

Early Childhood Intervention without Tears

Improving support for infants
with disabilities and their families

This is a companion essay to
TAC for the 21st Century: Nine essays on Team Around the Child
(Limbrick 2009)

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Improving support for infants with disabilities
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About the author

Peter Limbrick had a brother with cerebral palsy who was born a couple of years before Peter went to Liverpool University, UK to study zoology. Nicholas died at the age of forty from substandard care in a West Midlands NHS hospital.

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

From his One Hundred Hours experience, Peter developed and published the Team Around the Child (TAC) approach and has promoted this in the UK, Ireland, Sweden, Croatia, Canada and Australia. He has also developed the concept of Caring Activism to bring support from fellow citizens to vulnerable people of all ages.

Peter lives in the Black Mountains on the border between England and Wales from where he edits the online Interconnections News Service and its TAC Bulletin – both sharing information internationally, building knowledge and supporting teamwork around babies, children, teenagers, adults and elderly people who are disabled, marginalised or vulnerable.

Contents

Introduction	7
Chapter 1 The need for a new approach to early childhood intervention services	11
Chapter 2 History of the Team Around the Child approach	17
Chapter 3 Team Around the Child as a systems approach	23
Chapter 4 Team Around the Child as a multifaceted early childhood intervention system	33
Chapter 5 A reconfigured early childhood intervention service	41
Chapter 6 The reconfigured early childhood intervention service as a diagram with notes	55
Chapter 7 Getting started on a reconfiguration	65
Appendix	73
References and further reading	79

Introduction

This essay will suggest a new approach to early childhood intervention services to resolve particular problems that commonly arise in the way the services are presently delivered in many countries. In my view, this new approach represents a significant reconfiguration of early childhood intervention services that is necessary now to help parent-child attachment, afford proper respect to infants with disabilities and their families and protect and nurture the quality of life of children and families.

The impetus for this essay comes from my concern that early childhood intervention services can perpetuate two prevailing inappropriate assumptions. The first is that disabled infants can be treated very differently from typically developing infants with insufficient regard to their bond with their parents and to the quality of their childhood. The second is that parents and other close family members have to accept the inevitability of long-term stress, strain and exhaustion – often to the point that marital relationships falter, family members suffer physical and/or psychological illness and even that the family falls apart.

The reconfiguration I am suggesting here for early childhood intervention services is focused on infants who have a multifaceted condition – my preferred term for ‘multiple disabilities’. In my experience it is this group of disabled infants that most clearly shows the need for a new approach. This is because they can arrive with a bewildering mix of disabilities, often have extended and difficult times in hospital before they go home and might then receive fragmented and disorganised interventions for their various needs. Meeting the on-going needs for treatment and care of these children can make massive demands on their families.

There is no pretence here, though, that how any family adapts depends solely on the nature or severity of the infant's condition. But if we can get early childhood intervention right for infants with a multifaceted condition there will surely be benefits for all infants with a disability and their families.

My suggested new approach for early childhood intervention services has four major elements. They are listed below and then briefly described in anticipation of longer accounts in Chapter 5. The four elements are:

1. Reframing aims and ambitions of early childhood intervention services
2. Offering families of babies with disabilities a primary interventionist as the first approach
3. Fitting therapy and education programmes into natural activities of living and learning as far as appropriate
4. Helping families find a daily balance of higher-energy quality time and lower-energy quality time

Reframing aims and ambitions of early childhood intervention services

The aims and ambitions of early childhood intervention services for infants with a multifaceted condition can be usefully reframed by moving from the present predominant focus on the infant's development and learning to a dual outcome more respectful of infant and family and of their quality of life. In this new approach, success is perceived on a continuum and can be measured by the following:

1. Parents are gradually recovering self-esteem and confidence in their competence as parents and starting to feel they are again masters of their own ship. The family feels it has some quality of life and is moving towards a new version of their normal family life.
2. The child is settled in a nursery or first school. They have optimal opportunities for development and learning in natural situations at home, in the community as well as in the nursery or school.

Offering families of babies with disabilities a primary interventionist as the first approach

In the primary interventionist model within the Team Around the Child (TAC) approach, a single practitioner from the infant's TAC works closely with the infant and family. This is offered as the first support for new families and then the preferred model of support for particular infants and families in particular situations.

Fitting therapy and education programmes into natural activities of living and learning

Therapy and education programmes and goals are fitted as far as appropriate into the infant's natural daily activities of living and learning – mealtimes, dressing, changing, playing, etc. This takes away the requirement for infant and parents to do 'therapy sessions' in which parents must try to shift from parent mode to practitioner mode.

Helping families find a daily balance of higher-energy quality time and lower-energy quality time

As part of a considerate response to the stress, strain and exhaustion of infant and parents, practitioners support families in giving each day a balance between higher-energy quality time and lower-energy quality time. The former is for the natural activities of living and learning and the latter is for resting or for infant and parents just to enjoy being with each other and learning about each other – just 'being'.

The Team Around the Child (TAC) approach has been widely adopted in early childhood intervention services for infants who have disabilities. This approach uses close collaborative teamwork across professional disciplines and agency borders to support babies and young children who have a multifaceted condition. The suggested reconfiguration of early childhood intervention services in this essay maintains the focus on infants with a multifaceted condition and their families and is built around a strengthened TAC approach. I shall use 'TAC' both for the TAC approach and for an infant's individualised TAC team.

In writing the essay I have in mind people in countries, regions, cities or services who:

- are constructing their first early childhood intervention

service

- are considering adopting the TAC approach for their existing early childhood intervention service
- are already using the TAC approach and want to consider now to what extent their service helps parent-infant attachment, fully respects infants and actively promotes quality of family life

In using the term ‘parent-infant attachment’ in the essay, I acknowledge the bond can be between the infant and mother or father or another primary care giver. I am not suggesting that the infant can attach to only one person amongst their family and carers or that it can only happen at a particular time in babyhood.

While having in mind infants with a multifaceted condition, which can comprise some combination of physical, intellectual, sensory and other formal or informal diagnoses, I shall also refer to typically developing infants and draw comparisons between the treatment of both groups of children. An infant with a multifaceted condition can also have serious illness and/or limited life expectancy – all with implications for bonding, for respect afforded to the infant and for the family’s quality of life. My essay is intended to be relevant to support for this wider group of infants and families.

I sometimes refer to ‘therapy’ in this essay as shorthand to include therapy, education and play interventions to support an infant’s development and learning.

Because my suggested reconfiguration of early childhood intervention services is firmly based in the TAC approach and because not everyone is familiar with it, Chapter 2 offers an account of the evolution of its philosophy, principles and practice. This shows how TAC had its beginnings in the innovative work of a small independent charity called One Hundred Hours that worked with families in the UK in the 1990s. Chapters 3 and 4 present TAC in detail as a systems approach to early childhood intervention. Chapters 5 and 6 describe the suggested reconfiguration of early childhood intervention services and Chapter 7 offers ideas for moving forward. On page 56 in Chapter 6 is a diagrammatic representation of the reconfiguration. The Appendix has an account of a One Hundred Hours keyworker supporting a family during the first few weeks of a helping relationship that lasted several years.

1

The need for a new approach to early childhood intervention services

In this chapter I describe problems that can arise for infants and families while being supported by their early childhood intervention service. These include added stress and obstacles to parent-child attachment. Comparisons are drawn between treatment of infants with disabilities and those developing typically. Influx of refugees is posed as a new challenge and opportunity for early childhood intervention services.

Many challenges can arise for infants and their families as they receive support from their local early childhood intervention service – even when the service is well funded and has a full team of experienced and committed people. These challenges arise, in my view, when the service and its practitioners:

- pay too little attention to parent-infant attachment
- give insufficient respect to infants and to their families
- fail to protect the quality of life of infants and their families

The first year or two after the infant's disabling condition is suspected or confirmed, with or without the benefit of formal diagnostic labels, can be a gruelling time for the parents and the child. For the parents and other family

members, who might be experiencing mixed heightened emotions between joy and sadness, hope and despondency, the challenges to quality of life can include:

- upset, bewilderment, worry and confusion
- disrupted leisure, study and work routines for the family
- feelings of guilt: a parent might feel directly responsible for the child's condition. One parent might blame the other. One side of the family might blame the other side.
- a parent feeling disempowered in the face of so many 'expert' professionals and then feeling inadequate to the task of caring properly for the child
- an exhausting pattern of visits for assessment, medical treatment, therapy and case conferences in hospitals, clinics and centres and meetings about financial help, short-break services, etc
- home visits by various professionals, perhaps several each week, making the family feel the home is no longer a private domain and even that they are being observed and judged
- trying to manage all of this while deprived of sleep, worried about a downturn in the family finances, perhaps managing a deteriorating marital relationship and perhaps caring for other young children or teenagers
- home programmes from one or more well-meaning therapists and teachers. These 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' 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 the natural parental role to become a 'therapist' or 'teacher'.

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

All the above factors, each a serious challenge to quality of life of infant, parents and other family members, can also interfere with and impede the essential process of bonding between infant and mother, father or other primary care giver. This process might already have got off to a bad start if they were separated for a period immediately after the birth or if the baby stayed in hospital or a special unit while the mother returned home.

Bonding is hindered again if the infant's condition means that eye contact, cuddling, feeding, changing and playing are difficult to achieve. It can be that many of the normal baby and parenting activities are times of deep frustration, stress and guilt for the parent and unrewarding discomfort for the baby. Catching up on this parent-child relationship and trying to 'get over' the difficult times in hospital after the birth can be impeded or made impossible by the busy lives parent and baby have to lead, deprived of more natural and slower-paced parent and baby activity.

The result of all of these challenges can be that, while intending only to offer help and support, early intervention services in hospitals and community can inadvertently chip away at the child and family's self-esteem, resilience and quality of life from the earliest days. This is an untenable situation in early childhood intervention services that should instead be helping the family adapt to their new situation and helping infant and family members prepare for the countless challenges that lie ahead.

In this essay I want to draw a comparison between the common experience of infants with disabilities and of those developing typically and suggest that, in this light, our treatment of disabled infants and their families can be unnatural, extreme, and sometimes horrifying. It is my intention here to offer a reconfiguration of early childhood intervention services using a

strengthened TAC approach that fully respects disabled infants and their families and reduces these challenges to quality of life as much as possible.

In this suggested evolution of the TAC approach, I want to hold attitudes to, beliefs about and interventions for typically developing babies and their parents as one important standard against which to measure our intervention services for infants with a multifaceted condition.

In my experience, there can be a world of difference between the lives and experiences of a new family of a baby with disabilities and those of the same family months or years later. I have described a life for some new families characterised by upset, confusion, exhaustion and fear. Though there can be a natural strong disappointment and much unexpected disruption when the perfect baby does not arrive, it is wrong for anyone to attach all these negatives to the baby as though she or he is a tragedy.

As the family gradually adapts and the infant grows older, a time comes for most families when the child is no longer the focus of attention, when they have slotted into their place as a valued family member and as a valued pupil in nursery or school. Parents might feel older and wiser with much they are thankful for and perhaps recurring wistful thoughts of what might have been. These families would treat any comments about their child being a tragedy as misconstrued and offensive.

Accompanying a family on this journey, or at least on the first very important stages of it, can be an inevitable part of an early childhood intervention service. But whether the service assists the journey or impedes it will depend on how it is designed.

The journey will be different for those families whose baby or infant dies. There is still a journey but it continues without the child. One or more of the practitioners who worked with the infant and family might, if the family wishes, be able to continue supporting the family for a time. How well this works will depend on the quality of the helping relationship developed between parents and practitioners while the child was alive.

Early childhood intervention services in many wealthier parts of the world are facing a growing challenge from displaced people moving into their towns and cities. The world figure for refugees as I write is about sixty million. Half of refugees are children at the present count. This influx of refugees brings new populations of people of all ages to live with or alongside the existing population. Amongst these refugees will be infants

with disabilities as expected in any population. In addition there will be infants damaged physically and/or psychologically by the conditions their family has escaped from. Some of these incoming families will be properly housed, some will not. Some of the infants will be with their natural families, some will not.

While conflicts in Iraq, Syria and parts of North Africa are a major cause of the current refugee crisis, I do not think it is temporary phenomenon. In many parts of the world there is a gradual loss of usable agricultural land, reduced supply of water and, as a direct consequence, local strife, conflict and wars. Refugees fleeing these conditions will become a permanent feature in wealthier countries. This presents a challenge of adaptation for early childhood intervention services. Perhaps we should take this major displacement of people in recent years as a valuable opportunity to develop new approaches appropriate to changing populations in the future. The lessons we learn might also help develop effective services in low-economy countries.

2

History of the Team Around the Child approach

In this chapter I describe how the philosophy, principles and practice of the Team Around the Child approach grew out of the work of a small independent UK charity called One Hundred Hours. That organisation supported families of infants with a multifaceted condition during the 1990s. I also list published documents about One Hundred Hours and the TAC approach.

As an integral part of my suggested reconfiguration of early childhood intervention services, I am describing a strengthened Team Around the Child (TAC) approach – strengthened in terms of increased emphasis in practice rather than any changes to its philosophy and principles. But it does, nevertheless, amount to a step-change in the evolution of TAC and so it is appropriate to give an account of how the approach developed up to the time of writing.

The TAC approach developed directly from the work of the One Hundred Hours independent charity that offered, as a free service, a keyworker to families who had a new baby or infant with disabilities and, in some cases, serious illness. Some of these infants, often as predicted by medics, did not reach their second birthday. I took on the role of keyworker with the first few families in 1992. My previous work had included periods of teaching in schools for very young children with cerebral palsy and associated conditions. In that work I had come to feel strongly that

interventions for infants and support for their families needed to come much sooner. From that imperative came One Hundred Hours.

In retrospect, the major innovations explored and validated by One Hundred Hours were as follows:

1. We were child and family centred, worked mostly in the family home and were concerned for the child, for the parents, for any young siblings and for grandparents if they were on the scene.
2. We worked with each child as whole child and took an interest in all aspects of health, wellbeing, play, development and learning. We supported parents if and when they wanted to join a mother & toddler group or introduce their child to a playgroup or nursery.
3. We offered emotional support to parents and other close family members and when necessary signposted services and resources that could help them manage at home, get short breaks and family holidays and perhaps return to study and work.
4. We liaised as closely as possible with therapists and teachers who were also working with the child and supported parents in understanding and carrying out any home programmes these practitioners gave them.
5. When appropriate, and with varying degrees of success, we tried to get the infant's main practitioners to meet together with parents and keyworker at the family home to compare approaches and agree a unified plan of action.

One Hundred Hours published two surveys of its work: *When the Bough Breaks* (West 1994) and then *Listening to Parents* (Spencer 1999). Both were based on the views of parents who had used One Hundred Hours. As part of each survey, parents were asked for suggestions for improving the service provided by One Hundred Hours. The two following responses to that open question are representative and help validate the One Hundred Hours keyworker service:

Nothing except to say that One Hundred Hours has been an absolute godsend!! It has helped me regain my confidence as a mother which had been severely dented. My keyworker has been there through the

good times and bad picking me up when I am down. For being there for my husband too, as dads get left out so much because they are at work. (Spencer 1999: 23)

From another family:

We would simply like to thank One Hundred Hours for the support we received at a very traumatic time in our lives. We were given help which enabled us to come to terms with our daughter's condition and to gain the strength to move on in a positive way. It is as a direct result of the continuous support from One Hundred Hours that [we have been able] to push the medical services and education authority into providing the best for our child. (Spencer 1999: 23)

Hilton Davis, then Professor of Child Psychology at Guy's, Kings's and St Thomas' School of Medicine, in his foreword to *Listening to Parents*, praised the way keyworkers worked in partnership with parents:

...One Hundred Hours has real concern for the adaptation of parents as an essential element of help for children. This involves provision of a consistent individual working in an on-going partnership with the family, usually at home. The helpers work in a highly caring, genuine and empathetic manner. They accord parents respect by assuming their strength, competence and right to choose, and by following their lead. (Spencer 1999: 3)

There is an account of a One Hundred Hours keyworker getting to know and offering first support to a new family in the Appendix on page 73.

The successful work of One Hundred Hours was promoted in the new century by two publications, *The Keyworker: a practical guide* (Limbrick-Spencer 2001) and *The Team Around the Child: Multi-agency service co-ordination for children with complex needs and their families* (Limbrick 2001).

The first of these describes an effective keyworker service with case studies as an aid for people developing family support services. The second developed the theme of collaborative teamwork used in One Hundred Hours when families asked their keyworker to help the child's main practitioners work more closely together. In this Team Around the Child approach, one of the practitioners takes on the keyworker role.

The One Hundred Hours keyworker model of family support and the TAC approach to teamwork became integral to the UK government's Early Support Programme in England and Wales during the first decade of the new millennium. Interconnections published *Family-centred support for children with disabilities and special needs* in 2007 (Limbrick 2007). In her foreword to this collection of essays by various writers, Christine Lenehan, as Director of the Council for Disabled Children, wrote:

The second set of essays addresses how we translate active listening and embed it as part of the way services are delivered. There have been some major steps forward in recent years particularly around key working and early support. Peter Limbrick's early work on team around the child approaches transformed how we thought about services and enabled the move from services which met the needs of professionals to services which put parents and children at the centre. The government's Early Support Programme has subsequently promoted and developed this. So are we getting better...without doubt, but whatever service model we use, this book reminds us that the most powerful intervention is always created by the relationships we have with individual parents and children. The absolute humanity that underpins everything we do.

The TAC approach has been adopted in its entirety or in parts, in authentic and in less authentic expressions, in many countries. A major landmark in the progress of the TAC approach came with the adoption of TAC collaborative teamwork into the Australian government's *National Guidelines: Best Practice in Early Childhood Intervention* (ECIA 2016). This document, in listing various models of teamwork, describes the TAC approach:

The Team Around the Child (TAC)...is a teamwork model developed in the UK and has been adapted in Australia in a number of states. TAC is a systems way of coordinating early interventions for children and families who have complex needs and require interventions from a number of practitioners. The TAC model incorporates capacity building and evidence-based practices including: family-centred practice; strengths and interest-based practices; and the natural learning environment (Luscombe 2010).

Features of TAC include: each child's key practitioners agree to work as a closely collaborative and well organised team; a key worker

*is the main point of contact for a family and is primarily responsible for coordinating intervention; families are equal and valued members of the TAC and are involved in all aspects of decision-making and intervention; support is continuous and seamless (Limbrick 2005). As noted by the Victorian Government, **'there is a strong evidence base supporting the TAC approach as an effective way for a range of services to engage collaboratively and positively with families'** (page 15)*

While One Hundred Hours developed its keyworker model for family support within early childhood intervention during the final decade of the last century, I believe the support it brings is still unavailable to a majority of families in parts of the UK and other countries.

Both One Hundred Hours model and the TAC approach have always advocated watchfulness for the general wellbeing of infants with disabilities, their parents and other close family members. I feel we are on firm enough ground now to offer a strengthened version of the TAC approach and the keyworker role within it with increased emphasis on respect for infants and their families and nurturing their quality of life. This is offered as the next phase in the evolution of the Team Around the Child approach.

The following two chapters describe the TAC approach as it is now before this evolutionary change. This is intended to be helpful to people who are not using the approach or are using only parts of it.

3

Team Around the Child as a systems approach

In this chapter I describe the Team Around the Child approach as a system – a system in which each infant’s TAC has characteristics and potential that the individual people in it do not have on their own. Systems thinking leads us to consider the wholeness of each infant, the wholeness of the family, the interconnections between an infant’s various conditions and disabilities and the necessary interconnections between the infant’s main practitioners.

Systems theory or systems thinking observes that parts join together to make whole systems and that those can in turn become smaller systems within larger ones and so on. Bearings and spindle are part of the system of a wheel hub. Wheel hub, spokes and tyre are part of the system of a wheel. Wheels, saddle and pedals with other systems make a bike. Each system has new or emergent characteristics that were not features of the parts that made it. But the parts must be connected in the right way to get a particular set of characteristics. You can tour the country on a bike but not on an un-connected collection of wheels, saddle and pedals.

Moving from bikes to human bodies, systems thinking tells us we cannot consider kidneys, liver or lungs as though they were not operating in connection with the other organs comprising the bigger system of the whole body. Each of these organs is made up of the smaller systems of tissues, cells

and molecules and each functions in relationship with the other organs. When treating illness we have to see each organ as part of the bigger picture of an interconnected whole person. Keeping a narrow focus on this or that part of a system can render us ineffective in remedying problems in the whole. (For systems theory see Bertalanffy 1969; Capra & Luisi 2014)

TAC takes a systems approach to early childhood intervention by addressing wholes rather than restricting attention to their parts. The logical consequences of this are as follows:

1. The infant is respected and treated as a whole child with an entirely unique set of characteristics.
2. Infant and family together are respected and treated as a whole – the next level in the hierarchy of systems that goes up through community to nation and beyond.
3. The infant's particular collections of abilities and disabilities are understood to be interconnected – and emerging in the functioning infant as a single, unique, never-been-seen-before multifaceted condition.
4. Early childhood interventionists, concerned with an infant's development and learning, are not considered to be fully effective if they respond to an infant's multifaceted condition by focusing only on the parts that make it up. Instead, the practitioners around each infant and family must create interconnections between themselves – out of which will emerge a multifaceted intervention system that is unique for each particular infant and family. This is the TAC approach or the TAC systems approach.

The first three points are explained in the remainder of this chapter. The fourth point is the subject of the next chapter.

The infant is respected and treated as a whole child

With the commitment to focus on the infant, rather than on any single ability, condition or disability, comes the responsibility to see and respect the whole child – a child with their own unique interconnected entirety made up of personality, past experiences, memory, genetics, preferences, fears, sensitivities, sociability, attachment to parent, response to strangers,

pain threshold, sense of pleasure, sense of fun, etc.

A valid consideration, when planning respectful interventions, must be whether they, in their totality, would ever be thought appropriate for typically developing children – bearing in mind their psychological, social and emotional maturity and their right to a good quality of life. Respect for the absolute human integrity of the infant must be a fundamental consideration in early childhood intervention.

I want to start by referring to Magda Gerber (Greenwald & Weaver 2013: xv) who observes that infants need more than love and, accordingly, she advocates ‘respectful love’ which encompasses:

- respect for their confidence and competence
- respect for their authenticity
- respect for their moods and feelings, whether positive or negative
- respect for their stage-appropriate competence in all areas of development, based not on age but on readiness
- respect for their need for self-expression and communication
- respect for their style and tempo
- respect for their age-appropriate choices
- respect for their uniqueness in perceiving and interacting with the world, and finally
- respect for the miraculous way human infants are created

This seems to offer us a good start in rethinking our work with disabled infants and might nudge many of us into a different starting point when we are planning support for them.

While many practitioners and academics are divided into different camps with their own specialist areas of concern – for example language, movement, cognition – the young child is not. The temptation to think of an infant’s development and learning in separate parts is for our own convenience and requires a certain amount of purposeful blindness in order to maintain a particular focus. But seeing a child in their wholeness is not difficult. Watch an infant playing on the floor with another child or an adult. He or she brings everything into this: posture, movement, use of their hands and feet and mouth, sensation, perception, relationship, communication, motivation, memory, anticipation, preferences, sense of security, pleasure, displeasure, attention, approval and so on. This list of separate items loses its validity when we realise all these characteristics of the infant merge into

an interconnected and interactive whole and cannot be picked apart.

The TAC systems approach, then, is a straightforward answer to the dilemma, 'How can an early childhood intervention service cater for the whole child when many of the paediatric therapists and teachers specialise in just one area of development and learning?' TAC is collaborative teamwork in which parents and the main practitioners around the child come together to share observations, agree a prioritised list of needs and compose a more or less unified and coherent plan of action. This plan will incorporate the approaches and goals of each of the practitioners, focusing on those the child is ready for at this time rather than trying to do everything at once. How far this process goes of joining approaches and goals together will depend on the particular whole situation of infant, family and practitioners.

Out of respect for the infant and with an eye to what is felt appropriate for typically developing children, all development and learning interventions must:

- come without avoidable pain, fear or discomfort
- appear as natural activity in the home or other familiar and non-threatening places
- go at the child's pace
- fit in with their interests, mood and alertness at the time
- take place in the company of parent or carer and familiar practitioners with whom the child has an established warm and safe relationship.

This approach will look quite unexceptional to many parents of typically developing infants but might seem like an unreal dream to parents of those with disabilities. The keyworker has a special part to play in this respectful whole-child approach, both as the facilitator in TAC meetings when the whole child is considered and catered for, and then in supporting the parent in following the planned approaches with the child.

Respecting the disabled infant as a whole child in the TAC approach is part of the stance of seeing them first and foremost as a child and not thinking that in some way their disabilities mean they are something different from or less than a child. We all have our own mental image of what a child is, perhaps for some of us an idealised image of what a child ought to be – and we, as parents, certainly enjoy expecting the perfect baby. But is the corollary of this that the disabled infant is somehow demoted from the status of 'proper child' to something lesser and, if so, does this

help explain why some disabled infants get such a rough deal from some service providers, whether universal or specialist? This seems all the more likely when we consider widespread discrimination against disabled people in every country and the extreme difficulty many families experience in securing respect, equality and a high standard of education for their disabled child, even in the most developed and wealthy countries.

Magda Gerber's writing reminds us of the responsibility to look beyond disabilities to see the whole valid infant and then to respond to her or him in the same relaxed, warm, accepting and respectful manner we would use naturally with a typically developing child.

In the TAC approach, part of a keyworker's role, especially in the early days with each family, might be to help the parents and other close family members see their child as a complete and valid child rather than as something incomplete and in some way less than fully human. Every parent comes to parenthood with a more or less established set of beliefs, attitudes and prejudices. This mindset might include prejudice about disability, in which case parents have some thinking to do and adjustments to make. This might become a recurring subject for their keyworker as active listener.

Another impediment to a parent seeing the 'child' in the period after leaving hospital can be coming home with an overwhelming medical perspective about the condition, the prognosis and various on-going threats to health and survival. Parents might have a list of subtle signs to watch out for in the infant and then rapid treatment to organise. The new baby might be perceived predominantly as a patient or as an invalid in which case baby games become an irrelevance in the face of on-going nursing needs. When a keyworker or another practitioner can help parents get beyond this barrier and see they have a child who is a whole new person to relate to and with whom they can play baby games, they can help a family emerge from the negative into positive states of mind and start rebuilding respect for themselves as a valid family with a future. (See Appendix for Anya's family's experience of this.)

Infant and family together are respected and treated as a whole

While being child centred in the TAC approach, we must also be family centred. Each family with a child who has a multifaceted condition is

respected as a whole family within its community, with a culture and, probably, with much sudden and unexpected disruption of their normal family life. Families have a right to relevant culturally sensitive support during difficult times for their own sake and to empower them to support the disabled infant effectively. A reconfigured early childhood intervention service must, as a high priority, support a family's drive, when it comes, to move towards their version of normal family life.

I want to make the point again that there are two equally valid reasons for supporting a family with a new baby or infant with disabilities:

1. The family is probably in a very stressful time with no guarantee that it will survive in its present form. Offering relevant support is a humane response.
2. A supported family will be in a better position to support their disabled infant. This is likely to be the reason many service providers have in mind.

When One Hundred Hours began, the priority concern was to get regular and relevant development and learning opportunities to the infant sooner than would otherwise happen. As I had met many families of young disabled children, I was aware, as a secondary issue, there would be an element of emotional support and information-giving for parents. Responding to the spoken and unspoken predominant needs of families brought a significant early adjustment to this approach. One Hundred Hours became a family support system – albeit still with a strong focus on the infant.

We came to the view that an important part of the role of keyworkers was to accompany families through the most difficult times and then, in many cases, on their journey towards what they considered to be normal family life. As part of this adaptative process, the child might gradually become less the centre of attention, less thought of as 'special' and eventually more just a member of the family. It would be wrong to hope or expect that this repositioning of the child within the family will happen in the early years. It might come much later. But this journey, when a family feels ready for it, cannot be a return to what their life was before the arrival of the infant because so much is changed. This includes the structure of the family, its leisure, study and work routines and probably its finances. Also, parents and close family members might have adopted new priorities, life aspirations and belief systems.

A keyworker who is accompanying a family on this journey might

have a supportive role including:

- overtly valuing the family as well as valuing the child
- showing respect to parents, siblings and grandparents and others considered as 'family'
- responding to the family's needs and aspirations
- acknowledging the family's culture and belief systems
- working to their agenda (within child protection legislation)

This can be an empowering relationship in which parents gain or regain faith in themselves, become more confident in dealing with professionals and start to feel they are regaining some control over their lives.

An essential part of the role of an infant's TAC is to agree a family support plan. In the reconfigured early childhood intervention service the family support plan and the infant's development and learning plan are separate, but overlapping, documents. The family support plan is about the support the members of the family need in this new phase of their life.

No one working with a child and family should ever proceed on the basis of assumptions – they are bound to be wrong. But a practitioner who has already worked closely with some children with disabilities and their families is in a good position to anticipate what a newly encountered family *might* be experiencing and needing. Discussion with parents, in TAC meetings and during home visits can explore whether these anticipations are valid for this family.

A family support plan must address, as far as possible, the needs of the family in the categories below, but there is no suggestion here that all of the family's needs will fall within the competencies of TAC members. Suggestions of any sources of relevant support can be discussed with the family. Family support can be considered in the following three categories:

- I. Ensuring the interventions planned for the child will fit comfortably with the family's situation. Explorations include:
 - When we suggest something for the parent to do at home with the infant, are we sure the parent has sufficient understanding, energy, space, time and calmness of mind at this time? Will it take the parent away from the other children?

- Can the parent get the child (perhaps with young siblings in tow) to the places we specify at the times that we fix?
 - Can the family accommodate the number of practitioners getting involved?
 - What is the impact of the totality of provision on the day-to-day life of the family? Does it add to or detract from their quality of life?
2. Supporting the family as far as possible with the direct consequences of the infant's multifaceted condition. Explorations include:
- Do parent and child need short breaks away from each other? Does the family need short breaks and holidays together?
 - Is the family suffering from stress and strain? Are any family members struggling to adapt and cope? Is there need for discussion about formal counselling, psychological support or psychiatric support?
 - Is there a need to discuss fostering or adoption?
 - Is the family sleep-deprived?
 - Is the family becoming poorer? Is advice needed for money and debt management? Is advice needed about benefits and grants?
 - Does a parent need particular support to stay in work, get back to work or to continue studies?
 - Do two parents need help with their relationship?
 - Can a working partner's schedule be considered when appointments are planned?
 - Do siblings need someone to talk to for emotional support? Do they need help to maintain peer-group activity? Should someone talk to school staff about changed conditions at home?
 - Do grandparents need support or training in how to care for the child so they can share the care?
 - Is accommodation satisfactory? Is housing advice needed? Are adaptations needed?
 - Do parents need help to organise all their appointments to preserve their time, energy, money and spirit? Is it appropriate to designate some days and weeks in their diary

or calendar as 'FAMILY DAYS!' (except for emergencies)?

3. Supporting the family, as far as possible, with other needs that do not arise directly from the child's disability. Explorations include:
 - Is help needed with language?
 - Is help needed with understanding written documents?
 - Does a parent have needs because of a physical or sensory disability?
 - Does a parent have needs because of an intellectual disability?
 - Does a parent have mental health needs?

The family support plan should not become a fat document listing a host of support needs that are unlikely to be met within local resources. Needs can be prioritised and phased. It is essential that the family's keyworker does not take on family support tasks that fall outside their competence or available time and energy. There can be discussion in TAC meetings about what support TAC practitioners can offer and what might be available from other services. Some strength and resources will surely be found within the wider family and community.

The infant's single, unique, never-been-seen-before multifaceted condition

In my view we have all made a serious mistake during the last fifty years or so. We have known that an infant with a motor disability, or a language delay, or a visual or hearing impairment would most likely benefit from a physiotherapist, or a speech and language therapist, or a specialist teacher. The mistake we then made, for the best of reasons, was to decide that an infant with all of those conditions needed all of those practitioners and, probably, at the same time.

This additive and fragmented approach has put a massive strain on infants, families and support agencies. My argument, with all of those infants, families and practitioners in mind, is that we stop thinking in multiples, stop thinking that multiple disabilities mean multiple practitioners and multiple programmes. I want to go further and suggest that, in respect of a particular infant's development and learning, there cannot ever be

‘multiple disabilities’ – only a single and unique multifaceted condition.

I have found it useful to use the difference between ‘pantry’ and ‘pastry’ to explain the multifaceted condition. The baking ingredients on the pantry shelf represent the multiple diagnoses or labels of disabilities, while the resulting pastry is the multifaceted condition. Systems thinking tells us that flour, fat and sugar each have their own characteristics as they sit in their separate packets on the pantry shelf. We can move them to new shelves, replace any of them with better brands and use each of them in a variety of ways. But once they are cooked together into pastry, they emerge as a new whole entity with entirely new characteristics of nutritional value, texture, taste and smell. It is too late now to wish we had used wholemeal flour or brown sugar or vegetable fat. These ingredients can no longer be found in the pastry in the form in which they existed in the pantry nor can they be separated out from the pastry.

The TAC systems approach suggests an infant’s ‘separate’ disabilities of movement, vision, cognition, etc get cooked together as new multi-component skills are achieved. When an infant with cerebral palsy and vision impairment reaches for a bauble with increasing success, can we think of the motor skill separately from the visual skill? When an infant has hearing loss, intellectual disability and autism, they face a triple challenge in relating to and communicating with others. When they master the skill of answering the question, ‘Do you want a drink?’, I do not imagine the neurological pathway established in this new learning will have three separate strands in it corresponding to the three diagnostic labels. They are surely fused together in the infant’s learning.

So, by this thinking, these infants are not carrying a bundle of separate impairments and disabilities as they struggle to learn. Instead, each has his or her own multifaceted condition with the multiples of separate entities existing only in the minds of others. It is to this unique multifaceted condition that each early childhood intervention service must respond, eliminating its own multiples of separate practitioners and programmes and coming to an integrated system.

It is encouraging to remember that, while disabilities and impairments interact with each other as the infant’s neurology matures, so too do the infant’s emerging abilities, skills and understanding – all part of rich interactive mix of the globally functioning infant.

4

Team Around the Child as a multifaceted early childhood intervention system

This chapter gives an account of the Team Around the Child approach as a multifaceted early childhood intervention system. The approach includes close collaborative teamwork, some degree of integration of programmes and a special person or keyworker in close relationship with the family. The chapter describes TAC as it has developed so far and anticipates the next chapter that describes a strengthened TAC approach for a reconfigured early childhood intervention service.

The multifaceted early childhood intervention system is the fourth major emergent characteristic when systems thinking is applied to support for infants with a multifaceted condition. The first three were described in the previous chapter. This chapter describes the TAC approach as a successful multifaceted early childhood intervention system as it has evolved up to the time of writing. There are three sections as follows:

1. The collaborative teamwork of TAC
2. How the infant's programmes for development and learning can be integrated
3. A 'special person', 'keyworker' or 'primary interventionist' in the infant's TAC

Collaborative teamwork in the TAC approach

No multifaceted early childhood intervention system will ever be perfect – it is about people working with and helping other people with all the humanity, humility and imperfections that come with that. Such a system can be viewed as an aspiration to create a coherent package of development and learning support by integrating all multiagency and multidisciplinary interventions – a direct and respectful response to infant and family when the infant has a multifaceted condition.

Because the necessary knowledge, skills and experience for this can never be held by one person, there must be a collaborative effort at the core of which is the infant's individualised TAC in which people work together with familiarity, respect, honesty and trust. The relevant knowledge, skills and experience are brought into the child's TAC by parent or parents and the two, three or four main therapists, teachers and other practitioners around the child.

Collaboration merely means working together but the term 'collaborative teamwork' does not in itself define how it is done or what ends it should achieve. In broad terms, when it is adopted in early childhood intervention, it is as an antidote to fragmented and piecemeal work around a child and family that can cause duplication, gaps in provision, contradictory approaches, wasted money and added confusion and stress for the family. At worst, without close collaboration, there can be a sense of bewildering chaos that keeps parents disempowered, impedes the child's progress and stops the family moving forward with new or regained resilience.

We can think of two overlapping outcomes of collaborative teamwork in early childhood intervention: a coherent approach to the infant's development and learning; and some well-organised co-ordination of all the appointments the infant and parent have for the wider aspects of support for the child and family. The first is addressed in the child's development and learning programme and the second in the family support plan. The TAC approach caters for this dual aim. Accordingly, the functions of an infant's TAC include:

- building a picture of the whole child, of the child's multifaceted condition and of the child and family's strengths and needs
- helping parents get answers to their questions and, when invited, being in discussions with them about ways forward

- helping parents access all relevant support at the time when it is needed
- helping co-ordinate all appointments, treatment sessions, etc so that the total pattern is in the best interests of child and family with consideration of time, effort, money, stress and quality of life
- discussing with parents the appropriateness of additional sources of support for the family such as formal counselling or a sleep programme and helping to access them
- agreeing an integrated intervention system for the child's development and learning (see the section below)

How the infant's programmes for development and learning can be integrated

An integrated intervention system requires that the main practitioners involved with the infant's development and learning integrate as appropriate their approaches and goals instead of working separately from each other. The infant's TAC meetings are the ideal forum for planning this and offer graded opportunities for this integration. The degree of integration is always a TAC decision – not forgetting that parents are full members. Stages of increasing integration are as follows:

Stage 1: Practitioners and parents tell each other what they are working on with the child. This brings the benefit of seeing the pattern of interventions as a whole, resolving contradictory approaches and avoiding wasted time and effort when two people are offering similar work to the child. Judgements can be made about whether the child is being offered too many or too few people and programmes. Similarly, whether parents are being asked to do too many things at home. Parents, typically, are concerned when their infant's practitioners do not talk to each other, leaving the parent as the go-between. This is disrespectful to the infant and family and puts yet one more demand on the parent.

- Stage 2: Practitioners and parents adopt relevant parts of each other's approaches. This can increase the infant's opportunities for learning and practising particular tasks and facilitate the interplay between their various activities and abilities. For instance, each can offer the infant practice in the agreed signs, symbols or spoken words, each can incorporate the same postures and movements into their work with the child when it is appropriate.
- Stage 3: Practitioners and parents can work towards some degree of actually joining together the infant's development and learning programmes. This can be helped by agreeing to move from planning a discipline-based 'physiotherapy programme' or 'speech and language therapy programme' to a child-based 'getting dressed programme', a 'mealtime programme' or 'a playing on the floor and moving around the room programme'. In this way the infant gets whole-child learning opportunities in relevant situations and times and with natural opportunities to join abilities together. One outcome of this sharing process is 'collective competence' as explained below.
- Stage 4: It might be decided that one person could take on the work of another using the 'consultant model' in which one person hands over some part of their work with an infant to another TAC member who is competent to take it on with necessary support. This will reduce the number of people doing regular hands-on work with the child. This has direct advantage to the child, reduces the number of necessary sessions at home or in clinics, and supports service providers in their efforts to make the best use of their limited resources.
- Stage 5: The consultant model described above can progress, by TAC decision, into agreeing one of the team as the single primary interventionist who becomes for an agreed period of time the one practitioner doing most of the regular hands-on work with the child. The working unit now becomes a team of three (or four) – infant, parent (or parents) and primary interventionist.

Collective competence, mentioned above, answers the question, 'Who can be competent to offer whole-child development and learning opportunities to an infant who has a multifaceted condition?' Taking, for example, a baby with early diagnoses of blindness and cerebral palsy: the mother knows a lot more than anyone else about her baby but still has much to learn about both of these conditions and how they will impact on the growing infant. The paediatric physiotherapist might well have very little experience of blind children. Similarly, the vision specialist teacher might not yet have worked with any children with cerebral palsy. Competence only comes when these three people and the infant bring what they know and what they can do into a shared effort. Collective competence requires a degree of trust, shared aspirations and humility. (See Limbrick 2010)

A 'special person', 'keyworker' or 'primary interventionist' in the infant's TAC

Much valuable support for a family will come, if they are fortunate, from one person who, for a time, they consider a special person for them. This status of being special can only be conferred by the family: it cannot be imposed. The value lies in part in the quality of the relationship and partly in what the special person does in practical terms for the child and for the family. A special person might be described by the family at that time or in retrospect as 'an angel', 'a life-saver', 'someone there just for me' or 'someone who saved my sanity'.

Such a special person becomes in a sense the human face of a large, complicated and often frightening system, a more stable element in an ever-changing scene, someone to depend on in stormy times, a person to take strength from when feeling defeated. Such people might arise spontaneously for a family on a hospital ward or in a clinic, centre or home-visiting support service.

For many families whose baby has disabilities and/or serious illness from birth or soon after there will be, generally speaking, two overlapping phases of support: the time while the baby remains in hospital and then the time after the baby goes home. This change, which is rarely hard edged, can bring new community-based practitioners into the support system and perhaps some loss of valued support from hospital staff.

There is a clear need for a special person in the first phase while

the child is still in hospital and, if one arises, it is likely to be a nurse or a hospital social worker. Obviously, parents and other family members will need emotional support and reassurance and will want answers, in as far as there are any, to their many questions and apprehensions.

There is likely to be another requirement: the baby might need to be seen and helped by neonatologists, paediatricians, specialist consultants and nurses in a number of departments, perhaps in the same hospital, perhaps in one or more other hospitals. Each will add pieces to a growing complicated jigsaw puzzle that never gets put together into a whole picture that the family can digest and respond to. One experienced neonatal or paediatric nurse who becomes special to the family and helps parents build this whole picture as it develops is, or would be, very valuable. Hospitals can anticipate this need by having selected staff members who are skilled in developing helping relationships, are competent and experienced with disabled babies and have space in their working day to liaise with other medics as necessary and talk to parents.

While I argue for well-organised on-going support for disabled infants from their community services, I appreciate that the hospital culture, environment, workforce and shift systems do not lend themselves to the same degree of organisation and co-ordination. This essay focuses on the second phase when the baby has been initially discharged from hospital and is being supported at home with the local early childhood intervention service. Of course, many readmissions to hospital might lie ahead.

Thinking about a special person in this second phase after leaving hospital brings us to the TAC keyworker. Practitioners who can become 'special' for a family are an essential part of a well-planned early childhood intervention service and are certainly central to the TAC approach in which they are the keyworker chosen by the parents. There is always debate about what to call such special people. I am going to use the word 'keyworker' as I always have done in TAC writing and then 'primary interventionist' when the keyworker is the one person supporting the new mother and baby at home and then later supporting parents with the infant's development and learning programmes. The TAC keyworker is part of the child's TAC with a facilitating role and, almost certainly, the closest and most regular link with the family.

It is essential for each early childhood intervention service to create the time and space in practitioners' continued training and working

conditions for them to become special for families. Skills in developing a helping relationship as described by Hilton Davis (Davis & Day 2010) are a necessary part of this. This 'Family Partnership Model' is discussed on page 61 of this essay.

What each keyworker does within the TAC approach in support of an infant and family will come out of respect for them and will be in response to the uniqueness of the infant and of the family and to their current situation, worries and aspirations. The keyworker's efforts are always in response to infant and family needs. The functions of the keyworker and of the infant's TAC as a whole will obviously overlap. An important consideration is the very real danger of the keyworker being overloaded. The members of the TAC must be watchful for this and take on tasks when they can. The keyworking role can include:

- being the strongest link to the TAC for the family and the one selected to work most closely with the child and family
- being, with support of other TAC members, the interface between the family and all the agencies involved with the child
- supporting the parent and infant as they develop their relationship with each other
- offering emotional support, being an active listener and informal counsellor
- facilitating discussion at TAC meetings to agree needs of infant and family, prioritise interventions and formulate the action plan
- supporting parents in the agreed activities to promote the infant's development and learning
- being the champion of the child's quality of life and helping TAC practitioners and parents keep in mind the typically developing child as a comparison guide
- helping parents preserve their time, energy and spirit and reduce anxiety, stress and strain as much as possible – promoting the family's quality of life and supporting their journey towards the life they want to lead

The keyworker's task can be viewed as sitting with the family at the centre of the complex network of non-family people and organisations around them – a network that begins with the people in the TAC and expands out

through other people with some involvement and then further out to those on the periphery with minimal but necessary involvement.

A part of the keyworking role is to help keep an evolving balance between the development and learning interventions that could be offered to the infant and the readiness of the infant and family for them. This is an important role with a new mother and baby and during the infant's first years. While the infant has a right to all opportunities that will help him develop skills and understanding, these are less likely to succeed if the child is insecure, anxious or tired and if the parent feels emotionally distant from the child, is stressed, exhausted or sleep deprived.

For some infants and families there can be a TAC decision to reduce the number of hands-on practitioners, as far as appropriate, to a single primary interventionist to support the parent-child relationship and the infant's development and learning. This is an extension of the keyworking role with a deepening of the consultant model in which some TAC practitioners support the primary interventionist rather than work directly with the infant and family. These TAC practitioners keep contact with the child and family as necessary for on-going assessment and any new concerns that arise.

There are four major reasons that lead to the decision to offer a family a primary interventionist as follows:

1. To give close support to a new parent as they bond with the infant.
2. To allow the parent the best possible conditions for developing a helping relationship with just one practitioner if relating to the small group is difficult or daunting.
3. To reduce stress and strain on the infant.
4. To reduce stress and strain on the parent and family.

Once a service commits to giving due respect to disabled infants and their families and to promote their quality of life, delivering early childhood intervention through a primary interventionist can become the default mode. In my view, this is appropriate for *all* new babies and for infants with a significant sensory deficit, difficulties in relating or marked nervousness, fear and anxiety. Readers will surely have other children to add to this list. Provision of a primary interventionist can be considered a temporary phase until the child and family become ready for more people to be involved.

5

A reconfigured early childhood intervention service

In this chapter I will suggest how early childhood intervention services can be reconfigured to support the parent-infant bond, afford full respect to the infant and family and protect and nurture their quality of life. The four elements of the suggested reconfiguration are reframing of aims, adopting the primary interventionist model, fitting therapy into natural activities of living and learning and helping families maintain a balance between higher-energy quality times and lower-energy quality times.

This suggested reconfiguration of early childhood intervention services is intended for services already using a version of the Team Around the Child approach, for services who are considering adopting it and for people who are designing the first early childhood intervention service for their country, region or city. Because the essay describes an approach based clearly in infant and parent needs while avoiding overload of infants and families, it might also offer a starting point for adapting early childhood intervention services for populations changed by the arrival of significant numbers of refugee families and for people in low-economy countries.

One Hundred Hours began with a primary focus on the development and learning of the infant. Consideration of the family was an important but secondary issue until we responded to families' predominant needs and became a family support system, but still with the infant very

much at the centre. I want to suggest it would be valid to make the same shift in focus in early childhood intervention services for infants who have a multifaceted condition.

Australia's recent publication, *National Guidelines: Best practice in early childhood intervention (ECIA 2016)*, offers a good starting point as it answers the question, 'What is Early Childhood Intervention?' It states:

Early Childhood Intervention (ECI) is the process of providing specialised support and services for infants and young children with disability and/or developmental delay, and their families, in order to promote development, well-being and community participation.

Tim Moore, leading expert in ECI, states that the overall aim of ECI is to ensure that the parents or other key caregivers are able to provide young children who have disability and/or developmental delay with experiences and opportunities that promote the children's acquisition and use of competencies which enable the children to participate meaningfully in the key environments in their lives (Moore 2012).

ECI practitioners work in partnership with parents/caregivers, families and other significant stakeholders to enhance their knowledge, skills and supports to meet the needs of the child, optimise the child's learning and development, and the child's ability to participate in family and community life (Bruder 2010; Dunst 2007). (ECIA 2016: 4)

I strongly recommend these up-to-date National Guidelines for their broad scope with focus on the child, family, inclusion and teamwork and for the valuable reference list. But I want to suggest we should go further by giving increased emphasis to helping the parent and infant bond, respecting infant and family and protecting and nurturing their quality of life.

Any reconfiguration of the priorities, aims and mechanisms of early childhood intervention should logically start with what we know of the experiences of disabled infants and their families as they receive their local service. Keeping my focus on infants with a multifaceted condition in the countries I have some experience of, my list of concerns is as follows:

1. Infants receive therapy and education from a variety of practitioners in a variety of patterns of support. The success of these programmes depends on the competence of the practitioners, the parental contribution, the nature of the

infant's multifaceted condition and a myriad of other factors that defy measurement. There seems to be hardly anything quantifiable here and there are no guarantees on offer about what success any infant will achieve during these first years.

2. The infant can be subject to a variety of challenges in addition to those posed directly by the multifaceted condition. These can include poor nutrition, poor sleep, having to endure an unwelcome mix of procedures, busy days, and too many non-family adults to relate to and be handled by – in general terms a life we would not impose on a typically developing infant. All of this adds up to a failure to respect the infant and a severe compromise of the infant's quality of life.
3. Challenges to the family's quality of life are equally profound and can include anxiety, stress, poor sleep, a downturn in finances, accommodation no longer fit for purpose and threats to leisure activity, study and paid work. Parents can feel out of control of the family's wellbeing. There can be degrees of unwelcome exclusion from the usual social and community activity – for parents and siblings. Grandparents, if they are part of the family's life, can feel disempowered and unable to play the caring role they would wish.

If the above threats to quality of life persist for a majority of families even while the infant receives an early childhood intervention service in a wealthy and developed country, then, in my view, we need to take stock of what we are doing, how we are doing it and what we are achieving.

Early childhood intervention for infants with disabilities must have at its core a commitment to effective on-going support for their development and learning from competent practitioners. If we lost that focus then early childhood intervention would become meaningless.

But the concerns above suggest there is much more to be done if we want the child to grow in a viable and resilient family that has a place in its local community, has self-respect, is respected and enjoys the best possible quality of life. For the growing child, new skills and understanding achieved will be of limited value if the child has not formed an effective relationship with the parent, has poor self-esteem, lives with loneliness, stress and anxiety and is kept separate from their peer group.

The main components of my suggested reconfiguration of early childhood intervention services for infants with a multifaceted condition are:

1. Reframing the aims of early childhood intervention.
2. Offering all new families a primary interventionist as the best start.
3. Fitting therapy into the infant's natural activities of living and learning.
4. Giving each day a balance between higher-energy quality time and lower-energy quality time.

No family or early childhood intervention service should be pushed into taking any of these suggestions to the extreme. They are offered more as a direction of travel to alleviate threats to quality of life of infant and family. How far any of them find expression with an individual family will depend on the infant, the family, the practitioners and the whole situation. However, doing everything possible to help the parent and infant bond, respecting infant and family and working to support their quality of life remain the imperative.

Reframing the aims of early childhood intervention

The One Hundred Hours experience has something to offer in considering what an early childhood intervention service can aim to achieve for families of infants with a multifaceted condition. This charity, in common with all early childhood intervention services, offered a finite support system. Its name, 'One Hundred Hours', suggested a time-limited input which in theory could amount to two hours a week over a year, more intense work over six months or less regular visits over two or three years. In fact, the hours were never added up with any rationing in mind. Parents knew we were offering only early help. Some parents who had benefited from our on-going support, being aware of unmet need in other newer families they met in clinics and centres, generously suggested when they felt ready for us to move on.

Just as parents had a free choice in taking our service at the beginning, they could opt to end it at any time with or without giving their reason. The best circumstance, in our view, was when parents and keyworker both felt the time was right and entered a winding down phase

with less frequent visits. After this winding down phase, the keyworker was always available if the parent wanted to discuss something.

In general terms, when the keyworker felt it was appropriate to begin winding down, it was because the infant was settled into a nursery or early school and the parent was less in need of emotional support, less upset, more accommodated to having a child with disabilities, coping better, more empowered to secure the support her child would need in the future and was restoring a sense of being in control of the family's wellbeing. The family was more resilient now than in the early days and their day-to-day existence was moving toward their conception of a new normal family life. (It is interesting to recall that in only one case did the One Hundred Hours service come to its end for a family, mutually agreed, because the infant had achieved a desired level of development and learning.)

I suggest the two outcomes described above could be adopted as the primary objectives for early childhood intervention, namely:

1. Parents are recovering self-esteem, confidence in their competence as parents and starting to feel they are again masters of their own ship. The family is becoming more resilient, is integrating into its community as far as it wants to be rather than excluded from it and is enjoying the best possible quality of life. Family members feel they are moving towards their version of normal family life.
2. The child is settled in a nursery or early school place rather than being limited to the home. They have the best possible quality of life at home, in the community and at nursery or school. In all these places there are optimal opportunities for development and learning in natural situations.

I want to emphasise that within the support offered by any early childhood intervention service to help the family achieve these outcomes, the infant is offered the highest possible degree of development and learning support by competent practitioners. While the family is supported in getting back on its feet, the infant with disabilities is still the centre of professional attention.

This commitment persists when the infant has a shortened life expectancy, with or without a formal diagnosis of it, and when the infant has significant illness in addition to disability. Sue Boucher, Director of Communications for the International Children's Palliative Care Network

(ICPCN)¹ has kindly read this essay during its preparation and comments:

Some children have disabilities that may be caused by or co-exist with an illness or genetic condition likely to shorten their lives. While a diagnosis can give guidance on life expectancy, there will always be exceptions to the rule. No matter how brief the child's life, their right to enjoy the very best possible quality of life remains and these children and their families should be referred for support from children's hospice and palliative care services. Within these programmes, the TAC approach is seen as best practice in all interventions, providing a co-ordinated layer of specialised support while fostering the development of a close and loving bond between the affected child and his or her family.

Offering a primary interventionist within the TAC approach as the first support

In the strengthened TAC approach, a primary interventionist becomes the practitioner with the most regular and close contact with the infant and family. The primary interventionist functions within the infant's TAC with support from the other TAC practitioners in a consultant model in which they have direct contact as necessary and regular video observations of the infant's activities. There are two major roles for the primary interventionist: supporting the parent-child relationship and supporting infant and parents in the natural activities of living and learning. Once the infant is home from hospital and receiving support from community services the primary interventionist model should in most cases be the preferred option rather than exposing infant and child to a number of development and learning practitioners before they are ready. In the primary interventionist model the infant and family are afforded all respect and quality of life is protected by reducing the stress and strain of too many non-family people, too many programmes, too many places to visit and too many practitioners coming to the home.

In this way, time and space is created for the mother and new baby to get to know each other better and perhaps begin recovering from traumatic first days and weeks. The primary interventionist is with the

¹ Visit: <http://www.icpcn.org/>

parent or parents as they gain confidence in their own skills in the caring tasks of feeding, changing, playing, etc. When the child's condition makes some caring tasks more difficult, the primary interventionist is there to offer suggestions – but always starting with what the parent knows already. As success builds on success, parents and infant gain confidence and take more pleasure in the caring tasks. Life improves and their relationship deepens.

It might well be decided that supporting the parent and infant in this way is quite enough work for now. Other development and learning programmes, which might interrupt or impede this crucial work, can wait.

As infant and family gradually become ready, the primary interventionist and parent can introduce more elements of development and learning. Thus the first baby-care tasks become the foundation for the infant's natural activities of living and learning. As appropriate, the other TAC practitioners modify their consultant role and perhaps come more to the fore.

In earlier writings I have suggested the primary interventionist model as a remedy when it was felt a child and/or family were overloaded with too many practitioners and too many programmes. My feeling now, with a clearer focus on parent-infant bonding, respect for infant and family and for their quality of life, is that the primary interventionist model should be the first response to a family with a new baby with a multifaceted condition – rather than letting the family fall into crises of exhaustion, stress and strain and then trying to rescue them.

My suggested reconfiguration of early childhood intervention and the model of primary interventionist within it are informed in part by attachment theory. In this theory, originated by John Bowlby in the middle of the last century (Bowlby 1953), the bond between the infant and the mother, or another primary care giver, grows over time and is the foundation for the child's relationships and personality. Children with secure attachment do better in their future development than those without.

I am reassured by Carol Gerhart Mooney (Mooney 2010: 6) in her assertion that we are still learning about how babies and families connect with each other and the consequences when the connection is disrupted. If this continuing exploration includes infants with disabilities there will be benefit for those infants and families, for the people who support them and for the richness of attachment theory itself. But in the meantime, I want to argue that our treatment of infants who have a

disability, who have serious illness and who have shortened life expectancy must be informed by what we know about secure and insecure attachment and their consequences in typically developing infants and families.

Patricia Champion MBE has wise words for us about how we can support the relationship between baby and primary care giver through the agency of a single clinician operating within a team. Patricia is founder of New Zealand's Champion Centre. She says in private correspondence with me (Champion 2015):

The first emotional dyadic relationship does indeed need to be supported and scaffolded, primarily because the developmentally appropriate construct is that of the 'interpersonal world' (0 - 4 months) before the object world comes on stream. This happens in dyadic co-regulation, 'body to body', 'brain to brain' through sensory input. For infants with developmental challenges this period may extend for a considerably longer period, but it remains the fundamental building block for any intervention programme.

The task of the team is to engage in a detailed analysis of what the contributions are from all perspectives; biological, physical, social, cultural, language, cognitive, medical, etc. and then to design an intervention which encompasses these, according to developmental priorities delivered through the interdisciplinary approach of one (possibly more) clinician.

It is important to remain with a dyadic microsystem model, as the acquisition of a 'mind map' for mothering (by the caregiver) is as important as any intervention programme for the child in these early stages. This mind map for mothering will need to be supported to encompass the developmental challenges of the child and specific neurological perturbations which make up this particular little person.

She adds:

...the essence and core components of how human minds and bodies live and grow, that is through warm, supportive, responsive relationships, needs to be at the front of our minds.

Everything else, including the myriad of intervention programmes which now exist internationally, need to tuck in underneath those 'first principles'. They need to be congruent with those first principles – which of course have now been totally validated

by developmental neuroscience – to be supportive of the ‘first relationship’ emotionally, culturally, and of course developmentally. That is the best opportunity a baby with challenges can have for altering trajectories.

...interventions for infants, primary caregivers, and their families are about ‘learning and loving’. The ‘language’ of the mother-infant pair is an emotional language, not one consumed with, for example, feeding regimes, yet another piece of equipment, appointments with endless specialists, etc, etc. – all totally necessary, and appropriate, but beside, not in front of the emotionally driven, and emotionally sustained ‘primary relationship’.

I can say anecdotally that, as I have listened to mothers talking to and about their infants who have significant challenges, the content of their communication is primarily ‘action’ based and not emotionally based. This is in sharp contrast to the content used by mothers of typically developing infants. (Champion 2016)

Further:

The first principles of the infant mental health conceptual framework are predicated on biopsychosocial processes described for us much earlier by Bowlby and others and now by neuroscience researchers such as Alan Schore² and Stephen Porges³. Human infants (with or without special challenges) require a responsive, contingent, regulating experience with at least one person for their growth and development and the necessary components of caregiving – emotional and physical – from which a maternal bond develops and from which attachment style emerges. Putting it another way, the dyad (two person system) needs to move towards qualities from the caregiver that reflect ‘holding in mind’, ‘falling in love’, etc. Urie Bronfenbrenner, editor of *Making Human Beings Human*, (Bronfenbrenner 2004) once described it as, ‘I would die for you’.

The second part to this is that the caregiver’s history is everything when coming to this first relationship, including culture and belief systems, skills, own attachment history, previous loss, social and emotional competence, support of fathers or partners, fear,

² Visit: <http://www.allanschore.com/>

³ Visit: <http://stephenporges.com/>

anxiety, low mood, trauma, physical health, neonatal experience, medical and social supports, etc. The list is endless as to what contributes to this primary caregiving relationship and therefore how it plays out, especially if the infant has extra challenges. This is brain body of both infant and caregiver. This shows us what we need to pay attention to and engage with in both reflective and critical thinking if we are to support this early relationship in whatever roles we have.

I have recently been helped in my thinking about ways of doing this by two writers. The first is Dr Robin Youngson, author of 'Time to Care' (Youngson 2012) and part of a New Zealand movement called Charter for Compassion⁴. The second is Professor Linda Gilkerson of the Fussy Baby Network⁵ at the Erikson Institute in the USA. They both suggest ways of being with 'the other', putting the person and the 'first relationship' at the centre of professional practice.

Such questions as, 'How has it been for you to take care of this baby since we last met?' and 'What is the thing that is worrying you most?' become entry points in which the clinician models 'holding in mind' before clinical or other conversations begin. Trust is important when supporting this development of a 'good enough' dyadic relationship.

I hope I have adequately expressed in the above how complex, interactive and contextually relevant are the many contributions to the mother-infant bond and how the caregiver makes meaning of this relationship. (Champion 2016)

Dr Champion invites practitioners to consider the balance between infants' need for secure attachment and their need for therapeutic interventions. My suggested reconfiguration of early support for infants with disabilities strongly supports this invitation and proposes that some shift in emphasis towards a greater consideration of secure attachment would be beneficial to infants and families. Reducing the number of hands-on practitioners down to a single primary interventionist becomes the logical consequence of this rebalancing for some infants and families.

⁴ Visit: <http://www.charterforcompassion.org/robin-youngson>

⁵ Visit: <http://www.erikson.edu/fussybaby/>

Fitting development and learning programmes into natural activities of living and learning

With quality of life in mind, I want to argue that when we suggest parents work with the child at home on a new skill or understanding, we consider first if it can be incorporated into one of the child's natural activities, for example dressing or mealtime, rather than having to be special at-home therapy or treatment sessions.

Sophie Levitt tackled this issue in her book *Basic Abilities: A whole approach* (Levitt 1994). This has been a valuable guide for me in supporting parents with the home programmes suggested by their therapists and teachers. It is essential in therapy, she suggests, to focus on activities with disabled children that are most relevant to their lives. For infants, this means such daily activities as feeding, washing, dressing, toileting, playing, getting out of bed and moving around the house. Parents use what they and the child know already with help from therapists and teachers. These everyday activities become functional and fun and provide opportunities for warm and playful interaction between parent and child.

Sophie details the advantages in using what she terms 'daily living activities'. The advantages are summarised here as:

- Daily living activities use the abilities, senses, understanding and communication of the whole child
- Daily living activities create interplay between all of the child's abilities. For example, during dressing, the child uses hands and senses and controls balance.
- A child with multiple disabilities is rarely totally disabled and there will be residual abilities, for instance in vision and hearing. In daily living activities, these residual abilities can interact with each other and develop to their optimum levels.
- Physical disabilities can be treated within daily living activities – by incorporating 'therapeutic exercise' into the way in which a child learns a daily living activity
- Daily activities have more meaning for children. They are familiar, take place in well-known surroundings and lead to the child's growing independence.
- Brothers, sisters and other family members can participate. This can take pressure of parents.

- Time is saved as therapy becomes part of what has to be done anyway
- Different professionals can collaborate better. Effective teamwork is promoted as ideas are pooled for helping a child learn a daily living activity. A keyworker can bring together all the ideas of the team.
- Confidence grows sooner. The child's self-esteem grows and parents and carers grow in confidence as they discover how much they can help their children.

Basic Abilities: A whole approach is written for parents and practitioners and offers clear notes and diagrams for fitting therapy into daily living activity at the various levels of infant development. Sophie Levitt offers the important insight that, when we focus support on the parts of the daily routines that a parent finds most challenging, we are offering help where it is most needed – and giving maximum relevance to the new development and learning in what I am calling 'natural activities of living and learning'.

I have been privileged on more than one occasion to watch Sophie meeting for the first time a parent and young child with cerebral palsy. Several things are happening at the same time as Sophie and the parent sit on the floor together, usually with the child on the parent's lap or very close by. She is laying the foundation for a helping relationship with the parent, observing the child's global functioning and learning how the parent and child relate to each other. At some point, Sophie asks which part of the day presents the most difficulties and then focuses on that activity – learning what the parent does now and then offering appropriate modifications. Sophie's question becomes an entry point for relevant child and parent-centred support.

Much TAC wisdom and careful consideration is needed in deciding which development and learning goals to fit into which natural activities of living and learning and on how many occasions during the day. There is a very great danger for any of us in being overenthusiastic. The aim of these activities being enjoyable for child and parent and of providing opportunities for warm interaction will all be lost if a mealtime or bedtime, for instance, becomes a hard and tense struggle. It is essential these activities are preserved as enjoyable and meaningful natural activities of living and learning – part of the rich, rewarding days we would wish for every infant.

Balancing lower-energy and higher-energy quality time

Magda Gerber guides us in promoting an infant's development and learning while preserving a quality of life for infant and family. In *The RIE Manual for parents and professionals* under the heading 'Quality Time' (Greenwald & Weaver 2013: 16), she suggests quality time for the infant and parent is full, unhurried attention. She divides it into two themes with their own ebb and flow, 'wants nothing' quality time and 'wants something' quality time.

In the former, the parent wants nothing of the child except simply to be with the child, with all senses awakened, watching, listening, and thinking only of the child. In the latter, there is a goal to accomplish together, such as mealtime or dressing. It is still quality time but the child is helped to understand it is 'time for breakfast' or 'time to get dressed'. It is a time for learning to do a task together and inviting the child to co-operate. There are things to get done now rather than simply being with.

This ebb and flow of quality time surely has something to offer families who have a disabled infant. It can be part of an antidote to the stressed infant overwhelmed by too many demands and exhausted parents who have no time to themselves from getting up to collapsing in bed.

Joining Magda Gerber's thinking to Sophie Levitt's, the infant's development and learning goals can be the 'wants something' time of natural activities of living and learning. The relationship between parent and infant remains important as they share the activity together. Embedded in this is particular gentle attention to a posture, a movement, a communication, etc. Between those times are the lower tempo 'wants nothing' times when the infant rests (and so does the parent!) or parent and infant just enjoy being with each other with no pressure to do anything – but both enjoying quality time as they learn more about each other and deepen their relationship.

This reconfiguration of early childhood intervention with its strengthened TAC approach argues for a more child-friendly pace, reduced disruption to the normal running of the family and fewer practitioners doing hands-on work. It might not suit every family but each early childhood intervention service has a responsibility to offer a pattern of interventions its managers and practitioners believe to be in the best interests of child and family.

We have to anticipate parents who will have a natural urge to have everything that is available and sooner rather than later. This can come from believing the infant can eventually be cured by starting treatment early

in life and that maximum daily input will secure a better outcome. This drive can also come perhaps from a sense of guilt and wanting to put things right by investing a lot of energetic work under the direction of therapists and teachers. These are all very natural attitudes and none of us can claim to be immune from them when looking after our own child.

These beliefs and attitudes drive some parents to try every treatment or therapy they hear about – in their own region or country or further afield. This can at worst become a quest that drains the family finances, exhausts child and parents and makes them vulnerable to cheats and charlatans. Whether the family uses its own money or has a budget from a government agency, the task of finding out what is worth spending money on is daunting, probably impossible.

No early childhood intervention service that I know of offers a cast iron remedy to these pitfalls and dangers. In the end, parents will decide what they think is best for their children. As with all of us, a parent's impulse to take a particular course of action for their child can come from assumptions and beliefs that have never been brought into the open for proper consideration. A parent who has a trusted keyworker or primary interventionist to discuss these issues with will be at a distinct advantage.

I hope people working in early childhood intervention services will not feel I am suggesting an undue upheaval in principles or practice with this reconfiguration. It is an invitation to take stock of current practice from the perspective of parent-infant bonding, respect for infant and family and of their quality of life. This stock-taking should include, as one of its key measures, how the treatment of infants in the service compares with what is acceptable for typically developing infants. This measure will probably be easily available to the service from people who work in it who are themselves parents of typically developing children. The motivation and drive for the reconfiguration will come from seeing the experience of infants, parents and other close family members with what Magda Gerber calls 'new lenses' through which we see infants and what we do to them 'in a new light'. The task for managers, practitioners and experienced parents is to discuss and reframe the aims of their early childhood intervention service for infants with a multifaceted condition – and then to enhance procedures and practice within professional competences and disciplines. Full respect must be afforded to each and every person who works in an early childhood intervention service and to the contribution they make in their work.

6

The reconfigured early childhood intervention service as a diagram with notes

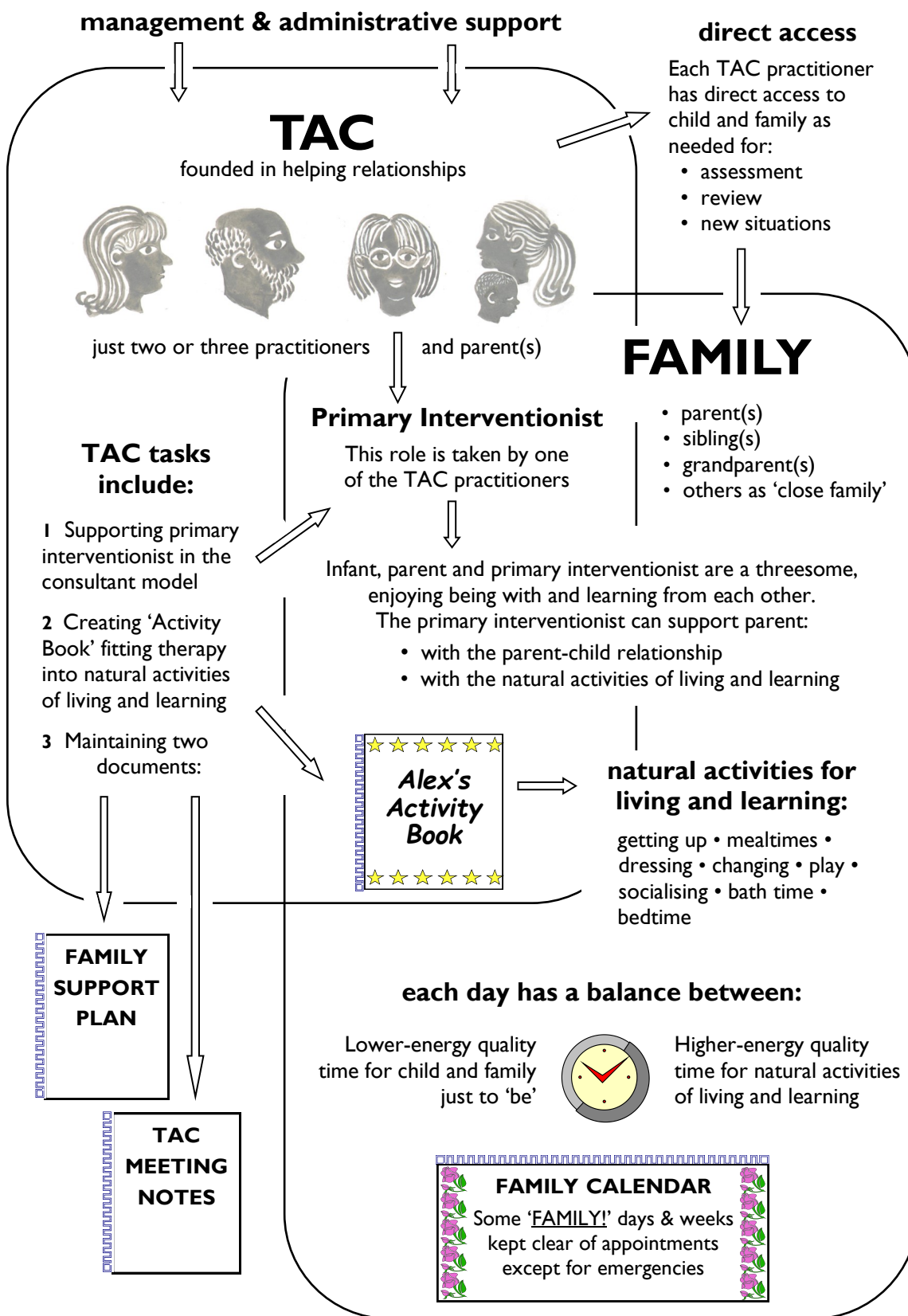
This chapter offers an overview of my suggested new approach to early childhood intervention services for babies and infants who have a multifaceted condition. The reconfiguration is based in a strengthened Team Around the Child approach. A diagram representing the new approach is followed by explanatory notes on its main aspects. These include an account of Davis' Family Partnership Model for readers not yet familiar with it.

The simplified diagram overpage represents a reconfigured early childhood intervention service using a strengthened Team Around the Child approach. The new approach aims to:

- support the developing parent-infant bond
- reduce exhaustion, stress and strain on the infant
- reduce exhaustion, stress and strain on parents and family
- promote the infant's development and learning
- support the family's journey to their version of a new normal family life

Explanatory notes follow the diagram and refer readers to relevant pages for further information.

THE STRENGTHENED TEAM AROUND THE CHILD APPROACH FOR A RECONFIGURED EARLY CHILDHOOD INTERVENTION SERVICE



Family

This is the group of people who are close to the infant and involved to a greater or lesser extent in their day-to-day care. The family can include biological parent or parents, foster or adoptive parents and other people with a formal parenting or caring role. There might be siblings (infants, children, teenagers or adults) and grandparents whose relationship with parents and general situation allows them to be practically involved. Other people, perhaps relatives, friends or neighbours might be designated as 'close family' by parents.

Helping relationships

Helping relationships between practitioners and family members *and* also between the practitioners themselves are the foundation of all Team Around the Child work. The major elements of these relationships are familiarity, respect, honesty, trust, humility and genuineness. (See the account of Hilton Davis' Family Partnership Model on page 61.)

TAC

TAC in this diagram represents the infant's Team Around the Child. It is an individualised team of just three or four people who come together in regular face-to-face meetings to share observations and agree a coherent action plan to support the infant and family. Parents are full members of their infant's TAC. Other members are the practitioners who are most closely involved. Without parents' involvement there is no TAC.

TAC meetings are not run as formal case conferences. They are family friendly, often take place in the family home and have a warm, positive and reassuring atmosphere. Each might last an hour or more. TAC meetings do not have to follow a fixed pattern – but are likely to begin with finding out how the infant and family are, asking how they are getting on with the agreed pattern of interventions and discuss any new situations that have arisen. The practitioners will share their observations from their points of view about the infant's wellbeing and progress and about any non-confidential aspects of family support they are involved with. The whole team will share thoughts and suggestions about ways forward and then the current action plan will be refreshed. The practical arrangements about venue, date, etc will be agreed for the next meeting.

Management and administrative support

There is no intention for any infant's TAC to manage without effective support. The local Team Around the Child approach must be planned and resourced by service managers and there must be administrative support for each TAC in organising meetings and producing the infant's activity book, the family support document and the meeting notes.

The primary interventionist

This is the TAC practitioner who, by TAC agreement and in response to the situation and needs of the infant and family, becomes the one person having most close and regular contact with the infant and family for an agreed period of time. The primary interventionist has two major tasks:

1. Supporting the parent-infant relationship
2. Supporting infant and parents in the natural activities of living and learning

For some families in the early stages, parent(s), infant and the primary interventionist will be a team of three (or four) people enjoying each other's company, learning about each other and exploring ways forward.

It is not possible to describe a typical session at home with these three or four people because infants, families and primary interventionists are unique and each session will be shaped by the current situation of the child and family *on that day*. But here is an outline pattern: The first part of the session is likely to be a conversation about how everyone is, any changes in the infant since the last session, any significant developments of any sort with consequences for the infant and family, how the infant and parents have experienced the natural activities of living and learning and any difficulties that have arisen. Then follows a discussion of how everyone has experienced the 'just being' times and the balanced days with the higher-energy quality times and lower-energy quality times. The role of the primary interventionist during this conversation is to be an active listener asking pertinent questions and being supportive.

It might well be that the session has been timed to coincide with one or more of the natural activities of living and learning, allowing everyone to share the routine and support each other in it. A video record might be made to show to other TAC practitioners. At some point there will be time for discussion of any issues that need to be aired. Before leaving, the

primary interventionist will confirm anything she has promised to do before the next session and list any questions she needs to discuss with the other TAC members. The date and time of the next TAC meeting is agreed. Fairly soon after the visit she will dictate notes for the typist. (Read more about the primary interventionist on pages 37 and 46.)

Direct access for TAC practitioners

In the primary interventionist model, the other practitioners in the infant's TAC stay in the background to support the primary interventionist as consultants. Regular video observations of the infant will help them in this role. How much direct contact they require with the infant and family must be their professional decision. Occasional direct contact will be necessary for staying in touch with the infant's development and answering parents' questions when new concerns arise.

TAC Meeting Notes

These are an on-going record of the TAC meetings with dates, times, people present, topics discussed and plans made to support the infant and the family. The notes should include *all* agreed actions, for example information to gather, people to contact for some reason, and the name of the TAC member who is going to do each one. The TAC Meeting Notes should be agreed at the end of the meeting and can be dictated for a typist unless an administrative person attends the meeting. They are copied to the parents and the infant's TAC Meeting Notes file is available to the parents at any time – and to other people only with parents' clear consent.

The infant's 'Activity Book'

This describes the agreed TAC plan for fitting the infant's programmes and goals into the natural activities of living and learning. It describes which programmes and goals, which natural activities they are fitted into (for example mealtimes, dressing, bedtime) and on how many occasions during the day and week – with respect for the infant and their quality of life as paramount considerations. There needs to be space for comments and recording successes. After full discussion with the people involved, the Activity Book can accompany the infant when they go to hospital, short breaks, playgroup or nursery so that the natural activities of living and learning can continue as appropriate.

The Family Support Plan

This document describes actions to support the family with the dual aim of responding to their needs and helping them as they support the infant. Agreed interventions to support the family must fall within the available time and competencies of the TAC members or of other available people and services. The Family Support Plan and the infant's Activity Book are separate documents but with overlapping considerations. (Read more about the family support plan on page 29.)

Natural activities of living and learning

The infant's programmes and goals for development and learning, whether provided by therapists, specialist teachers or others, are fitted into the natural activities in the infant's and family's day – as far as it is appropriate. This puts the therapy into whole-child activity which is relevant to the infant and family, incorporates plural aspects of child development and gives space for the infant to integrate abilities and understanding they have already achieved. (Read more about fitting therapy into the natural activities of living and learning on page 51.)

The balance of quality time in each day

Helping the family achieve this balance of higher-energy quality time and lower-energy quality time is an important part of the effort to reduce exhaustion, stress and strain on the infant and on the family. The natural activities of living and learning are the higher-energy quality time when infant and parent take pleasure in, for instance, a mealtime or bath time that offers rich opportunities to learn new skills and practise others. When necessary, the primary interventionist supports the family in overcoming difficulties in these activities.

The lower-energy quality time comes between the higher-energy activities and can be a time for the infant and parent to rest or sleep, for the infant to be awake and enjoying infant things without adult involvement (an opportunity many disabled infants rarely have) or for the infant and parents to just enjoy being with each other, learn more about each other and deepen their relationship. (Read more about the balance of quality time on page 53.)

The family calendar

Most families whose infant has a multifaceted condition have a very full diary or calendar that drives them on day after day. Typically, new appointments are written into the calendar as the arrangements are made so that the days and weeks fill with no opportunity to rationalise times and journeys or to plan breaks. The suggestion here is that the family looks ahead to mark some days and even an occasional week as 'FAMILY!' and commit to keep them free of appointments except, of course, for any emergencies that arise.

The Family Partnership Model

The helping relationship and the active listening within it come from the work of Professor Hilton Davis who developed the Family Partnership Model. Below are extracts from his essay 'The Helping Relationship: Understanding Partnerships' (Davis 2009). My experience as a keyworker in One Hundred Hours and later, while working to promote the Team Around the Child approach, tells me that effective helping relationships are essential between TAC practitioners and family members and between the TAC practitioners themselves.

Speaking about supporting parents, Hilton tells us:

However, without disputing the need to provide evidence for the effectiveness of the Model, I am concerned that we have been seduced by our technological world into looking for cures and thinking of the content of what we do, the techniques and methods, as opposed to the process and style. I should like to suggest that support is not just derived from information and techniques, but also from the human qualities of the person with whom parents work. Whether or not there is evidence for the Family Partnership Model, as an individual, I actually want to live in a world that treats all people with dignity and acknowledges the importance of relationships in all our lives.

Speaking of helper qualities, Hilton says:

In order to facilitate the processes I have just described, it is assumed within the Model that all helpers require a basic set of personal qualities in addition to the knowledge and skills that constitute the professional

expertise of the helper. For the sake of simplicity, the Model includes a set of six qualities that derive in large part from the seminal work of Carl Rogers. I use the word 'qualities', not to suggest that they cannot be learnt, but to indicate that they are internal to the individual and have to be demonstrated to have effect.

The six qualities in the Model are respect, empathy, genuineness, humility, quiet enthusiasm and personal integrity. Hilton tells us:

Each might be seen as a complex set of attitudes, which together determine the behaviour and skills of the helper and in turn facilitate the development of the relationship and the process of helping. One might perhaps sum these qualities up by saying that success in facilitating the helping process and achieving positive outcomes is to some degree determined by the helper being able to communicate to the parent that:

- *they (the parent) can manage and what they think and believe is of the utmost importance*
- *the helper is trustworthy, not all-powerful, cares for them and has strength to walk with them on their journey, while perhaps questioning the path the parent might choose*

Hilton lists 'concentration/active listening' as the first in his list of helper communication skills. The other skills are prompting and exploration, empathic responding, summarising, enabling change, negotiating and problem solving. Hilton tells us:

Each of the items in the list implies a set of skills that must be used throughout the helping process or at specific stages. Being able to concentrate completely on the people seeking help is crucial at all stages and is the basis of actively listening to them through all one's senses and attempting to understand completely what they are saying. Prompting and exploration skills (e.g. asking open questions) are the means by which one enables the person to talk about the issues important to them and to explore their situation thoroughly. The skills of empathy and summarising are the means by which the helper attempts to indicate a grasp of what the person means, feels or thinks.

These are also the ways by which the processes of change may be initiated and followed up with other methods such as providing new information, tentatively presenting different ways of thinking, or

inviting the person to consider, for example, inconsistencies in their views. Throughout the process the skills of negotiating should be prominent to ensure that the person is in agreement with what is happening and to resolve any potential conflicts. And, finally, there is a set of skills required when attempting to consider specific problems and to find ways of managing these. This includes the skills of prioritising, goal-setting and creatively generating strategy options to be evaluated with the person.

7

Getting started on a reconfiguration

In this chapter, I offer suggestions for starting a reconfiguration of an early childhood intervention service. The first move can be some sort of survey or audit of the experience of families who have used or are using the existing service. An essential element is involving practitioners from the beginning to capitalise on their knowledge and experience and to address any apprehensions. Families who know the service should also be involved. I suggest how to present the reconfigured service to new families and to families already using the service.

Seeing infants and families through Magda Gerber's 'new lenses' might come for some people like a light bulb suddenly switching on, while others will want to wait for evidence of a need for change. For some the lenses will not seem so new. I envisage two approaches to an audit of the experience of infants and families using a particular early childhood intervention service.

The first suggested approach is to invite observations from members of families whose child was supported by the service in the past. The older the child is now, the more distance the people will have for considered retrospection, applying what they know now to what they experienced then. Whether this survey is done by interview or as a paper exercise, the questions can be designed to explore:

- to what extent the parent(s) and infant were supported or

- impeded in getting to know each other
- to what extent parents feel the infant was valued by the service and treated with respect, perhaps in comparison to how typically developing infants are treated
 - to what extent parents, siblings, grandparents and other close family members feel they were valued and respected
 - what in general terms the quality of life was for the child and family at the time and what the service did that was helpful or unhelpful in this

Parents who have used the service would have a valuable contribution to make in framing the questions and perhaps helping run the survey.

My second suggestion for an audit, perhaps running alongside the first, is to make some measure of the psychological wellbeing of infants and family members who are using the service now and perhaps of some children and family members who used the service in the past. Practitioners whose experience and knowledge is around disability, might feel such psychological measurement is beyond their competence. The answer might be to recruit support from a local service that does deal with psychological wellbeing. If it is a service that mostly deals with adolescents and adults, its managers and practitioners might need to be persuaded to think about children. If it is a service that deals with the psychological wellbeing of children, they might need to be persuaded to think about infants with disabilities. My experience in the UK is that there can be resistance when asking practitioners to take on new work in this way, perhaps because of pressures of time, perhaps because the new work falls outside their professional experience.

While both of these approaches have their merits, another approach might be to try on Magda Gerber's new lenses.

Any significant new approach to or reconfiguration of a service that supports people in need can be perceived as a threat by people who use the service and people who manage it or work in the service at the grassroots. Acknowledging this and responding to it is a major factor at all stages of the reconfiguration – from first exploratory meetings to implementation. Leaving people's concerns and apprehensions unacknowledged and not involving them in discussions will result in failure. I want to address first an approach to practitioners and then to families who use the service.

Practitioners and their managers

In the essay, *Horizontal Teamwork in a Vertical World: exploring interagency collaboration and people empowerment* (Limbrick 2012), I develop the argument that when practitioners and managers integrate their work with those in other local services and agencies, as in the collaborative teamwork of the TAC approach, they move into a new sort of workplace where people treat each other, more or less, as equals. I contrast this new 'horizontal' workplace with the more 'vertical' workplace of traditional organisations with top-down hierarchical management. In my experience, this horizontal workplace brings practitioners and managers a new set of freedoms, satisfactions, challenges and threats and must be very carefully designed. It cannot just be left to happen on its own. *Horizontal Teamwork in a Vertical World* is intended to assist in this design and management process.

It follows then that an important part of reconfiguring an early childhood intervention service is an early and continued consultation with the people already working in it. This will make full use of their experiences and knowledge and provide opportunities to listen to concerns and address valid apprehensions and fears. In *Horizontal Teamwork in a Vertical World* I suggest current users of any service – families in the case of early childhood intervention – will have a valuable contribution to make to the reconfiguration, either as individuals or as members of local support or campaign groups.

People who need background reading as they get involved in the reconfiguration can be referred to *TAC for the 21st Century: Nine essays on Team Around the Child* (Limbrick 2009) and Australia's new *National Guidelines* (ECIA 2016).

Families

Families fall into two categories for the purposes of this discussion: new families coming into the service and families already receiving an early childhood intervention service that is being reconfigured.

For new families, many early childhood intervention service will already have promotional material in a variety of formats and languages. This can be adapted with a description and rationale of the major elements of the new service and of the TAC approach within it. The following letter is offered as a general outline of a message to families that can be adapted for each local situation. Parents who are already receiving the local service and who might have been involved in the reconfiguration could help write or

adapt it. Similar information could form part of an individually tailored letter sent to each family coming into the service. Language is always important: trying to avoid being too technical, I have used the terms 'special person' and 'primary worker' instead of 'primary interventionist'. The terms used should be a local decision. My suggested text:

Dear Parent,

We are here to help you as you get to know your new baby. Two or three of the people here who already know you and your baby will join you as her or his Team Around the Child or TAC. This small team, with you in it, will plan the support you and your baby need.

When the people in this small TAC have got to know each other, we will ask you to decide which of them should be your 'special person' or 'primary worker'. She will be the professional you see most, visiting you at home and when you come to the Centre. She will work with you to help your baby. She will not be on her own because she will have the other people in your baby's TAC supporting her.

Your baby and your family are very important to us. Giving you the regular help of just one primary worker will mean your baby is not overwhelmed by too many people before he or she is ready. It also means you and the others in your family have a chance to get to know your baby and carry on with everyday life without too many people getting in the way.

We believe you know your baby best, even if you do not think so at the moment. The best way to help your baby learn will be if we add what we know to what you know. The best times for him to learn are in the natural times of playing with you, changing, bath time, mealtimes, etc. If we work together we can make these activities rich learning experiences and enjoyable times for you, your baby and other members of the family.

Babies can get tired, and parents too! Breaks, rest and relaxation are important. It is also very important that there is quality time every day for your baby just to be with you enjoying your company and getting to know you and the others in the family better. Life does not have to be all work!

Your primary worker and the others with you in your baby's TAC are there for you. When we all work together your baby will have the best possible start in life and your family will be all the stronger. We are happy to discuss our work with you at any time.

I do not imagine any early childhood intervention service suddenly imposing a whole new approach on families they are already helping. This would be against all the philosophy, principles and practices of TAC. The new service would ideally be made available first to new families. However, an early childhood intervention service whose practitioners and managers like the suggestions of primary interventionist, therapy fitted into natural activities of living and learning and balanced quality time for families would surely create opportunities for their existing individual TACs to move in this direction when appropriate.

Within the well-organised process of preparing practitioners for the reconfigured early childhood intervention service, training is an important factor – for services who are not yet using the Team Around the Child approach and for those moving to a strengthened TAC approach. All TAC practitioners need to be able to perceive the wholeness of each infant and feel confident in broadening to some extent their horizons beyond their specific professional discipline and practice. Many experienced practitioners, for example in early years and nursery settings, already have a high level of skill in this. For others, some additional preparation and training will be needed.

On-going professional development training can be designed to cater for all local TAC practitioners, part of which can be people sharing their knowledge and skills with each other – just as in the consultant model in individual TACs. Parents can be involved, sharing their understanding, experiences and skills with others. The process of using the strengthened TAC approach and providing training for it will gradually develop a local workforce with enhanced whole-child understanding and skills and a deeper awareness of the experiences of families.

In conclusion

In this essay I have described how some infants who have a multifaceted condition and their families might be given unsatisfactory support from their early childhood intervention service even in wealthy well-developed countries. This results in my view from the way support is delivered rather than from any lack of commitment or effort in practitioners or their managers. I have suggested that ineffective early childhood intervention support can get in the way of the parent-infant bond, be disrespectful to infant and family, reduce an infant's opportunities to develop and learn and

impede the family's drive to a new version of liveable family life.

This must be true for many services around the world including some that are already using the Team Around the Child approach. For this reason my suggested reconfiguration of early childhood intervention is based on a strengthened TAC approach with a primary interventionist for all new families for as long as necessary, with therapy and education programmes fitted as far as appropriate into natural activities of living and learning and in which families are supported in using their energy most effectively in balanced quality time during each day. The strengthened TAC approach is intended to:

- reduce physical and psychological stress and strain on the infant and on the family
- make space for the baby and parents to get to know each other and enjoy each other's company
- avoid infant and parents living under pressure in a state of continual exhaustion
- protect, promote and nurture a good quality of life for everyone in the family.

I have suggested the beginning of the process of reconfiguring an early childhood intervention service must be a refreshed agreement about aims. My suggestion for a dual aim is firstly about parents regaining self-esteem and confidence with the family becoming resilient in their new situation, and secondly about the infant being respected, having a rich experience of the natural activities of living and learning with the best possible quality of life and being settled in a nursery or first school. These aims will be adapted for infants with a multifaceted condition who also have serious illness and/or a short life expectancy, but the aims of being respectful to infant and family and nurturing their best possible quality of life, while never making things worse for them, cannot be changed.

This enhanced TAC approach with its primary interventionist, natural activities of living and learning and the ebb and flow of quality time offers early childhood intervention services a new mindset, getting infants and families off the conveyor belt of exhausting dawn-to-dusk activity on almost every day of the week. It is an antidote to the temptation to counter an infant's disability with education and therapy programmes that, in the minds of many caring and concerned parents, can never be done often enough. The new Team Around the Child approach attempts to return to

the infant the babyhood they would otherwise lose. It allows parents to fulfil their natural role of bringing their child up with their best knowledge and skills and with specialist help when needed.

My suggestions for this reconfiguration are offered as ideas for early childhood intervention and early support services to consider in discussions involving managers, practitioners, parents and other family members. At best, they offer everyone a different way forward with an emphasis on greater respect for the child and family and a thoughtful consideration of the balance between the infant's need for interventions and the whole family's need for a quality of life. My suggestions are offered to support any early childhood intervention service that strives to do the best it can in accompanying families on their journey to a new version of their normal family life.

The ideas in this new approach might help some parents think afresh about the impact caring for their infant has on the family and it might help early childhood interventionists think afresh about how their work affects the infant and family – perhaps using Magda Gerber's new lenses.

Appendix

Anya, her family and her keyworker

This account is taken from Anya's keyworker's notes and so describes a real situation, but with names changed. While each child and family and the situation they find themselves in are unique, there is nothing unusual or exceptional in this account in One Hundred Hours terms. The experience of Anya, her family and keyworker reinforces the following elements of One Hundred Hours thinking and practice:

1. Early childhood intervention, for the sake of the child and the family, should come as early as possible. Anya and her family would almost certainly have benefited from earlier help with play activity and in getting answers to their many questions.
2. Ideally, the regularity of sessions and the duration of each session is determined by the needs of the child and family at the time. Anya's family had at the beginning six or seven visits per month with each visit lasting about two hours. Other families had more frequent visits perhaps of more than two hours during difficult times. Some families wanted only weekly visits of between sixty and ninety minutes.
3. Within a ninety-minute or two-hour session there is usually enough time to focus on the infant and to talk to parents or other family members. This avoids the tension that can arise in a practitioner trying to work with an infant while the parent is upset and crying, or attending to the parent's need while being conscious that an opportunity is being missed to

extend the infant's learning.

4. Parents of disabled babies and infants need a trusted and knowledgeable person to talk to in an on-going helping relationship. There are so many questions to ask and so many thoughts to sort out.
5. There can be benefit for the whole family when parents or other family members are supported in giving the child the best possible experience of being alive. This can mean seeing the child and not the disability. It can mean helping parents see they have a valued new family member and not a little invalid to nurse.

Anya was approaching her first birthday when the One Hundred Hours keyworker made the first working visit to her home. Anya's parents had asked for this free service and this first session followed a period of phone calls and informal meetings while her mother, father and grandparent learned more about what One Hundred Hours could offer. There followed two years of regular home visits by their keyworker until Anya started school on a part-time basis. After that time, the keyworker stayed in touch with occasional visits during a few more years and was able to help with some issues that arose about Anya's education.

Families had a variety of reasons for having a One Hundred Hours keyworker. Some would articulate their expectations of the service very clearly. Other families felt they wanted support but did not go beyond general terms and were not asked to. Anya's family were in the latter category but it was clear their wanting a keyworker came from their deep care and concern for Anya.

Anya stayed in hospital for a few weeks after birth and was given a diagnosis of cerebral palsy before going home. She was under the care of a paediatrician at the local child development centre and had been seen intermittently during this first year by a physiotherapist and twice by a speech and language therapist. She did not attend playgroup or nursery and was mostly at home with her mother, Jo.

For most sessions with the keyworker Anya was at home with her mother while occasionally Anya's father or grandparent was also present. How each session began depended on the immediate situation and any new concerns. In most sessions there was time focussed on Anya and time for conversation with her mother, usually with a cup of coffee. There

were occasions when Anya was asleep so the session changed accordingly. The relationship between the family and the keyworker was warm, trusting and respectful and sessions were relaxed.

During the first weeks of One Hundred Hours support the keyworker wrote to Anya's paediatrician, physiotherapist and speech and language therapist with the aim of developing future collaborative teamwork around Anya and her family. The keyworker learned from Anya's parents about what these practitioners had already said and done and suggested Jo tell them each time she sees them what was happening in the sessions with the keyworker. This would be an opportunity for them to keep up to date with what Anya is doing and to comment on the approach if they wished.

Topics of conversation with Anya's family ranged widely and could be focused on Anya or be of a more general nature. Confidential conversations were not recorded in the keyworker's notes and are not listed here. First topics included Anya's habits, her likes and dislikes, her birth, her time in hospital and how she reacted to coming home.

There were many conversations with Jo on her own, some with laughter and some with tears. The keyworker's role varied between being an active listener and giving or promising to get information. Advice was never offered – a One Hundred Hours rule. During these first few weeks topics included vision, hearing, epilepsy, medications, head circumference, cerebral palsy, children who die, guilt, survival and length of life, sleep, appetite, feeding and drinking skills, stiffness, eczema, reflux, use of hands, use of hands and eyes together, play, vocalising, physiotherapy, exercises, speech and language therapy, early communication and understanding, finger sucking, crying, teething, weight, blood in faeces, cranial osteopathy, playgroup, nursery, school, drinking bottle, cup, spoon, potty training and constipation.

The topics 'children who die' and 'guilt' are put together in the above list and were linked in the conversations. When an infant has a multifaceted condition and an uncertain future, a parent's mixed emotions can include fear the infant will die and, at the same time, apprehensions about how difficult life might be for child and family in ten, twenty or thirty years if the child survives. These apprehensions can feel to a parent almost like hoping the child will die – and then guilt arises.

The time spent with Anya as the main focus was always with parent and keyworker sitting on the living-room floor with her. The adults responded to her mood and energy level and tried to develop any activity

Anya initiated. Jo was always keen to do the exercises given her by the physiotherapist and was much less enthusiastic about the speech and language therapist's suggestions. This pattern continued with the strong parental hope and anticipation of Anya learning to walk.

The following extracts from the session notes have been selected to focus only on play activity. Early conversations with her parents indicated that Anya did not play. When awake, her time between caring activities were spent propped against cushions on the sofa or doing the physiotherapy exercises. This seemed to be a pattern set when she first came home from hospital many months ago. Play was not a parental expectation and Anya had no collection of her own toys.

Session 1: Anya was happy and smiling propped against cushions in an armchair. Her hands were mostly in her mouth, first one then the other, and she held a rattle when it was put in her fingers but could not release it. She repeatedly took the rattle to her mouth. She was moved to a supportive floor seat, which she had occasionally used before, with a plastic tray, which she had not used before, and a shiny bell was held within her reach. She looked at this and once or twice accidentally knocked it. This excited her. While the adults talked she did reach and touch the bell while it lay on the tray. The keyworker suggested parents suspend noisy toys in front of her when in this sitting position. Jo was delighted that Anya had sat to the tray and knocked the bell.

Session 2: Jo was pleased that Anya has been using her hands more since the last visit and has been vocalising more. Someone has rigged up a frame for Anya which consists of toys suspended from a bar which clamps to her tray. During the visit Anya sat in the floor seat propped forward with padding up to the plastic tray with the suspended toys. She once or twice knocked the toys while, some of the time, looking at her hands. She also made occasional contact with toys placed on the tray.

Session 3: Anya was sitting in the floor seat with her tray and suspended toys. She was not touching them or looking at them, instead she was sucking her fingers (either hand). Later, held in a supported sitting position on the keyworker's knee

with Anya's knees flexed and her feet held flat on the floor, she reached for and touched a suspended bell. She then grasped the bell in first one hand and then reached again and grasped it in the other – while looking at it. Jo said she had never reached for something she was looking at before. Later, Anya was seated on the floor with supporting props. She did not reach for a toy in front of her on the floor but did then touch a bell that was draped with a ribbon over her foot.

Session 4: *Anya has now developed the ability to reach to the floor to pick up a toy while she is seated on the floor.*

Session 5: *With a pop-up toy and with a telephone with small buttons, she showed improving manipulation while looking at what her hands were doing.*

Session 6: *When she was fingering some small toys she picked her spoon up without help and put it in her mouth.*

I want to re-emphasise that these extracts focus only on use of hands in play and cover only the first four-week period. In One Hundred Hours terms this is part of the 'getting to know each other' phase. These notes have not fully reported the family's delight from the first session onwards at seeing Anya play with toys. They had not expected this ability.

Anya's story vindicates the original One Hundred Hours idea that children with disabilities will benefit from the earliest possible support for their development and learning. It seems very unlikely that eleven-month-old Anya's readiness for this play activity matured at exactly the same time the keyworker started visiting. It is much more likely that Anya was responding to a new situation and was awakened to new possibilities in her life. Focussing on Anya's play activity helps me make the point that early childhood intervention for a child with disabilities has a direct bearing on quality of life. While 'hand/eye co-ordination' or 'visually directed reaching' are valid terms describing a developmental stage, reaching for toys for Anya was just play in the here and now. Life now could be less passive and much more exciting. With keyworker intervention, Anya achieved the normality of an infant at play. And play is fun!

Conversations with the family suggested they had always thought of Anya as a sick baby and as an invalid. While parenting Anya required watchfulness for signs of ill health, careful feeding, managing crying

episodes and getting her through the practicalities of each day, it had not included baby play activity with fingers, toes, rhymes or playthings. Parents and grandparent were loving and caring but were taken over by the idea of Anya as a medical case – not so much as a child. The time spent on physiotherapy exercises were part of that mindset.

This was not uncommon in One Hundred Hours experience. Parents who have accompanied their baby through a medical crisis with survival at risk and then weeks or months of hospitalisation before the baby comes home, can maintain a medical view of their baby and even see their role as more nurse than parent. It could be that the professionals who first support the baby and family are similarly medically focussed and do not mention the importance of baby games and play – but it could also be that parents only hear what they are ready to hear and what seems most relevant to them at the time.

There is no intended accolade for Anya's keyworker in the above account. The keyworker did what all experienced nursery workers and teachers do on meeting a new child – quickly appraise the child and the situation and engage them in some sort of play or social activity. This does not wait for a formal assessment. Within the first seconds or minutes, the child's response is observed and the activity is adjusted as necessary. It seems highly likely that Anya could have started playing earlier if she had joined a playgroup or nursery, but there are very many reasons why parents of infants with disabilities can delay or decline these opportunities.

It is my experience that this sort of early childhood intervention, wherever it happens, can help bring the disabled infant and the family out from the 'medical world' into a more normal place with less restrictive assumptions, attitudes and activities. Anya's new play activity lifted the whole family and raised their opinion and expectations of her – and I think perhaps of themselves as a family.

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