Early Child and Family Support
Principles and Prospects

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About the author

Peter Limbrick's career has taken him into special schools as both teacher and senior manager and into two voluntary projects as director. The first, One-to-One, was part of the UK movement in the 1970s to get children and adults with intellectual disabilities out of institutionalised care. The second in the 1990s, One Hundred Hours, pioneered keyworker support for families whose baby had neurological impairment.

Peter developed and published the Team Around the Child (TAC) approach in 2001 and has promoted this as an essential part of effective integratred early child and family support in the UK, Ireland, Sweden, Croatia, Czech Republic, Canada and Australia.

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I hope that one day soon there will be an early child and family support system in every part of every country for families whose baby or infant has significant challenges to development and learning.

So that this early support can be fully integrated and effective, each family should be offered a locally relevant version of the team around the child (TAC) approach.

Contents

Introduction

This book is about effective support for babies and infants who have significant challenges to their development and learning and for their families who might seek help in bringing up their children. My definition of this substantial and growing population of pre-school children is left deliberately broad. It includes, firstly, children with various physical, mental and sensory conditions or genetic syndromes that can impact negatively on development and learning and, secondly, children whose progress is significantly impeded by negative environmental, physical and social conditions in which they are being brought up.

The purpose of the book is to contribute internationally to discussions with service providers, families, academics and local and national administrators about how to provide effective integrated early child and family support when parents ask for it. I hope it will be read by everyone whose life and work is touched by these babies and pre-school children. The motivation for the book is very deep frustration that there has been very slow progress in developing this early support during the half century of my working life. I know parents, practitioners and managers around the world share this frustration.

Key messages

Early Child and Family Support Principles and Prospects is about families whose baby or infant has significant challenges to development and learning. The key messages are as follows:

- Families of babies and infants who have very special needs are an oppressed minority group in all countries. Any process for establishing or improving early child and family support must also address elements of this oppression.
- All children and their families are deserving of the best possible quality of life. Relevant support can include helping parents create a new version of normal family life.
- Parents have the right and responsibility to bring up their children. The major role of early support practitioners is to help them in this when they ask for it.
- Helping a new child develop and learn is primarily an education issue. In the interests of inclusion, on-going support is best offered in community education settings rather than in hospital outpatient and therapy departments – depending on local facilities.
- Families seeking support will benefit from a locally relevant version of the team around the child (TAC) approach achieved within available resources.
- The various people in any locality involved in early child and family support are best treated as a coherent and unified workforce and brought into a collective effort.
- Because change in early support is happening around the world so slowly, this book envisages local early support task forces to help establish or improve local systems and work to counter oppression. These would operate at the grassroots where the families are.

How the book began

The book comes in large part from four series of articles[1] I wrote during 2020 and 2021 as follows:

- The first, in seven parts, 'Positive environments for early child and family support', was written as contributions to discussions in the Early Childhood Development Task Force (ECDtf)[2].
- The second, in ten parts, was entitled 'Team Around the Child (TAC) Principles' written primarily in response to invitations to speak in countries I was prevented from flying to by the pandemic.
- The third in three parts was entitled 'What is the best way to promote early child and family support in a city, region or country?' This was prompted by 2021 being the twentieth anniversary of Team Around the Child being published in 2001.
- The fourth in three parts was entitled 'Families whose baby or infant has significant challenges to development and learning are a severely oppressed minority group.' These three articles were short editorials in TAC Bulletin[3].

The first, third and fourth series of articles are absorbed into Chapter Three on prospects for creating effective early child and family support. Chapter Two lists five propositions for adjusting the balance between health and education followed by two essays from the Positive Environments series discussing teaching, therapy and collective competence. Chapter Four, entitled *Zen in the TAC approach,* was written in 2011 to suggest Team Around the Child support should be kept as uncomplicated as possible for everyone's sake and with children treated as whole beings.

The first part of the book's title, *Early Child and Family Support* needs no explanation but if I had followed recent custom I would have used the internationally-recognised term *Early Childhood Intervention (ECI)*

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[1] See Notes starting on Page 77

The reasons I have not done so are because:

- the word *intervention* can have a flavour more of authority and interference coming from outside the family than of respectful partnership with the family
- the term was coined before it was widely acknowledged there should be a more deliberate and purposeful focus on families

Early child and family support and the team around the child approach

I define early child and family support as follows:

> 'Effective integrated early child and family support is a flexible and responsive support system that is offered to parents (but never imposed) when their new or expected baby or infant has, or possibly will have, significant challenges to development and learning.
>
> The system is built by local agencies (health, education, social care and others) working together to create seamless support for the family and education opportunities for the child. It lasts between birth and nursery, kindergarten or school – with overlaps at transitions.
>
> Parents are helped to bring up their child and are fully involved and empowered in how their child and family are supported and in how local early child and family support is designed and monitored.'

Where early support comes from will vary between countries. In some localities there will be education, health and social care agencies with a number of practitioners helping each child and family. In other localities there might be only one or two agencies working locally providing families with only one or two practitioners. Some families in some countries will have no help at all.

A central theme of this book is that supporting a baby or infant's development and learning is primarily a family issue that requires an early empathetic and proactive focus on the whole family. This remains true when the new child has a multifaceted condition, when there are on-going health issues and when life expectancy is short or very uncertain.

Another central theme is the need for close teamwork when a child and family are helped by a number of practitioners. Close teamwork requires all people around a particular child and family to communicate effectively with each other and create a whole approach to support the family and promote the child's development and learning. Continuing reference will be made to the Team Around the Child approach (TAC)[4] as a successful example of integrated teamwork – multiagency, multi-disciplinary and transdisciplinary. If effective integrated early child and family support is our aspiration, then some form of the TAC system is one way to achieve it. I define TAC as follows:

> 'TAC is a practical approach for providing effective integrated early child and family support to children and their families. Parents and the child's key practitioners (regardless of professional discipline or employing agency) come together as a small individualised team that is referred to as the child's TAC.
>
> Its function is to share observations, aspirations and approaches and then create a single unified plan of action to support the family as they bring up their child.
>
> A balance is maintained between the child's opportunities for learning in natural everyday activities and the child and family's quality of life. Each child's TAC is warm, friendly, flexible and supportive to all its members.'

Now that I have given my definitions of early child and family support and TAC, I hope readers will check to what extent the approaches fit their situation and how the definitions might need modifying to be fully relevant.

The TAC system is best seen as an invitation and an opportunity for close collaborative teamwork involving parents and practitioners. While TAC is an antidote to disorganisation and fragmentation, it does not prescribe what decisions each child's TAC will make about such necessary details as assessment of strengths and needs, integration of separate programmes, record keeping, etc. This is because each child is unique, each family and their situation is unique and the bringing up of children varies between and within cultures.

Balancing education and health

Readers will find a very strong appeal in this book to release early child and family support from out-dated medical attitudes. Changing *early childhood intervention* to *early child and family support* is one example of freeing ourselves from inappropriate institutional attitudes that are much more medical than educational. My reasoning in this stems from seeing a baby or infant's development and learning as primarily an education concern.

Effective integrated early child and family support must involve elements of education, health and social care in a flexible and evolving response to the child's condition and the family's situation. However, we can only achieve this once we are clear about the different roles of practitioners in these support services. I see confusion in many countries that detracts from effective support and might cause additional stresses and strains for everyone involved – including children.

As an example of this, I believe support for a baby or infant's development and learning should happen first in the family home and then in nurseries, kindergartens and first schools. Traditional confusion between roles of health and education practitioners can result in children and parents having to make regular visits to hospitals, health centres and clinics. In Chapter Two I argue that much of the good work in hospitals' paediatric therapy departments is much more about education than health. When there is confusion in this, there will be repeated unnecessary visits to hospitals and health centres impeding attachment processes at home that require calm and quiet times and reducing opportunities for inclusion in local community facilities for play, education and social interaction.

My use of particular words

The word *disability* will be used very sparingly indeed. This word describing what a person cannot do has no place in early child and family support.

Development and learning are about education and education is about what babies and infants might learn to do based on what they can already do. *Disability* is a wholly negative word coming from medical thinking that carries within it a negative view of future prospects. We certainly do not need this word or the attitudes behind it for babies and infants.

When considering a baby or infant's development and learning, I also discount the term *multiple disabilities* and others like it that suggest plurals. I think it is more realistic to refer to these young children as each having a single unique multifaceted condition. This brings all diagnoses and challenges into an interconnected whole and guides us in making a multifaceted response that connects all aspects of support for development and learning into a coherent system. I am sure though that *multiple disability* has validity in the medical world with both adults and children.

Early child and family support is a short form for *effective integrated early child and family support* and is sometimes further shortened to *early support.*

Practitioner is a person employed by a local education, health or social care agency with a greater or lesser qualification in some aspect of support for babies, young children and their families.

A *key practitioner* is someone in a trusting relationship who has close and regular contact with a particular child and family.

Parent includes people acting in a parental role and *family* is as defined by parents and can include siblings, grandparents and significant others.

The original essays and articles were quickly written, sometimes to a tight deadline. In putting this book together I have taken every opportunity to improve my writing and make sure I am expressing myself as clearly as possible. In doing this I have made no substantial changes to the thoughts and ideas. Where I found repetitions in the articles, I have left them in on the basis that they are coming to the same thought from different angles.

Chapter One

Ten principles to guide effective integrated early child and family support

This Chapter about principles is in two parts:

1. Ten principles with explanations
2. Reviewing principles for local relevance

PART 1: Ten principles with explanations

Principles can be thought of as agreed rules or standards that come from vision and values. Principles inform practice. My principles are not fixed forever because early support for children and families has to be flexible and responsive to local conditions in each city, region or country. But in the task of establishing or improving effective integrated early child and family support we must have a vision to get us started and must have local principles we agree to work to. Vision and principles become the basis for evaluating early support.

Principle 1

When two or more practitioners are working to support the same child, they should talk to each other as often as necessary.

In this way they can share observations and tell each other what they are doing to support the family and to help the child develop and learn.

Before we dismiss this as being too obvious, we should explore if it is happening effectively around children we know. In my experience there is generally insufficient communication across disciplines and between agencies. The result can be added confusion for parents with contradictory advice and separate approaches to the child's development and learning that might not fit together.

Do we need research into this situation? It would certainly be good to research the damaging effects on children, parents and practitioners when people do not talk to each other, but I cannot imagine any research concluding that it is best practice for people around the child not to talk to each other!

If people are not talking to each other, or not doing so effectively, there must be reasons. If you are a practitioner, many reasons might already have occurred to you. If you are a parent or family member, then you will have your own insight into the situation. Here are three major reasons that occur to me:

There are no relevant protocols or mechanisms

While practitioners might feel the need to talk to the other practitioners around a child, there might be no mechanism for it. This can be true both within a single agency (for example health, education, social care or a voluntary agency) or across agencies. When there is no mechanism, it is almost certainly because there are no established multidisciplinary and multiagency protocols requiring and enabling people to talk to each other. This is the fundamental situation that the TAC system is designed to address within early child and family support.

There is no time or place for sharing information and observations

Practitioners' job descriptions and busy routines might not allow for these necessary conversations, leaving practitioners who are under pressure to make what they feel is the most efficient use of their time. The result can be a fragmented approach in which duplication, confusion and chaos waste valuable time for families. Time is used more effectively in a TAC system with meetings and reports reduced to a minimum, with the number of people working with the child and family reduced and with the fewest possible appointments in different places. TAC meetings can be in the child's home or another place that suits the parents. Practitioners' communications with each other can be face to face or virtual. Conversations with parents can also be virtual but in my experience this should only happen once an effective face to face relationship is established.

A lack of trust or self-confidence

Practitioners are human beings and there can be emotions and attitudes involved in sharing their work with other practitioners. This is natural in all professions. The situations of children and families can be very challenging with few hard-and-fast answers to questions and few ready-made solutions to dilemmas. Often practitioners are working without certainty and with some nervousness abut exposing themselves to others in conversations around a child, especially if there is a lack of trust. I wonder if this is particularly true for newly qualified practitioners? A TAC system within early child and family support provides time and support to help practitioners grow confidence, trust and respect.

When people around a child make time to talk to each other, the positive outcomes can include the following:

- People will start relationships with each other in which respect and trust can grow.
- Parents will be reassured to know their practitioners are talking to each other.

- Everyone can share their observation about the child.
- Parents and practitioners can tell each other what approach they are using and what goals have been set for the child's development and learning.
- Any duplications and mismatches in approaches can be resolved.
- The few people around the child can start becoming a mutually supportive team with shared aspirations – the TAC ideal.
- The team can lay the groundwork for making a single unified action plan.

I hope readers will see there is nothing very weird, unprofessional or revolutionary in this first principle. But it is very difficult to make it happen in the UK and in other countries I work in. Too often, staying separate seems to be the default professional position.

Principle 2

Parents have a rightful place in their child's TAC. This is because the child belongs to the parents and no plans or decisions should be made without parents being fully involved.

Before work begins, there should be an informal outline agreement between parents and the practitioners who are going to provide support.

This second principle should not need any justification because it is what most parents would expect. There has to be flexibility in this so that a parent can be accompanied by a grandparent, older sibling or trusted friend and so that a family member or another trusted person can step in if TAC discussion is beyond the capacity of a parent at that time.

Some parents might be nervous of the situation and afraid to speak up. In this case, one practitioner who has a good relationship with the parent can offer support before, during and after each TAC meeting. It is a strong rule of TAC that each person has an equal voice and that each person's views are respected. As the child belongs to the parents, then parents' views are very important indeed.

When there are differences of view, perhaps about a course of action, there must be careful negotiation in which no one's views are ignored or dismissed. Perhaps time is needed for more information to be gathered. Perhaps the parent and a professional can arrange to meet to go over the issues more thoroughly, in which case perceived difference might dissolve. Perhaps the discussion can wait till a later date. If a parent or another TAC member feels they are being ignored or bullied, then trust and partnership will be lost.

The venue chosen for TAC meetings must suit the family. TAC meetings can work well in the family home if that is what parents want. Other venues must be accessible, welcoming and non-intimidating. Pre-school siblings must be welcomed and catered for.

It is advisable for there to be some sort of very basic agreement between parents and early support practitioners at the beginning before practitioners have detailed knowledge about the child and parents' situation, strengths and needs. This means that parents will know what to expect. It also means everyone can evaluate in three, six or nine months' time whether or not people are working in the way they said they would. Here is an extract from *Bringing up babies and young children who have very special needs*[5], pp 57-58:

> 'I do not advocate legal contracts between agencies and new parents. Also, it would be inappropriate for a practitioner to offer assurances to parents about what their baby or infant will achieve. But parents must be given some idea of what is on offer when they accept a support service. In my view, a modern early child and family support system should explain clearly to parents what they are offering, how they will work and what broad outcomes can be reasonably expected.
>
> This can be in the form of an initial agreement or informal contract emerging from discussions between parents and support agencies. The following are just three examples of items for such an

agreement written by the agency and agreed with parents:

- We respect your right and responsibility to bring up your child. We will offer you support in this when asked.
- We will value and respect your child, treat them as a whole child and support you in giving them the best possible quality of life with freedom from discomfort and pain as far as possible.
- We will work with you to make sure support for your child is properly organised to reduce tiredness, stress and strain on your child and on yourselves as parents.'

Principle 3

> $_3$**Once TAC members have each acquired first knowledge of the child's strengths and needs and of the family's situation, they agree a single unified holistic action plan.**
>
> **This should conform to the initial informal agreement made with the family.**

The Team Around the Child approach has a primary objective of preventing the fragmentation that occurs inevitably when the people around each child act separately from each other – and even, sometimes, in ignorance of who else is involved. To help reduce fragmentation, TAC members create a single action plan rather than a collection of separate plans. This reduces the potential confusion and overload when parents have a separate plan from each of the people involved.

This TAC action plan is unified because it brings everyone's work into a coherent pattern in which all parts fit together harmoniously. Included here are approaches to the child that parents have established as well as those of practitioners. The plan is holistic because it considers all relevant parts of the child's development and learning. Included here can be movement, communication, dexterity, cognition, posture, self-esteem, feeling, memory, listening, looking and more.

Each child's TAC is a continual learning process. When the initial informal agreement was made between the family and practitioners at the time when the family were accepting this support, very little was known about the child except that their needs seemed to fit with what the support service could help with. The practitioners' first sessions with the child bring their knowledge to a deeper level so that they can roughly plan their future work and contribute to the action plan. As work progresses, each practitioner continues learning about the child using their preferred informal or formal assessment processes. The action plan outlines how TAC is going to operate as a whole but does not give details of each practitioner's separate programmes. An action plan can include the following:

- The names, roles and contact details of practitioners who will be regularly and practically involved.
- Information about where these people will do their work/play with the child – in hospital, clinic, centre or child's home.
- The particular elements of the child's development and learning that will be prioritised in this phase of the early support process.
- Information about any sessions to be done jointly by TAC members with shared sessions or integrated programmes.
- The intended regularity of the various sessions.
- Any plans for using at-a-distance conversations with phone or video.
- Any plans for filming the child to aid team discussion and observe progress.
- The date of the TAC meeting when the action plan will be reviewed and refreshed.

As practitioners learn more about the child, so will they learn more about the family's situation, strengths and needs. Family needs can be extensive requiring much more time and skill than is available from TAC members. Where there is agreement about getting some outside help to the family, for instance about sleep, this can be put into the action plan. The decision here might be to suggest parents contact another professional or agency or for a practitioner to make the link with parents' permission.

The unified action plan is an agreed outline of how support will be offered in the first phase and, broadly, of what the work will focus on. After an agreed period of time, the plan is refreshed or re-written for the next phase. Obviously, the written plan will be shared between TAC members. If there is a need for other people who are supporting the child and family on a less regular basis to see the plan this is only done with the agreement of parents. When a parent has spoken to a practitioner in confidence, this would not be discussed in TAC meetings and any agreed decisions would not be written into the action plan. An example might be discussion of relationships within the family or of private money matters.

Principle 4

> **Each child's TAC comprises the small number of people who have the most regular and practical involvement with the child.**
>
> **There is no manager in authority, each member gets support from the others and everyone has an equal voice. This is horizontal teamwork at its best.**

There is no point in the TAC process within early child and family support if it does not effectively support, inform and empower parents and other family members. TAC meetings are always in a positive and encouraging mood even when there are very difficult issues to discuss. This gives practitioners the very demanding task of being honest and sensitive at the same time. The aim is for each TAC meeting to be a positive experience in which parents know they are listened to, understand they have an active part in planning support for the child and family and feel strengthened for the tasks that lie ahead today and tomorrow. Part of this is the very human process of people supporting each other. This can require personal qualities that are different from professional skills.

Many of the babies and infants who require early support have multifaceted conditions for which there are no ready-made programmes. Also, many of the families are in very difficult and challenging situations.

Practitioners who try bravely to support a child and family on their own might soon be overwhelmed. TAC meetings are designed so that practitioners, as well as supporting parents, can support each other. No one has to feel they are struggling on their own. This means that practitioners need to be able to relate to each other with honesty, empathy, trust and respect – the same qualities they must use in their relationships with parents and other family members. These relationships take time to develop.

Each TAC might have people from a variety of disciplines and agencies. This means it cannot have a manager as if it were in a traditional vertical hierarchy. Instead it has the flat power structure of horizontal teamwork. The following are extracts from *Horizontal Teamwork in a Vertical World*[6]:

> 'Each TAC is a horizontal structure because the child's TAC practitioners are temporarily removed from their hierarchical relationships and work with each other and with the parents as equals. Each TAC has a facilitator to help the meeting run well and arrive at an agreed action plan, rather than a team manager or leader who exercises authority.' (p 23)
>
> 'Horizontal teamwork brings an awareness of the inter-connectedness of all elements of the child or service user's situation and needs enabling the practitioner to contribute naturally and almost instinctively to a whole approach.' (p 59)
>
> 'The TAC model provides an excellent training ground for practitioners who have not worked before with children with a multifaceted condition. (Managers and practitioners will need to consider how far it is appropriate for newly qualified practitioners to work in horizontal teams before they have become confident in their practice and have developed a solid foundation for their work.)' (p 60)

Principle 5

Action plans in early child and family support are designed to reduce the child and family's exhaustion and stress as much as possible.

Child and family are helped to have the best possible quality of life. Bonds of attachment between the new child and significant family adults are nurtured.

There should be no longer an easy assumptions that parents and other close family members must accept long-term stress, strain and exhaustion. With stress and exhaustion marital relationships can falter, family members can suffer physical and psychological illness and some families will fall apart under the strain. TAC members will always be available to discuss the causes of a family's stress and exhaustion, whether the subject is brought up by an empathetic practitioner or a family member.

It is essential for family members to have a person they know and trust to discuss their upset, bewilderment, worry and confusion. There can be feelings of guilt if a parent feels responsible for the child's condition, if one parent is blaming the other or if one side of the family blames the genetics of other side. A parent might need help with self-esteem and confidence if they feel disempowered in the face of so many practitioners in expert mode and consequently feel inadequate to the task of caring properly for the child.

It will help if one person can be proactive in learning from parents if life is too busy with repeated assessments, medical treatments, therapy sessions and case conferences in hospitals, clinics and centres. This must include learning about travel difficulties and costs and additional problems when there are pre-school siblings to cater for. It will also be necessary to ask how many home visits are made by various professionals because these can be sources of stress, can make the family feel the home is no longer a private domain and even that they are being observed and judged. In traditional fragmented services no single practitioner can ever know the whole picture of how support is being provided.

Parents can be asked about any difficulties they might be having with home programmes from one or more therapists and teachers. Home programmes can work well for some families but for others the work is difficult to fit into the available time and space and can add to parents' stress and tiredness. Parents might blame themselves if they feel they are not doing the programmes well enough or often enough. Also, some parents do not easily modify their natural parental role to become a pretend therapist or teacher.

Parents must be asked about the child and family sleep routines. Many parents are struggling with all of the above issues while they are sleep deprived because of the child's sleep patterns. Parents will be anxious if siblings are also sleep deprived in the same way and failing at school.

Babies and infants can also suffer anxiety, stress and exhaustion. The following extract is from *Early Childhood Intervention without Tears*[7] pp 12-13:

> 'Parental tiredness, stress and general downheartedness will impact directly on the infant. But the child with a multifaceted condition has other threats to wellbeing and quality of life, including:
>
> - busy days, busy weeks
> - perhaps sleeping badly and experiencing bodily discomforts, anxiety, fear and pain during days and nights
> - a growing throng of non-family people each expecting the child to relate to them and accept being handled by them
> - being trundled around to a variety of locations for appointments that are organised without proper regard for feeding, sleeping and play times. This makes it very difficult for parents to establish infant routines.
> - home-visiting professionals intruding on home life and natural home activity
> - home therapy programmes delivered by parents that might be experienced by the infant as unpleasant and unwelcome interruptions of the natural flow of infant and family activity'

Quality of life for the new child and family is enhanced for the present and future when there are good conditions for developing early bonds of attachment. This is equally true for all children. The necessary good conditions include: child and adults being as free of stress and exhaustion as possible; adults having quality time to spend with the child in a calm atmosphere; the child being calm and pain free for these quality times.

Following this fifth principle, the first task is for practitioners to listen to parents and other family members to learn what their situation is, what is causing exhaustion and what is causing stress. The second task is to be imaginative and creative in making an early support action plan that reduces exhaustion and stress as much as possible.

Principle 6

> **It is the responsibility of parents to bring up their child. It is the responsibility of early support practitioners to support them when they ask for help. The TAC system within early child and family support offers respectful partnership rather than authoritative intervention.**
>
> **Parents are helped to find an evolving balance between the needs of the child and the needs of the family.**

Human society in its infinite variety of cultures recognises that parents have the right, the responsibility and the skills to bring up their children without interference. This is the respectful starting point in integrated effective early child and family support and practitioners do not move in to help with the child's development and learning until they are asked to do so. After that, the helping relationship begins by acknowledging the family's knowledge, strengths and skills.

Local cultures determine broadly how families bring up children and, within their culture, each family has their individual way of doing things. Support cannot be effective unless this is explored, understood and respected. Practitioners, who might come from a different culture and might have different levels of education, social status and income, will fail to establish a helping relationship with parents if they try to impose their own way of doing things. The task is to start with what parents know about their child and then make full use of the skills they already have in helping their child develop and learn.

While this work in the past has been called early childhood intervention, any insensitive attempt to intervene between the child and the family or between the parents and their normal routines within their culture will be disempowering and result in a loss of trust. Here is an extract from *Bringing up babies and young children who have very special needs*[5] under the heading 'Whose child is it?' pp 78-79:

> 'It is not an inappropriate question. Parents often report that practitioners move in on them, sensitively or insensitively, when the baby or infant has very special needs in a way they would not do with other parents. Parents of typically developing infants are left largely to their own devices with freedom to use their natural parenting skills and learn as they go along. If parents stay within the very broad limits set by their culture and society, they are not checked or taught or challenged.
>
> Parents might lose this freedom when their baby or infant has very special needs. From the first hours or days of the child's life, there can be an expanding host of experts telling parents what to do and how to do it. The assumption is that practitioners know best and that new parents know little or nothing. There is an unspoken message to parents that bringing up the child must now be a group effort led by experts.
>
> Few parents at this time can resist this takeover and will take to heart the message that they are not up to the task of bringing up their new child. The result can then be a very dangerous mix of an infant with very special needs and parent or parents who are undermined, deskilled and feeling out of control....'

An important part of a child and family-centred approach is to help parents achieve a working balance between the needs of the child and the needs of the family as a whole. The balance will change as the whole situation changes. A new baby might have to be the focus of attention for weeks or months at the expense of family relationships, the needs of siblings and family finances. But this is not sustainable and parents might welcome support in finding a balance in which the whole family increasingly has some quality of life and can avoid breaking apart.

This will be an on-going process in which parents and other family members have opportunities with a trusted practitioner to discuss such topics as anxiety, guilt, aspirations, inclusion, future prospects and, for some, life and death. These conversations will inevitably be a mix of experience, knowledge and emotion.

Lastly, just as TAC practitioners can support families with their child's development and learning, so can they offer to support staff members when the child enters a nursery or first school. These staff members will almost certainly value the special knowledge and skills held by members of the child's TAC. The family will value this continuity in the child's opportunities for development and learning.

Principle 7

> **Activities to support the child's learning and development are integrated into the child and family's natural everyday activities.**
>
> **Teachers, therapists and other practitioners around the child support parents in learning how to help their child in these activities.**

All new children develop their understanding of the world and learn their first skills in manipulating it during the natural activities of taking food and drink, relating to parents and other family members, being washed, being bathed, being undressed, being dressed, getting ready for bed, playing with toys, moving around the room and moving around the house. All of this learning starts from the first days at the same time as bonds of attachment are developing. Development and learning in these basic tasks begin in the family home and then continue in nursery or first school.

When asked to do so, early support practitioners can support parents in learning how to manage these activities as pleasurable learning experiences. Parents can decide which activities they want to focus on rather than trying to tackle them all at once. Some parents will choose those everyday activities that are presenting difficulties at the moment, for instance, managing clothes or getting the child to sleep. Working with the child and family in this way:

- avoids discipline-specific programmes
- ensures new learning is relevant to the child and family's situation, routines and culture
- provides daily opportunities to understand and practice new skills
- helps the child develop their part in the life of the family (not forgetting the need for fun and games)

All natural activities provide opportunities to develop understanding and skills in all aspects of child development; posture, movement, dexterity, communication, cognition, seeing, hearing, touching, etc. They also provide early learning about relationships, emotions, choice, consequences, sequences and purpose. As an example, all of this can happen in the activity of getting a child dressed at the start of the day. Practitioners can offer focused guidance in this when a parent is finding difficulties because of the child's physical or sensory challenges.

The paediatric physiotherapist, Sophie Levitt, has pioneered this approach. We read in her *Basic Abilities - a whole approach*[8] that it is:

> '... a new practical approach for those caring for a child with multiple disabilities. For the first time parents are enabled to use the child's everyday routine as part of a developmental programme that will help the whole child...
>
> With its positive approach, its emphasis on what the child can do and its methods which reinforce each other to benefit every aspect

> of development, this warm enlightened book enables parents to make a genuine contribution to their child's [development and learning].
>
> The integrated functional approach also provides a framework into which professionals can add their own special knowledge and skills.' (This fitting description comes from the publisher.)

There is no suggestion here that parents should turn every natural activity into a lengthy education session. This would only add to their tiredness and stress and detract from the child's enjoyment of life. Each parent must come to a balance that suits them and the child, that offers appropriate opportunities for development and learning, that fits with the child's interest and capacities and that uses the time available to the best advantage.

Providing early education in this natural and relaxed way will enhance the child's quality of life by being more fully involved as an active participant and understanding more about everyday routines. Parents' quality of life and self-esteem are enhanced as they increase their competence and confidence in bringing up their child.

Principle 8

> **In supporting a child's development and learning, practitioners and parents avoid using such terms as *multiple disabilities* and think instead of each child having a single unique multifaceted condition. The task then is to integrate all their work and play into an individualised multifaceted response for each unique child.**
>
> **This approach develops and uses collective competence.**

The term *multiple disabilities* is entirely inappropriate when supporting a baby or infant's development and learning. First of all, the word disability is wholly negative and comes from the medical world. It contributes to a negative mind set in the family and practitioners around the new child and lowers expectations for progress.

Secondly, the term assumes that challenges to a young child's movement, dexterity, seeing, hearing, cognition, etc. are existing separately from each other. This cannot be true. For example, when a baby has cerebral palsy and impaired vision, each challenge will impinge on the other and jointly influence hand-eye co-ordination.

The well-meaning but ill-considered medical approach to these children in many countries has been to provide a separate practitioner for each diagnosis or challenge. This overloads babies and infants, exhausts parents and creates confusion and contradictions. It offers the child no help in internally integrating the work in each area of development.

In my understanding the new child's conditions and challenges interact with each other rather than staying separate. The positive side of this is that progress in one area of child development, for instance vision, will support progress in another, for instance movement. We come to see that the traditional separate areas of child development are not so separate after all. There is merit then in seeing each new baby and infant in their interconnected wholeness – and then seeing all their challenges and abilities as a single unique multifaceted condition. In the multifaceted TAC response within early child and family support, practitioners move away from discipline-specific programmes towards relevant, functional and purposeful play/work activity.

Practitioners and parents working closely with each other to create a multifaceted response will naturally develop collective competence. Each natural activity, for instance, drinking from a cup, playing with toys, moving around the floor, is multifaceted and brings together various elements of the child's understanding and skills. The people around the child, all with separate experience, understanding and skills, must now contribute to a whole approach by learning from each other. Collective competence is achieved when one of the people, often the parent, has learned how to help a child take socks off or drink from a cup without needing the other people in attendance – but remembering everyone's skills are integrated into the new whole approach.

Collective competence can make it possible to reduce the number of practitioners around a child to just one for a period of time. This can help reduce stress and strain on the child or family or both. I described this approach in *Primary Interventionists in the Team Around the Child Approach*[9] (before I came to feel that intervention is not an appropriate word for this work). Here are two extracts:

> ‘Within the TAC approach, primary interventionists are not a defining feature. They are an option for a TAC to adopt if it is felt necessary for the child and family. A primary interventionist is the person chosen in TAC discussion to work with a child and family for a period of time when TAC members (remember parents are fully involved) feel there should only be one person offering most of the direct support...’ p 20.
>
> ‘All the necessary expertise, knowledge and skills for teaching these multifaceted activities reside not in the child’s primary interventionist, but in the whole TAC team – practitioners and parents. It is the TAC members who fully brief and support the primary interventionist to become competent in supporting parent and child in the chosen activity.’ p 22.

Appropriately reducing the number of regular appointments and sessions while the family has just one competent practitioner with whom they get on well can support parents in keeping family life as normal as possible.

Principle 9

Support for a new child's development and learning is much more an education issue than a health issue. Visits to hospital and clinics are kept to a minimum.

There would be great benefits if paediatric therapy could be redefined and differently organised.

In TAC philosophy, a baby and infant's first learning in balance, movement, dexterity, communication, cognition, social skills, vision, hearing, confidence, emotions and everything else comes under the umbrella of education – which I define as the acquisition of new understanding and skills with or without teaching and instruction.

It is a hangover from the last century that much of this early learning has been thought of as a health concern and made the responsibility of paediatric therapists in hospitals and clinics. Paediatric therapists, usually highly trained in an aspect of child development, have an extremely important contribution to make but they are not educators trained in the science of how babies and infants learn and, in very many cases, are not specifically trained to see the whole interconnected child.

The consequence of this historical anomaly is that new children and their parents might have months or years of regular visits to hospitals, centres and clinics for therapy. The negative aspects of this can be:

- a continual drain on family time, energy, money and spirit
- disruption of the child's natural daily routines
- additional and unnecessary stress and anxiety for child and parent
- reduced opportunities for learning and for developing bonds of attachment in a calm and unhurried atmosphere at home
- regular reinforcement of the medical idea of a problematic disability to be treated (if not cured)
- loss of opportunities for inclusion in more natural baby and infant social/educational environments

In my understanding, paediatric therapists have a dual role with babies and infants: firstly, they support the acquisition of new understanding and skills (*education* in my terms); secondly, they offer essential medical interventions to do with swallowing, respiration, muscles, joints, etc. Obviously, for the second of these it might be necessary for the child to attend hospitals and clinics. But the education element is best supported in the family home and then in nurseries, kindergartens and first schools. This is inclusive practice.

When a new child has a multifaceted condition, the TAC approach in early child and family support brings the understanding and skills of parents, teachers and therapists into a collective effort to support development and learning. All of these people have separate abilities and approaches that can be brought together to create collective competence to support whatever new learning is being focussed on.

The TAC approach advocates bringing paediatric therapists out of their hospitals, centres and clinics to work/play with children where they are in their natural settings – at home or in nursery or school. Following these early child and family support principles, a large part of the role is to help parents acquire new understanding and skills as they bring up their child. When there is TAC agreement to reduce the number of practitioners around the child, one or more practitioners can for a period of time reduce their direct contact and become advisors to the others.

Following this thinking, the term paediatric therapy, is a misnomer since these practitioners are either supporting education or providing health treatment – neither of which needs to be called *therapy*. In planning early child and family support in a city, region or country, I would dispense with the word therapy while greatly valuing the skills and experience of practitioners who are at present known as paediatric therapists. This argument is developed in Chapter Two in a discussion of re-balancing health and education contributions to early child and family support.

Principle 10

Parents are not treated as passive recipients of early child and family support. They can work at the grassroots alongside practitioners to create a local integrated system that counters institutional and oppressive attitudes and reaches all the families that want this sort of support.

Parents of all children have a right to be fully involved in decisions about the health, education and wellbeing of their children. It is logical and natural for parents to be included in their child's TAC as genuinely equal partners. It is equally appropriate for representative parents and family members to be involved in promoting, evaluating and improving early child and family support in their city, region or country.

This is not common practice in my experience. Instead parents, siblings and grandparents can be organisationally discounted including:

- being generally treated as lesser beings and confronted by professional snobbery
- being thought incompetent to contribute in any real way to discussions about how early child and family support is provided
- being excluded by default from meetings about service provision

The injustice of this becomes clearer when we equate it with keeping black people out of discussions about racial equality or excluding women from discussions of supposed male superiority. In my view, the families I am talking about in this book are a disempowered and oppressed minority and this dismissive treatment is just one element of it.

For parents and other family members to have their rightful place in developing early child and family support, it is necessary to counter out-dated institutional attitudes that are often strongest in more highly paid people and more common in medical services than in nurseries and schools.

In *Bringing up babies and infants who have very special needs*[5] I have offered my working definition of *institutional*:

> 'I am using the word institutional to characterise provision that is impersonal, inflexible, meeting the needs of agencies rather than of children and families, neglectful of human rights, and persisting only because it is the cheapest and easiest option. My description of out-dated support is meant as a comment on how some agencies model their support systems and is not meant to characterise the practitioners working in those systems. I have met very many genuine, sensitive and empathetic practitioners in both traditional and modern agencies.' p 77.

During the last hundred years in the UK, disabled women and men, members of their families and friends have been very powerful in changing how people with impairment are thought about. They have helped establish national or local organisations to campaign for rights and to provide support. This has greatly influenced how public services operate.

In the same way, parents and other family members can be very powerful when they get together to enact change in early child and family support. This must include parents and family members whose children have grown beyond infancy and parents whose child has died, if they are willing. None of this is easy, but I see no other way to move these children and families from society's margins and accelerate the pace of change. This idea is taken further in Chapter Three in a discussion of early child and family support task forces.

PART 2: Reviewing principles for local relevance

My ten principles for effective integrated early child and family support are listed here so readers can decide how relevant each one is to their local situation and how they might need to be modified.

1. When two or more practitioners are working to support the same child, they should talk to each other as often as necessary. In this way they can share observations and tell each other what they are doing to support the family and to help the child develop and learn.

2. Parents have a rightful place in their child's TAC. This is because the child belongs to the parents and no plans or decisions should be made without parents being fully involved. Before work begins, there should be an informal outline agreement between parents and the practitioners who are going to provide support.

3. Once TAC members have each acquired first knowledge of the child's strengths and needs and of the family's situation, they agree a single unified holistic action plan. This should conform to the initial informal agreement made with the family.

4. Each child's TAC comprises the small number of people who have the most regular and practical involvement with the child. There is no manager in authority, each member gets support from the others and everyone has an equal voice. This is horizontal teamwork at its best.

5. Action plans in early child and family support are designed to reduce the child and family's exhaustion and stress as much as possible. Child and family are helped to have the best possible quality of life. Bonds of attachment between the new child and significant family adults are nurtured.

6. It is the responsibility of parents to bring up their child. It is the responsibility of early support practitioners to support them when they ask for help. The TAC system within early child and family support offers respectful partnership rather than authoritative intervention. Parents are helped to find an evolving balance between the needs of the child and the needs of the family.

7. Activities to support the child's learning and development are integrated into the child and family's natural everyday activities. Teachers, therapists and other practitioners around the child support parents in learning how to help their child in these activities.

8. In supporting a child's development and learning, practitioners and parents avoid using such terms as *multiple disabilities* and think instead of each child having a single unique multifaceted condition. The task then is to integrate all their work and play into an individualised multifaceted response for each unique child. This approach develops and uses collective competence.

9. Support for a new child's development and learning is much more an education issue than a health issue. Visits to hospital and clinics are kept to a minimum. There would be great benefits if paediatric therapy could be redefined and differently organised.

10. Parents are not treated as passive recipients of early child and family support. They can work at the grassroots alongside practitioners to create a local integrated system that counters institutional and oppressive attitudes and reaches all the families that want this sort of support.

Chapter Two

Adjusting the balance between health and education in early child and family support

This chapter is in three parts:

- Five propositions for adjusting the balance between health and education in early child and family support.
- Contrasting a therapy approach with an educational approach to the early skill of moving on the floor.
- Joining therapy and education – an early personal experience.

The five propositions began life as an eight-part essay exploring positive and favourable environments for providing effective integrated early child and family support. They were then presented as *Five propositions for de-medicalizing early child and family support in a radical redesign*[10]. A central theme was that opportunities for inclusion in local education facilities should be maximised and visits to hospitals reduced to an essential minimum. The second and third parts are essays that formed part of the original eight-part essay.

PART 1: Five propositions for adjusting the balance between health and education in early child and family support

Proposition 1

Children's visits to hospitals and other health centres should be reduced to the absolute minimum

The thinking behind this proposition includes:

- These medical environments can create and perpetuate negative attitudes in children, families, practitioners and communities.
- Hospitals are busy, neurotic and morbid places that can impact on short and long-term mental wellbeing of children and parents.
- Visits to hospital can be expensive, time consuming and disruptive of normal child and family routines.
- Regular visits to hospital interfere with the quality time at home that promotes attachment, and disrupt or prevent inclusion in local settings for play, socialising and education.

Negative attitudes

Hospitals and health centres are instituted to offer treatment for illness with some expectation of cure. In this atmosphere children can easily become patients in the eyes of parents and others and take on a dependent and powerless self-image as we might all do undergoing hospital treatment. Children are separated from their peers with such medical terms as *disability,* a label that might never wash off, and *developmental delay* that seems to hold the promise of catching up. I see no good reason for labelling a child at the beginning of life as disabled.

Neurotic and morbid environments

Hospitals are described in detail as neurotic and morbid environments in the first of the seven 'Positive environment' essays. Hospitals offer a rich daily mix of potential stressors with various degrees of mental disturbance, conflict, anxiety and fears. Staff members, patients and outpatients (adults and children) are all influenced by this environment.

Children as outpatients might feel like I do sitting in a dentist's chair. Parents might have fearful feelings especially if the hospital brings back memories of the time around the birth of the child. The kindness of staff members might help but some deep-seated apprehensions can persist.

Disruption

Regular trips to hospital can be stressful, time consuming and expensive, especially with young siblings and any necessary equipment for mobility, nutrition, respiration, etc. Appointment times almost never consider the child's routines for sleep, food, drinks, changing and play. Everything has to be put aside to meet the hospital's needs for time and place.

All children might need to visit a hospital for health reasons and the children we are considering here are no exception. There might also be a need for some occasional visits to specialists, for example neurology and genetics. The principle in early child and family support is to avoid a regime of regular visits for needs other than genuine health needs.

Interference with attachment and inclusion

Attachment requires quality time in a safe space with trusted parents, siblings, other family members and others who are significant in the child's life. Such quality time requires the absence of stress and rush. When a family's calendar is full of hospital visits, this quality time is diminished.

When a baby or infant's childhood is disrupted by regular visits to hospital and health centres, opportunities for inclusion in local play, social and education settings are reduced or eliminated. This is to the detriment of the child, their local peers and the people who work in the local settings. The child has a right for this to be properly considered when a regime of hospital visits is being planned.

Proposition 2

Early child and family support requires us to think of each child as a learning child, moving our thinking away from disability, dysfunction, delay, etc.

Avoiding medical mindsets, we can consider how to best support a baby or infant's development and learning at home and then in their locally available play and education settings. I am defining education as the acquisition from birth of new and relevant understanding and skills, whether or not there has been adult support for it.

The term *learning child* is entirely positive and displaces such medical terms as *invalid*, *sick child*, *patient*, *disabled child, atypical child, abnormal child*, etc. Children who have on-going needs for additional support can then join all the world's other children as learning children. This is where they belong and have every right to be. Then parents, teachers, therapists and other people involved only have to consider what support each child might need for their development and learning – whether the task is holding a spoon or managing a first musical instrument.

When a baby or infant is predicted or suspected to have only a short life, we should still see her or him as a learning child, work towards the best possible quality of life and consider deeply the emotional needs of child, parents and other family members.

Proposition 3

It is important to recognise that much of what we call paediatric therapy is actually education

Early learning for babies and infants includes looking, listening, sitting, standing, rolling, crawling, using hands, making choices, communicating *yes* and *no*, recognising pictures/symbols/words, managing emotions, developing self-esteem, relating to others, empathising, continence, making plans, etc. All these new understandings and skills build on what the child has already acquired and will endure if they are relevant to the child's daily routines at home and at school.

Young children develop and learn in the company of family members and friends and with people who work in nurseries, kindergartens and first schools. Development, learning, play, socialising and daily routines all integrate naturally.

For some children, specialised help is necessary from paediatric therapists but calling it *therapy* is a historical misnomer. When they are helping the child acquire new understanding and skills in posture, mobility, communication, etc. it is the same education that other people around the child are also involved with. While acknowledging that much of traditional paediatric therapy is really education, we must also acknowledge the special understanding and skills that paediatric therapists bring to the task. Their deep knowledge and experience is indispensable.

Proposition 4

A primary task of specialist early child and family support practitioners is to educate parents and other people around the child

I am using the term *specialist early child and family support practitioners* to include paediatric therapists, teachers, play specialists, psychologists and others who are qualified to work with babies and infants who need additional support for their development and learning. Because early learning is in the family home, nurseries and first schools, it is logical for much of each specialist's work to happen in these natural places where the child is at ease, surrounded by familiar people, furniture and toys and is involved in familiar daily routines.

Society gives parents the right and responsibility to bring up their young children and the great majority in all countries do so without seeking any professional help that might be available. When a baby or infant has particular development and learning needs there is logic and fairness in locally available specialists supporting parents in their role, when asked to do so. This means sensitively helping parents acquire the understanding and skills they need to bring up their child.

In this approach, there is a focus on the parent as much as on the baby or infant and working with the parent in a supportive and advisory capacity goes alongside working with the child. In this thinking, some sessions could usefully take place in the absence of the child.

This advisory role continues when the child enters a nursery or first school where the specialist early child and family support practitioners' work is to help nursery and school staff acquire the understanding and skills they need to support the child's development and learning. Children and parents will benefit greatly from this careful continuity.

Proposition 5

All specialist practitioners in early child and family support should be considered as a coherent group in each locality's workforce

While members of this proposed grouping share the role of helping in the education of babies and infants who need additional support in their development and learning, they will not have the same professional training nor be employed by the same agencies. The first of these is a distinct advantage in bringing a wide range of knowledge, experience and skills into the constellation. The second, under existing conditions in many countries, requires effective integration between separate health and education agencies in early support services.

This coherent group would need to have two layers: firstly, teachers, paediatric therapists, psychologists, play specialists, etc; secondly, people less expensive to employ as home support workers and nursery/ school assistants, etc. This second group, working sometimes under the guidance of the specialists, would work and play with children on a more regular basis. Training for this workforce must cover, at appropriate levels, the science of how babies and young children learn.

PART 2: Contrasting a therapy approach with an educational approach to the early skill of moving on the floor

This essay was written as part of the 'Positive Environments' series. The sessions I describe are constructed from my experience over many years. There are three subheadings:

- A therapy approach to the early skill of moving on the floor
- An education approach to the early skill of moving on the floor
- Discussion

A therapy approach to the early skill of moving on the floor

For this, we are a fly on the wall observing a single session in a hospital's paediatric physiotherapy department, centre or clinic. A baby boy or infant is supine on a therapy mat with a physiotherapist kneeling at his side and the parent nearby but not too close.

The therapist knows the child well. He has significant motor issues with a neurological cause. She had carried out an assessment schedule before attending a multidisciplinary assessment meeting to compare notes with other practitioners and agree a plan for the child's future treatment. This plan had included regular physiotherapy sessions in the hospital with some home visits if possible.

The therapist is working on the new skill of rolling from supine. Her work to date has shown that the child is developmentally ready for this and she has told the parent what the new task is. She will help the child roll from back to side and observe how he responds. From this she will know how to proceed. She manages the child with kindness.

One approach she uses is to turn the child's head to one side and hold it with one hand. She uses the other to press at a particular point on the child's torso. The child's knees come up and he rolls to the side. In another approach she initiates rolling by bringing one leg up and over the other held straight. She began the session with some relaxation exercises and was careful to practise rolling to both sides from supine.

The parent is pleased to see some progress. The child has not been entirely happy with the explorations and has shed a few tears. At some point, in this session or a later one, the therapist will suggest how this new rolling skill could be practised at home.

[PLEASE NOTE: In very vague terms I have described work that requires deep knowledge of motor development, of infant reflexes and of dangers to be avoided. I hope no one uses my crude outline as a guide to action. I am not a physiotherapist.]

An education approach to the early skill of moving on the floor

We are a fly on the wall now in part of a community children's centre, kindergarten or nursery. The child we are focusing on has the same motor issues as the child with the physiotherapist above. A teacher is observing the baby or infant who is lying on his back not doing anything in particular. She kneels at his side, talks to him very gently and holds a toy above him. It is a toy she knows he has responded to before so she talks to him about it and jiggles it so it makes its noise. She might even have a familiar song to go with this toy.

Seeing that she has got his attention, she slowly puts the toy on the mat to his side. The child shows he is excited now and seems to be trying to turn his head to see where the toy has gone. Still talking or singing to him, she helps him roll with gentle pressure at his shoulder or hip. Once on his side he looks at the toy and she helps him touch it with the hand that is uppermost. There is much praise and excitement. She returns him to his back and then plays the same game going to the other side.

Quite soon, they both decide the game is over and she changes the activity to something less demanding. When she gets an opportunity she will show the child's parent what they were doing because rolling to the side is something new which he might do again at home (if he is not already doing so). The teacher makes a note of the child's response intending to discuss it with colleagues. She wonders if she was helping him in the right way.

Discussion

Now that I have used two imagined scenes placed at opposite ends of a spectrum, many readers will jump to the same conclusion as me that it would be ideal for the two practitioners (paediatric physiotherapist and teacher) to join their knowledge, skills and experience in a joint effort of collective competence – and including the parent who knows so much more about the child. Staying with the ideal, this should happen in an education setting to avoid as much as possible the busy, neurotic and morbid mind sets and atmospheres in general hospitals. The physiotherapist's support would probably be intermittent rather than being with the child as regularly as the teacher is.

To reinforce my argument, I will compare and contrast the two approaches. The child in the hospital session will be Child A and the child in the education setting will be Child B. There is no reason why they cannot be the same child. For simplicity, practitioners are female and children are male.

Both practitioners are motivated to help the child using their care and skills. Both will try to share all or some of these skills with the parent so they are better equipped to bring up their child.

Child B is helped in the education setting that is part of his normal life. Child A has had a journey to hospital that has disrupted normal feeding/ sleeping/ playing routines. Child and/or parent might be nervous and apprehensive in the hospital environment and consequently unable to make the most of the session – or even react against it.

The therapist with Child A might feel that a few tears are inevitable and will sensitively continue the work. The teacher with Child B might want to avoid tears as much as possible and will take comforting a crying child as a priority. It is possible that Child A's tears come in part from the strangeness of the environment and/or is picking up the parent's feelings.

Child A was a patient fitted into a planned treatment slot of fixed duration. There is pressure here for the therapist to make the best of the time available. Child B is in a familiar environment with familiar child-centred routines and is relaxed. He is more or less available for un-forced interactions with staff members depending on many factors including tiredness, mood...

Both practitioners know the child's development and learning so far and can judge readiness for new learning. It is possible the therapist had set a rolling-to-the-side target before the session or even at the end of the previous session. The teacher had no such target in mind. She initiated the rolling game spontaneously when the child looked at the toy and some instinct made her move the toy to the side.

Therapist and Child A might perceive the rolling activity as an exercise, while teacher and Child B saw it as a game (but, for the teacher, of developmental significance).

The teacher was aware of Child B's pleasure/displeasure, attention, interest, motivation, vision, hearing, preference for a particular toy and, perhaps, of an emerging skill of touching the toy with his hands when in an appropriate position in which he could see both toy and hands. All of this came into the game. At the most basic and clinical level, the therapist might have focused only on Child A's motor activity. (I have seen this basic clinical approach but I assume it is rare. On the other hand, any parent who tries to learn from videos on the internet will probably see this clinical approach to rolling.)

Both of these activities could have been in the child's home with practitioners doing home visits.

I hope this comparison helps justify my ambition for early child and family support to move out of hospitals into education settings and for a child's on-going development and learning to be considered an education issue rather than a health issue. I acknowledge I have described two opposite ends of a spectrum without describing what happens in the middle where perhaps, therapy becomes less clinical and, regrettably, teachers are less whole-child in their knowledge and skills.

PART 3: Joining therapy and education – an early personal experience

I would not be writing this ‘Positive environments for early child and family support’ essay if I did not have strong views on these issues so perhaps it is appropriate to show how these views began to develop. For this I need to go back to the early 1980s. I had recently moved from a London-based campaign to get people out of institutions and had a space to fill while deciding on a career direction. When I applied to the local education department for a temporary teaching post they sent me to a special school for children with health conditions and physical disabilities on the basis that I had a post-graduate qualification in special education. The job was for a second nursery teacher.

Some history of education in England will help. Prior to 1970 children with significant intellectual difficulties were labelled ‘mentally handicapped’ or something worse and deemed ineducable. Instead of going to school, they were sent to training centres run by health services. This harsh attitude gradually changed and government legislation[11] afforded them the right to go to school where they would be taught by qualified teachers. Following this, the recommendations of the important Warnock Report (1978)[12] were enshrined in law in 1981 saying that children with special education needs should, whenever possible, be included in mainstream schools. Different sorts of special schools would cater for children with long-term complex and multiple disabilities. Included in these were special schools for children with *moderate*, *severe* or *profound* learning disabilities (crude labels I have never come to terms with).

This PH (physical handicap) school to which I was directed catered for children up to school-leaving age whose intelligence was in the normal range. The population included those with heart conditions, respiratory problems, muscular dystrophy, metabolic disorders, birth defects caused by thalidomide, etc. They were a mixed bunch in a very happy and settled school with teachers who, as far as I could see, did not impose ceilings on any child’s progress. The school belonged to the local education authority and was a relatively new building with plenty of light and space. Class sizes were limited to 12-15 children with one teacher per class. There was a nursing team and a therapy team but no psychologist, social worker or home-liaison worker. Children were removed from their classroom for therapy and medical attention in another part of the building.

The situation I found in the nursery was of two groups of young children. The larger and well-established group were typical of the rest of the school population. A smaller group, entering the school quite recently in post-Warnock conditions, might otherwise have been admitted into schools for children with learning disabilities. Perhaps someone had raised questions about the intellectual capacity of these children and so they had been sent to this PH school. They had physical conditions including cerebral palsy, known genetic syndromes and other conditions with no label. I am sure these children, because of their levels of general functioning, would have been deemed ineducable in the recent past. Each of these children had what I now term a multifaceted condition. I learned in time that no effective early child and family support had been provided.

Nursery staffing comprised a teacher (two after I arrived), two NNEB (National Nursery Examination Board) nursery nurses and two bathroom assistants. It was a harmonious team under the leadership of the first teacher. One nursery nurse felt that the new children were not appropriate admissions while the other was warm and accepting.

There was no established curriculum for this new intake and teacher and nursery nurses by their own admission were out of their depth. These children arrived by taxi or school bus, were carried in and laid on bean bags because there was no nursery equipment for them. They were much more patients than pupils. They soon came under my wing as the new teacher with valid experience. This temporary post stretched into months and then years and I was able to achieve the following by working collaboratively with the other nursery staff, nurses, therapists and parents:

- The children stopped being *patients*. They were increasingly involved in games, social activity and learning. Their personalities were recognised, hidden potentials came to light.
- Each child was eventually equipped with a tailor-made nursery

chair with the voluntary input of an unemployed carpenter. Once a child was promoted from bean bag to chair and table they were seen in a new light. Now they could be with the other children for snacks, mealtimes and going-home songs.

- The main body of children had a morning story-time as a group. The new group had so far stayed on their bean bags for this on the periphery. With help of nursery nurses I made a group of these new children with activities including responding to their name, smiling, looking at me, looking at another named child, moving hands, handling a teddy or toy, listening for their name in a song, expressing some sort of *yes* and *no*, making simple choices and so on. I worked/played with each child individually or in pairs at other times of the day. I spent a lot of time on the floor with the children to the surprise of other staff members.
- As each child showed new understanding and skills, their parents were invited in so they could see what their child was doing and for an exchange of observations and information – the start of a home-school relationship.
- In most cases this opened the way for me to visit the child at home. This was always a rich and rewarding experience.

My central point is that as a teacher I could not on my own create good positions for drinking, eating, listening, use of hands, hand-eye co-ordination. Nor could I create activities to promote head control, moving on the floor (rolling, crawling), alternative communication including a form of *yes* and *no*, making choices, etc. All of this required collaboration with therapists and, when necessary, nurses – as did the design of chairs and other home-made postural aids. An early part of my work was to build trusting relationships with these colleagues and to bring them into nursery activity instead of them seeing children in their clinical rooms. It is fair to say that these new children were largely an unknown quantity to the nurses and therapists so we were all learning together, with me supplying the education impetus to lift the children out of patient mode.

The transdisciplinary Team Around the Child approach was evolving here as was my deep respect for health professionals and the need for respectful collaboration in horizontal teamwork. I also learned lessons about the value of home visits and the need to respect parents and keep them fully informed and involved. The principles I established for myself then and which have informed my later work include:

- Seeing a child as a patient at home or in school and treating them as such is not conducive to development and learning.
- No single person is competent to offer a whole approach to a child who has a multifaceted condition.
- Collaboration is essential between educators, health workers, parents and others as necessary.
- Each person's skills are to be respected. Collective competence is created when all join together around each individual child.
- Teachers cannot function with these children without this teamwork. Collective competence must address play, learning, posture, communication, cognition, dexterity, eating, drinking, sleep, nutrition, oral hygiene, constipation....
- When, using collective competence, a child is being encouraged, for example, to move on the floor to reach a toy, it is impossible to say which part of the activity is play, which part is therapy and which part is education. With these children, all firm boundaries are dissolved between education and health and between teachers and health workers. A child's natural activities transcend these labels.

In conclusion

Although new legislation had provided school places for children with intellectual difficulties, there was still a strong tendency, as I found, for some children to be treated as patients. The theme of this serialised Positive Environments essay is that children of any age should be treated as learning children, a major part of this being to avoid offering early child and family support in hospitals and clinics as far as possible.

Chapter Three

Prospects for offering effective integrated early child and family support to all families

Offering effective integrated early child and family support to all families who want it must be the aim in any country if we want to move beyond projects supporting only a limited number of children and families. There is no logical reason for supporting some families in any city, region or country while leaving others who want help to cope on their own. But this selective approach is happening everywhere. This chapter addresses major barriers to progress with suggested ways forward under five headings:

- Out-dated institutional attitudes and medical conservatism
- General prejudice and discrimination
- Families as an oppressed minority group
- The common failings in top-down reform
- Local early child and family support task forces to accelerate the pace of change

Out-dated institutional attitudes and medical conservatism

In the UK there has undeniably been in my lifetime a prevalent attitude in public services that ordinary people should passively take what they are given and be grateful for it. The great majority of people have not been accustomed to argue with administrators or to challenge the views of professionals. At worst, people who ask questions have been labelled as trouble-makers. Institutional attitudes were covered in *Bringing up babies who have very special needs*[5], pp 85-86. The following is an abbreviated version:

> '...we can see outdated support...and the prevalent attitudes within traditional agencies as a halfway point between institutional care and a sensitive respectful approach that fully recognises the rights of children and parents. My reasons for this...include the following:
>
> - Parents are suddenly involved with agencies in processes they have not actively opted for over which they have no control.
> - Parents...can [be]...patronised, criticised and disempowered... [while]...in crisis and needing sensitive support.
> - Babies and infants can be subject to medical procedures that take little account of pain or levels of anxiety.
> - When interventions are planned, there might be no thought given to child-parent bonds of attachment.
> - Parent and child might have to travel to a variety of places for treatment sessions. [Often]...to meet agencies' needs with no thought given to the family's time pressures and tiredness.
> - Attending appointments can be a drain on family finances because of travel, parking, eating out and child care.
> - Appointments...might [give no]...thought to child's comfort, quality of life...routines for feeding, sleeping and playing.
> - Babies and infants can be parked on waiting lists so that 'early' intervention comes later and later.
> - Practitioners give themselves importance they do not give to parents...they want their own understanding and skills to be respected, [but]...do not respect what parents know and do.
> - New parents find themselves having to share their parenting role with practitioners in partnerships – as inferior partners.
> - Support for babies and infants' education can be offered primarily in clinical treatment sessions though the actual need is for a combined medical, educational and play approach.
> - Babies and infants' need for natural learning in everyday

> activities is given secondary importance to goals set by practitioners in their clinical environments.
>
> - Parents can be asked to continue therapy at home in conditions that are not ideal and with the spoken or unspoken threat that not to do so will disadvantage the child.
>
> I am not suggesting any agency or practitioner wants to be cruel to children or parents, but there can be a prevalent institutional medical hangover that we need to become aware of and address.'

The fact that early child and family support, whether a well-organised system or a piecemeal arrangement, commonly has a strong medical input can significantly add to any institutionalisation in the support for children and families. There are two elements to this.

Firstly, the medical world of doctors and hospitals is a powerful institution that can influence our birth, health, wellbeing, reproduction, mental states, dying and death. In general, citizens rightly value the medical world, have an instinct to trust it and a reluctance to set themselves against it for any reason. Secondly, paediatricians, alongside neurologists and other hospital paediatric specialists, are probably the most highly trained and highly paid professionals many ordinary people are likely to meet and have regular contact with. They hold great power and authority and, socially, inhabit a world very different from most people.

The medical world is not given to fads and fancies. Instead, it strongly clings to its history, traditions and tried-and-tested approaches. It is a conservative institution that protects its systems and its personnel and offers great rewards to its senior staff members. I have always been aware of the term *medical arrogance* and have sometimes seen it at work in TAC meetings, but the conservatism of the medical world is much broader and deeper than any particular medic's professional style. The character of the medical world can present formidable challenges to people arguing for radical change in early child and family support. But I must finish by saying I have worked alongside many medical people of great sensitivity striving to improve support for the children in their care.

General prejudice and discrimination

As the task is to improve early child and family support within cities, regions and countries, it might be helpful to consider how their citizens regard these children and families. Social change in any democracy is dependent on prevalent attitudes and perceptions of the general public.

Disability is generally perceived as a negative. This is not surprising because the word itself means a lack of something. My Chambers Dictionary defines the word as *lack of power; lack of legal power or qualification; a difficulty especially physical* so it is not surprising that social reformers choose other more positive words in its place. But, so far, the general public do not and the negative view of people labelled as disabled leads to widespread discrimination in education, health, employment, law enforcement, etc. so that disabled people can find life an unequal struggle at school, in or out of work, in their neighbourhoods and in their social and sexual pursuits. At worst, discrimination can lead to a life of poverty and bullying with deep feelings of fear, rejection and loneliness.

There is no cushion preventing these negative attitudes impinging on babies and infants who have been medically labelled at the beginning of their lives as being disabled. Many parents and siblings speak of suffering discrimination themselves as a result of the new child's diagnosis. None of this inspires optimism that the general public is likely, as things are now, to demand improvement in early child and family support in their locality or that it will eagerly support any new allocation of public money at the level required.

I have made some generalisations here based on my own long experience in early support. I am aware that very many people of all ages labelled by themselves or others as disabled lead entirely happy, productive and fulfilled lives.

Families as an oppressed minority group

It is valid to describe families of these babies and pre-school children as a severely oppressed minority group. They can suffer prejudice and discrimination, have to struggle to survive with inadequate resources, are financially impoverished, socially isolated and, typically, sleep deprived. Study, work and careers are interrupted or terminated. Family members' mental health and the new child's bonds of attachment are put at risk. These harsh conditions impact negatively on everyone in the family.

In very many, or most, countries there is legislation catering for the educational needs of children of school age. In only a very small minority of countries is there legislation that considers the needs of babies and pre-school children who have significant challenges to their development and learning or that considers the needs of their families. An important consequence of this is that there are no official bodies to appeal to when early support is inadequate or absent. Families in most countries must thrive, struggle or sink without government intervention. The stark choice for parents when support is absent or inadequate is to put up with it or go into battle without any sort of official recognition or help. Is this true where you are?

When we look for causes of this oppression, we see a group of families in all countries that largely exists outside of public consciousness and whose struggles and triumphs are not reported in press and media, not researched or helped by academics in their local colleges and universities and not recognised by their elected political representatives.

For a variety of reasons, the general public might rarely or never come into contact with families whose baby or infant has significant challenges to development and learning. This can be because:

- the child is in hospital for periods of time and then has frequent visits to outpatient departments – all keeping the child away from the normal childhood places
- parents are physically unable or nervous about joining other families in mother and baby groups, playgroups, etc.
- a child's special buggy and the medical equipment some children have with them make people nervous of approaching and starting friendly conversations
- parents' tiredness, low self-esteem and stress result in them keeping themselves to themselves

When the medical world attaches the word *disability* to a new child then the child and family can be subject to the prejudice and discrimination that people who have physical, sensory or mental impairments might suffer at all ages. At worst, this might bring a dismissive response from the average woman and man in the street when they hear about the plight of these families. While oppressed people can and do struggle, more or less effectively, to improve their conditions, parents in this oppressed minority are probably too tired, too busy and too impoverished to fight campaigns. Also, the preschool years pass very quickly, after which parents might then be in a long struggle for effective education! When the general public and civic bodies are not aware of a minority group in their locality and are not witness to their joys and struggles, we should not be surprised that public money is not channelled in their direction to fund effective integrated support.

I am aware, though, these families are not usually described or thought of as an oppressed minority group. A common and more or less dismissive attitude is that fate has given each individual family a very unwelcome challenge that most of us would never expect or cope with. These families are not usually considered collectively as a social group deserving of serious political or academic attention. The merit in talking now about oppression of a minority group is that we can move the discussion towards the rights of children and the rights of families. When those rights are established in a city, region or country they can be evoked to help remove elements of oppression – discrimination, poverty, isolation, lack of support, etc.

The common failings in top-down reform

It is always tempting to believe that if we influence policies at the top of local and national governments and at the top of public agencies and non-government organisations, then new policies and improved practice will inevitably filter down to the children and families who need early child and family support. There is some logic in this top-down approach because the people at the top can establish policies, have authority over people lower down in the hierarchies and can allocate resources. The people in these very senior positions are undoubtedly powerful, yet there can be three pitfalls in this approach:

- Policy and practice can be perverted and distorted in the filtering down.
- The new work survives for only a short time.
- The new work does not spread out horizontally at the grass-roots to embrace children and families beyond the limited scope of the initial new initiatives or pilot projects.

Being aware of the limitations of the top-down approach can encourage us to consider other approaches and, when we use a top-down approach, show us what safeguards we must build into it.

How policy and practice can be perverted and distorted in the filtering down

It is unlikely that senior people at the top of our vertical organisations can share the same long-term commitment and passion for improved support for these children and families that we find at the grass-roots. This is inevitable. While they might initially give everything to a new initiative to build or reform early child and family support, they will have other pressing challenges on their desk next week or next month. The same will be true for managers lower down in the hierarchies. These middle managers who have the responsibility to pass down the new work will have varying levels of passion, commitment or enthusiasm and will accordingly vary in the amount of time, energy and resources they want to devote to it. The same must be true for the practitioners at the grass-roots who work with children and families. Each will have attitudes about the new policies and practice and views about the benefits or challenges they bring to their present way of working and to their professional standards.

Emotions have their part to play too. Effective integrated early child and family support relies on teamwork that relies in turn on a high level of honesty, trust and respect between colleagues. The filtering down process can founder here when practitioners do not yet have the required personal skills for genuine teamwork.

Sadly, perversion, distortion and delay in enacting new policies at the grass-roots can happen even when the new policies come in some sort of legal framework.

Why new work might survive for only a short time

New systems for a city, region or country's effective integrated early child and family support are likely to be fragile and might eventually succumb to one or more common threats. This can be because:

- ministers, managers or practitioners lose their initial enthusiasm and commitment
- initial funding comes to an end and no new sources are found (as very often happens to pilot projects)
- the plight of another group of people in need comes to the fore and takes precedence over the children and families we are discussing here

Why the new work might not spread out horizontally

The only valid intent must be to offer effective integrated early child and family support to all who need it in each city, region or country. There is no logic or fairness in restricting the effort to only a limited number of families. By this logic, each new initiative must have two phases:

- Firstly, to establish a new system for a first group of children and families.
- Secondly, to roll successful work out horizontally across the city, region or country.

This second phase presents very different challenges from the first and is often neglected. The first phase can be seen as the easy part and is counted as a success when a number of families are helped. The official reports and press releases will reflect the achievement with new benefits brought to these families but, at the same time, fail to mention the number of families who have not been helped and might never be. Arithmetically, it might be that of the children and families who need the new work, only 10%, 5%, 1%, 0.1% or 0.01% or fewer have been helped. The second phase is very important indeed but might be neglected because it does not have all the glamour and excitement of the first pioneering project. But in fact, it is only the second phase that justifies the energy, time and money invested in the first.

An example of a failed top-down approach was the work Interconnections did with the UK government. The then Labour government set up an innovative nation-wide Early Support[13] project early in the 2000s and involved Interconnections in a minor way in its planning and promotion. TAC became part of the new government guidance for supporting babies and infants who had multifaceted conditions. In very many localities, TAC became commonplace with the appointment within public services of *TAC Co-ordinators*, a new role to oversee local TAC development. Very sadly, Early Support came to an end in 2015. First of all the 2008 banking crash meant local authorities were now starved of the cash they needed for new initiatives and the project gradually ran out of steam as the Labour government changed to a Conservative government in 2010. My impression is that the new government under David Cameron as prime minister did nothing to help keep the Early Support project going despite the Cameron family having an infant son with very significant disabilities.

This is a personal and very brief account of the rise and fall of UK's Early Support project. From my perspective its very welcome focus on babies and infants and their families has since been lost. The story shows what can happen when there is over-reliance on government authority and resources. The great advantages can disappear as soon as one government gives way to another in the democratic process. The Early Support project was too short-lived to create lasting cultural change despite all the good work that happened within it.

Local early child and family support task forces to accelerate the pace of change

I have talked of personal frustration in how slowly effective integrated early child and family support is being implemented since I started working in this field half a century ago and since Team Around the Child was first published twenty years ago. While some localities in some countries are moving very slowly towards effective systems, others appear to be static or regressing and some have no systems at all. This was the problem at the beginning of this century and has been made worse since then by the number of children orphaned and/or damaged and traumatised in conflict zones, by the number of families displaced by turmoil in Iraq, Syria, Afghanistan and other countries and by growing populations of people moving, perhaps because of climate change, to places where they have a chance of finding water and food. It feels that children who have a nurturing family life, adequate nutrition, a stable home and mental health could be becoming the exception. Many cities, regions and countries that are already struggling to develop early child and family support must, in their planning, cater for significant numbers of families moving in on a temporary or permanent basis.

In the previous pages of this book I have suggested many features that I feel must be built into early support that is being newly established or enhanced. But these changes need favourable conditions some of which lie beyond the powers of local parents, practitioners and managers. I am never sure how significant and lasting social change happens but I suspect it largely lies beyond the powers of politicians who are often elected for only short periods of time.

If we discount politicians and chief executives in public services as reliable proactive catalysts for reform of early support for children and families, then it seems to me we have to look for some form of grass-roots activism in which parents are not left to campaign on their own. This leads me to the idea of local early support task forces which I will define for now as follows:

‘A local early support task force will be independent of, but in a

> constructive relationship with, local authorities and will work to improve the local early support system or, if there is not one already, to establish a new effective integrated early child and family support system. Membership and activities will reflect local conditions. Parents and other family members will be at the core alongside local practitioners who are in close contact with families and have a deep sense of the need for reform. In addition there can be people from local academic institutions, caring activists and others with campaigning experience.
>
> Each task force's main work will be to build constructive dialogue with executives and managers in public services, with local politicians, press and media, colleges and universities and with other local voluntary organisations and campaign groups concerned for people of any age who have impairments. The purpose of this outreach is to make the unmet needs of children and families known and to recruit support for change.'

I hope readers can envisage some sort of early support task force in their own locality. I outline below possible task force activities to build effective early child and family support and to counter some elements of oppression but in doing this I am aware that, once a new task force comes into being and the local situation is acknowledged, it will be obvious where it needs to focus its energy and creativity.

Parents, siblings, grandparents, and other family members would be representative of local families. They might no longer have pre-school children in their families but are committed to improve support and have the necessary time and energy to be activists in this cause. Practitioners know at first hand what local families experience and want to support parents in fighting for change knowing that parents and family members cannot campaign effectively on their own. Parents and practitioners have different backgrounds, experience and knowledge and can take power with each other from this broad base.

My definition above has referred to caring activists. In *Caring Activism: A 21st century concept of care*[14], caring activism is described as a secular concept of care for vulnerable people of any age who are struggling with ineffective support or with no support at all. Caring activists can befriend vulnerable people, provide practical support and advocate for change.

I was also careful to include people from local colleges and universities because, in my view, academics carry a responsibility to support effective integrated early support which they have not yet taken up. This view is included in *Integration made possible*[15]:

> 'It has never seemed logical or fair to expect practitioners to settle easily into joint working arrangements when they have had no experience of it or preparation for it in their university or college courses... Relevant professional training would: encourage practitioners to see the whole picture of a person's condition and situation in addition to the more focused concern their discipline requires; offer a Systems Theory[16] perspective emphasising interconnections and interdependence; provide opportunities in lectures and projects to mix with people on other courses to learn about their studies, concerns, practice, ethics, etc.' p 115

I do not imagine any two early support task forces being the same in how they come into being, how they are composed or what they focus on. Also, each might choose an alternative name to *task force*. But it might be helpful if I describe in hypothetical terms what a local task force might achieve as follows.

Collecting local information as a starting point

This will launch the evidence base. It will build up over time and should include a summary of unmet needs of children and families and of good practice from local agencies and services. Real stories, written or filmed, about children and families, positive and negative, will be valuable when approaching people and organisations for support. Support from academics would be valuable in collecting and presenting this information. A crucial part of this research is to find out if there is any government legislation or guidance focused on babies and infants who have significant challenges to their development and learning and/or focused on support for families.

Avoiding reliance on the top-down approaches

The initial impetus for change might come from frustrated parents and practitioners forming a local task force. It might be from senior people starting a top-down process and wisely deciding to help promote a grass-roots task force in a combined top-down and bottom-up effort. A major role for the task force in this will be to keep a strong awareness of the dangers inherent in top-down approaches and argue to build effective antidotes into the planning.

Countering oppression

No local task force should expect to achieve this fully but each could usefully address particular elements of families' oppressed situations. For example, financial impoverishment would be explored, acknowledged and talked about in press and media. The evolving early support system could provide support and information about benefits and debt management, could design an approach to help employees secure more flexible work arrangements to allow for care and hospital visits and could support students of any age seeking more flexible course arrangements so their studies do not have to be terminated.

Reasons can be explored when social isolation is a significant issue for local families with an effort to remove barriers that discourage or prevent family members of any age taking part in social activity. This will include helping local groups, organisations and facilities to be more aware of this group of families and learn how to welcome their members and accommodate to their needs. Local siblings who are becoming or have become carers are a group deserving of all possible help in this.

When exhaustion is an issue for local parents, they can be surveyed to find common factors. Helpful approaches might then include helping service providers create new systems that rationalise appointments in terms of repeat visits, distance of journeys, etc.

I do not need to write a long list here. Activists in a local task force knowing local families, being aware of local resources and being motivated by an urge for change will be inventive, brave, creative and forceful far beyond the limits of what I can say here to counter elements of oppression. While individual children and families will be helped along the way, the main purpose of each task force is to help build an effective integrated early child and family support system in which common elements of oppression are anticipated and addressed.

Encouraging and supporting local education services to be involved

This effort will depend on the present level of involvement. If the local education services are aloof from babies and pre-school children then there will need to be a prolonged campaign to show their senior people and elected officers what the unmet needs are and how education could be brought to these children in practical terms.

Where there is some involvement of education services, then this can be reviewed by the task force to evaluate how babies still at home are supported, the level of inclusion in nurseries and kindergartens, the involvement of specialist teachers (for example in sensory loss and autism) and the skill levels of education practitioners in helping parents learn how to support their child's attachment, development, learning, quality of life and self-esteem.

Countering institutional attitudes

This will no more be a quick local campaign than would be ending oppression, countering prejudice and discrimination or adjusting the balance between health and education supports. The champions in this are surely family members who will speak from the heart of their real experiences from birth (or conception) onwards. They can speak of the support they expected to receive, the support they did receive and their hopes for families following in their footsteps. They will speak about attitudes, emotions and humanity. They will speak of what helped them, what did not help them and what set them and their child back.

The methods can be seminars, workshops, conferences, residential weekends and any other ideas for getting family members, practitioners and managers into the same space to listen and talk to each other. Perhaps practitioners in the taskforce, or others with necessary skills, will facilitate these exchanges so that strong emotions are given appropriate space at the same time as allowing constructive conversations.

Countering prejudice and discrimination

This means reaching out beyond the small world of children who have significant challenges to their development and learning to the big world of each city, region or country's general population. Effective relationships between each task force and the local press and media will be essential. There should be regular press releases about all aspects of the task force's work, human interest stories describing some of the joys and frustrations of families and articles that relate current affairs, democratic issues of the moment and new official guidance or legislation to this small oppressed population of children and families.

There can be valuable co-operation here between the task force and local organisations and campaigns focusing on people with disabilities and perhaps established by disabled people themselves.

When there is a combined top-down and bottom-up approach with elected officers and senior people at the top of local services working in collaboration with a grass-roots task force, there will be many rich and productive opportunities for sharing information, getting messages out to the bigger world and supporting each other's efforts and initiatives. Successes, small or large, will come directly from the commitment, energy and imagination of task force members. The task force's drive for reform might even filter up through elected officers, press and media to influence discussion at national government level.

As I write, there is a story on a different subject developing in the national press and media in my country. It is about racial discrimination in

English cricket teams and has burst into public awareness quite suddenly with a persecuted player giving a witness statement to a government committee. Amazingly, press and media coverage has almost equalled that given to two major events happening at the same time: COP 26 in Glasgow and the UK government's failed attempt to disband a committee that had exposed the corrupt activity of one of its own members of parliament.

I take encouragement from this unexpected exposure of serious oppression that had up to this month (November 2021) remained hidden, having no great interest to the general public, press, media or government. I do not feel competent to analyse how oppression that had long bubbled under the surface so quickly gained widespread attention. But I am sure one factor was the detailed personal story of one well-known cricketer subjected to prejudice and discrimination that was then followed by other players coming forward to tell their stories. I am sure this will result in permanent reform of the game.

It will be a giant step forward if there can be this sort of exposure of the oppression suffered by the families considered in this book. Local early support task forces can work to expose oppression of families on their patch and hopefully one day the stories will add to a reform momentum.

Chapter Four

ZEN
in the Team Around the Child approach

This essay was inspired by Satish Kumar's book *No Destination*[17] in which he describes his journey as a monk around the world to talk peace to the nuclear powers. His simple approach, with his companion, was to walk everywhere without travel plans or money. In the same spirit, but on a very different level, I have always believed that when supporting children and their families we should keep everything as simple, human, direct and straightforward as possible. This essay is an attempt to describe how the Team Around the Child approach avoids all unnecessary confusion, division and compartmentalisation and works to protect families from the seemingly inevitable bureaucracy and complexity of public services.

*

We can use the word *Zen* in two ways. There is the Zen of the Japanese tea ceremony which can be practised by people in all walks of life. Then there is the Zen of a monk in deep meditation on the absolute. This essay uses Zen in the first of these two meanings with characteristics that include simplicity, gentleness, harmony, reverence, humility, integrity and the taking of great care.

In pursuit of Zen, I am going to focus on wholeness, striving for clarity and simplicity by eliminating unnecessary complications and fragmentation. There is the wholeness of families, the wholeness of each child and the wholeness of each child's multifaceted condition. To help each child gain new understanding and skills, there is the wholeness of early child and family support teams and the wholeness of their integrated approaches combining education, play and the work of paediatric therapists. Then there is the wholeness and naturalness of the child's learning in everyday family life.

This Zen perspective on care and support for babies and pre-school children who have very special needs allows me to put intuition alongside evidence-based practice and humanity alongside science. These young children are, in the majority of situations, brought up by their parents in family homes where laboratory conditions do not apply and in which family life cannot be reduced to data. How babies and infants learn is essentially a mystery before which we should stand in awe. There are no technical manuals telling us how to help each of these unique children learn. For these reasons, practitioners can combine best practice with humility, intuition and humanity taking what each child's parents know and do as the starting point when they asks for help.

The wholeness of families

Without being sentimental or naïve about the vast range in composition, caring and competence of families around the world, we can acknowledge that most children start in some sort of family life being cared for by one or more parents. Baby and birth mother are part of a first wholeness. This extends to embrace other family members within the close family. This whole family, in its entirety, must be the concern of people who come along to help the baby or infant gain new understanding and skills. This is for three reasons.

Firstly, when a baby or infant is found to have significant disabilities that will impact on development and learning, all aspects of family life can be affected. This includes relationships, work, study, leisure, finance, housing and resilience. Families can fall apart, belief systems can change dramatically and there can be overwhelming negative emotions. Asking new parents to focus on their child's needs for learning and development might not be realistic at first. Effective support for the family's immediate practical and emotional needs might have to be the priority.

Secondly, support for parents as they promote their new child's understanding and skills is best begun in the family home within the family and its natural daily activities. All children's first learning is in the activities of feeding, bathing, nappy/diaper changing, moving around the room, managing clothes, playing, socialising and bedtime. Some clinic sessions outside the home might be necessary but activities here are in danger of not appearing relevant to child or parents. Also, the child might feel unsafe in the clinical environment and therefore not ready to learn.

Thirdly, we must consider new children's growing attachment to parents and other family members. Our social and emotional life as children, teenagers and adults is influenced by our early attachment or the inadequacy of it. Each new child with very special needs and their family members need calm, unhurried quality time with each other for bonds of attachment to grow. Practitioners who get in the way of attachment are sowing seeds of psychological ill health for child, parents and others in the family. Two steps to promote attachment are:

- Offering timely emotional support for parents and perhaps siblings and grandparents.
- Keeping appointments away from home to a minimum, reducing exposure of the new child to non-family adults with whom they are not familiar and eliminating non-essential home visits.

A coherent and sensitive pattern of support will preserve everyone's calmness, energy and patience and make space for stress-free quality time.

The whole child

Every child comes complete as a whole child. There is no exception to this. There is no such thing as *half a child*, *almost a child* or *not quite a child.* This wholeness is not diminished by a child's unique condition. Each and every child is deserving of love, care and respect. Each child has rights.

This is worth emphasising because some people will describe others as something less than fully human when discriminating against them or preparing to hurt them. Children and adults who have very special needs all around the world suffer discrimination. This influences their schooling, social activity, employment opportunities and sex life. These children are first exposed to prejudicial attitudes in babyhood and infancy. To counter this we must fully value each new child whatever their situation, condition or life expectancy.

The whole multifaceted condition

When supporting a new child's understanding and skills, we observe that abilities and disabilities interact with each other. When a child develops intention, attention, communication and dexterity in dressing and undressing tasks, these new skills will also be of benefit at mealtimes and in play and social activity. Impairment in vision will affect how a child learns to move around the room. Impairment of movement will affect visual perception and sense of space. There are no separate parts in a baby or infant. Practitioners who specialise in a single aspect of child development must use their knowledge in the context of the whole child's learning. When we simplify a child's plural diagnoses (of perhaps sensory, physical, intellectual and behavioural challenges) to a single unique multifaceted condition, we can develop a whole approach to learning. This avoids the fragmented approach that would treat a child in bits and the multiple-practitioner approach that can keep the child, parents and practitioners stressed and exhausted.

Whole teams

A group is different from a team. Members of a team work in relation with each other with shared trust and an agreed goal. If the people around a baby or infant who has very special needs are just a group of separate people there will be fragmentation, confusion and chaos with added frustration, exhaustion and stress for child, family and practitioners. When the main people caring for and supporting the new child (practitioners and parents) come together as a team around the child (TAC) they can build a whole picture of the child and family and of their abilities, strengths and needs. There can then be a unified plan of action combining what the practitioners know with what the family knows.

A whole approach

The TAC response to the child's wholeness and to the interconnections between the child's abilities and impairments is to integrate education, play and the work of paediatric therapists to help the baby or infant gain new understanding and skills. Members of a TAC gradually increase their ability to work with the whole child. Collective competence emerges with time allowing some reduction in the number of people who need to work directly with the child at any one time. The care and support becomes less complicated and more sensitive to the child and family.

The wholeness of learning in natural life

This brings us back to the family home and away from the clinic environment. Now education, play and the work of paediatric therapists can be brought together and focused on each family's daily activities of mealtimes, getting up and going to bed, dressing and undressing, socialising and playing. This is where most children achieve their first learning. Now child and parents can see the relevance of new understanding and skills, the child learns in natural situations, parents enhance their skills in bringing up the child and the family is strengthened. The child is just a child and not singled out as someone very different. The parents are just parents without having to be therapists.

Summary

This is my account of Zen in the care and support of babies and infants who have very special needs. It brings together separate elements of established good practice into a whole approach that I have used as a teacher and as a child-and-family keyworker. Keyworkers or *key workers* are a great asset in pursuit of wholeness.

In *The Keyworker: a practical guide*'[18] the keyworker is described as:

> '... Both a source of support for the families of children with disabilities and a conduit by which other services, including treatment, therapy, education, respite and benefits, are accessed and used effectively.' p 13.

The approach I have described in this essay responds to the need children who have very special needs have for increased sensitivity, to the needs families have for respectful support as they bring up their children and to the need practitioners have for flexibility in their pressurised work schedules.

Notes

(All websites checked at the time of going to print.)

1 **Links to the four articles:**

'Positive environments for early child and family support'
https://www.tacinterconnections.com/index.php/allnews/developmentsintreatment/3377-positive-environments-for-early-child-and-family-support-part-1-hospitals-are-often-neurotic-environments-and-are-therefore-to-be-avoided

'Team Around the Child (TAC) Principles'
https://www.tacinterconnections.com/index.php/allnews/developmentsintreatment/3511-team-around-the-child-tac-principles-part-one-people-around-the-child-should-talk-to-each-other-translate-this-article-if-you-wish

'What is the best way to promote early child and family support in a city, region or country?
https://www.tacinterconnections.com/index.php/allnews/developmentsintreatment/3530-what-is-the-best-way-to-promote-early-child-and-family-support-in-a-city-region-or-country

'Families whose baby or infant has significant challenges to development and learning are a severely oppressed minority group.
https://www.tacinterconnections.com/index.php/allnews/commentopinion/3628-editorial-families-whose-baby-or-infant-has-significant-challenges-to-development-and-learning-are-a-severely-oppressed-minority-group-this-is-why-there-are-no-effective-support-systems-part-1

2 Early Child Development Task Force (ECDtf):
http://ecdtf.org/

3 TAC Bulletins:
https://www.tacinterconnections.com/index.php/allnews/tacbulletins

4 (i) Limbrick, P. (2001) *The Team Around the Child: Multi-agency service co-ordination for children with complex needs and their families.* Worcester: Interconnections

(ii) Limbrick, P. (2009) *TAC for the 21st Century: Nine essays on Team Around the Child*. Clifford: Interconnections

5 Limbrick, P. (2019) *Bringing up babies and young children who have very special needs*. Clifford: Interconnections

6 Limbrick, P. (2012) *Horizontal Teamwork in a Vertical World: Exploring interagency collaboration and people empowerment*. Clifford: Interconnections

7 Limbrick, P. (2017) *Early Childhood Intervention without Tears*. Clifford: Interconnections

8 Levitt, S. (1994) *Basic Abilities: A whole approach*. UK: Souvenir Press

9 Limbrick, P. (2018) *Primary Interventionists in the Team Around the Child Approach*. Clifford: Interconnections

10 Five propositions for de-medicalizing early child and family support in a radical redesign: https://www.tacinterconnections.com/index.php/allnews/developmentsintreatment/3483-five-propositions-for-de-medicalizing-early-child-and-family-support-in-a-radical-redesign

11 Education (Handicapped Children) Act 1970: https://www.legislation.gov.uk/ukpga/1970/52/enacted

12 The Warnock Report (1978) Special Educational Needs 1978: http://www.educationengland.org.uk/documents/warnock/warnock1978.html

13 The Early Support Programme is no longer on UK Government's website. Here is an historic local example: https://www.rbkc.gov.uk/children-and-education/children-and-family-services/early-support-programme

14 Limbrick, P. (2016) *Caring Activism: A 21st century concept of care*. Clifford: Interconnections

15 Limbrick, P. (2020) *Integration Made Possible: A practical manual for joint working*. Clifford: Interconnections

16 Capra, F. and Luisi, P. L. (2014) *The Systems View of Life: A unifying vision*. Cambridge: Cambridge University Press

17 Kumar, S. (1977) *No Destination*. Llandeilo: Mochyn Du

18 Limbrick-Spencer, G. (2001) *The Keyworker: a practical guide*. Birmingham: Handsel Trust and WordWorks

Relevant Links

(All websites checked at the time of going to print.)

Included here is a sample of established and new international thinking in child and family support. A larger collection of relevant resources can be found at:
https://www.tacinterconnections.com/index.php/allnews/tacbulletins
Various articles by Peter Limbrick written in the decade since 2011 can be found at:
https://www.tacinterconnections.com/index.php/essays

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Are you worried about your child? (Brochure in various languages):
https://www.tacinterconnections.com/images/Guide2-to-Support-Families-of-Children-with-Complex-Needs.pdf

Caring for kids new to Canada - A guide for health professionals working with immigrant and refugee children and youth:
https://kidsnewtocanada.ca/

Child Rights Connect:
https://childrightsconnect.org/

Children's Rights International:
https://www.childjustice.org/en/

Core care conditions for children and families: implications for integrated child and family services:
https://www.socialventures.com.au/assets/Core-care-conditions-for-children-and-families-implications-for-integrated-child-and-family-services-SVA-CCCH.pdf

Current Developmental Disorders Reports:
https://www.springer.com/journal/40474/

Developing holistic integrated early learning services for young children and families experiencing socio-economic vulnerability:
https://www.socialventures.com.au/assets/Developing-holistic-integrated-early-learning-services-for-young-children-and-families-experiencing-socio-economic-vulnerability-SVA-and-CCCH.pdf

Disability-related stigma and discrimination in sub-Saharan Africa and south Asia: a systematic literature review (Bhavisha Virendrakumar et al):
https://research.sightsavers.org/wp-content/uploads/sites/8/2021/05/Sightsavers-systematic-review-into-stigma-and-disability-FINAL.pdf

Dost Education - an innovative approach to supporting parents of young learners in rural India:
https://www.youtube.com/watch?v=8-3yU0gNEeg

Early Interventionists' Ratings of Family-Centered Practices in Natural Environments - Report (Tomeny, Kimberly R et al):
https://journals.lww.com/iycjournal/Fulltext/2021/10000/EarlyInterventionists Ratings of Family Centered.2.aspx

ECDAN (Early Childhood Development Action Network):
https://www.ecdan.org/

ECE (early childhood education) Accelerator Toolkit:
https://www.ece-accelerator.org/toolkit

Eurlyaid:
https://www.eurlyaid.eu/

Fatherhood Institute:
http://www.fatherhoodinstitute.org/

From consumer to partner - rethinking the parent/practitioner relationship (Tim Moore et al):
https://apo.org.au/node/313949

Grandmothers - a neglected family resource for saving newborn lives (Aubel, J): http://gh.bmj.com/cgi/content/full/bmjgh-2020-003808

GRDDC (Global Research on Developmental Disabilities Collaborators): https://www.under5disabilities.org/

Human Rights Watch: https://www.hrw.org

Illich, I. (1976) *Limits to Medicine*. London: Penguin

Inclusive Early Childhood Service System (IECSS): https://www.ryerson.ca/inclusive-early-childhood-service-system/about/

Institutionalising Parent-carer Blame: https://cerebra.org.uk/research/institutionalising-parent-carer-blame/

ICPCN - International Children's Palliative Care Network: http://www.icpcn.org/

Model For Early Years Family Intervention Supports: https://cerebra.org.uk/research/a-model-for-early-years-family-intervention-supports/

Mothers caring for seriously ill children at greater risk of serious health problems: https://www.togetherforshortlives.org.uk/mothers-caring-for-seriously-ill-children-at-greater-risk-of-serious-health-problems/

Parenting interventions to promote early child development in the first three years of life: A global systematic review and meta-analysis (Joshua Jeong et al): https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003602

Planiopolis: A portal of national education plans: https://planipolis.iiep.unesco.org/

Researchers and Parents - Better Together:
https://kidsbrainhealth.ca/index.php/2021/08/04/researchers-and-parents-better-together/

Sibling Support Project:
https://siblingsupport.org/

The Envelope For Curious Conversations To Evolve Family Practice:
https://theenvelope.commons.gc.cuny.edu/

The porridge-like framework: A multidimensional guidance to support parents of children with developmental disabilities (Provenzi L et al):
https://www.sciencedirect.com/science/article/abs/pii/S0891422221001979#!

UN (United Nations) Convention on the Rights of the Child:
https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

UN Convention on the Rights of Persons with Disabilities (CRPD):
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

UN Disability Inclusion Strategy:
https://www.un.org/en/content/disabilitystrategy/

UNESCO - United Nations Educational, Scientific and Cultural Organization:
https://en.unesco.org/

UNICEF - driving change for children and young people across the globe:
https://www.unicef.org/