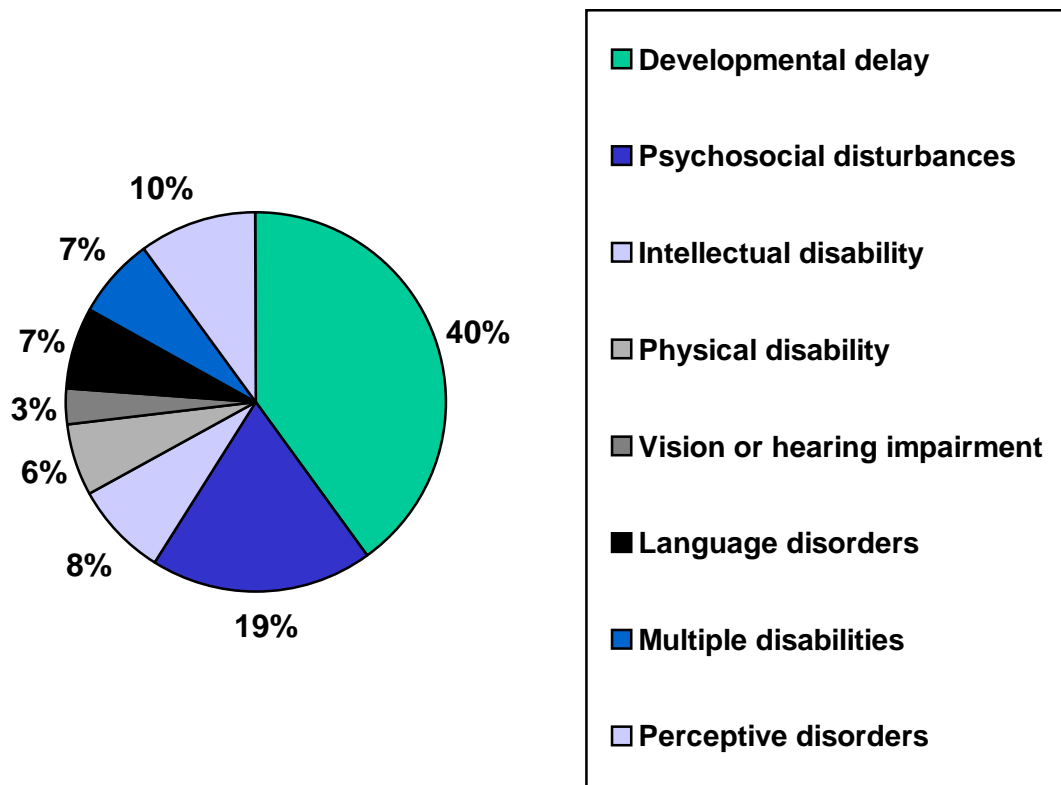
Figure 1. Summary of results from a 2001 epidemiological survey of children presented at early aid centres in Mecklenburg-Vorpommern categorised by primary disability (Sohns, 2001)

This pie chart shows that children with physical, mental and multiple disabilities comprise only 20% of all children. The majority are children without clear-cut diagnoses. Nonetheless, these children and their families are without doubt in need of support and care. In many of these cases, it is still difficult (partly due to the young age of the children) to decide if the cause of the disability is organic, if the child is showing initial symptoms of a learning disability, or if their difficulties are due to environmental factors delaying or inhibiting their development. Therefore, it is important to concentrate on the resources available within each child and each family, and to try to establish situations and attitudes that foster a healthy development.

To achieve this, it is not sufficient to work only with the knowledge and the techniques of remedial pedagogy. Other qualifications become necessary, and the knowledge of many disciplines is needed. In response to these requirements, many early aid centres in Germany have developed an interdisciplinary system of professionals working in teams, ensuring in this way ongoing cooperation between professionals of different disciplines (medical, pedagogic, psychological and therapeutic). Through the Law of Rehabilitation, all of the following aspects, and those previously discussed, are required of early aid services: interdisciplinarity, a holistic approach, social integration as a major goal, and a preferred focus on preventive approaches (SGB IX (9th Social Code); Sohns, 2002).

The different early aid tasks and the difficulties in realising them

According to the holistic approach, several different tasks have to be achieved by the interdisciplinary team. It starts with the important aspect of *early identification* of children in need of early aid, aligned with specific developmental risks. Different approaches are used to identify these children. The majority is seen during the regular developmental screenings performed by family doctors and paediatricians. If they suspect that there is need of further diagnostic interventions, they can refer the children to the social-paediatric centres or early aid centres. Unfortunately the access to the social-paediatric centres is made difficult by long waiting lists (up to one year), and, in many regions, there are great distances to be covered by families who may not have the financial means of doing so. The access to early aid centres is dependent on the authorisation of the request by Government's social administration and public health service physicians. Families from socially disadvantaged segments of society are especially reluctant to comply with these formal requirements as they feel stigmatised by them. Therefore, it has been proposed, and formulated within the Law of Rehabilitation, that access to initial visits to early aid centres should have low threshold criteria, which allows worried parents to get help without bureaucratic barriers. The financing of such an 'easy entry' system still awaits a solution.

Another task is the *diagnostic* element in the process of early aid. Dependent on a child's individual circumstances and reported difficulties, different professionals assess the child and the family. One of the professionals is allocated the family liaison role and collates the results from the home visit, interviews and assessments. Subsequently, the interdisciplinary meeting takes place. In this meeting, the desires and needs of the family, as well as the results of the professional assessments, are discussed, and, as a result, an individualised plan of aids and therapies for child and family is drawn up. This procedure should be orientated by the *International Classification of Disability, Functioning and Health* (Kraus-de-Camargo, 2007; World Health Organisation, 2007). The completed plan has the function of a contract between the family and the early aid centre, establishing goals to be achieved and the methods which have been agreed.

As the realisation of the plan often requires contact with other services and administrative agencies, as well as professionals outside the early aid centre, it is important that the interdisciplinary team coordinates these contacts and includes them in a cooperative network. This *regional networking* is an important task to guarantee an effective process and should be supported adequately by the financing organisations.

Under this system, *intervention and education* of the child have the same status and importance as *advice and support* offered to the parents or other relevant people. It is still very common for financing bodies to stipulate that early aid should be a specific intervention performed on the child, and orientated by the impairments that have been diagnosed; they are therefore willing to fund only those procedures that have taken place in presence of the child. This attitude obstructs the need to provide support to families in a more flexible manner and according to necessity. Especially with regard to the increase in numbers of children with developmental disorders or 'behavioural problems' from social disadvantaged families, it might be more effective to counsel the parents and other people involved than to stigmatise

the child as 'disorderd' by offering 'therapy'. Another example of the important services needed by parents is the support offered in the period immediately after being informed that their child has a significant disability or chronic illness. It might be more effective in the long term to invest in counselling of the parents in this early phase than to deliver several intensive developmental therapies later in their child's life. So, regarding the task of *taking action*, it is desirable that a high level of flexibility in offering the most urgent support, as identified by parents and professionals, is possible.

Development of 'complex aid' – present and future issues

The Law of Rehabilitation introduced the legal term of 'complex aid'. This term describes the complex, interdisciplinary cooperation between pedagogic and medical-therapeutic services necessary to support children with disabilities and their families. It offers the opportunity to develop more effective and more individualised approaches for the growing number of children with developmental risks. As many of these children grow up in socially disadvantaged situations, it will be necessary to take into account the findings of neuropsychological research regarding resilience and vulnerability. Early aid services are also facing the demotivating challenges of restrictive financing and competition, which militate against cooperation between professionals. It is necessary for interdisciplinary teams to learn to develop transdisciplinary competencies to face the challenges ahead. At the moment, many of them are still working as multidisciplinary teams, with many different professionals maintaining contact with one child or one family. With an increased transdisciplinary competence, it would be possible to reduce the number of professionals liaising with the family, but, to do this, the team will need to cooperate more closely, and the different professionals will have to support one another.

In practice, the ways in which the county administration (responsible for financing pedagogic aid) and the health insurance companies (responsible for financing medical-therapeutic aid)

have complied with the law since 2001 is disappointing. It seems that administrative services are experiencing great difficulties in developing a financial model incorporating these different types of aid. Their primary strategy seems to be to delegate the maximum of responsibilities to the other administrative service instead of cooperating with one another. Early aid professionals and specialists have not been invited to take part in any of the official meetings held at administrative and political levels to discuss possible solutions to the financial questions. Fourteen out of the 16 states have agreed a so called 'framework of agreement' for financing 'complex aid'. However, the terms of these agreements show, in the majority of cases, a great discrepancy with the original intention of the law. They propose multiple diagnostic procedures – an approach which hinders interdisciplinary cooperation – and do not allow financial provision for the important interventions of counselling and supporting the parents.

However, at least these agreements achieve a more formal cooperation between pedagogues in early aid centres and family physicians. In those states (Bavaria and Northrhine–Westphalia) where the districts have used the framework agreements to draw up formal contracts between early aid centres and the social administration and health insurance services, the early aid centres are suffering massive financial cutbacks, reduction of their family-centred work (Bavaria) or lack of finance to employ qualified professionals (Northrhine–Westphalia). Among early aid professionals, the hope persists that with a broader application of 'complex aid', the structural and financial demands will show more clearly that amendments can be made to the framework agreements to allow adequate financing of the good intentions reflected in the Law of Rehabilitation. It might be necessary in the near future for the federal government to take responsibility for the law it created by specifying more precisely the form of administrative cooperation between social administration and health insurance services.

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CHAPTER 10

Therapy or special education – which is which?: An infant/toddler perspective

Juergen Kuehl[1]

Introduction

We know that child development is very complex and that effective early aid or early childhood intervention is based on a multi-professional assessment as a prerequisite for therapeutic and educational cooperation. In Germany, a law from 2001 requires pediatricians, therapists, psychologists and educationalists to work together to develop a joint action plan which describes the contributions of the different specialists, including the parents (Jetter, 2004). The intention on one hand is to improve the effectiveness of early aid by cooperation and, on the other, to guarantee participation as defined by the International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001). Such cooperation is not possible without a mutual understanding between different specialists. But how can they come to a shared decision, from their different professional perspectives, about the appropriate intervention response to a child's difficulties or limitations?

Infants and toddlers do not differentiate between therapeutic intervention and special education, but process the experience in their own way. It is important to learn how they might understand the intervention. The first part of this chapter is therefore dedicated to theories of child development. The second part reviews our knowledge about the effects of early childhood intervention on the infant or toddler, and articulates what is important in establishing a daily routine for them. Finally, the implications of this knowledge for the different specialists dealing with a child and their family are summarized.

Child development

At first glance, it may seem to be quite self-evident that there is a big difference between the way a little child sees and understands the world, and how an adult does so. However, we do not often consider the young child's view, and we rarely ask about how their understanding of an intervention might be constructed. The infant or toddler cannot tell us about their individual view. We can only try to learn about it in an indirect way using the results of investigations in different fields of child development and neurobiology as an aid to our understanding.

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Human relationships

Resulting from his work in orphanages in the 1940s, René Spitz (1973) identified the absence of contact with a significant caregiver (a mother or someone fulfilling her role) as a major cause of dramatically delayed development in infants, or even their death. He also observed this among children living in families who were not able to care sufficiently for them. From Spitz's work, we have learned that:

1. For the development of a human being – as for every living organism in the world – living conditions are of vital significance
2. Human abilities develop to a full extent only in continuous interaction with other human beings, and lack of this interaction, for a child, can lead to impaired development or even death.

In analysing the exchange between two people and their environment, in terms of neurophysiology, developmental neurology and neurobiology, we discover two basic biological facts: (1) life is essentially constituted of motor activity (Touwen, 1984); (2) this motor activity is not possible without its 'invisible partnership', which is receptiveness. The central nervous system organises these two inseparable phenomena within a single system, generating the vital exchange between the child and their environment, other people and material circumstances through motor activity. This interaction takes place continuously and does not depend on a specific quality of motor activity.

A person's perception of their environment is based on the receptiveness of their sensory abilities. The resultant neural transmission from these organs allows them to note chemical, optical, acoustic and material qualities of the environment as well as to register the quality (for instance the goal directed effectiveness) of movements. The brain analyses and interprets this continual neural stimulation and organises the information. The interpretation is dependent on the way in which their individual brain functions.

Perception can be understood as the basis of interpretation, and interpretation is an internal processing of the conditions of exchange between the child and their environment, which leads to the formation of their hypothesis of the 'outside world'. 'Acting by moving' regulates the child's hypothesis, maintaining it in a state of equilibrium. The relationship between a child and the 'real world' is therefore represented by a 'virtual world'. A 'virtual world' is constructed individually by the brain and is constituted from all those situations in the life of the child that they have interpreted as 'meaningful'.

As mentioned above, the exchange between the child and their environment is vital. The individual quality of its continual modulation depends on the efficiency of the child's sensory organs, their motor capability, and the processing capacity of their brain in relation to individual development and also to the specific environment. Yet, there is no fundamental difference in the actual process, whether the child has an impairment or not (Largo, 1998). These basic elements lead to an individual view of the 'outside world', which could be called the subjective 'reality of relations' between a child and their environment. This autonomous process, based upon an internally and individually regulated system of interaction, is a biological phenomenon and characterises every human being.

The later psychological definition of autonomy as independency is based on the fundamental biological autonomy of every developing child. Yet autonomy is dependent on the respective context. It must be understood as a distinctive individual mark in the *actual* relation to the environment, depending on the *actual* situation. We can observe a child's autonomy if we are able to interact with them at the appropriate level. This is the key to 'reciprocal understanding'. Conditions for interaction are a shared insight into a situation of mutual exchange, which is very different from the general validity of 'objective' assessment instruments, but nevertheless helpful for professional work.

Planning intervention, whether therapeutic or educational, is abstract, intellectual and professional work. Yet when interventions are implemented they enter into real life as interactions between different people who communicate and cooperate. Interaction takes place in a situation within which the child acts using their abilities. The child itself is an agent of change, and the *initiatives* they take in the course of this interaction are the source of our knowledge about their autonomy and creativity. In the course of such interactions, the professional can be accepted as an interesting partner by the child. This means of diagnostic investigation runs counter to conventional 'objective' assessment which is normative and based on a theory of linear development, where variation is regarded as a pathologic symptom. If only this 'objective' diagnosis is used to interpret child's situation, the perspective of the child itself, as described above, is not taken into consideration.

This means of detecting evidence of children's autonomy, creativity and competence through interaction provides a valuable basis for distinguishing between 'subjective' and 'objective' (tests) approaches to assessment. If we use a subjective approach, we are much more able to determine whether a disruption in communication or cooperation is a consequence of an 'objective' impairment, which may be unchangeable. Also, if the conditions of interaction are

altered and adapted in favour of the child's activity, the child may autonomously initiate an interesting exchange in another way.

In promoting a child's social development, professionals are fundamentally important in influencing the conditions of the child's environment to make autonomic action possible. To do so effectively, in addition to the so-called objective assessment, they need guidance on how to develop subjective and personal communication and cooperation with a child at their developmental level, based on a perception of the child as a competent (instead of an incompetent) partner who is interested in interacting with them.

If we try to understand a child's view of the 'outside world', we need, in addition to the knowledge of the development of motor activity and sensory receptiveness, an insight into emotional development. A person's consciousness of their autonomy and creative agency on one hand and the so-called 'unconscious' on the other hand are located in two different regions of the brain. Simply speaking, some areas of the cortex are involved in 'consciousness', while the basic brain structures known as the 'limbic system' are responsible for the 'unconscious'. Both elements exist as a unified system. They develop and change together throughout life, and determine our interpretation of the 'outside world' as a unity through interaction between motor activity and sensory receptiveness described above. It is important to follow this hypothesis of the unity of 'consciousness' und the 'unconscious' in the view of the child's early development.

Brain development

Cell nuclei connected by pathways are activated as basic brain structures in early pregnancy long before the differentiation of the cerebrum. They function cooperatively as the so-called 'limbic system', where emotions initiate brain activity and emotional experiences are fixed. A specific structure called the amygdala is activated very early and is responsible for the quality of emotional memory. Another important component of the limbic system, called the 'hippocampus', develops much later in mid-pregnancy and is responsible, in association with other elements, for the content of memory. At the same time, parts of the frontal cerebral cortex differentiate into what will later form the location of associative thinking. The biological requirements of the frontal parts of the cortex for reflexive thinking are not developed before about two and a half years of age (Roth, 2001).

For the first three years of an infant's life, they interact on the basis of fundamental biological need. In communication with parents or other caregivers, they slowly expand their ideas about the world. Motor activity, motor and sense experiences develop reciprocally alongside

daily routine, and form the components used by the brain for the construction of the infant's 'virtual world'. In this way, the growing child develops a conception of the world as existing separately from themselves. At the same time, their sense of 'self' becomes more firmly fixed. The 'virtual world' of a child, so established, is the only existing operational basis for their interactions, and constitutes the foundation of their self-confidence. The exchange between 'conscious' and 'unconscious' is the key to their understanding.[2]

Emotional development

This expanding 'virtual reality' offers a hypothetical insight into the emotional understanding of the infant and the toddler. 'Emotional' is derived from the Latin word, 'movere', meaning 'to move'. The word itself describes experience through the medium of motor activity (Neuhaeuser, 2004). Early emotions emerge when the infant learns to differentiate between their own physical state and sensations of external origin. This is a basis for the development of a consciousness of their being the agent of their own actions, which later enables them to choose between different strategies of action. The ability to use a variety of strategies offers increased possibilities for the exploration of the environment, which, in turn, finally lead to a basic consciousness of the 'self' in communication and in intentional activity. These interactional abilities at the emotional and intentional level enable the child to distinguish between themself and another acting person. The child learns that he is able to induce a reaction that has to be responded to. Such reciprocity is conducted emotionally and is vital. As a consequence, one has to acknowledge that, at the beginning of life, activity is inseparable from emotion, and that emotion stimulates activity. This simultaneity accompanies us throughout our life, and our conscious activity always has an earlier unconscious origin, which seems to be more important than consciousness.

The individual view of a child concerning the 'outer world' was described above as the internal 'reality of relations' between a child and their environment. This reality of relations is based on emotions – the younger the child, the more unconscious the level of perception, and their experiences are always saved as an emotional memory. It is therefore important that professionals respect the emotional level of interactions with a child as a basis in therapy as well as in education.

In conclusion, we learn that an infant or a toddler perceives the 'real world' internally, entirely as a 'virtual world'. Every person playing, cuddling or working with a child is their partner in interaction, and the meaning in this interaction is decisive for the child's later ability to maintain an interaction that is based on emotional exchange. Referring to studies concerning

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[2] It has to be stressed that the brain always works as a unified system, as a constitutive part of the whole human organism. The theoretically separated parts exist only in a state of co-dependency.

the effects of early childhood intervention or early aid, the conditions of interaction seem also to be decisive for progress in development. These will be addressed in the following section.

Effects of early childhood intervention

Looking at the results of studies concerning the effects of early childhood intervention, it is difficult to summarise the impact of early childhood intervention concisely. A short-term effect of motor function training is obvious, but these effects stabilise only if the child has had the opportunity to practice these skills as part of a daily routine. If interventions focus on looking at the disabilities and finding appropriate opportunities to stimulate individual activity, instead of 'normalising' impairments, the results of interventions seem to be more effective for the child because the impacts of training are stabilised (Bower, 1996). It has been recognised for about 30 years that the effects of interventions are often not discernable in terms of a direct relationship between therapy and progress in development. The intended goal may not be achieved. However, often the child's overall state of health improves which may be more important for the child and could serve as a basis for later progress.

The quality of development does not only depend on unchanging neurological impairments, but also on the ability of the parents to interact in an appropriate manner with their child. If there has been early support for the parents from professionals, a long-lasting effect can be seen, which not the case is if parents have not had any help. Such support is generally focussed on the child's daily routines as well as on the parents' emotional contact with the child (Blair and Ramey, 1997). Analysing the implications of these statements, one could suggest that the support described works with the child's conditions of interaction (i.e. putting at the child's disposal an 'interaction space' (described above) for their autonomous activity).

Progress in development, of course, depends on the level of impairment as well. Yet sometimes professionals cannot detect functional progress using diagnostic instruments, as the child learns to use and vary the motor strategies they have developed in daily life situations appropriately, thus increasing their participation (Ferrari, 1998). It is important to emphasise that, in interacting with parents (as well as with professionals) and the material environment, the child selects situations and strategies that correspond to their emotional level of development. (By their actions, even a very young or a very impaired child can clearly indicate which ways of interaction correspond or do not correspond to their level of emotional development.)

Looking at the studies of the effects of early childhood intervention or early aid in addition to a child's measurable functional progress, there are many other observations to be found (Kühl, 2002), such as:

- improvement of quality of life, including for very impaired children
- improvement of goal-directed activity
- longer periods of attentiveness
- increasing activity in interaction and raising interest in the environment
- increasing competence in daily routine
- transfer of functional abilities to new situations
- increasing autonomous decisions in interactions
- increasing expression of emotional participation – positive and negative.

These points show clearly the necessity of broadening the focus of observations of effects when professionals have to plan interventions. These points can be interpreted from the perspective of participation, which is decisive for children with all varieties of problems and impairments in their development (Kühl, 2002):

- The indicators described above have a qualitative character and are generally not measurable within a conventional assessment
- These points are important for interactions, hence they depend on specific situations and individual partners
- These factors have been developed under systemic conditions. A system is composed of a large variety of factors, which makes difficult to detect the decisive ones.

As a result of this understanding of the effects of early childhood intervention, the context in which therapeutic or educational action is embedded seems to be of great importance. The child itself decides autonomously, at an emotional and unconscious level, what is meaningful and interesting for the continuation of interaction. The professionals can certainly discover this through functional progress, yet the above described indicators are perhaps more relevant as points of guidance. They indicate the child's emotional perception of the quality of interaction. Moreover, a partnership in interaction does not only depend on a specific professional technique, but on personal qualities such as acceptance and empathy.

Conclusion

When parents or professionals discover a deviation in a child's development, they first question the origin and then consider the possibilities for intervention. First of all, a diagnosis should be established. If no causal treatment is possible, early childhood intervention or early aid has to be set up. Planning early childhood intervention cooperatively between different professionals, knowledge of child development, as described above, has to be taken into account. This helps to establish a shared view of the individual child's likely level of interpretation of the world and their abilities in interactions.

Interaction between the child and their parents or caregivers is generally constructed, on the one hand, by the child, who needs support in nearly every area of their daily routine and, on the other hand, by the parents who are available to give this support in an appropriate manner, adjusting it in the course of the child's development. In this 'interaction space', the child autonomously adjusts their own contribution depending on the emotional context as well as their abilities. This 'interaction space' is the foundation of the individual child's sense of security and exists whatever the quality of interaction might be.

At the moment when a child's development is judged to be asynchronous or even aberrant, the perception of the child by the people around them changes. The focus shifts on to *problems* within the interaction and on changing its *quality*. Consequently, there is a risk that the child as a *person* will get out of focus and, instead, that only the problems will be emphasized. These problems do not primarily exist for the child, but do have a great significance for the parents and professionals. As a result, the usual pattern of the child's relationships and interactions becomes disordered and an emotional problem.

From the child's perspective, therapeutic or educational interventions carried out by strangers, as well as the change in the behaviour of their parents, represent unfamiliar patterns of interaction. They realise that something is happening which is different from the previously learned and familiar ways of interaction. They realise that there is resistance to usual motor activity, that there is unusual physical positioning, frustrating physical restrictions, restrictions in motility and forced interactions. The normal reciprocity of interaction is – at least partly – interrupted. There is no developmental basis from which the child can rationalise this new situation intellectually. At this stage, they will have only developed abilities consistent with an emotionally dominated memory, and therefore their emotions will become unstable – for example, oscillating between fear and motivation. The fundamental question arises how the child can integrate their fear without losing interest and activity.

When the child is confronted with fundamental environmental changes, their brain normally reacts with a higher level of arousal and agitation. In extended situations of stress, anxiety is followed by reactions of flight, avoidance and defence. It is well known that stress reactions inhibit learning. These experiences of processive adverse reactions, when often repeated or on-going, are fixed in the limbic system as an unconscious memory. If they continue over a long period, they become resistant to deletion, which will restrict conscious access to memory at a later date. For the development of personality, it is of crucial importance how experiences are fixed as emotional memories in the amygdala. It is obvious that the initiation of early childhood intervention to support the child's development can be detrimental to personality development, even if beneficial for other areas. Decisions about therapeutic and educational interventions must be based on the requirement to satisfy both the child's emotional and intellectual needs at their appropriate level.

Therefore, isolated functional training, whether therapeutic or educational, which does not correspond to the child's activity, is at risk of suppressing the child's emotion-based, autonomic regulation of interactions. If, on the other hand, the child is accepted as a partner and their activities are respected as initiators of interaction, the 'interaction space' allows the possibility of introducing functional elements which may be useful for the child.

The acceptance of the child as a partner in therapeutic or educational interactions corresponds also to the basic concept of 'participation' of the ICF. The goal of these settings must be mutual action, expressed in communication and cooperation, which offers the child interest, pleasure and significance. These professionally structured situations are based on the meeting of two people. The child recognises the partner as a human being, and makes the decision on an emotional basis whether to accept the partner's intervention as part of an interesting and meaningful communication or cooperation or not. The results can be identified and recorded as part of a long-term assessment.

There is a big difference between a professional who is interested in interacting with a child and in becoming better acquainted with them and a professional who wants to help the child by using their technical expertise. The first will try to understand the child's view of the situation, and will infer this on the basis of interaction between two individuals who are mutually interested in each other. They will note whether the child is able to distinguish between different people as partners from the way they interact. The second will be confronted with a child as co-operator who may demonstrate that they do not accept everybody's intention to work with them. We can conclude that a child is perfectly able to

distinguish individual people, albeit in an emotional way and that this does not depend on any *special* professional qualities of the person interacting with them.

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CHAPTER 11

Building Bridges: The centrality of the relationship for empowering people in Early Childhood Intervention and beyond

Efthalia N. Kaderoglou[1]

This work is dedicated to the memory of my father, Nikos Kaderoglou, and of my teacher and companion, Ioulios Iossifides. They both live in my heart.

Do I want to be an expert?

The helping professions are to do with human relationships. Preachers, doctors, nurses, teachers, counsellors, psychologists, advisors and many more get a professional training in order to help other human beings. Their interaction with people in need of their services forms a path of communication, and this on-going communication forms a relationship between them. Does this relationship play a major or minor part in the growth and empowerment of the people who need help? Are there characteristics or special qualities that constitute a healing relationship and foster the healing and empowering process? Are there any rules in this kind of relationship? What are the expectations of the professionals, and what are the expectations of the people in need of their services? On what ground do they meet each other?

For many decades, the healing professions were characterised by the priorities, the expectations, the hierarchy and the roles stemming from the

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medical model that has been prevalent all around the world. According to this model, a priest certainly knew the way to save a sufferer, a doctor knew the way to cure a disease, a nurse knew the correct daily care for the sick, a teacher knew how to transfer knowledge to the students, a counsellor knew the way to advise the troubled, an early interventionist knew the way to handle disability. They all knew how to lead other people to a safer, more correct, more suitable path. They all knew what was best for other people. They all undertook this responsibility for other people's welfare. They were all experts in doing that.

Early enough in my training years, I was taught how to preserve the role of being an expert by carefully setting my professional boundaries. I was taught that I had to strive to control emotions, behaviours and interactions, and to limit my expression of my own feelings and most importantly those of the people that I was helping. Furthermore, as a fresh holder of a postgraduate degree on early childhood special education, I was prone to believe that competency in the subject and good academic qualifications were the cardinal factors for success in facilitating children's growth and empowering families. Having being merely trained in behaviour modification techniques, the outcome measures of the intervention were assessed through a comparison of mastered and emerging skills towards a baseline. I was trained to become a *child-focused* early childhood intervention *expert*, but there was nothing there telling me how to become a *family-centered* early childhood invervention *advisor*.

In my own family, as a child I met many professionals who were experts on disability. I grew up in an environment in which disease, doctors and therapists were on our daily schedule. None of these professionals ever cared or even attempted to reach out to me as a person. I was a tiny little creature, a small daughter, an insignificant other, definitely invisible to their eyes, so my limited role was to follow orders and any advice given. As a professional, I was not prepared to do otherwise, but I was determined not to become one of 'them'.

These early experiences that have wounded my soul were the reason I always found the underlying meanings of the role of the expert profoundly disturbing. Being an expert could certainly boost my ego, as I could indulge in feelings of great self-worth every time I put people back on the 'right track'. Being an expert also insinuated that I knew better than the person in front of me what was best for him or her. It implied that I was in a higher position, and that all the intervention needed had to be designed and led by me. It also meant that the focus of the intervention had nothing to do with me and my own growth as the benefit was one-way – directed towards 'the person of a lesser God' that needed my help. Furthermore, being an expert implied that I did not believe that every person had inner capacities for self-empowerment, self-healing and growth.

As a result, I found myself, from the very beginning of my professional career, wondering if my role could be any different. Could I treat other people as people and not objects? Could I leave my thirst for control behind? Could I

ever trust the process of our human interaction by truly believing and trusting that the other person was fully capable of finding their own way towards empowerment? If all these were possible, what were the conditions that would create a safe haven for a therapeutic relationship and bring growth to both parties?

Soon I came to realise that if I communicated well with parents, I could build a trusting and caring relationship with them. My role was to foster their children's development by facilitating high quality parent–child interactions and family-orchestrated child experiences in the context of their immediate environment through the medium of weekly home visits (Guralnick, 2001). However, my relationships with the mothers I worked with grew deeper and deeper, and soon surpassed the typical professional boundaries and became friendships. Subconsciously, I had violated the taught fundamental rule about professional boundaries. To me, it felt much more honest to take part in 'the dance of intimacy' as a key person who was kindly hosted in the middle of a family life if I did not hold back my emotions or act a part just to keep the 'client' happy. To me, there was no way I could 'care – but not too much' as I had been instructed to do. Either you care or you do not. Either you are sincere or you are not. I did not want to be the expert. I wanted to deepen my perception by relating to these people and by prizing their inner resources as human beings capable of overcoming any difficulty.

 Surpassing my professional boundaries had been easy for me, as I was working as a freelance advisor and had no boss or agency to curtail my

controversial views on the subject. I have to admit no remorse or ethical dilemma over this decision. This was just my way of working. Until recently, I did not realise the great impact of this early decision.

Although my friendship with the mothers grew deeper and deeper, soon I realised that this was not enough. Each family needed a social support network that was not present in any form. Peer support groups were not common at that time in Greece. Suspicion, guilt and fear of stigmatisation hindered people from forming such groups. In the course of my search for an atypical support network for each one of these families, I decided to cultivate the conditions myself and bring these people together. Soon some of the families and myself had formed a special circle of friends, a special 'tribe'. In this tribe, they were the experts, and I was thrilled to be among them serving as uniting element.

The tribe

I met three of my special families when their children were diagnosed with autistic spectrum disorders (ASD). The children's age at the beginning of our partnership ranged from 2.8 to 3.5 years old. The mothers were in their early thirties, housewives and definitely desperate. All three families were of middle class socioeconomic background. We worked together for almost five years, and then my 'professional' role eventually came to an end after the completion of the transition period when the children entered primary school.

Nevertheless, my friendship with these individuals lasts until today, 10 to 13 years after the end of the intervention process.

Throughout these years, the lives of the members of the tribe have changed dramatically, including my own. Among other things, some years ago I had to relocate to another city. Our tribe, although separated by distance, preserved its dynamics by exchanging emails, phone calls and visits regularly. We kept sharing our news, thoughts and feelings in a sincere and genuine way. The children grew up, finished primary school and entered high school. They moved on their way academically and socially through a society who cruelly stigmatised people with ASD.

I used to believe and advocate that it was the eclectic approach of the intervention programme that had brought significant change in the lives of these families (and therefore, by implication, the competence of the interventionist on the subject of autistic spectrum) by utilising principles and strategies from an array of known methods. Nevertheless, in later years I often questioned this assumption, wondering what factor in our partnership was most crucial for these people. What was truly important to them during the intervention period and beyond? How had forming 'the tribe' affected them? Ten years after the beginning of our partnership, I decided to shed some light on these issues.

Methods and considerations

It is commonly held that the proximity to the question being asked offers potential for bias. Could I conduct an investigation that was tied to my own work and to people I considered friends rather than clients without bias affecting the results? Olessen (1998) states that biases can be considered 'resources' and can be helpful in guiding inquiry and data gathering. Through my four-part role of researcher/early interventionist/friend/reference person for more than a decade, I had an overview of the investigation from different perspectives over an extended period of time. Nevertheless, validity checks were utilised in order to control contamination through bias. My expectation was that my experience as an integral part of the 'tribe' could offer insights and access that would enrich data collection and analysis.

I firstly searched my bulky family records in which I had included field-notes not only during the intervention period, but also through this whole 10- year period. Categories were identified and refined through selective coding (Strauss and Corbin, 1998). At this stage, a colleague was asked to replicate this analysis to ensure inter-rater reliability, and this did not result in any changes to themes in the data.

Then I conducted semi-structured interviews with the three mothers (Maria, Jenny and Voula), focusing on the most representative themes which had emerged through the initial analysis of documentary records. I chose to use semi-structured interviews because, within the remit of the identified themes, it felt most appropriate to use a rather free-flowing conversational style of interview for these people I had known so well for so many years.

Furthermore, our long friendship gave me the advantage of having a good rapport with them without any effort. I looked forward to exploring their subjective opinions and beliefs, reflecting upon the wider implications of what they had said, and then searching for patterns of contradictions and consistencies between the three interviews. The individual interviews were transcribed and analysed using categorical content analysis.

The mothers' perspectives: what was fundamental to promoting empowerment in the intervention process?

The mothers' relationship with the ECI provider

All mothers stressed the importance of the relationship that had been built between them and myself as the major factor that had facilitated their empowerment. There were several emergent themes from the data analysis (see Figure 1) pointing to specific qualities of the relationship that the mothers thought were crucial:

Authenticity

Authenticity in our relationship was described as 'not wearing a façade', being a 'real person', 'speaking the truth':

> *When I met you, I found a person whom I knew was sincere and would never leave me in the dark. You were real, you were not pretending, and I knew I could ask anything and get true answers.* (Interview, Maria, 9-7-2006)

I had a person in front of me, not scientific showcase. You had the nerve to remain human and meet me half way. (Interview, Voula, 12-7-2006)

Carl Rogers (1967) described the qualities that facilitate empowerment and personal growth. The first quality is realness or genuineness of the counsellor. The counsellor is a real person entering a relationship without presenting a front, coming into a direct personal encounter with the client as a person.

Empathic listening and care

A second, concurrent theme was the ability of the interventionist to demonstrate empathic listening. Maria commented:

I had found my voice. I was used to that feeling that my voice just evaporates and nobody listens. When we met, I knew straight away…said …'Oh my God, finally I am heard.' (Interview, Maria, 9-7-2006)

Showing care and empathy in crises and emotionally intense situations were also described:

I remember the moment when he [Antonis] actually called me 'Mom' for the first time. I had waited two years for that to happen, and I knew that

it was equally special to you. It was our celebration. (Interview, Jenny, 10-7-2006)

…when my father died, I knew I could call you right away 'cause you knew all the context of my life. You could understand my loss. (Interview, Maria, interview, 9-7-2006)

Rogers' second prerequisite condition for facilitating growth is empathic understanding. The facilitator establishes a climate in which the person is understood from their point of view – not evaluated, not judged, simply understood (Rogers, 1967). Later studies also stress the ability to demonstrate concern, empathy and the ability to respond thoughtfully in emotionally charged situations as important interpersonal skills for ECI providers (Gilkerson and Taylor Ritzler, 2005).

Unconditional acceptance, trust and respect

The mothers' feeling of being trusted and respected was another powerful theme. Being accepted without conditions seems to have led to empowerment, fostering a better self-concept and a more efficient management of parent–child interactions:

Looking back, I realize that there were times at the beginning that I was truly surprised by what I saw in your eyes about myself. You believed

in me, much more than I believed in myself. Thank God it was

contagious! (Interview, Jenny, 10-7-2006)

Voula commented on our partnership:

This is a very liberating feeling – to know that someone trusts you –

although he might be aware of your weaknesses or faults. (Field notes,

20-4-1996)

Acceptance, trust and respect are the ingredients of 'unconditional positive regard', the third condition for building a therapeutic relationship according to the person-centered theory. The facilitator cares for the other person in a non-possessive way, valuing them as an imperfect human being with many feelings and much potential (Rogers, 1967).

A surprising sub-theme that can offer a deeper understanding is that of the *immediate perception*. Jenny and Voula reported that they had a sense of trust, acceptance and respect in the relationship with the interventionist even from the second home visit. Maria felt sure about this element after the fifth home visit. This finding coincides with findings of Barrett-Lennard (1962) and Tausch (1973) as cited by Rogers (1980) stressing that the elements of trust and pure acceptance are sensed by the clients almost immediately in the course of the first month of a therapeutic relationship with a counsellor and could even be used as progress indicators.

Continuity and sustainability of relationship

All mothers thought that a major factor contributing to their empowerment was the continuity of our relationship through time. This continuity was described as 'availability', 'emotional commitment', 'frame of reference'.

> *One thing I find crucial is that since we met I never felt alone. You were available for me; I knew I could count on you on every occasion.*
> (Interview, Maria, 9-7-2006)

This continuity of relationship was put to the test when I had to move to another city. Voula reported:

> *We were in this together. When you left, I thought I'd lose it, but after a few months I understood that we were still connected, never mind the distance. It's the heart that counts.* (Interview, Voula, 12-7-2006)

Bertacchi and Norman-Murch (1999) stress the centrality of relationships to work with families, arguing that the continuity and sustainability of relationships between early childhood intervention providers and parents is associated with sustained, healthy, parent–child interactions and improved family functioning.

The mothers' relationship with each other

Data revealed three major themes that described the effects of the mothers'

friendship on the course of their life after forming the tribe (see Figure 2).

Community feeling

All mothers reported a shared feeling of community based on common

experiences of hardship due to their children's atypical development and

behaviour. This feeling of community seemed to be infused by the same

relationship-building traits that were reported in the relationship between the

mothers and myself described previously.

a) Honesty, open acceptance:

> *There's a sense of freedom, you know. The truth is spoken. You don't*
>
> *have to care if you might be misunderstood, 'cause we accept each*
>
> *other as we are.* (Interview, Jenny, 10-7-2006)

b) Empathic understanding:

> *I know their state by the blinking of their eyes, by the breaths they take*
>
> *when we speak on the phone. We don't need to talk. We just know.*
>
> (Jenny commenting on her relationship with Maria and Voula; Field
>
> notes, 12-1-1997)

When one of us talks, the rest simply know what is going on...

Understanding each other is our natural Prozac! (Interview, Voula, 12-7-2006)

c) Sustainability of the relationship:

It's like a secret promise that, no matter what, we will be there for each other. (Interview, Maria, 9-7-2006)

It seems that there is a parallel process of 'layering' as Gilkerson and Koper (2004) and Moore (2007) describe how one relationship can affect all the others at all levels in relationship-based early intervention. It is evident that the 'home culture' that had been developed between each mother and myself during early childhood intervention was transferred into the 'tribe culture' without any guidelines being given.

Emotional unloading

All mothers described that being part of the tribe meant undertaking the role of a 'breakwater' for each other. This was seen as a natural, mutual process of 'lending a hand to one another'. Humour, as a trait, was present on numerous occasions in field notes entries. Indeed, interview data were saturated by this sub-theme as a great strategy for emotional unloading for all members of the tribe.

Maria was laughing with all her heart while explaining to Jenny and Voula [what had happened]. She actually acted out the whole scene of George climbing over the cashier's desk at the supermarket, and roaring in the parking lot when he became distressed by an annoying commercial jingle that the speakers had played in the store. I think we wet our pants laughing. (Field notes, 26-1-1998)

It's amazing that often I am able to convey very difficult moments that actually devastated me in a very lighthearted way, and we end up laughing about these incidents. It removes the tension – the laugh, I mean… (Interview, Voula, 12-7-2006)

The veteran effect

Maria had welcomed Jenny into the tribe, and then the two of them had, in turn, welcomed Voula as a new member. The oldest member helping out the newest seemed to be true for Jenny and Voula, but not so evident between Maria and Jenny. In their case, although Jenny was new to the group, it was her that supported Maria and not the other way around. Jenny would come up with a lot of suggestions and practical solutions for Maria about surviving the day with her son. What could be the reason for that contrasting pattern? Could it be due to differences in temperament? Maria always needed more time and space to open up to new relationships. On the other hand, Jenny reported that she received a lot of support from Maria when marital relations with her husband were strained. Therefore, the veteran effect was still evident

only with a different focus. On the other hand, by the time Voula entered the 'tribe', Maria was able to offer her consolidated expertise:

> *She [Maria] was so helpful when it got very tough for Petros and me. She has shared many strategies with me. Some worked; some didn't. She and Jenny kept me going.* (Interview, Voula, 12-7-2006)

Abraham (1998), Copp (1998) and Grandey (2000) all identified peer support as an important moderator of emotional labour. Equally Rogers (1980) quoting Richard Farson reminds us: 'The population that has the problem also has the best ways of dealing with it.'

Reflection – implications for practice

Following the tracks of these families' life journeys along with mine made me realise that the qualities of what I have been calling friendship were described as crucial factors for personal empowerment and growth. These findings are not new, as Carl Rogers has been articulating the conditions for facilitating growth and healing since the 1950s. Nonetheless, it seems rather important to me that by focusing on our common life journeys, I came upon a description of conditions for empowerment that none of my academic training had highlighted for me. Although not prepared or taught to engage in such a way with my clients, I now feel very grateful that I blindly and rather stubbornly followed 'a way of being', a way of relating to the mothers that stemmed from my own early experiences. I am deeply grateful that I simply followed the rule of my heart by putting people first and valuing our interaction through the

course of the intervention programme and beyond. Kelly (1999) suggests that the focus of early intervention efforts should be making relationships. Kalmanson and Seligman (1992, p.48) also state:

> *The success of all interventions will rest on the quality of provider–family relationships, even when the relationship itself is not the focus of the intervention.*

It also seems that the relationships among the members of this tribe were viewed 'as the organisers of development and as the basis for all intervention' as Weston et al. clearly describe (1997, p. 5).

Peer support seems to be another crucial issue in fostering early childhood intervention effectiveness, especially when other resources are not available. Pairing veteran parents with newcomers seems to create a safe haven for venting emotions as well as offering a voice of experience to new families. Further research could shed some light on the mechanisms that foster the infusion of the 'empathic culture' already present in some family–service provider relationships among the families themselves through an informal peer support group.

Implications for training

The findings of this study stress the mobilising nature of nurturing, genuine and empathic relationships in an early childhood intervention context. A

Rogerian perspective was adopted as almost all saturated themes from this research coincided with the conditions analysed in person-centered theory. People come first; relationships between people are brought to the fore with a focus on that which lies between them.

This study suggests that there might be a hidden curriculum for new practitioners in the field of early childhood intervention. Providing empathic understanding, conveying unconditional positive regard, presenting authenticity, and cultivating trust are personal qualities vital to the role of an early intervention provider. Unfortunately, these qualities are often not recognised as essential elements within a training curriculum for early childhood intervention providers in Greece. As Moore (2007) suggests, personal qualities of genuineness and warmth should be recognised as important initial staff selection criteria. He believes that future practitioners should be trained in core relationship skills and relationship-based practice. But can empathy be taught? Fortunately, literature suggests that it can. Aspy (1972), Guerney et al. (1970), Rogers (1980), Bertacchi and Norman-Murch (1999), Gilkerson and Ritzler (2005) and Moore (2007) emphasise that the ability of empathy and other necessary relationship skills can be cultivated through practice and reflective supervision. The supervisors must possess a high level of empathic understanding to support the parallel processes that will enable team participants to develop their own empathic understanding. It is suggested that processes during team work will be mirrored in the staff's relations with families they work with, promoting better relationship-based practices.

Building bridges: love as the healing factor

Carl Rogers, a charismatic and insightful man, has been very cautious in choosing the words to describe his revolutionary theory on personality, growth and healing. While setting down the infrastructures that would allow the comprehension of the necessary and sufficient conditions of a therapeutic relationship, he actually avoided talking about love, although love seems to be the hidden message of 'unconditional positive regard'. In the 1950s, avoiding politicising love seemed to be a very sound decision. Love as a term has been tormented and maltreated for centuries, bearing different meanings, carrying varied motives and displaying diverse expectations. It could have been disastrous for the future of the person-centered approach to counselling, psychotherapy and teaching if Rogers had dared to be that bold. But I cannot stop wondering whether we are still afraid to talk about love as our feet are already walking down the path of the new millennium. Is love still not scientific enough to be included in academic textbooks? Is love to hard to teach? Is love too hard to be expected? Is love still a taboo in academic circles? What is it that forbids us to talk about the ultimate condition in a healing and growing process?

Bozarth (1992, 1998) has stressed that love is the healing factor in human relationships, as receiving love is a fundamental human need that nourishes and strengthens our soul, mind and body. Furthermore, Gendlin (1996) has also highlighted the other side of the coin: that a person demonstrates a

fundamental need to offer love to other people around them. So why can't we give love one more chance? Why is it still so hard to release our fears and simply be whole people, including our sentiments and feelings, instead of being cognitive rocks full of expert knowledge in front of our clients?

Our clients are real people just as we are. They need to be valued, trusted and loved for who they are. If they receive love, they can regain their personal power, and they will love us back. Through this stream of love, we bond, we quench our biggest anxieties, we gain food for our soul, we meet our brothers and sisters, we belong to the world, and we create a new humanity where interconnectedness and interrelatedness is better understood (May, 1969; Thorne, 1991). Love allows us to transcend our circumstances and realise that the personal is also universal, and that people do have the power to change. If only they believe… If only they share love…

Part of this chapter is based on a paper presented by the author at the 2nd International Conference of the International Society on Early Intervention, Zagreb, Croatia June 14–16 2007 with the title, 'People first: a Rogerian perspective towards early childhood intervention'.

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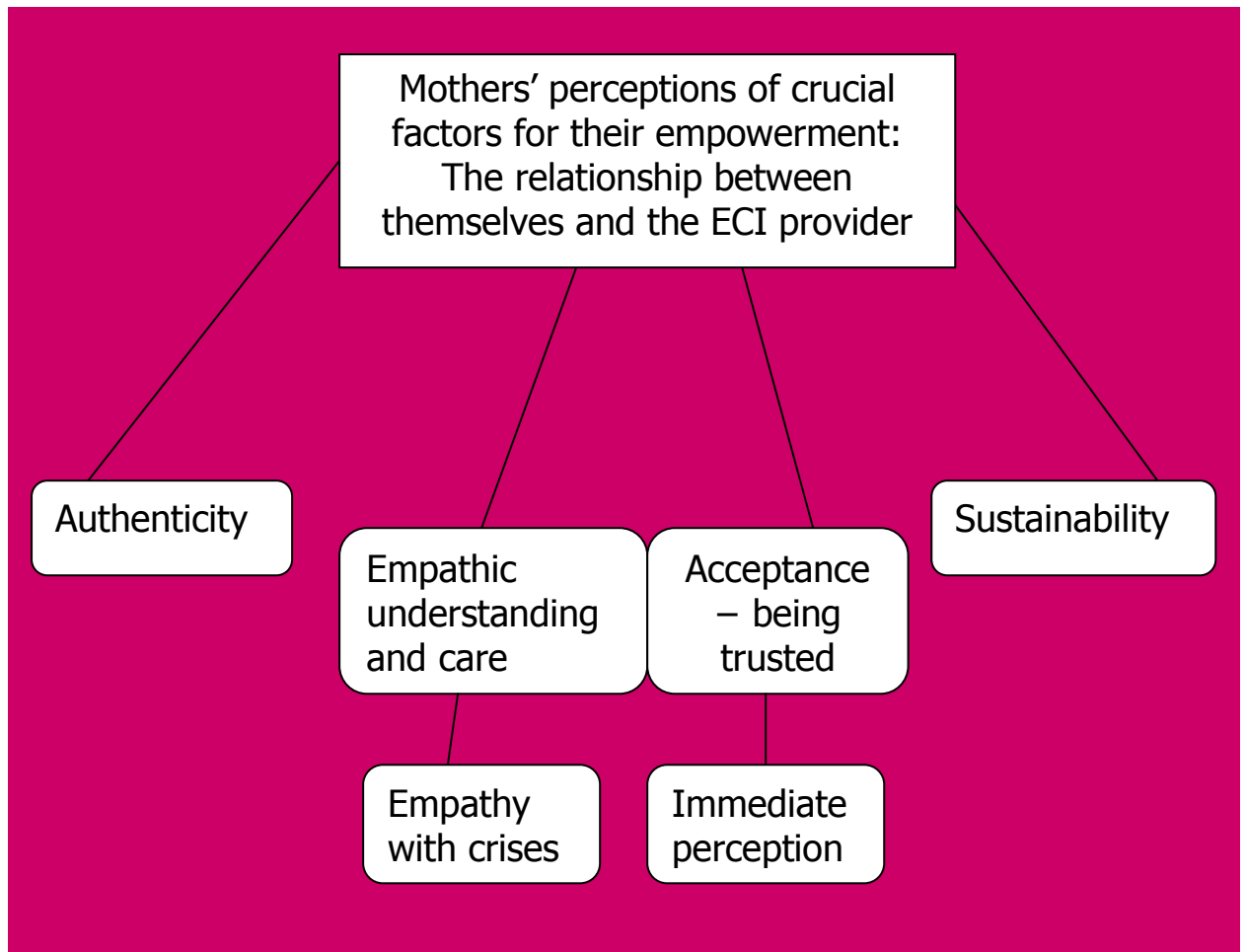
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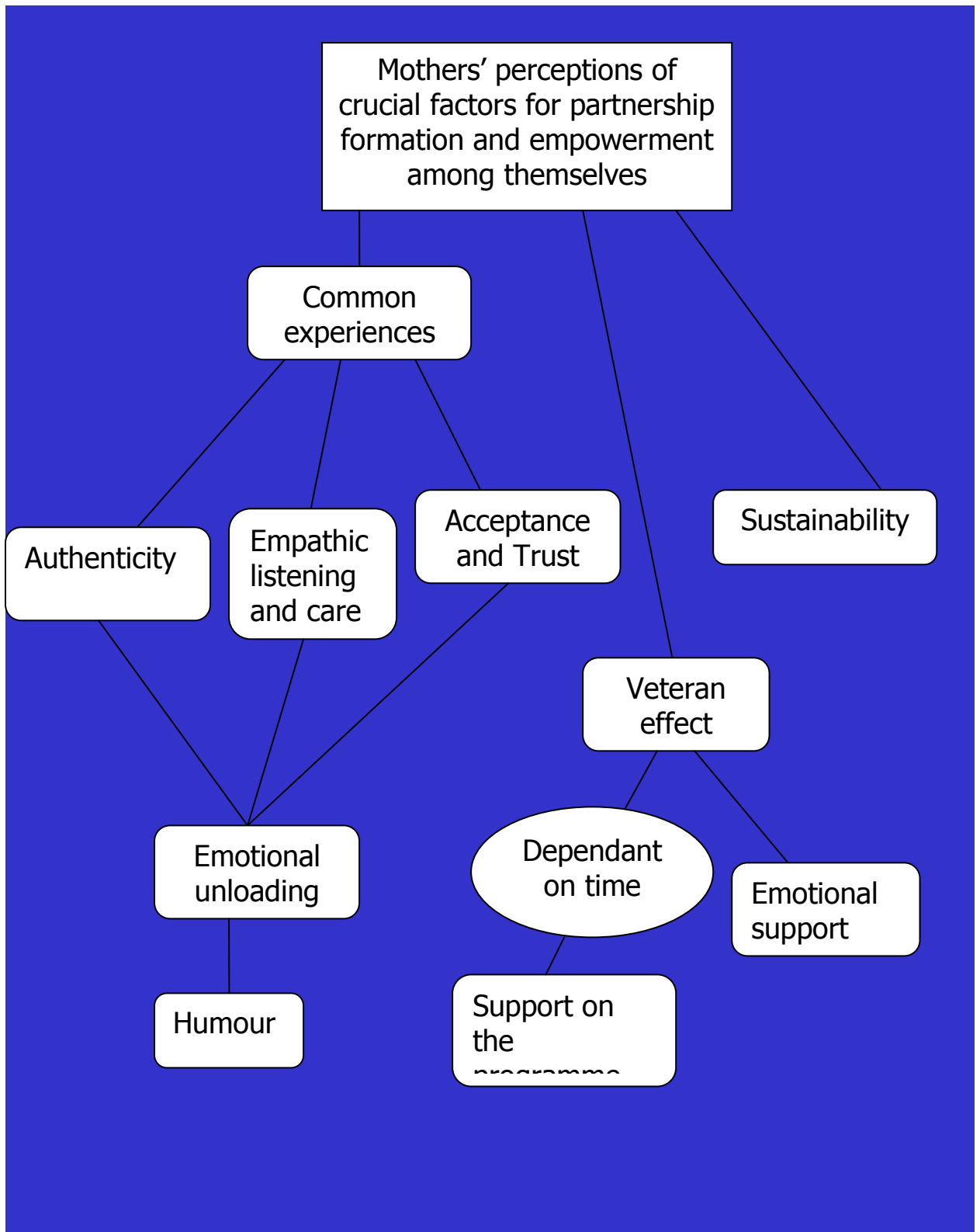
Figure 2

CHAPTER 12

Transdisciplinarity: a key to a holistic intervention approach

Jacques Schloesser[1] and Marijke Kafka

"Damit das Mögliche entsteht, muss immer wieder das Unmögliche versucht werden" [Trs.

"To make the possible happen, you have to try the impossible again and again."]

(Hermann Hesse)

Summary

While early childhood intervention has evolved from a mono- or multidisciplinary approach to interdisciplinary professional collaboration, the authors share the conviction, based on years of practical experience, that the professional training of 'early interventionists', important as it may be, is not the main issue in the actual intervention process. Building strong, trust relationships with children and their families, and helping them to find their own ways of dealing with their personal situation, is the core business of early childhood intervention as we understand it. Transdisciplinary cooperation among professionals and with families, as outlined in the following pages, appears to be an efficient way of implementing a holistic, child-centred and family-oriented early childhood intervention model.

Key words

Knowledge transfer, resources, reflection, reliable relationships and trust, coherence of intervention

Introduction

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[1] Secretary of the European Association on Early childhood Intervention – Eurlyaid; Director of SIPO Early Intervention Service

Much has changed in the last few years regarding the practice of early childhood intervention for children with a developmental delay or disability and their families. Advances in genetic and neurobiological research have increased enormously our knowledge and understanding of the profile of disability conditions and their presentation. The influence of the environment and key attachment figures on the development of the child, and the impact of the child's disability on the family system, are increasingly important considerations for professionals. The positive effects of reliable and appropriate support delivered within the family context cannot be denied any longer. In this chapter, the holistic and resource-oriented approach to early intervention is endorsed, and the supporting theory is discussed in the context of practical work carried out at two early intervention centres – one in Germany and the other in Luxembourg..

What is early childhood intervention?

In its 2005 report on the situation of early childhood intervention in Europe, the European Agency for Development of Special Needs Education states that:

> *ECI aims to support and empower the child, the family and the services involved. It helps to build an inclusive and cohesive society that is aware of the rights of children and their families.*

This clearly indicates that aims and objectives of early childhood intervention should be set on three different levels:

1. The child level
   - To prevent, as far as possible, disabilities or developmental delays resulting from impairment (primary prevention)
   - To offer the child the best possible opportunities to develop its full potential and self-esteem

- To enhance and support the child's inclusion and participation in its family and social contexts

2. The family level
   - To support and strengthen within-family resources, both emotional and practical
   - To offer information on the child's specific needs, as well as help and support to empower families
   - To help families to access the services and social resources available by informing them about existing possibilities

3. The societal level
   - To enhance social inclusion and participation of children with special needs and their families
   - To enhance the creation and development of social resources for the benefit of children with special needs and their families.

Early childhood intervention clearly cannot meet all of these challenges by simply applying discrete therapies to children in individual areas of development. In our view, transdisciplinary cooperation among professionals, and between professionals and families, are necessary conditions for implementing a holistic, family-oriented, early childhood intervention model.

The situation in Germany

It is a fact that early childhood intervention services are accessible to the child and its family only when there are clearly identified impairments. The social legislation in Germany is still largely based on a mechanistic model with separate categories of support which are delivered by service providers to the beneficiaries (i.e. people with an identified impairment) with the intention of eliminating the deficit as soon as possible.

In Germany, there are 12 different codes of social laws SGB (social legislation) I–XII. These address different needs, including:

- *Disease*

  If a child is ill, they can make use of the medical and therapeautic services available. In cases where immediate cure is impossible, adaptive devices are employed to facilitate everyday life (SGB V).

- *Education*

  Assistance with their child's education may be granted to families if the care and youth welfare agencies believe that, by doing so, a threat to the child's well-being and their placement in a foster family or children's home can be avoided (SGB VIII).

- *Care*

  Home care services are paid for by the care insurance company only if the child needs substantial nursing input in comparison with other children of the same age (SGB XI).

- *Participation*

  Criteria for participation stipulate that the child has been or will remain impaired for at least six months (SGB XII).

- *Disability*

  The confusion around agreed criteria for receiving disability services was supposed to be addressed by SGB IX. However, the definition used is a general one which includes all people with disabilities, rather than being specific to children eligible for early childhood intervention and their families. Parents are still contesting the wording of this section.

Early childhood intervention in Germany is an eclectic model and relies on contributions from individual services. Children and their families can receive early intervention only if they are eligible for at least two intervention types simultaneously; for example, medical/therapeutic, educational and psychological services. The other two services of care and youth welfare (mentioned above), which could play an important role in early childhood intervention for children and families, are generally not involved. However, the method of determining the appropriate package of support has not yet been properly developed.

Early Childhood Intervention at Marli-Mobile Frühförderung Lübeck

Early childhood intervention at Marli GmbH – a not-for-profit organisation for people with disabilities founded in 1984 – is based on the idea of Lebenshilfe Lübeck und Umgebung e.V., the local health authority and paediatricians' kindergarten for special needs in Lübeck. In 2007, the organisation cared for 446 children and their families. Most of the children involved with the centre are referred for early childhood intervention by their paediatricians. Children and their families who are in need of early childhood intervention are supported by a range of professionals.

First of all, it is necessary for the professionals involved to review the systems already in place for the child and to rationalise them, since an excess of services does not necessarily ensure an excess of success! Thus, it is sometimes necessary to prioritise service delivery in the child's and their family's best interests. In addition to this, the services provided by local authorities have become increasingly influenced by the idea of profit maximisation. Official figures give the impression that the number of services commissioned has increased linearly with the number of children who are clinically diagnosed. However, in the face of a financially critical situation, funding agencies often try to share the available support between as many cases as possible.

Due to the complex procedure involved in establishing children's eligibility to receive early childhood intervention, the much needed immediate support is delayed. Unfortunately, our social legislation assumes that people may try to make unwarranted or illicit use of services, and therefore there are significant barriers which prevent children and their families from accessing early childhood intervention easily. This is one of the reasons that parents are reluctant to apply. It is worth noting that since our early childhood intervention centre was founded, we have never come across a child who was receiving early childhood intervention services without needing them.

The eclectic model of early childhood intervention results in a multi-professional approach, which reflects our social legislation and the policy of providing different types of service simultaneously. When professionals from different disciplines are involved separately, there is a danger that the service delivery can be disjointed. However, when the transfer of knowledge among professionals is systematic, within a multi-professional team, this approach can become interdisciplinary. Interdisciplinary working is recommended by pedagogues and doctors who specialise in early childhood intervention, as well as by the interdisciplinary team at Marli GmbH, as the appropriate mode of delivery for therapeutic, orthopedagogic and psychotherapeutic measures. According to the International Classification of Functionality, Disability and Health (ICF), early childhood intervention needs to support the child in three areas: structures and functions, activity and contextual factors.

Early childhood intervention in Luxembourg

Luxembourg has, mainly due to its relatively small territory and population, nothing as coherent as a *system* of early childhood intervention. There are only three service providers in this domain, compared with over a thousand in Germany. Two of these service providers come from a medical and rehabilitative background, while the third promotes a psycho-pedagogical and holistic model of intervention. The latter – SIPO asbl – will be the focus for

this section, as it is familiar to the authors, and the one which is closest in its philosophy and intervention approach to the German model described above.

Service providers in Luxembourg are private, non-profit-making organisations. As a consequence of early childhood intervention being a minority field, the need for specific legislation has not arisen until recently. Currently, services have to fulfil a number of conditions, mostly of a technical nature, to become authorised as early childhood intervention service providers. These minimum quality standards are defined in the 'general conditions' section of an annual financial agreement between the services and the Ministry of Health or the Ministry of Families.

Current policy developments are tending towards a model of individual entitlement to service provision for children and their families. This new legislation will be applied to such different domains as day care, early childhood intervention, counselling activities for parents, etc. Central to this new policy approach will be a system of tariffs associated with the different services available. The money to commission services will be paid direct to parents and their children in the form of 'service-cheques', and no longer to service providers. This will allow families to make personal choices about the services they receive to suit their individual circumstances – a development which is similar to the UK trend.

Early Childhood Intervention at SIPO

SIPO was founded in 1981 by members of the National Association of Special Pedagogues in Luxembourg. During the first years, the staff were made up only of special pedagogues. However, over time, professionals from different specialist backgrounds, such as occupational therapists, speech therapists, pedagogues and psychologists, expanded and diversified the team. Professionals from an increasing number of different fields work with children and their families, and they tend to bring into this work specific knowledge and expertise gained through training and years of experience.

The fundamental concepts guiding SIPO's service provision model are:

- Transdisciplinary cooperation

- A holistic approach to intervention: the child is considered as a unique and complete person – not a collection of different problems or handicaps or delays. Service delivery is focused around the child's strengths, resources and their various 'life contexts' (e.g. family, school, day care, etc.); the family's social circumstances and their participation are of particular concern in this intervention model, and the active participation and autonomy of the child in the intervention are promoted by professionals

- Partnership with families: although the child is at its centre, the intervention work is always oriented towards families and their specific situation, needs and resources. Families are actively involved in intervention planning and delivery, and have control over decisions concerning their child.

- Networking with other service providers around the child and the family: early childhood intervention is one part of a system of possible service provision around families. To achieve coherence, effectiveness and efficiency, all of the professionals involved in an intervention have to seek the coordination of their input to the benefit of the child and family.

One of the requirements in achieving the holistic approach mentioned above is to keep the number of professionals working with a child and its family to a minimum. Thus, for each family, there is generally one professional in charge of the initial and ongoing assessment process and one professional in charge of the weekly interventions, based on an individualised intervention plan developed in cooperation with the parents during the assessment process. Parents do not therefore have to deal with many different professionals, each of whom considers themself an expert in their domain. They know whom

to approach with their concerns, and can be quite sure that this person knows their situation and that they will not have to state their case over and over again.

This way of service organisation sets the conditions for collaboration between families and professionals, based on mutual knowledge, trust and respect. Families do not feel as though they are being passed from expert to expert, each of whom is unaware of or, at worst, even uninterested in their personal situation. Parents and professionals can come to know and value each other as people striving towards common goals.

Transdisciplinarity is not a common characteristic of teams. Most teams are multidisciplinary at best. It does not come down to just 'a state of mind'. Transdisciplinarity in early childhood intervention demands a reconfiguration of service delivery processes and procedures, as well as finding ways of genuine cooperation among professionals, and between them and the parents. Transdisciplinarity is a result, even a logical consequence, of a thoroughly implemented, systemic interdisciplinarity. Interdisciplinarity supposes that professionals not only work together to share all of their expertise and knowledge (multidisciplinary model), but that they also assimilate them into a coherent approach or programme to the benefit of the child and the family. Transdisciplinarity takes this a step further by trying to achieve this goal with a minimum number of professionals involved who, regardless of their basic professional specialism, will deliver a programme to meet the jointly agreed professional goals of the wider early intervention team. For example, a speech and language therapist, in addition to specific speech and language goals, may also work with the family towards psychological and pedagogical goals using a combined approach. The basic assumption of this model is that a well-trained, highly qualified and open-minded professional, relying on clearly defined procedures and documentation tools, is able to implement the complete intervention work with a child and its family, from initial assessment, through actual intervention, to final orientation. Transdisciplinarity is a systemic, structural model.

General principles for transdisciplinarity in early childhood intervention

Early childhood intervention is based on the following assumptions:

- Every child develops best when they have a secure emotional attachment to their primary carers in a supportive, family environment

- Parents know themselves, their children and their own circumstances better than any professional

- In the widest sense, early childhood intervention means learning

- The child receiving early childhood intervention and its family, as well as the early interventionist, have individual resources

- These resources may not be continually available but can be activated in different situations

- A family with a small child is in a phase of fundamental change in which it is necessary to have stable, social setting for a successful intervention outcome

- Early childhood intervention must be available on an as-needed basis without bureaucratic obstacles.

Furthermore, the transdisciplinary model assumes that:

- A reliable relationship between the early interventionist and the child and their family is more important than the application of a particular method

- Any early childhood intervention includes medical, educational, therapeutic and psychological elements

- Transdisciplinarity demands a high degree of knowledge transfer between professionals of different disciplines.

In the initial interview with the child and family, the lead early interventionist nominated by the multidisciplinary early intervention team determines whether early childhood intervention is

needed and possible. This includes primarily the issue of problem definition, the attribution of the cause of impairment and the selection of the process as well as taking a detailed case history and profile of need.

The first home visit makes it possible to explore with the parents the family's existing support systems and any barriers to successful intervention posed by their circumstances. According to the information imparted, a provisional contract is completed. Further diagnostics must be continuously carried out, and the planning of early childhood intervention must be done together and in agreement with the parents.

One prerequisite is that the early interventionist possesses comprehensive knowledge of child development and of the development of family structures in different phases of life and contexts. In addition, they should have in-depth knowledge of at least one technically appropriate procedure. A second important condition is that they accept the family in the context of their existing everyday life and coping strategies. Many families involved in early childhood intervention have outstanding and for the processing phase of their new situation suitable strategies for action that we appreciate and positive support and revived. First and foremost, it is important for the early interventionist to operate from a perspective informed by the family system and to develop a reliable, professional, but also a somewhat friendly relationship, not one based purely on the child's diagnosis and a professionally imposed incentive and treatment plan.

The transdisciplinary model of working requires:

Of professionals

- A sound knowledge of and expertise in typical child development and the possible deviations from the norm. Professionals must, for instance, know what language skills a three-year-old child should have, as well as the expected level of intellectual and motor

skills. They should be capable of identifying the symptoms of a wide array of possible disabilities, and the range of appropriate pedagogical and/or therapeutic interventions which can be used with these children.

- Open-mindedness to the perspectives and methods of professionals from other disciplines and the ability to integrate them into a coherent, sensitive and effective intervention programme (i.e. knowledge transfer): professionals cannot remain within the limits of their specific discipline, as this would not allow them to get a complete picture of the child's developmental situation. They have to be able not only to build up knowledge of different disciplines, but also to assimilate it into a sensible and sensitive intervention model.

- Respect for the families' ways of living and patterns of interaction, and recognition of their needs and resources: professionals are specialists who are at the service of children and their families. They have to be able to enhance and support, on the basis of their specialist knowledge, families' search for ways of coping with the specific situation of a child with a disability or specific needs. They also have to value, respect and support the ways in which parents and children deal with their own situation at certain points in their lives. These 'solutions' might work for a particular time and a particular period. They may then have to be reconsidered. Change is frequent. Professionals need intellectual and emotional flexibility and adaptability.

- Emotions are important resources for a workable parent–professional relationship. Like the mothers and fathers involved in early childhood intervention, Early interventionists are human beings. The differences between them depend only on the setting and the commission that parents give them. In our early intervention centre, two of our colleagues are mothers who were formerly involved with the centre through their own child's early childhood intervention programme. They are reflective practitioners, well aware of their own limitations, and bring their special resources into the team. The systematised transfer of resources needs flat management hierarchies and the willingness to work in partnership with other professionals.

Of service providers

- A clear definition of processes from admission of a child to conclusion of the intervention work: professionals must be provided by their employers with clearly defined work processes and stages. They have to know who is supposed to do what, how and at what time. Precise organisational charts are required. Transdisciplinarity is not everyone doing what they like when they like.

- A certain standardisation of procedures and documentation as far as this is compatible with individualised interventions: to allow professionals to work in a transdisciplinary mode, they must be provided with the necessary tools to operate in a similar way each time a child is newly admitted to early intervention. Service providers have to determine which developmental scales and tests they want professionals to use when profiling a child, otherwise each professional will just use the tool they know or like best. In the same way, questionnaires have to be designed that can be used with all (or most) families, and files have to be set up in a standardised way to facilitate team members' access to them.

- The possibility of formalised professional discussions and exchanges as well as of ongoing professional training offered to staff members: employers cannot expect their staff to fulfil the requirements outlined above, if professionals are not allowed necessary and sufficient time to discuss with colleagues, to learn from each other and to extend their knowledge and resources through ongoing training. Time has to be allowed for them to do all this formally and not just by chance over a half-hour lunch break.

The main advantages of the transdisciplinary model are:

- Coherence of the intervention plan and the steps within it

- Facilitated coordination involving a minimum of different professionals

- Actual partnership with families and easy identification of contact people for families

- Enhancement of ongoing and mutual professional exchange and training among colleagues leading to an ever-increasing expertise at service provider level

- Enhancement of efficient organisation within the service provision.

Barriers to the transdisciplinary process are:

- Profiling carried out on the basis of the personal preference of the early interventionist instead of being standardised

- Inflexible discipline

- Lack of openness regarding own professional behaviour for fear of exposing professional weakness, and therefore the risk of poor performance assessment ,

- Occupationally rigid hierarchies

- Unclear organisational processes

- A low opinion and expectation of colleagues and families

- Trying to run early childhood intervention as a profit-making business

- Children and families not being able to let go of professional support despite positive achievements.

How does transdisciplinarity early childhood intervention work in practice?

Each child and its family are allocated a personal early interventionist. The assignment of this 'lead' early interventionist is agreed by the heterogeneously composed specialist team after the early childhood intervention coordinator has conducted the initial interview in the parents' house and has gathered and discussed the information with the professional team. Early childhood intervention coordinators are early interventionists who have not only a great deal

of experience in the field, but also the ability to assess the needs of families, and review and integrate appropriately the professional resources from the different professional disciplines represented in their early intervention team to meet the families' needs . The application of the support identified in the ICF for children and young people is of great importance.

Structural interdisciplinarity ultimately evolves into transdisciplinarity. Usually, in the latter case, the various professionals from multiple disciplines are not individually involved with the child and family, but their combination of methods, resource diversity and specialist advice are integrated within an agreed intervention and delivered by the most appropriate professional within the team. This transdisciplinary approach succeeds mainly by means of precise technical competence. Early interventionists must continuously reflect on their professional actions and know their own limitations. Each child is discussed within a professional team, even if the early interventionist thinks that everything is running very well. On the one hand, all colleagues benefit from the positive examples reported to the team by the early interventionist; on the other, it is important to have other professionals' views and attitudes informing the early interventionist's own action.

Possible steps of transdisciplinary action in early childhood intervention:

1. The lead early interventionist consults with other discipline specialists within the team on a rotational basis.

2. The lead early interventionist consults another colleague regarding a certain issue within the family, and then this is discussed further with the specialist team.

3. The lead early interventionist works alongside a second colleague because the application of a specific method is temporarily of great importance. This is discussed within the specialist team.

4. The lead early interventionist changes, and the child and their family are seen by another early interventionist from the early intervention centre. As the intervention progresses, it may become more appropriate for a specialist from a different discipline to take over the lead responsibility. This is discussed within the specialist team.

5. The early interventionist refers the child and their family on to another social or medical service, and organises for knowledge transfer to take place.

6. Conductive aspects of the transdisciplinary process are a vital part of the perspectives and attitudes of early interventionists.

Early interventionists do not define themselves primarily through their professional discipline (special teacher, doctor, physical therapist, speech and language therapist, social worker, psychologist, occupational therapist, etc.), but as a human being who brings to their professional activity their individual social skills, their unique life history, their past, current and anticipated life situation, and their related experiences, interpretations and actions. This also includes expertise acquired through education and training and their own experiences of therapy. The child and their family are not the objects or 'users' of our early childhood intervention service. (Such an attitude puts emotional distance between the family and professional, and emotions are an important resource in early childhood intervention.) They are co-participants. The desired outcome can be created only from a dynamic human relationship between the families receiving early childhood intervention services and the professionals involved.

Conclusion

The transdisciplinary early childhood intervention model presented here does not pretend to have any scientific status, but it is certainly a piece of evidence-based practice. Putting the

child and the family at the centre of our efforts, and organising resources as efficiently as possible to achieve the maximum benefit for these families, make good sense.

The transdisciplinary model is very demanding for the professionals involved. They cannot be specialists in just one domain and focus on their own purposes. They have to be open to ongoing training, both formal and, most of all, informal. They have to continually learn from colleagues, from families and from children. They have to adapt their ways of thinking, their intervention models, and their everyday practice to the ever-changing realities of the families they work with.

Transdisciplinarity is demanding at the level of the service provider as well. Service providers have to set up very clear procedures and ways of documentation that are standardised so that staff know what to do, and how and when to do it. However, procedures should be flexible enough to allow for individual adaptations if required by a child's or family's situation.

To us, the transdisciplinary model of early childhood intervention is the best way we have found yet to efficiently deliver meaningful services in a respectful way to children and families.

CHAPTER 13

The importance of partnership between parents and professionals

Dirk Mombaerts[1]

Summary

This chapter considers the position of parents of children with disabilities in the context of a changing society which has seen its response to disability evolve from segregation to inclusion. The journey has been a long one with many pitfalls. Parents were not always involved in the care of their children with disabilities. However, during the last 30 years, the status of parents in relation to the professionals they meet has altered greatly. The second half of this chapter will suggest ways to address parents' perspectives in early interventions. Only if professionals respect parents' points of view, will they become true partners in early childhood intervention.

Introduction

The birth of a child with disabilities in a family causes a radical change. Not only they are confronted with the extra medical care and the developmental problems associated with their child's condition, but also their own feelings are confused. Their familiar lifestyle has become disrupted, and their future uncertain. Nevertheless, the parents are the primary caregivers and the main educators of their child, and it is of great importance to support them by increasing their personal competences in the education of their child.

Increasing parents' competences in the crisis situation following their child's birth, however, is not straightforward, and many professionals focus mainly on the problems of the child and much less on the experience of the parents. However, to make a success of early childhood

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intervention, we have also to look at and to address the experience of the parents. The main goal of early childhood intervention should never be determined by the professionals alone on the assumption that they can do much more with the child than the parents; it must be one that the parents too feel comfortable with in the context of *their* education of their child and of their own family routines and responsibilities. As professionals we must be humble. We should never forget that the child belongs to the family, and that support must also be given to the family system. In the past, it was not always so. Parents were often excluded and not at all involved in their child's education.

The changing status of parents in special education

The following paragraphs give a short historical overview of the changing status of parents in the special education of their children during the last 100 years by describing four models of care – characteristic of Belgium, but also much of Western Europe.

The charitable model

This was the first model of special care for children with disabilities. Some religious communities opened dedicated institutions for these children out of charity. From this period comes the stereotypical image of a huge, imposing building (a monastery or nunnery) in a rural environment.

We can imagine the scenario. A taxi brings the parents and their child to the entrance of the religious house. They ring the bell, and the door opens into a big, gloomy hall. A sister welcomes the parents and the child. She leads the family into a small visitors' room, where the mother superior greets the parents. She tells them that the nuns will care very well for their child, and, after 15 minutes, two other sisters take the child into the dark nunnery. The mother superior brings the parents back to the hall, wishes them a good return trip, and invites them to visit their child at Christmas and at Easter.

Parents in this period were not involved in the education of their child. Professionals believed that it was not good for parents to develop a close relationship with a child with disabilities so that they were protected from a sense of personal failure and, later, disappointment in the child.

The medical model

In the second period, starting at the beginning of and continuing throughout the 20 °century, the medical model was the most important. Children with disabilities became interesting to the medical profession as objects of medical study, and, for first time, doctors became associated with the institutions. They started categorising the disabilities, and then began to treat the children. In this way, the care of children with disabilities became professionalised. At first, treatment was only medical, but later came paramedical, educational and psychological programmes, and finally special education was introduced. The world of children with disabilities had changed into a world of 'experts'. This model reduced parents to incompetent persons, who relied upon a team of professionals to educate their child. Their own expertise went unrecognised, and they were reduced to being proxies for doctors and therapists.

The systematic model

From 1950, the first ideas about the need for 'acceptance of disability' began to be described. Kübler Ross's theory on the mourning process was translated to the experience of parents of children with disabilities, and these parents became the focus of 'family therapy'. Parents were not happy about becoming the object of care following the medical care for their child. They contested the assumption that they needed family therapy as a result of their

circumstances. This was also the time that the first self-support groups for parents of children with named disabilities started.

The partnership model

In recent years, the partnership model has been current. Parents and people with disabilities are no longer objects of care, but the equals of professionals. Guidance on optimum support for a child with disabilities begins with an open dialogue between parents and professionals. The needs identified by the parents are the starting point for the intervention.

Table 1 below gives a concurrent overview of the status of people with disabilities in society. Paradigm 1 comes from the time of the charitable model and the first institutions; Paradigm 2 is synchronous with the rehabilitation centres, special schools and all the developmental programmes (e.g. Frostrig, Delacato, Petö, etc.); Paradigm 3 represents the time of home support services in early childhood intervention, autonomic living by people with disabilities, and personal assistant budgets.[2]

Table 1. The status of individuals with disabilities in society

(adapted from © Maes)

Paradigm	Human vision	Status	Action	Place	Policy
1. The paradigm of deficiency	Human being with limitations	Patient	Delivering care	Residential institution	Segregation
2. The paradigm of development	Human being with possibilities	Pupil/disciple	Training, coaching	Special centres	Normalisation, integration

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[2] Paradigm 3 has existed in Belgium for two years now, and is implemented in a similar way to that in some other countries (e.g. Norway, Finland, and Sweden). People with disabilities or their parents can be awarded a budget from the government relative to the severity of their disability. With this money, they can become an employer and enlist people to organise their care and support.

3. The paradigm of Citizenship	Human being with rights and duties	Citizen	Supporting	Community housing	Inclusion

We can celebrate the fact that such a massive transition from the charity model to the partnership model has been made, but, in practice, all these models still exist, as the following examples illustrate.

For a few months, a child with disabilities who used our early childhood intervention service was terminally ill. The parents chose to give their child palliative care at home for the last days of his life. The doctors in the hospital agreed that there should be palliative care, but they suggested to the parents that it should be given in hospital because they thought it would be too hard for the parents to see their child dying at home. This is an illustration from the persisting charitable model.

The medical model, where the professional is regarded as an expert, also still persists. How many times do we hear professionals complaining because parents do not do the exercises they have prescribed or use the resources they have provided? Often, professionals claim the power to decide what parents and their child with disabilities should do. In this model, examples of equality and dialogue with parents are the exception.

The impact of trends in a changing society

In today's society, 'individuality' and 'personality' are key concepts. The human being has become more and more an individual with freedom of choice. Over the last few years in Europe, this freedom has escalated.

At the beginning of the 20° century, people were no t so focused on their individuality. Societal living was defined by the power of the group. As a human being, you belonged to a family, a village community, a political movement or a religious society. The values of these groups were more important than individual values.

In the Middle Ages, little individual freedom existed at all. Only since the 18 °century, and the Enlightenment, has the concept of personal freedom become important. In that period, human development crossed a threshold: the concept of 'I ', previously subordinated to the group identity,' we ', was awakened in the human psyche – first, in our way of thinking – 'I think therefore I am' – then later, 'I feel' and, finally, ' I do'. In recent years, this evolution in thought has become mainstream. We can see now that today's children are already much more individual than we were. We are more defined by the groups to which we belong than they are, just as our parents identified much more strongly than we do now with the groups of their day. The influence of the group has decreased, and individual freedom increased.

Traditional values in daily social life, in education, in marriage only just survive…just. Together with the rise of materialism – necessary to awaken our ego in the first place – we have seen individuals become more isolated. Never before in Europe have so many people lived alone. It is the price we pay for our freedom from the group, but maybe at the end of this evolution, we will be able to show love to each other, not because our social group demands it, but from personal choice. Then, the traditional values will be truly integrated in the human psyche.

This journey towards self-identity and personality also involves people with disabilities. The importance of the peer group has decreased; the disability is now of less importance than the person. This is evident in the importance of individualised approaches, inclusion, and the provision of personal budgets for assistance and support. This evolution makes it no

longer possible to deny parents equal partnership in the support of their children with disabilities.

In the Middle Ages, a disability was seen as a punishment from God, and people with disabilities were regarded as sub-human. Now, we have the Declaration of Human Rights, which upholds the right of children, of people with disabilities to live without discrimination. Partnership is not a choice – it is the only way forward for the future.

Creating partnership with parents

The first step is to develop a good rapport and **open communication** with parents; and here we, as professionals, have some problems. The main problems in our communication with parents are described below.

We are trained to understand. We are very empathic, and from the moment that parents start to talk to us, we begin to understand, nodding our heads: 'Yes, I understand… Of course… etc. If a mother says, 'It's so hard to come to the therapy', we answer, 'Yes, I understand. It's not easy.' If she says, 'It's so difficult when my husband asks if our child will be able to walk,' we answer, 'I understand. Such questions are not easy.'

What do we mean by always saying, 'Yes I understand'? We make many interpretations and hypotheses about what going on with this mother, but it is rare that we check with the mother to make sure our assumptions are right. Why *is* it difficult for the mother to come to therapy? Is it hard for her to see other children with disabilities, to have to arrange some special activity to do with her child after therapy to make up for a challenging experience, because her other children have to stay longer at school, because there is too much traffic in town, because her husband chooses to go to the pub at that time, or maybe because she feels the therapy is not effective enough? It may be that she thinks that her husband will leave her

because she has given him a child with disabilities, so she feels guilty and wants the child's disability cured very quickly through intensive therapy. By 'understanding' too readily, we prevent meaningful communication between the parents and ourselves as professionals. As professionals, we have to learn to say, 'Sorry, I don't understand. Can you tell me more?'

We are trained to answer. Professionals like it when parents ask questions; it makes us feel competent and important. We often have a pre-prepared response in our mind when we give advice. Although the advice may be good, it is often wasted because it is offered at the wrong moment or to the wrong person.

A father asks us, 'Can my child [with multiple disabilities] use the organised transport service from the day care centre?' 'Yes, of course,' we reply. 'We will organise special seating in our bus.'

A mother tells us, 'My baby can't sleep. He's waking up all the time, and I become so tired. What can I do?' We respond, 'Oh, it's important always to use the same routine at the same time of day; you'll see it will help… and if he's waking up during the night, it's important that you don't take him out of his cot.' What should this mother answer if her little child has been sleeping in the parents' bed because of the sleeping problems? She will keep quiet.
We all know those quick answers very well!

As professionals we are 'experts', and we like to focus the communication on our specialism. If a mother says, 'Why is my child is unable to walk?', we quickly will explain that it is due to brain damage, and that all children with such a CT scan have the same problems, but that with a good therapy, we can try to train other parts of the brain to take over the function of walking and… However, is this the answer the mother was looking for? Maybe this mother meant by her question, 'What did I do wrong to have such a child?' or 'Why was the doctor so incompetent that he could not prevent my child having brain damage?'

We acknowledge the emotions of the parents. We talk about problems of acceptance of their child's disability, of structuring the educational environment, of depression, even of psychotic behaviour. But what's in a name? We give a name to the emotions, and we think that in that way we can understand them. However, in our communications with parents, we really seek to avoid parents' emotions. We try to control our conversation with them so that we do not shock them; we are afraid of giving them bad news; we try to avoid making them cry.

We like to restrict our communication with parents to our specialist area – medical antecedents, therapy programmes, toys… We like to structure our conversations with them to take account of our specialisms; intake with both of the parents, questions about the development from the child, assessment,…

Ultimately, if we want open communication with the parents as equal partners, we may have to interrupt our conversation with them to make sure we have understood what they mean. We must be brave enough professionally to say, 'Sorry I don't understand' or 'I think I have missed something. Can you explain it again?' We have to avoid giving quick answers, and we must stop steering the conversation towards our area of specialist knowledge. We have to explore what parents really feel, what their fears and their hopes are.

The Kangoeroe parent communication framework

In the Kangoeroe early intervention service, we use a framework to explore the needs of parents. If parents come with a question, a problem, a remark, we hold one simple question in our mind, and this is:

With what, who comes, just now, here?

I know that this question has no grammatical sense, but it is our mnemonic to avoid the problems mentioned above.

With what?

Parents come to professionals with all kinds of problems: developmental problems, medical problems, sleeping problems, feeding problems, problems with brothers and sisters, transport problems, anxiety, helplessness, anger, feelings of guilt …

Who comes?

The problem does not always belong to the person who asks the question? We have to explore with them who the problem really belongs to. We can do this with some straightforward questions without initially focusing on the problem itself, and, in doing so, we can avoid giving a quick answer:

- Do you talk about this problem with other people?
- How you talk about it?
- Who took the decision to bring the problem here?

Just now?

We will be aware that some of these 'problems' have already existed for a long time, and yet, at a given moment, they are announced. But why just now? Why was it not considered a problem before?

Why here?

Often parents ask us questions that are outside our field of competence, and even though they know that this is the case, they ask the question nevertheless. Why? Sorry, I don't understand? Why are you asking me this question?

Keeping this simple question in our minds during the conversations with parents can help us. By using it, we can learn many things about how a family system works, and we can avoid giving good advice to the wrong person. In the next step of the framework, we can explore how the different people involved with the problem think, feel and act. What outcome are they expecting, and what they will do if this is not realized?

Conclusion

We have to ask many open questions of parents before we really can understand them. It is the only way forward. We need to be unafraid to ask questions – they are a condition of reaching the equality with parents that is necessary for true partnership. And if we understand that each newborn child, with or without disabilities, is not like an empty bottle that we have to fill with knowledge and competences, but is a person who brings their own capacities and richness to this world, and that the main goal of their education should be the development of those personal capacities and richness by creating the right conditions, then we will understand that we need parents as the main partners in the education of their child and that their feelings and experience are even more important than the knowledge of the professionals.

The study of loss and grief for multidisciplinary grief counselling

Herman de Mönnink[1] and Ed Nolens[2]

Introduction

The inability of a client[3] to come to terms with loss following, for example, the diagnosis of disability can be compared to a smouldering peat-moor fire, which burns underground setting off new symptoms at the surface again and again. In this chapter, it is suggested that early attention paid by professionals to the loss-related responses and complaints of clients or their families can facilitate the process of clients coming to terms with their loss. The chapter further indicates how the study of grief can be beneficial to the caring professions when confronted with clients who are experiencing grief. It also introduces a 'Framework for professionals in grief counselling and grief therapy: a tool devised to ensure quality of grief counselling through multidisciplinary cooperation' (see Appendix).

The key issue in this chapter is the identification of effective interventions by professionals in response to a client's experience and expression of loss. These interventions are summarised in the Framework mentioned above. A case history (differentiated from the main text by the use of italics), written by Ed Nolens from his practice as a medical social worker, illustrates the theory described.

Understanding the anatomy of loss and grief

> *Perhaps we busy ourselves too quickly with finding a way out. Making room for loss experiences is essential, too. Or could this be too threatening to us?'* **(**Professional at the Congress, **'**Loss and Mourning in Nursing', November 2001)

Grief counselling dates back to around 1980, when the taboo against recognising the impact of loss on a person's mental health was diminishing. The supporting theory deals with systematising knowledge and skills for professionals in relevant occupations, such as nursing, medicine, social work and physical therapy. The premise of grief counselling is that

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[1] Traumapsycholoist specialising in grief therapy (www.verlieskunde.nl)
[2] Clinical social worker in a medical centre, the Netherlands
[3] When 'client' is mentioned in the text it refers to the client system (i.e. 'client and family'). In case of a client who is unable to give consent due to their youth, permanent or temporary mental incapacity, etc., it refers to their parents, spouse and/or other relatives.

people are able to – and can be enabled to – actively and consciously say farewell to the cause of their grief in their own way and at their own pace, .

In coming to terms with loss, the client has 'grieving work' to do – characterised by Freud as 'Trauerarbeit'. While doing this, however, attentive support from understanding professionals seems essential. Whether it is saying farewell to a deceased loved one, to health (e.g. their own or their child's), to their job or to their homeland, clients in need may make an appeal for help from the caring professions. And this appeal will be more urgent if the client's own support networks are failing.

The study of loss and grief describes the processes likely to be associated with it, providing information on 'the anatomy of loss' and coping with loss as well as some knowledge of interventions in grief counselling. The theory offers possible answers to questions like: what kinds of loss are foreseeable in the course of a human life; what coping processes can be labelled normal or complicated; what are the responsibilities of health care agencies in relation to loss and grief counselling?

Care when cure is impossible

> *Robert was born seven years ago after a problem-free pregnancy and a home-delivery. A few weeks after his birth, problems with his eyesight were found. At 18 months, Robert's parents noticed his movements steadily weakening, and when he was three years old a brain tumour was diagnosed. In the following year, Robert spent more time in hospital than at home, having to endure chemotherapy and radiation therapy. When at home again, he fell ill after a few months and eventually ended up in the university hospital once more. A penicillin cure administered to him by a regional hospital had caused an eight-day coma. The university hospital diagnosed meningitis, with possible blood-poisoning, resulting in brain damage. One of the consequences was a left-sided hemiparesis.*

> *Robert's parents had to go through two horrible years, witnessing the process of their son's health going downhill within a short time. The fear of losing their child was immense, and has never left them completely. Each night, the parents still make sure that Robert is sleeping peacefully and not having an epileptic seizure. In our talks, it became clear that they were still experiencing a lot of anger about the way they had been treated by some of the hospital staff. These topics were among the first to be addressed.*

Loss confronts us with the limits and boundaries of life. The consequential feelings of vulnerability are universal, as is professionals' sense of discomfort at the confrontation with loss in their practice. Yet, in these modern times, there seems to be a complicating factor.

We lead our lives in an era of autonomy and control over a great many areas of life. This autonomy is a result of immense medical, and social progress. Around 1900, life expectancy was only about 40 years. To modern people, the idea of autonomy in life has brought about an illusion of control and invulnerability, which is shattered when we are confronted with loss. In many cases, a cure cannot be effected. When physicians, counsellors and other paramedic professionals are prepared only for healing – for the positive outcomes of health care – their feelings of discomfort in the face of incurable cases are bound to be strong.

Professionals trained in grief counselling take for granted that healthcare is not only about healing, but about loss, too. Having learned to shift perspective from cure to care when appropriate, they can work from *both* the diagnosis-prescription model *and* the experiential counselling model. In experiential counselling, professionals are equipped with a range of techniques, which enable them to provide care when cure appears impossible. There are many areas in nursing where experiential care is already being given. In hospices, palliative care is a form of experiential care for the dying; in psycho-geriatric care, validation and reminiscence therapy are examples of experiential care; in primary care, too, the experiential care model is gradually gaining ground again. In short, the theory of grief counselling and training in associated techniques provide professionals with the understanding to provide adequate care for clients who are confronted with loss and grief.

Ineffective approaches
In the process of mastering grief counselling, professionals become aware of the personal parallel process between themselves and their clients. For example, as the client expresses powerlessness and sorrow, the professional may become personally affected by similar feelings. During training, the professional is made aware of this phenomena of transference and counter-transference. Professionals who are not familiar with them may be ineffective in treating the client.

> *Robert was now attending school. Quite suddenly, and despite positive reports (according to Robert's parents), they received a phone call from the nursery school teacher during the summer vacation, who asked them to put in an application for a*

place at the Mytyl School for children with learning disabilities at the rehabilitation centre. It soon became clear that social workers had also been involved in this decision, having already started the procedure of preparing a possible placement at the Mytyl School. Reluctantly, the parents went for an introductory talk. Robert had also strongly resisted the idea of changing schools, they said. As they felt they had their backs against the wall for want of a good alternative, they went along with the placement. There was an initial screening done by the rehabilitation physician, who then introduced them to the teacher. Robert started out in the nursery class, and after a few weeks was introduced to the physical therapist, the occupational therapist, the speech therapist, the child psychologist and the social worker. Then there was a meeting. Present were the child psychologist, the Mytyl School social worker, the parents and the paediatric team social worker.

The professional who is not properly trained in grief counselling can exacerbate their client's grief by using an ineffective approach. The process is also known as 'secondary victimisation': the client becomes a 'victim' for the second time through the actions of the professional. There are five patterns of professional behaviour recognised as likely to result in a professional 'victimising' the client. These are Rescuing, Accusing, Avoiding, Distancing and Brainwashing.

In the **rescue** pattern, the professional is preoccupied by his personal need to efface himself on behalf of the client. In this so-called 'Mother Theresa Syndrome', it may be that the client's actual cry for help is made secondary to the fulfilment of the professional's need to help. In the second pattern, the professional **accuses** the client of 'not responding properly' to the professional's 'rescuing' activities. The underlying message may be: 'You're absolutely fine now. I've given you a lot of attention. Your continuing grief is obviously a means of fulfilling your craving for attention.' The rescuing and accusing patterns are points of the so-called 'Rescue Triangle' of victim/rescuer/accuser. In this model, the professional has overstepped the professional boundary; they behave patronisingly towards, and become unprofessionally 'close' to, the client.

In the other three victimising patterns – avoiding, dissociation and brainwashing – the professional keeps too great a professional distance between themselves and the client. For example, in the pattern of **avoiding**, the professional ignores clients whom, they feel, have become emotionally too close, thus avoiding self-exposure to such a client or situation. In the =distancing pattern, the professional does not so much avoid contact with the client, as become intentionally distant, steering the client away from addressing the emotional needs

they are communicating. In the **brainwashing** pattern, the grieving client is 'consoled' with the explanation that 'the situation is a challenge' or encouraged: 'Cheer up, it's all going to be fine. It's a beautiful day today, isn't it? Let's make the most of it.'

These five victimising patterns, while they may enable the professional to deal personally with the emotional side of their job, cause additional distress to the client.

Forms of loss

> *Loss is an issue that appeals a lot, because you're dealing with it every day.*
> (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001)

Professionals more often than not associate loss with death. However, there are many more loss situations in the course of a human life that also need to be addressed by the professional. These are not necessarily related to the ultimate loss (death), but to losing other parts of one's life structure, such as a limb or one's health. A professional who associates loss only with death may not pick up on other possible losses, and may underestimate their significance.

> *The social worker of the paediatric ward had, together with Robert's mother, identified the mother's feelings of grief, and had recommended that she continue counselling with the school social worker, who could help her progress in the process of coming to terms with all her emotionally intense experiences. Robert's mother went along with this. In suggesting this contact, the paediatric ward social worker was clearly preparing to refer Robert's mother to a colleague for grief counselling, showing some reluctance to let go of her contact with the parent.*

Loss situations in different domains in care

Whether working in hospital or primary care, in general health or in mental health care, the professional worker, however young, is frequently involved in the many facets of loss: miscarriage, stillbirth, cot death, birth of a child with a physical disorder, the death of a child, the diagnosis of a chronic disease, loss of mobility, amputation of a limb, burns and mutilation, menopause, climacteric complaints, divorce, inability to work, physical or mental

decline, a growing incapacity, dementia and a sense of mortality Apart from these direct losses, there are also some indirect manifestations of loss which impact on care practice, such as the uncompleted processing of previous losses (after war, adoption, abandonment, etc.), secondary losses that could stem from any of the primary losses mentioned above, such as loss of mobility, work, spouse and friendship, as well as deep-seated feelings of loss of independence, control, one's own dignity, pride or a future. Sometimes a loss can ruin someone's life, bringing about the feeling of their lives collapsing, or threatening to collapse, like a house of cards.

In Mönnink's book on the study of loss and grief – *Verlieskunde: Handreiking voor de beroepspraktijk* (2008) – the aforementioned losses are classified into six life domains:

- Body – appearance, bodily functions, vitality
- Spirit – personality, qualities, cognitions, verbal expression, sense of vitality, self-esteem sense of security
- Relationships – (grand)parents, siblings, spouse, friends, colleagues, pets
- School or work – paid and unpaid work, recreation, schooling, hobbies, housekeeping
- Parenthood – children
- Hearth and home – culture, country, place of residence, citizenship, home, fashion and accessories, books, photographs, cuddly toys

The existential crisis following loss

> *After a loss, people contemplate the meaning of life. This may, from time to time, bring about a lot of anxiety and worries.* (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001)

A loss may suddenly turn life completely upside down, disrupting and unsettling it. People are bewildered. They are thrown off balance. They find themselves going through a crisis. They feel damaged, confused. They say they feel as though they are falling into a black hole. According to the theory of loss, these people are experience an 'existential vacuum' which can trigger a truly existential crisis.

The void after a loss causes a psychological earthquake, vitally unsettling the client. They have been *fundamentally* damaged in terms of their sense of control, self-esteem, justice and perspective of the future. When a client's sense of control has been challenged, they tell us

they have lost their grip. When loss affects their self-esteem, you can tell by remarks such as 'I feel worthless/stained/numb/guilty.' When loss damages their sense of justice, clients experience feelings of unfairness, wondering: 'Why me? Why now? Why?' When clients become aware of their future having been swept away, their perspective of the futurehas been disrupted.

Grief counselling aims to focus on this damage to the client's value of life. The professional shows understanding towards the client, while together they estimate the damage done. The professional may ask the client to reconstruct past events, deal mindfully with the present situation, and develop attainable goals for a future that will be different. Various grief counselling techniques can be supportive, and, despite the fact that sometimes words fail to describe the loss adequately, the client feels they are being heard and accepted. Their emotions are regulated, giving them something to hold on to again.

To be able to overcome the crisis, a transitional period is needed from 'the old life' into 'the new life'. Coming to terms with loss is about letting go of the old and starting afresh in remembrance of the past. The client is encouraged to go through the pain of the loss in order to be able to establish a new equilibrium. To put it differently, processing loss is searching for a bearable new stability imposed on the 'shambles' of the loss. It is a process of transition, going from *unfreezing* (melting away the old equilibrium) through *moving on* (transition) to *refreezing* (establishing the new equilibrium).

Instead of living through their loss, many clients 'choose' to live their lives through denial. Such a survival tactic may temporarily bridge the gap caused by the loss, but it offers no lasting comfort. By seeking refuge in a displacement activity (e.g. in work, new relationships or alcohol and drugs), new problems are piled on top of the old ones. Instead of going through fundamental self-contemplation, these clients prefer to flee from the painful reality of the loss, which leaves them clinging to 'the old life' and stagnating.

What responses to loss are normal?

> *When a client feels sad after a loss for a period of time, I would not consider this to be a depression. Yet, an increasing number of clients are prescribed antidepressants. Natural sadness is labelled an illness much too soon. We should be normalising instead of medicalising responses to loss.* (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001)

Robert's mother gave the information about Robert and all the consequences of his poor prognosis in a somewhat cynical, humorous way, which is why I asked her if she was keeping on her feet with humour. She agreed with this, stating that she allowed any feelings to surface she would go mad! This made me ask whether she actually liked talking to me. She admitted to wondering if it really helped. I didn't go into this, and instead asked after the new pregnancy. 'Oh yes, that's also progressing, I guess'. She confirmed that she was feeling detached from her pregnancy. I said it was important that she should pay more attention to her unborn child. She did not reply to this, but said she would bring the subject up at our next session. In conclusion, I summarised our session, and together we imagined a personal archive boxand filled it with the following:

- *Robert's horrible illness – cancer – and her fear of loosing him*
- *On top of that the even more traumatic experience of Robert's eight days of coma , narrowly escaping death*
- *Having to face the facts: that her child was coming home with severe damage: paralysis, epilepsy, near blindness*
- *Finding out that Robert was not going to be able to go to a regular school because of his brain damage*
- *Knowing that Robert had one blind eye and could see only 10% with the other one*
- *Anxiety about the future*
- *Her immediate worry about Robert not wanting to go to the Mytyl School*
- *Worrying about how she was going to raise a child who was so vulnerable*
- *Worrying that the new pregnancy was more than she could cope with at the moment.*

The last item made her laugh and say: 'Yes. Let's not talk about that for some time to come, shall we?'

We made a new appointment, leaving the choice of subjects to reflect on in the interim up to her. I invited her husband to come, too. She did not think he would come. I had the feeling that she did not want him to come, and asked her if this was correct. She doubted if he would have time. When I asked whether the two of them had been sharing what had happened to them, she said that so far they had hardly done so at all; it was all too painful. I indicated that I would return to that topic with her at a later date.

There's no standard response to loss. Naturally, a loss is very personal, as is the response to it. Yet, there is a range of predictable responses to loss. An understanding of these responses is required for recognising the clients' symptoms and those of their relatives. The standard responses to loss are described (Mönnink, 2001) on an individual, communication and cultural level. Therefore, coming to terms with loss is no longer approached as a purely individual matter, but as a life-task, whether or not this is communicated to or shared with others: sympathy lightens sorrow.

The normal response to loss on an *individual* level is summarised in the concepts of Resistance, Farewell and Accommodation.

Resistance

In the resistance response, the client resists the pain of the loss by taking the sting out of the bad news. They may act as if there never was any bad news. Resistance to pain may take the shape of numbness, denial, dissociation, searching, merchandising or dismay. All of these forms of resistance are shock absorbers keeping the painful realisation at bay.

Farewell

In this phase, the painful reality of the loss filters through, naturally causing all kinds of responses. Beside sorrow, the normal responses are anxiety, anger, hurt, disillusionment, depression or relief. In this response, people discharge their pain by crying with grief, trembling with anxiety and screaming in anger.

Accommodation

The client may mentally accommodate themself to the loss. Just as the pupils in the eye accommodate to the varying intensity of light, the 'spirit' accommodates itself to the new situation of the loss. This is recognisable through a clients' well-considered decision to stop therapy, and their finding peace in their situation.

Resistance, farewell and accommodation are all normal responses to loss. They will not necessarily occur in any fixed order. Repeatedly, the client may slip back into resistance or sorrow or seemingly accommodate, adjusting to their new situation. According to current understanding, it is considered normal for a person to return to previous loss-responses in the case of 'triggering stimuli' such as birthdays, photographs, images on TV or sounds that remind them of their loss. Today, coming to terms with loss, therefore, is no longer considered to be the same as 'forgetting', but is seen as mindfully going on living, while

actively remembering the loss. Likewise, it is considered a normal phenomenon for grief to be re-activated.

> *Robert's mother had remembered my remark about her cynicism; apparently she had needed somebody to tell her. It had affected her more than she had expected. We discussed this for a while, because it undeniably had a lot to do with all she had had to endure. She agreed she was very angry indeed about everything! She stated that she did not feel like focusing on this right now, but that she would rather talk about how to deal with Robert being difficult at home.*

> *Things had improved remarkably at school, and she reluctantly admitted that she was having more problems accepting the Mytyl School than Robert. Yet her questions were directed more towards: 'How can I put Robert on the right track? How can I bring him up?' From what she told me it became clear she was feeling sorry for Robert and that it was hard for her to give him firm guidance. I indicated that, especially for vulnerable children, it was very important to create an environment at home in which they could feel secure, which sets firm boundaries. It was Robert who ruled the place, actually, said his mother, giving a humorous account of what took place at home.*

> *I became aware of my client showing less resistance, taking in what I said more easily. I told her so, and she confirmed that things had indeed become a lot better. The transition to the Mytyl School had evidently brought some peace at home after all.*

The three Os: Open acceptance; Order in the chaos; Orientation to the new future
The normal loss responses on a *communication* level are the responses to loss by the client and how they, and others affected, interact with those around them – – spouse , siblings, parents, their extended family, friends, neighbours, colleagues, co-participants in a support group, etc.. The normal, communicated, loss-processing responses are represented by the 'three Os': 'Open acceptance' of the loss within the relationship; 'Order out of the chaos' caused by a loss in the relationship; and 'Orientation to the new future together as well as remembering the past'.

An example of 'Open acceptance of the loss' is when parents, having lost their child, are sensitive to each other's responses and pain, sharing them and showing mutual understanding. 'Order in the chaos' implies that these parents pay attention to the lost

equilibrium in their relationship, acknowledging that everything is different, not only on an individual level, but also in their relationship with one another. 'Orientation to the new future' is when the couple start making plans again, a 'prolonged' start together: 'Yes, this is how we can cope with it together.'

'Blaming', 'Self-blaming', 'Robotic', 'Diversion'
Clients who have learnt to communicate adequately about their loss can effectively rid themselves of emotional strain. They can also find a new equilibrium within their relationships. However, communication about loss does not always pass off without complications. There are four ineffective communication patterns which interfere with the normal process of coming to terms with loss. These are 'Blaming', 'Self-blaming', 'Apathy' and 'Diversion'.

People may have learnt to react by blaming others when suffering from pain and strain, implying that: 'Because of you I'm in pain now. It's because of you that I have to go through all of this.' An increase in complaints or blame for psychological damage could be based on this pattern too. The second ineffective pattern of communication linked to pain and loss is where the communicator blames themselves: 'I'm sorry, I am the one to blame for all this. No doubt it's my fault.' Clients seem to present themselves as insignificant and withdraw into themselves. The third such pattern after a loss is a distancing response, in which clients present asrobotic, intellectualising the loss: 'After all, each loss is a challenge.' The fourth of these communications is 'diversion': changing the subject. Communication with a client who responds within the scope of one of these patterns often is not harmonious and takes up a lot of energy. Often, these behavioural patterns have been acquired at an early age or within the family, and are repeated in difficult situations.

> *Outraged – that's what Robert's mother was about that doctor; through his actions, they had almost lost their child. I asked if this had been communicated to this physician. No, because this doctor had retired. Did they feel like filing a complaint after all? No – that would not be of any use. It would hurt too much.*

> *Robert's mother talked about the stay at the University Hospital following this episode and about the fears they had had that they were going to lose Robert. I explored this in detail. Her distress became visible. It was a mystery to her that Robert himself should remain so positive, although he frequently spoke with them about dying. I asked how this felt, being his parents. 'Very odd, as if I'm talking to a grown-up. At*

momenst like that I almost forget he's a child'. It frightened her, though, and she always tried to change the subject.

She described how delighted they were when Robert came home from the hospital, but, at the same time, how upset they had felt about him having so many difficulties compared to other children:

- *A drain in his head*
- *Epilepsy*
- *The need for growth-hormones due to permanent brain damage*
- *Difficulties with walking, hemiparesis*
- *Very bad eyesight*
- *Medication for a non-functioning thyroid*

… and yet he was a happy child.

The attention paid by Robert's mother to her unborn baby had become positive, enabling her temporarily to shut out her earlier misery. We made an appointment for me to make one more house call, together with the paediatric psychologist, before the new baby's birth and observe Robert. She appreciated this very much.

We admired the new nursery and had the opportunity to watch Robert with his family. Surprising to us was the behaviour of the father who, without hesitation, began to talk about the distressing experiences during the past years; this was different from how Robert's mother had predicted he would behave. The circumstances at home had improved a great deal, and Robert enjoyed going to school a lot. The parents were trying to focus on giving him structure and making some demands of him, which he seemed to accept very well. Over the past few months, he had tried to gain attention a few times by retching, but this had almost come to a stop. He was now attracting attention in a socially acceptable way.'

Normal responses to loss on a *cultural* level consist of traditional rituals that become apparent in our multicultural society and in healthcare. These may govern farewell ceremonies such as sacraments, cleansing, conjuring evil spirits, the use of incense and other objects. Nowadays, grief responses on a cultural level may be newly modified rituals, being a mixture of traditional rituals and contemporary aspirations.

Complications in mourning

The criterion for recognising complication in loss processing is *damage.* When a client causes damage, or threatens to cause damage, to himself or to people around him, there are good grounds to take immediate action. We can speak of complications when the client's life remains dominated by the consequences of their loss with no signs of amelioration, or there may be a continuing lack of response or the response exhibits signs of compulsion. The person might be very depressed, neglect or isolate themselves, or become aggressive or suicidal. An example of extreme complications in mourning happened to the family of a dentist: after having lost a son to cancer, the parents killed their remaining children, then tried (and failed) to take their own lives. What has sadly happened more frequently lately is that people have isolated themselves after a loss, and have been found dead in their homes several weeks later.

Some homeless people are known to be burdened with unprocessed loss situations: bereavements, as well as divorce, as well as redundancy. People who eventually end up feeling that they having nothing left to lose may commit suicide. The question in cases of mourning complications is whether the care workers involved are capable of recognising the early signals. A list of indicators of mourning complications can be found in the Appendix.

The responsibility of health care agencies to create favourable conditions

> *Grieving for a loss can be so sad. But how am I to divide my available time to make room for showing my sympathy? For a terminally ill patient who had just returned from hospital to die at home, the instructions said: 'a 10 minute wash'. Straight after this, I had to hurry on to the next patient for '5 minutes of drops'. After my duties, I decided to go and pay another visit to the first patient.* (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001).

It is the responsibility of health care agencies to create conditions for practising not only according to the medical model of care, but also according to the experiential care model. When there are waiting lists for the first priority – curative care – experiential care is bound to suffer.

No wonder that many professionals complain about the dominance of recovery targets in healthcare, and that grief counselling is categorised as 'palliative care'. A professional put the lack of favourable conditions in this way: 'There's no policy on grief counselling, no directive, no protocol, no clarity as to how much time we are allowed to spend on it'. The core issue for many professionals is the lack of time. Although signs of mourning are recognised, nothing can be done, much to their frustration. This was put into words by another professional: 'You notice the signs, but it usually ends with just that. Just because of insufficient human resources, you are unable to go into it and explore. You hear what is being said but you can't offer any support.' Policy on time management and human resource to put grief counselling into effect is needed. It is the responsbility of the health agencies to create favourable conditions for both cure and care. In terms of targets: 'a 10 minute wash' should be combined with '30 minutes of experiential care'. Healthcare agencies should commit themselves to creating conditions for a first-rate practice of cure and care.

Conclusion

> *Nothing is as practical as a good theory. (Kurt Lewin)*

The frequent confrontation with clients and families experiencing a loss justifies, in anticipation of this aspect of professional practice, a systematic and structured preparation during professional training. The professional will then feel properly qualified to support clients who are wrestling with life's agonies and to cope with distress in professional practice. Learning how to address the client's emotions, as well as their own, means that the professional is unlikely to victimise the client who experiences a loss, but is able to support them with compassion.

APPENDIX

Framework for professionals in grief counselling and grief therapy

Professional supporting the client in care (e.g. within primary care agencies, work related organisations, schools, etc.)	Symptoms (in behaviour) of the client/patient/resident/ employee/etc.	Interventions helping with loss
PSYCHOSOCIAL CARE		
I. Physician		Doctors/nurses/teachers/ physical therapists/managers/ personnel officers
1. Signalling grief	Hypothesis: direct or indirect attention-seeking behaviour related to loss	Observe Record behaviour Identify intervention needed
2. Grief counselling	Test hypothesis: is there any proof of a link between the complaints and a loss?	Anamnestic grief counselling by primary care professional: the story of the loss
3. Grief screening	Identify: • Loss related complaints • Risk factors • Complications • Available time – is it sufficient?	Is there evidence to suggest the need for more intensive care? (Go to 4.) If screening shows complications or contra-indicators, prepare referral (Go to 6.)
4. Preparing a transfer to grief counselling	• Client's acknowledgement of their need for help • Attributed need for help	Make proposal: e.g. 'You need/are entitled to more care. I recommend social work. Consent (Go to 5.)
PSYCHOSOCIAL COUNSELLING		
II. Social worker		Social work
5. Multimethod social work practice	• In-depth grief counselling • Coexisting problems • Loss responses – complex/normal/ uncomplicated	Differentiated diagnosis De-stressing interventions In case of contra-indicators (e.g. complicating factors following screening), prepare referral (Go to 6.)
III. Specialist care (e.g. by traumatologist, psychologist, psychiatrist, mental health agency)		Grief therapists, debt advisors, pastors, creative therapists

6. Grief therapy and other specialist approaches	• Complicated, interrupted loss processing according to the damage criterion • Other specific complaints	Specialists in grief counselling and other specialisms
IV. Self-care: who is taking care of the carers?		All professionals mentioned above
7. Self-care for professionals working with grieving clients	Emotions-based work-stress of professionals themselves – being emotional, feeling distressed/upset	Support by colleagues, reducing the strain; possible assistance from within the organisation

Notes

STEP 1: Signalling grief

The term signalling grief can be understood as follows: systematically recognising the correlation between the client's (or other's) perceived attention-seeking behaviour and a sustained loss. There could be a recent change in the client's behaviour, showing a direct or indirect need of some attention to be given to their mourning. The client (or spouse, for example) asking for some attention for the loss in a direct way may ask questions like: 'Can you spare me a moment, please, because something has happened to me?' or 'I can't handle this alone; could you help me, please?' Asking for the professional's attention for the loss in a more indirect way could be done by drawing attention to something else indirectly related to the grieving, rather than to the loss itself.

The withdrawn or difficult client

Signalling loss generally is an inextricable part of care. For good care should automatically be about signalling all sorts of cries for help, loss included. However, the need for counselling in coming to terms with a loss is not always recognised, as the specific signals are often overlooked, resulting in the client not getting the attention they deserve.

STEP 2: Grief counselling

Grief counselling is a form of individual, client-centred, one-way care. The aim of grief counselling is to give the client the opportunity to tell the story of their loss and, through this, to find proof that the expressed complaints are linked to this loss. Grief counselling is a form of experiential care for the client and their family, which provides tools for the professional to identify the client's areas of loss that need attention (e.g. the fear of bad news; the feelings of depression). The professional makes use of a suitable mix of counselling techniques, allowing the client optimal space.

STEP 3: Grief screening[4]

Grief screening is about assessing the client's need for extra support to cope with their loss, and whether any additional specialist focus on their loss is indicated (e.g. from the nurse, the general practitioner, the social worker, the vicar, the psychologist). This may result in a referral.

STEP 4: Preparing a transfer to grief counselling

Here, we are talking about the client's prepared transfer to a colleague in the same or another profession. The phrase 'preparing a transfer' is preferable to 'referral' in relation to the process and nature of the counselling intervention. In broaching this with the client, the following form of words could be used: 'You deserve to be seen by my colleague. What would you say if I ask him/her to come and visit you?'

STEP 5: Multimethod social work practice

This implies social work treatment of the client's sticking points or blocks in coming to terms with his loss. Often there is a lot of strain resulting in the client having stress-related complaints. Indications to call in a social worker are: a particular source of stress requiring some additional social care; and a diversity of stress sources, such as a plurality of losses (multi-loss situations), entwined grieving (as a result of both a loss and a trauma), cumulative problems (a recent loss on top of previous losses) and multi-problem situations (having to come to terms with a loss as well as housing problems and child raising issues, etc/; any other complex problems which do not result in complications.

The social worker makes a list of areas to be addressed, and their exact nature and difficulties. They systematically and methodically attend to all occurring points of distress (e.g. 'It's not entirely clear to me what the doctor told me,' 'I don't see any way out. What in my life is worth living for?'). The targets of the social work interventions are stress-reduction and greater stability – individually, in communication, and socially – until the client has calmed down and can go on, under their own power. By carrying out the screening, the social worker can also ascertain any possible complications. If so, preparation of the transfer to specialist care is indicated.

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[4] The term 'screening' generally stands for detailed investigation (Roos, 2001). Diagnostically speaking, screening is a form of epidemiology of large groups of people used, for instance, to gain insight into the extent and gravity of phenomena such as breast cancer and sexual abuse. Here, the term is also being used as a synonym for a regular diagnostic examination.

STEP 6: Grief therapy and other specialist approaches

The term 'grief therapy' refers to specialist treatment of mourning with complications by an accredited psychologist, psychotherapist, psychiatrist or mental hospital. When the client is likely to put themself or their relationships at risk – by self-neglect and self-mutilation, suicide intent and attempts, threatening or showing aggression – then grief therapy is called for.

In case of specific difficulties, other specialist treatment can be called for (e.g. a pastor for spiritual problems; debt advisors in the case of complicated money problems; a creative therapist for problems expressing emotions; a psycho-motor therapist in case of problems with motion; and a case manager in the event of logistical problems arising from the involvement of multiple care agencies and services on a single case.

STEP 7: Self-care for professionals working with grieving clients

The term 'self-care' is about care for all the professionals involved (e.g. nurses, general practitioners, social workers, pastors, grief therapists, child therapists and others) in supporting each other as colleagues. The premise is that caring for grieving clients is likely also to impact on the professionals themselves. Alleviating the strain of the compassionate work will prolong their commitment and good health.

Besides the support of the head of department or immediate colleagues, self-care may consist of co-counselling between colleagues so that accumulation of stress/distress can be prevented – for example, in a weekly 60-minute session, two colleagues may take turns to listen to each other for 30 minutes each,. Counselling between colleagues is a pre-emptive measure to avoid burn-out. Establishing a team of colleagues to be on stand by in case of more severe incidents can be very beneficial, too.

Ineffective management of long-lasting, medium stress (e.g. organisational problems, strained relations between team members) or high stress (e.g. death of a team member) situations eventually may lead to stress accumulation. This may result in overload and even in burn-out. With ineffective management of acute, extreme stress situations (e.g. client assault or other traumatic incidents), there is the risk of trauma complications (such as Post-Traumatic Stress Syndrome). Self-care is a shared responsibility of the individual worker, colleagues, heads of departments and management.

Reference

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CHAPTER 15

Further training course for specialists in early childhood intervention

Karin Mosler[1] and Anna Kirchschlager[2]

Background

When the Interdisziplinäre Frühförderung und Familienbegleitung (IFF-FB) was first introduced as an early childhood intervention service provision for families in Austria, it was above all specialised educationalists who were active in this field. They were soon joined by other professionals – psychologists, social workers, therapists, doctors and others. All of these people drew on the basic training in their discipline. In some cases, this was focussed on the family and in others on the child. A clear need was perceived, however, for a shared further training provision complying with the IFF-FB principles of responsivity, integrity, family proximity, cooperation and continuity.

At IFF-FB, further training has been offered in various organisational forms for over 20 years. We have aimed to close the gaps in profession-specific training by extending the continuing professional development concept to prepare specialists from different disciplines as fully as possible to undertake early childhood intervention tasks. It is ultimately in their own interest to be able to deal with families on a basis of respect, and to take targeted action of an uncompromisingly high standard. The training was originally offered as on-the-job training in the form of weekend courses, and was then developed as a full-time course leading to a diploma. It is provided today as a university postgraduate programme with 90 ECTS[3] points affiliated to the Graz University Medical School.

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[3] European Credit Transfer and Accumulation System: a student-centred system of transferable credit points awarded on the basis of the student workload required to achieve the objectives of a programme, objectives preferably specified in terms of the learning outcomes and competences to be acquired. More information about this system is available online at http://ec.europa.eu./education/programmes/socrates/ects/index_en.html

Early childhood intervention has developed an occupation identity over the years, and we consider it to be highly beneficial when this multi-professional specialist group can participate in a shared field of action, with each of its members experiencing a sense of collegiality in tackling the problems they face together. Moreover the distinct identity that has been established for the profession is the basis for an efficient and coherent service.

We present the early childhood intervention curriculum in this chapter with accompanying explanations as required.

The broad perspective

Effective family-centred early childhood intervention requires individual members of an interdisciplinary intervention team to have, in particular:

- A basic knowledge of early childhood intervention from the perspective of other disciplines, such as medicine (especially paediatrics), psychology, special education and sociology
- Knowledge of the early childhood intervention-specific, practical, developmental intervention activities in various functional areas, especially those of emotion, cognition, learning and behaviour as a whole
- Knowledge of the appropriate resources for intervention
- Knowledge of the various modes of action and their effects on the individual within a particular system that form the basis for decisions about specific forms of intervention.

The personality and competency requirements in dealing with the people involved are inextricably linked with the transfer of theoretical knowledge into effective and tangible measures. These issues are of central significance in the work because early childhood

intervention does not take place in a regulated professional environment, but within the private family system. The awareness of the far-reaching consequences of interventions into dynamic family living systems requires ecological-cybernetic thinking and sensitivity.

Interdisciplinary Early Intervention (IEI) deals with the principles of **responsivity, integrity, family proximity, cooperation and continuity.**

Responsivity (starting as early as possible) – because insights into the appropriate fields clearly demonstrate the importance of initial experiences for the holistic development of the personality.

Integrity (a holistic perspective) – because a person is the unity of body, spirit and soul, and the influences on any one of these areas also has effects on the other areas which need to be carefully considered and balanced with one another. Each individual is also a part of a family system and should not be separated from this personal background.

Family proximity – because abstract, systematic assistance in areas of impairment relating to the child *is not* the aim of early childhood intervention. It should instead be oriented towards a practical and systemic approach to considering the capabilities of the child and the given possibilities in the family domain, with the aim of making family life as pleasant as possible.

Cooperation – means both constructive team work, and also direct cooperation with associated professional groups; this also includes public relations work to influence perceptions in society.

Continuity – because early childhood intervention represents interactive work, and its efficiency depends to a great extent on the cooperating personalities involved (including

families if they so wish), a cooperative and functional professional team should never be disrupted for trivial reasons.

In order to provide an additional professional qualification relating to the principles mentioned above, the training itself must be oriented towards these principles. Such training should therefore include:

- Learning how to deal holistically with life and its challenges without detaching the intellect from the person and their emotions
- Transferring perceptions which concern the person as a whole
- Deliberation about the powerful influence of the emotions on memory (recollection, loss of memory, memory blocks) and creative processing
- Real comprehension – not only through the verbal explanation of concepts, but also through the actual shaping of opinions
- Recognition of interrelated factors and the effects of interventions which do not end as intended.

The acquisition of these skills cannot be easily achieved through traditional training. Learning and teaching must be a constantly changing process which is oriented towards basic perceptions in adult education.

Personal feelings of responsibility, willingness to change, the search for connections and consequences and the discovery of new approaches to known areas of knowledge, including respect for the individual ability and potential of each student, informs the basic structure in the transfer of educational content. In most of the current training for psychosocial professionals, the emphasis is still on the theoretical transfer of knowledge. Thus the activity, qualifications and capabilities which are later required for effective group facilitation are largely neglected.

Although we all use language, many people, even in the caring professions, are not able to communicate effectively and adequately. Practical activity, which is primarily a meeting between people in the fields of work mentioned, clearly shows gaps in the competencies of individual personalities – e.g. blind spots, unresolved conflicts or even the personal traumas – which cannot be sufficiently balanced through purely technical competence. This leads to huge conflicts and set-backs in working collaboratively with other professionals if these areas are not considered or worked on.

In addition to a facilitative capacity – that is, the capability of providing a repertoire of meeting strategies, conflict resolution strategies and crisis intervention strategies – professionals need to be self-aware so that issues in their personal background do not cloud their professional judgement.

The content of the training resulting from these needs is presented in the following paragraphs. The elements are essential requirements for supporting people and should be preceded by an intensive personality development task focused on the personal background of participants. These personality development tasks relate to the area of 'facilitative competence' and cannot be separated from it.

In the area of facilitative competence, the emphasis is placed, together with consideration of the above-mentioned individual personal experiences, on the transfer of strategies which will enable future early intervention specialists (ICEI) to do justice to their complex occupation. By assimilating these strategies and methods for effective information acquisition and discussion, the following capabilities are generally encouraged and developed:

- Addressing previously existing factors in a flexible and creative way
- Introducing oneself as a person with one's own concerns

- Conveying appreciation and respect

- Conveying a fundamental and growth-oriented view and attitude

- Releasing the potential of those taking part

- Supporting, promoting or awakening the personal conflict of those involved.

General objectives of further training

This specialised additional training focuses on three main areas addressed below.

1. Fundamental principles of professional knowledge focusing on early infancy

- Medicine and medicine-related forms of therapy

- Communicative and interactive training in early infancy (applied psychotherapy)

- Education in general, psychology, sociology/social work, law

- Remedial education in early intervention

The objective is the realigning of approaches and attitudes (personality development), enabling the graduates to recognise the individual problems in affected families and to work objectively with the family members in view of their personal circumstances. The participants should be able to develop and carry out the relevant support activities with the family in the area of early development (from the birth of the child up to 3 or 6 years of age; in exceptional cases, also older). The ability to work as a team must be learnt in the course of teamwork, and is an essential for activities within ICEI. An established technical and personal competence for responsible work should be achieved through critical reflection and the processing of practical experiences. Transfer of insights and skills is also relevant to the handling of all necessary administrative tasks and public relations work.

2. Personality development and facilitative capacity

Self-reflection

- Explanation of the reason for choosing this profession

- The discovery of personal strengths, resources and creative possibilities in dealing with oneself and others

- The processing of one's own shortcomings and 'disabilities'

- The discovery of possibilities for dealing with one's own 'pain', conflicts, crises, illnesses, guilt, shock, etc.

- The ability to balance one's own conflicts (e.g. blackouts, fear, shortages in work, etc.)

- The willingness to understand oneself as a being who is undergoing constant evolution and change who questions oneself, reflects and is prepared to change

- Clarification of one's personal background

- The basics of effective communication and their practical application

- Working with complex strategies in dealing with parents and children

Managing discussion

- Communication model and rules

- Reports and opportunities for discussion in the work place

- Forms of differentiated perceptions and information acquisition, representation systems (and additional principles of the NLP)

- The basics of discussion based on speech therapy

- Discussion strategies relating to the fields of work

- Reinterpretation

- Mental techniques in work to balance typical support symptoms (focusing, recreation, creative visualisation, agreement on plans, planning of projects of will, conclusion and release, formulistic resolution development, etc.)

- Insight into and understanding of the problems of families with disabled children (initial meeting, acceptance problems, realistic knowledge of problems)

- Knowledge of family therapy procedures

- Technical competence in disabilities and the area of youth welfare

- Knowledge of further medical-therapeutic or social-educational measures

Systemic family work

- The basics of systemic thinking and its possible application in working with children and their families
- The personality model, the definition of a resource and deficit system and the resulting implications for work
- The basics of team work
- Responsibility and competence (e.g. within the scope of psycho-therapeutic work)
- Supervision
- Interaction and cooperation

Working with the child in early development from birth

- Knowledge of the regulatory development procedures (physical, mental, social) and education in terms of the child's personality as a whole
- Knowledge of possible impairments and their consequences
- Knowledge of relevant development activities, materials and legal possibilities

Facilitative activity (educational/social)

- Goal-oriented versus problem-oriented work
- Modelling of occupation-specific subjects: decision-making and creativity strategies
- Initial discussions
- Resource-oriented tasks
- Complex discourse strategies
- Crisis intervention

Cooperation

- Insight into the areas of activity of other occupational groups which are involved with disabled persons and social work

- Possibilities for constructive cooperation with other experts, institutions and authorities and collaboration within the cooperative team

Public relations work and organisation

- Insight into the necessary administrative tasks and their implementation

- Handling technical equipment (e.g. video)

- Contact with the public

3. Practical training

General principles

Tuition must on the one hand be based on the requirements of ICEI and on the other hand be supported by the previous knowledge and occupational and personal experiences of participants. The main focus, in addition to that of knowledge transfer, is on exemplary learning and case presentations and discussions, including role-playing supported by various teaching media. Depending on the subject, apart from lectures, relevant time should be allocated to discussions or work within small groups and also self-awareness. The participants should undertake independent work on teaching materials and the exchange of practical experiences (project work). The content of the curriculum in the practical sections is compiled in such a way that the observational capacity and sensibility of participants is particularly integrated within their behaviour and cooperation with other people.

Conclusion

The statutory requirements will only permit an IFF-FB activity after completion of this further training in early childhood education. This highly qualified activity has resulted above all in providing women from relevant professional fields with the opportunity to return to work at a high professional level and in a family-friendly form. To this extent, it complies both with the

European trends in social policy on the one hand, while supporting families in difficult situations in life and with an even greater potential for expansion on the other. The employment market is still open in this area – and men in particular are much needed for the profession. The tendency to foster parenting skills in families extends far beyond the areas of disability or social need. We want to approach closer to our goal of closing the knowledge gaps in profession-specific training in early childhood intervention by providing multidisciplinary continuing professional development through cooperation both in Europe (through the European Society on Early Intervention – Eurlyaid) and worldwide (through the International Society on Early Intervention (ISEI)) so that all families needing and seeking support in responsible parenting actually get it – to a high standard and uncompromised by commercial interest. Investing in children is an investment in the future – children ARE our future!

CHAPTER 16

European Curriculum for Professional Training in Early Childhood Intervention

Manfred Pretis[1]

ENGLISH ABSTRACT

Early Childhood Intervention (ECI) fostering the development of vulnerable young children and families is one of the most complex bio-psycho-social services. Based on previous definitions of requirements (ecological approach, teamwork, transdisciplinary integration of knowledge, practice), a common European foundation for ECI in terms of a training curriculum, which allows comparability and inter-changeability is presented (**www.ebiff.org** and www.precious.at). Evidence-based competences are the basis for a 120 European Credit Transfer System (ECTS) point curriculum. There are three competency types: a) process-oriented (e.g. identification, involving the family, intervention/evaluation); b) functional (e.g. management and academic); and c) personal. Including an individual assessment of their own training portfolio, this syllabus facilitates a tailor-made approach for postgraduate students and professionals in the field – within the diversity of the European professional landscape – towards a common foundation in ECI. The European Qualification Framework (EQF) and ECTS serve as the global framework. Emphasis is given to the training of personal competences (self-reflection, communication and supervision) and the practical transfer of knowledge and skills in terms of a learning outcome model. Future development will focus on the creation of a European master's degree in ECI, integrating inter-university cooperation and usage of ICT.

GERMAN ABSTRACT

Interdisziplinäre Frühförderung, die darauf abzielt, die Entwicklung von verletzlichen Kindern und deren Eltern zu fördern, ist eine der komplexesten biopsychosozialen Dienstleistungen. Aufbauend auf bestehenden Definitionen beruflicher Anforderungen (ökologischer Ansatz, Arbeit in einem Team, transdisziplinäre Zusammenführung von Wissen und Praxis) wird eine europäisches Ausbildungscurriculum präsentiert, das hohe Vergleichbarkeit und Flexibilität im Sinne gegenseitiger Anerkennung gewährleistet (**www.ebiff.org** und **www.precious.at**).

Empirisch abgesicherte Kompetenzanforderungen an die Fachkräfte bilden die Basis für das 120 ETCS umfassende Curriculum: Dies sind a) prozessorientierte Kompenzen (Erfassung von Risiken, mit der Familie in Kontakt treten, individuelle Intervention, Evaluation); b) funktionale: (managementorientiert und akademisch) und persönliche. Indem eigene bereits durchlaufene Ausbildungsportfolia berücksichtigt werden, bietet dieser Lehrplan einen maßgeschneiderten Ansatz für postgraduierte Lernende und tätige Fachkräfte, um in der Unterschiedlichkeit der europäischen Frühförderlandschaft eine gemeinsame Basis zu schaffen.

Das Europäische Qualification Framework (EQF) und das Europäische Credit Transfer System (ECTS) dienen als Referenzmodell in Richtung Vergleichbarkeit. Im Rahmen des „learning-outcome Modells" wird spezifische Aufmerksamkeit dabei dem Training persönlicher Kompetenzen (Selbstreflexion, Kommunikation und Supervision) und dem praktischen Transfer gewidmet. Die zukünftige Entwicklung wird die Schaffung eines „Europäischen Masters in Frühförderung" umfassen, indem interuniversitäre Zusammenarbeit gesucht wird und verstärkt neue Kommunikationstechnologien eingesetzt werden.

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FRENCH ABSTRACT

L'intervention précoce interdisciplinaire qui vise à soutenir le développement d'enfants à risques et de leurs parents, est une des prestations de services « bio-psycho-sociales » les plus complexes. Sur base de définitions existantes d'exigences professionnelles (approche écologique, travail en équipe, intégration transdisciplinaire de savoirs et de pratiques) un curriculum européen de formation est présenté. Il garantit un degré important de comparabilité et de flexibilité dans une optique de reconnaissance mutuelle. (www.ebiff.org).

Le « European Qualification Framework » (EQF) et le « European Credit Transfer System » (ECTS) constituent les modèles de référence dans un sens de comparabilité. Dans le cadre du modèle « learning-outcome » une attention particulière est portée sur le développement de compétences personnelles (autoréflexion, communication et supervision) et sur le transfert en pratique. Les développements futurs comprendront la création d'un « master européen en intervention précoce » qui recherchera une coopération interuniversitaire et qui se servira fortement des nouvelles technologies de l'information et de la communication.

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European Curriculum for Professional Training in Early Childhood Intervention

Manfred Pretis

Background

The complexity of daily work

Maria (aged 37 years) has worked in the regional Early Childhood Intervention Centre in Austria since 1995. Normally, on Monday mornings, she visits a family with a 9-month-old baby who has Down´s Syndrome. The parents are still very worried about the development of their child and most of the 1.5 hours spent within the family is set aside for counselling the parents and contacting the local physiotherapist.

Her next visit is to a family with social disadvantaged background. The father shows symptoms of alcoholism and has recently lost his job. Police have recently had to intervene twice due to marital violence. The social worker is worried about possible developmental delays in their daughter, Jacqueline (aged 3.5 years) and implemented preventative strategies. Here, Maria's duties mainly consist of creating "space to play" for Jacqueline. Progress is slow as the parents tend to avoid professionals, so she has little opportunity to talk with them.

Finally, Maria goes to see a family with background of migration. Ethnic Turkish Can (aged 2.5 years) shows symptoms of early Attention Deficit/Hyperactivity Disorder. The family does not understand the symptoms and thinks that Can is 'behaving badly'. Coaching the family to help them understand that their child is neither a 'bad' nor a 'mad' child is the main goal within this family system.

Maria's experience described above shows that working in the context of Early Childhood Intervention (ECI) primarily requires professional openness, respect and patience towards the enormous diversity of challenges within family systems. This pre-existing complexity is enormously increased if we take into account the European diversity of systems, screening methods, intake structures, interagency coordination, children qualifying for services, practices and standards (Dimova, 2005; Soriano, 2005). Guralnick (2005) warns that, due to the complexity of the challenges, the task of working in ECI can easily overwhelm even the most dedicated of professionals. Much still needs to be done in establishing evidence-based,

best practices across Europe – especially taking into account the different forms of organisations and professional approaches. Uniformity should not be expected nor is it – in the European context – intended (Pretis, 2006a). However, especially for parents, in terms of best available quality at least, comparability of professionalism in Europe should be a given (Pretis, 2006b), taking into account that there is growing evidence that ECI-specific professional training is connected with higher impact parameters:

- Higher attributed effects (Pretis, 1998a) regarding ECI in children with Down's Syndrome
- Better informed parents and less need for support (Granlund and Björck-Akkesson, 1996)
- Greater development/adequate stimulation of the children (McMullen and Alat, 2002).

The key expectations of parents regarding this professionalism are:

- The best service available for their child based on the best and newest information and methods which avoid harm (Godfrey, 2006; Lampropoulou and Mavrogianni, 2000; Pretis, 1999).
- Professionals who listen to them as families and involve them in dialogue (Carpenter, Attfield and Logan, 2006).
- Respect for their family values, beliefs and preferred pace (Höfer and Behringer, 2002).
- Professional support to 'Help us to do it ourselves' (statement of a father within the Validation Conference of the European Agency in Brussels 2004).

Based on diverse European working groups (Helios II, Eurlyaid (www.eurlyaid.net), European Agency (www.european-agency.org), EBIFF (www.ebiff.org), PRECIOUS (www.precious.at) and even a transatlantic consortium (ECI-NET), there is a significant consensus about the general concepts of ECI, but notable differences regarding the actual practice.

Pretis (1998c) points out that everybody gives his/her approval to terms like:

- Person- and family-centred intervention
- Ecological foundation for actions
- Holistic approach
- Necessity of transdisciplinary cooperation
- Respect for the belief systems and values of the family.

However, at the level of professional practice, the concrete implementation of these values might differ significantly, as this aspect is based on knowledge and skills of the professional, personal experience and belief-systems, or possibly supervision or professional feedback. This does not mean that everybody in ECI has to follow the same model or that a new type of professionalism should be created in Europe. Nevertheless, this aspect highlights the necessity of a common 'language' and competence profile in ECI and a basic common understanding related to evidenced-based practice indicators which should respect diversity, enable flexibility and deliver a comparable response to need. This is the principal idea behind a European curriculum which has to respect the diversity of national traditions. However, this common foundation allows comparability, especially for parents, so they can obtain the best available services for their children and themselves.

To summarise, essential characteristics of a common European curriculum for ECI are:

a) **A general open framework** in terms of **key areas**, necessary competences and skills, and complementary contents which allow for a variety of national idiosyncrasies (e.g. teaching traditions, terminology).

b) **Respect for and complementarity to existing national training initiatives**

c) **Respect for and inclusion of personal professional training portfolios:** The curriculum defines basic requirements (professional knowledge and skills assessed as being generally necessary for ECI practitioners) and acknowledges equivalence in profession-specific individual training portfolios (e.g. as a psychologist, doctor, social worker, kindergarten-teacher, etc.). It is suggested that a **screening tool** should be used to assess equivalence.

Basic hypothesis of a European curriculum

Based on preparatory work by the Eurlyaid-group (Detraux, 1998) and the author's own empirical research (Giné and Pretis, 2005) as part of the European Leonardo da Vinci project EBIFF (www.ebiff.org), four major tenets form the basis of the curriculum:

1. Necessary competences
2. Practical transfer/internship
3. Comparability and interchangeability towards state-of-the-art European frameworks.
4. Implementation of a European Master (www.precious.at)

1) Necessary competences

Paul (43a) is one of the few male professionals in Early Childhood Intervention. He is provides ambulant and mobile services to 25 families, particularly in rural areas. His basic education is physiotherapy. He did some in-service training on holistic intervention, but he has noticed that communication with young single mothers who have a disabled child and with grandparents seemed to be challenging for him, as his basic training had not included training on how to work cooperatively with parents. He found it especially challenging to listen to parents' worries. Paul often went home after work, trying to find solutions for his clients. It was difficult for him to imagine how single parents with a severely disabled child could find energy to organise their daily lives. During professional supervision, it was suggested to Paul that he attend some training on empowerment and communication in challenging situations with parents. In this way, he completed his individual portfolio and added to his basic education complementary contents. This is how a European master's in ECI should work: respecting and assessing individual portfolios and complementing them through relevant, supplementary training.

Professional competences in ECI cover three major areas:
a. Process-related areas
b. Function- or management-related areas
c. Person-related areas.

a) ***Process-related competences** **are directly connected to the work with children and parents:*** how to approach families; how to assess the needs of the families; how to create an intervention plan together with the family; how to work with the child and family during the interventions; how to document and evaluate the process. Process-oriented competences follow the structure of the ECI process (or simultaneous processes) (Pretis, 2006b).

b) ***Functional competences** **are indirectly connected to the process-related competencies, and mainly focus on the relevant context of the work:*** how to work in a centre; how to manage administration and projects; how to organise and lead a centre; how to address the needs of specific target groups; how to manage a thesis (in terms of academic requirements). Functional competences focus on the setting of ECI processes (e.g. institution, laws, academic requirements).

c) ***Personal competences*** (Pretis, 2005) (e.g. communication skills, utilising own resources, self-reflection and resilience, etc.) play a key role regarding the complex interaction of the professional with the family and the ECI team. Guralnick (2007) describes the need for a translational process between the knowledge of professionals and its acceptance and implementation in families. This aspect can be regarded as innovative and has stimulated broad discussion and feedback within the scientific community. The aspect of increasing self-advocacy of people with disabilities ('Nothing about me without me') also emphasis the obligatory need for transparent and respectful communication from professionals. Competences of communication and self-reflection are therefore summarised under the aspect of 'personal competences'.

2) Practical transfer/internship

As ECI is seen primarily as a transactional process (Sameroff, 2000), these transactions, in terms of observable behaviour, cannot be imparted by mere knowledge transfer but require concrete, 'hands-on' practice, accompanied by feedback and/or reflection. To enable this, opportunities for 'practical transfer' and internship have to be facilitated.

3) Comparability and interchangeability between state-of-the-art European frameworks

The curriculum is based on current mainstream European systems – the European Qualification Framework (EQF), the European Credit Transfer system (ECTS) and the 'Learning outcome model'. Furthermore, individual screening modules at the beginning of the training facilitate the validation of prior training. This reference increases the comparability within the European Union of existing structures or similar professional training.

However, taking into account the different EQF levels of professionals working in ECI (e.g. early years teachers, nurses, social workers, psychologists, speech therapists, physiotherapists, doctors, etc.), it can be supposed that an ECI training should be located (at least) on EQF level 6 (a full master's level or the equivalent – 120 ECTS points).

Table 1. Reference levels of the European Qualification Framework (EQF) defined by learning outcomes (Levels 5, 6 and 7)

(http://ec.europa.eu/education/lifelong-learning-policy/doc44_en.htm)

	LEARNING OUTCOMES					
	KNOWLEDGE	**SKILLS**	**MANAGEMENT**	**LEARNING**	**INSIGHT, COMMUNI-CATION AND SOCIAL**	**PROBLEM SOLVING**
EQF level 5	• Use broad theoretical and practical knowledge that is often specialised within a field and show awareness of limits to knowledge base	• Develop strategic and creative responses in researching solutions to well defined concrete and abstract problems • Demonstrate transfer of theoretical and practical knowledge in creating solutions to problems	• Manage projects independently that require problem solving where there are many factors some of which interact and lead to unpredictable change • Show creativity in developing projects • Manage people and review performance of self and others. • Train others and develop team performance	• Evaluate own learning and identify learning needs necessary to undertake further learning	• Convey ideas in a well structured and coherent way to peers, supervisors and clients using qualitative and quantitative information • Express a comprehensive internalised personal world view reflecting engagement with others	• Formulate responses to abstract and concrete problems • Demonstrate experience of operational interaction within a field • Make judgements based on knowledge of relevant social and ethical issues
EQF level 6	• Use detailed theoretical and practical knowledge of a field. Some knowledge is at the forefront of the field and will involve a **critical understanding** of theories and principles	• Demonstrate mastery of methods and tools in a **complex and specialised field** and demonstrate i**nnovation** in terms of methods used • Devise and sustain arguments to solve problems	• Demonstrate administrative design, resource and team management responsibilities in work and study contexts that are **unpredictable** and require that **complex problems are solved** where there are many interacting factors • Show creativity in developing projects and show initiative in management processes that includes the training of others to develop team performance	• **Consistently evaluate** own learning and identify learning needs	• **Communicate**, ideas, problems and solutions to both specialist and non-specialist audiences using a range of techniques involving qualitative and quantitative information • Express a **comprehensive internalised personal world view** manifesting solidarity with others	• **Gather and interpret relevant data** in a field to solve problems • Demonstrate experience of operational interaction within a complex environment • Make judgements based on **social and ethical** issues that arise in work or study

EQF level 7	• Use highly specialised theoretical and practical knowledge, some of which is at the forefront of knowledge in the field. This knowledge forms the basis for originality in developing and/or applying ideas • Demonstrate critical awareness of knowledge issues in the field and at the interface between different fields	• Create a research based diagnosis to problems by integrating knowledge from new or inter disciplinary fields and make judgements with incomplete or limited information • Develop new skills in response to emerging knowledge and techniques	• Demonstrate leadership and innovation in work and study contexts that are unfamiliar, complex and unpredictable and that require solving problems involving many interacting factors • Review strategic performance of teams	• Demonstrate autonomy in the direction of learning and a high level understanding of learning processes	• Communicate project outcomes, methods and underpinning rationale to specialist and non-specialist audiences using appropriate techniques • Scrutinise and reflect on social norms and relationships and act to change them	• Solve problems by integrating complex knowledge sources that are sometimes incomplete and in new and unfamiliar contexts • Demonstrate experience of operational interaction in managing change within a complex environment • Respond to social, scientific and ethical issues that are encountered

Even taking into account the diversity of training delivery in Europe (from informal in-service training in many European countries through to master's degree courses in Spain), a basic training (e.g. a bachelor degree or equivalent experience in the field) and personal requirements (e.g. personal stability) should represent basic eligibility criteria for learners.

The concept of '**Learning outcomes**' is introduced in ECI, as it perfectly reflects the three basic assumptions of the curriculum (competences, practical transfer and comparability). Learning outcomes can be seen as a manifestation of what a learner is expected to know, understand and/or be able to demonstrate after completion of any learning process or at the end of a period of learning. This includes:

- **knowledge** – in terms of cognitive competence involving the use of theory and concepts, as well as informal tacit knowledge gained by experience, skills and wider personal competences
- **skills** – those things that professionals should be able to do, when they are functioning in a given area of work, learning or social activity
- **wider personal competences** – knowing how to conduct oneself in a specific situation and ethical competence involving certain personal and professional values.

Table 1: Example of a learning outcome description of the cluster 'Development and learning'

Related knowledge	Related skills	Wider Personal Competences
In depth knowledge of normal bio-psycho-social development, including in depth knowledge about classification systems and learning	Ability to apply various theories and derived methods of diagnosis or intervention	Ability to integrate knowledge from different sources. To talk to parents about various developmental approaches, their impact on expectations, emotions and developmental needs of the child and the family

Biological development and interdependencies	Content 1.1.1.:	Fundamentals of neuroanatomy and neurophysiology of child development
	Content 1.1.2.:	Developmental neuropsychology (cognitive development, psychomotor development, language development)
	Content 1.1.3.:	Brain plasticity theories
	Content 1.1.4.:	Scientific studies on child personality (biological bases)
	Content 1.1.5.:	Theories of child physical development

	Content 1.1.6.: Theories of child functional development
	Content 1.1.7.: Classification systems (*International Statistical Classification of Diseases and Related Health Problems*; *Diagnostic and Statistical Manual of Mental Disorders*; *International Classification of Functioning, Disability and Health*)

The diversity of professional pathways in ECI

A variety of professional disciplines, as mentioned above, come together in ECI. The issue is how to combine the specific professional perspectives and training (e.g. as a doctor, psychologist, nurse, special educator, etc.) with a common European foundation. The creation of a new category and identity of professional (e.g. in Switzerland in terms of 'FruehererzieherIn' (Early Educator) and, partially, in Austria with 'Interdisziplinaere FruehfoerderIn und FamilienbegleiterIn' (Early Educator and Family Tutor) (Pretis, 1998b)) cannot cover the diversity of national approaches and might provoke massive resistance by well established professional organisations. The way forward, exemplified in the European curriculum, is to respect prior training (e.g. psychology) and to add complementary components that are either foundational to ECI or complementary to professionals' own portfolios. The idea is that, through complementary qualification, a doctor would be able to call him-/herself an ECI specialist.

As described above, a personal screening tool (available via internet on www.ebiff.org) can be implemented to establish training equivalence. This tool allows feedback about knowledge and skills that a learner has already acquired in his/her basic training (e.g. as a physiotherapist, doctor, psychologist, psychoptherapist, social worker, etc.), and thus which components of ECI training have been attained, and which are still unfulfilled and need to be completed.
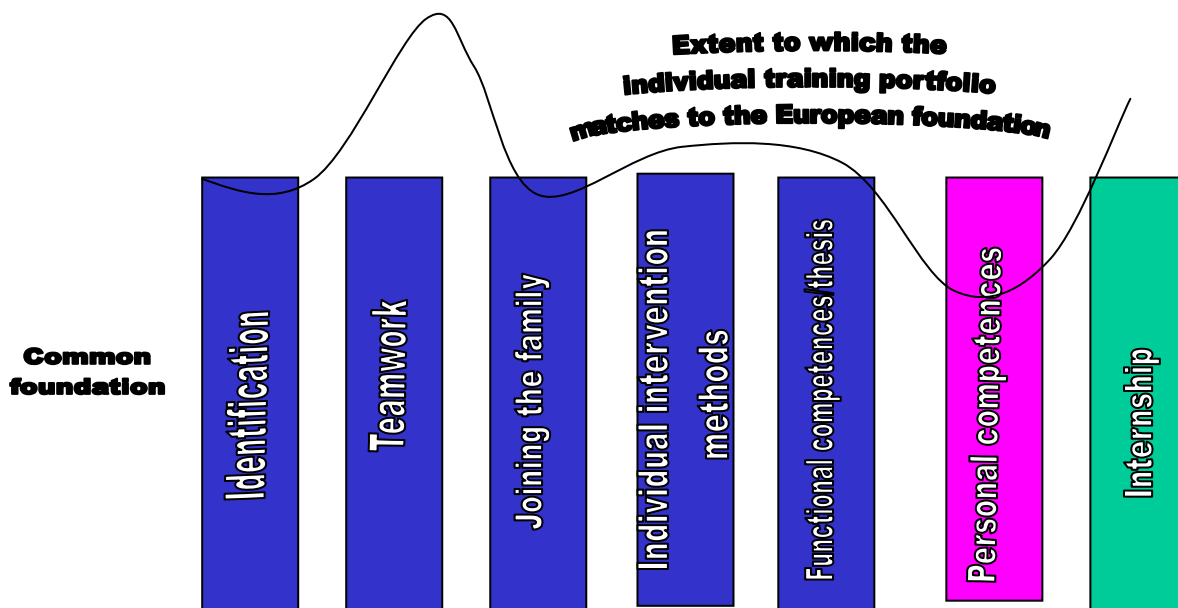
Figure 1. Example of an assessment of the individual training portfolio regarding the proposed key areas of the European curriculum

Figure 1 would indicate, that our simulated professional – in terms of human resource management towards a European master's degree – in future should, to a greater extent, look for specific seminars focusing on personal competencies, such as 'supervision'.

The key areas of the European curriculum

The eight key areas of the European curriculum are supported by an empirical study carried out in 2005 among parents, professionals and researchers (n=117) and expert focus group findings – including former attempts on the European level (e.g. Helios II, 1996). Findings show high perceived relevance of the suggested areas: 88–96% approval. In addition to the identification of relevant key areas, associated training contents (see Table 3) were clustered.
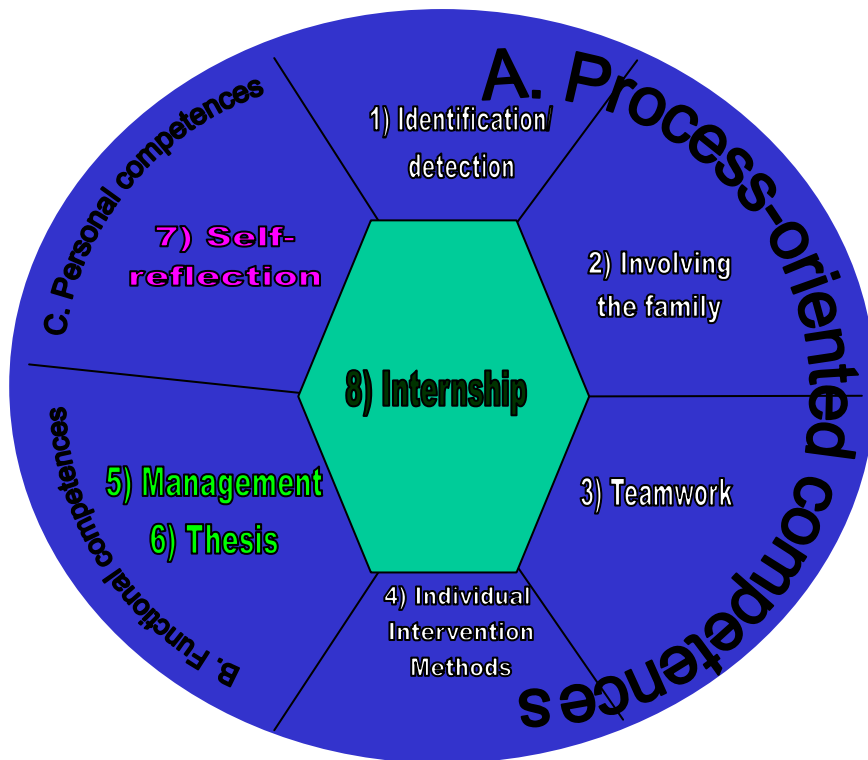
Figure 2. Eight relevant key areas structured by the three competence groups: (a) process-oriented; b) functional; c) personal)

It is noteworthy that, in terms of a common European foundation, that every key area suggests **basic obligatory** components which the professional has to cover to be able to work with vulnerable children and their family and **complementary** components – facultative contents which, to a large extent, depend on the evaluation of an individual's prior training.

Table 2. Overview of the eight key areas of the European ECI curriculum and their associated contents

Competence	Key area	Related contents		Recommended ECTS points
		Basic/obligatory	complementary	
Process-oriented competences	**1. Identification**	**Holistic knowledge of child development: (biological, psychological and social development)**	• Development and learning • Various disabilities • Related domains (e.g. pedagogy, genetics, neurology, etc.) • Assessment tools for the early years • The impact of the environment	20–30
	2. Involving the family		• Various challenges that families encounter • Family systems coping with disability and/or social disadvantage • Various challenges that professionals encounter in communication and interaction with the family system • Empowering families and the concept of partnership with families	15–20
	3. Teamwork	**Basic dimensions and processes within a transdisciplinary team**	• Making teams work • Ethics in ECI • The quality of ECI (as a team process) • Research in ECI	5–10
	4. Individual intervention	**Planning the individual intervention process**	• Key concepts and philosophies in ECI • Evidence–based intervention methods • Documentation • Evaluation in ECI – processes and outcomes	20
Functional competences, including academic competence	**5. Management**	**Functions and roles within ECI centres**	• Relating to the function in an ECI team • Relating to the target groups • Relating to institutional requirements • Relating to legal frameworks	5–10
	6. Academic performance	**Thesis**	•	20–30
Personal competences	**7. Self-reflection**	**Reflection on one's own preconceptions**	• To activate one's own resources • To reflect on one's own professional activities • To reflect on one's own emotional reactions and their impact on interactions	10
	8. Practical transfer	**Internship**		20–30

The impact of the European curriculum

In 2006/2007, the European ECI curriculum was piloted. Approximately 230 individual participants and four training institutions in Austria took part in the assessment of their personal training portfolios or institutional training offered. For 122 participants (53%), a full concordance of their own portfolios with the European foundation was observed based on available data on the internet (www.ebiff.org); in addition, 17% of the remaining portfolios showed a partial concordance.

In Lithuania, a specific master's degree in ECI was implemented based on EBIFF, and modifications relating to ECI were made to existing programmes (mostly in special education) in Estonia, Spain and Austria. Working groups on ECI were implemented in Slovakia. In Belgium, a specific ECI training course was designed. In Spain, the discourse showed an impact on the White Paper on Early Childhood Intervention (Real Patronato sobre Discapacidad, 2005). A current Leonardo da Vinci project, PRECIOUS (Professional Resources in Early Childhood Intervention: Online Utilities and Standards), will try to implement a European master's degree and promote the idea of using online tools and the online library launched by the International Society on Early Intervention (ISEI) (www.depts.washington.edu/isei/ptrl/PTRL_purpose.php/). Along with these tangible effects, there has been increased discussion within the scientific community. The online assessment tool is still available and used by professionals.

Further steps

A European common foundation in ECI can be regarded as a major milestone. For the first time, basic competences for a variety of professionals working with vulnerable children and their families are described. This is based on a decade of discussion (Detraux, 1998; Peterander 2003, 2004; Pretis 2005, 2006a) and on an intensive discourse between many relevant stakeholders, including parents.

Current requirements for the best available quality of services, and also the ongoing discussion about the necessary financial resources (Speck, 1999) and efficiency have helped to prepare the ground towards a common European foundation in ECI. Assuming that specific professional training will increase the quality and the efficiency of services, in many countries the issue of training in ECI becomes more and more relevant. Also, progress is being made from the perspective of funding bodies. For example, in the UK a steering group is looking at establishing a centre for ECI (Carpenter and Russell, 2005); in Germany the umbrella organisation of ECI centres suggested a draft framework of the curriculum (Die Vereinigung für Interdisziplinäre Frühförderung (VIFF), 2005); furthermore some specific

training courses can be identified (e.g. in Bavaria, also in cooperation with Sweden). In Neubrandenburg, two bachelor's degree courses are offered. In Spain (Giné et al. 2005), Portugal and Lithuania, master's degrees are being introduced. In the Czech Republic and Slovakia, basic structures of early interventions, including special training, are being discussed (Pretis, 2005). In Switzerland and, partially, in Austria there is specific training which regulates the entry of professionals into the labour market. In other countries, ECI is included in courses on special education (Estonia) or offered by non-governmental organisations in terms of in-service training (Belgium, France).

These diverse efforts might lead in future towards a European master's degree in ECI, as proposed in PRECIOUS, or towards cooperative networks (ECI-NET) that would provide coordinated training towards a common foundation in ECI, which has been especially requested by the new member states of the European Union.

To manage the more and more observable shortage of resources on the one hand and the diversity of languages in Europe on the other, a strong movement towards ICT-based training tools will be necessary. The ISEI professional training library can be identified as a best practice example, but also new communication software will allow easier access to state-of-the-art knowledge and also skill training. For example: online supervision might be possible using subtitling systems; case reflection can be supported by video conferences. While this will not replace face-to-face training, it might decrease existing language barriers, distances between learners and the latent discussion about finances in Europe.

We must not forget an important factor in terms of lifelong learning: the motivation of learners: What motivates professionals who have worked for 20 years or more in their field to enrol on courses and invest energy in training? As with child development, the development of a professional can be regarded in a holistic way. To reinforce professional strengths, let us learn from each other', and establish a common professional understanding to meet the needs of vulnerable children and parents. Validating prior training and experience, facilitating planned but also incidental learning, curiosity and necessity might motivate professionals to continue their own learning processes. If professionals can decide **what** (related to their own training portfolio) **where** (in terms of international exchange and easy accessibility of information) **when** (in terms of online-learning) and **how** they can learn (e.g. by peer-interaction), the idea of a European master's degree in ECI will become a reality.

Concluding summary

ECI is one of the most complex of bio-psycho-social interventions, as it integrates knowledge, skills and wider personal competences from heterogeneous fields in pedagogy, medicine, psychology, social work and other related fields. ECI reflects a high amount of responsibility and requires – besides the necessary knowledge and skills in specific disciplines – a high level understanding of learning processes within dynamic systems. Early Childhood Interventionists work <u>in</u> and <u>with</u> families, and thus need personal skills of communication, self-reflection and team work. Therefore working in ECI should require, at least, a master's degree or level 6 or 7 within the EQF.

Professionals' personal resources, in terms of their individual portfolios, should be taken into account more often to facilitate their individual learning processes within the context of their continuing professional development needs in a way which values their prior practical experience. A European master's qualification which is resourced through online materials (e.g. Precious (www.precious.at); the Professional Training Resource Library of the International Society on Early Intervention) and which supports individual learning pathways, will offer an easily accessible means of enhancing the skills of professionals and, indirectly, the quality of services.

Questions for reader reflection

- Which competences do you – personally – assess as most important in work with vulnerable families?
- Which competences would you assess as missing regarding your personal training in ECI?
- How can you make it evident from your professional perspective that structured training in ECI increases the quality of services?
- What would personally motivate you to work towards a higher qualification in ECI?

Recommended further reading

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Useful websites

International Society on Early Intervention: www.depts.washington.edu/isei

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