Primary Interventionists

in the Team Around the Child approach

A guide for managers and practitioners supporting families whose baby or infant has a multifaceted condition

Peter Limbrick

interconnections

BACK COVER -

Primary Interventionists

in the Team Around the Child approach

What are the first concerns when a baby or infant has very special needs? Firstly, their survival. Secondly, their attachment to the mother. Thirdly, support for the child and family keeping in mind their quality of life.

Many parents say they get more stress from how services are provided than they do from their child's special needs. When the baby or infant is stressed and anxious, attachment to the mother is impeded.

Some parents feel their child and family are swamped by too many practitioners and too many separate programmes. And many practitioners feel swamped by having too many children on their case-load!

When a child and family are supported by a single primary interventionist whom they know and trust, the child is less stressed, the family has a better quality of life and pressure is taken off practitioners.

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About the author

Peter Limbrick had a brother with cerebral palsy born a short time before he went to study zoology at Liverpool University. Nicholas died at forty years of age.

Peter's career has taken him into special schools as teacher and senior manager and into two voluntary projects as director: One-to-One and One Hundred Hours. One-to-One was part of the UK movement in the 1970s to get children and adults with 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 published *Team Around the Child: Multi-agency service co-ordination for children with complex needs and their families* in 2001and has promoted this approach in Australia, Canada, Croatia, Czech Republic, Ireland, Sweden and all parts of the UK.

Peter edits the international Interconnections News Service and its online TAC Bulletin about babies, children and young adults who are disabled, marginalised or vulnerable.

Books by Peter Limbrick published by Interconnections:

The Team Around the Child: Multi-agency service co-ordination for children with complex needs and their families (2001)

An Integrated Pathway for Assessment and Support: For children with complex needs and their families (2003)

Early Support for Children with Complex Needs: Team Around the Child and the Multi-agency Keyworker (2004)

TAC for the 21st Century: Nine essays on Team Around the Child (2009)

Horizontal Teamwork in a Vertical World: Exploring interagency collaboration and people empowerment (2012)

Caring Activism: A 21st century concept of care (2016)

Early Childhood Intervention without Tears: Improved support for infants with disabilities and their families (2017)

Edited by Peter Limbrick:

One-to-One: An experiment in community participation in long-stay hospitals (1976). Published by Inter-Action Trust

Family-Centred Support for Children with Disabilities and Special Needs: A collection of essays (2007). Published by Interconnections

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When a baby or infant is found to have very special needs:

The first concern is for the new child's survival, health and freedom from pain.

The second concern is for the new child's bonds of attachment to the mother or another primary carer.

The third concern is to meet the needs of the new child and family together, keeping quality of life to the fore.

(Peter Limbrick)

Contents

Introduction

This essay is for practitioners and managers in public, private and voluntary agencies that support families of babies and infants who have disabilities and special needs. It is also for parents, grand-parents and other family members. It argues for a modern approach to help parents help their children develop and learn.

There is a focus on children who have very special needs with two or more diagnoses of disabilities or impairments, i.e. a ‘multifaceted condition’. However, the approach is also appropriate to families whose child has less complicated needs.

This modern approach is more sensitive to babies and infants, reduces stress and strain on the family, nurtures attachment between the child and parents and takes pressure off practitioners. Problematic overload is avoided. Quality of life is protected.

In Chapter 1, I offer reasons for leaving old ideas behind and bringing support services up to date within the Team Around the Child approach (TAC) – shifting the emphasis from a medical mode to an educational mode. A key part of this is a move away from fragmented services in which multiple practitioners give a child multiple programmes. The essay shows that a single primary interventionist selected from the child’s TAC members can support parents as they help their child learn. Each primary interventionist is briefed and supported by the other members of the child's TAC.

Chapter 2 gives stories of four representative families. The first, about Jamie, illustrates some of the stresses and anxieties parents might experience during the first months and years as they adapt to having a new child who has disabilities and special needs. It is my long experience that out-of-date support services can inadvertently add to these stresses and strains. The stories about Adam, Tuyen and Megan show how the TAC approach can, for some children and families, move towards the primary interventionist model.

Chapter 3 addresses some additional considerations in transforming traditional support into up-to-date early child and family support with TAC and, when necessary, a primary interventionist. Discussed here are interventions focusing on the child's natural activity, TAC assessment processes and training.

The primary interventionist model is not offered as an absolute. It will benefit some families who feel overloaded with practitioners but not all. Some children and families will benefit if their TAC adopts the model in part rather than in total. Modern support systems, including TAC, must adapt flexibly to each individual child and family. We should no longer require children and families to adapt to the needs of support agencies.

Some early childhood intervention teams will see that the primary interventionist model in a modern system is not very far from their present good practice with some families.

1

Moving towards the primary interventionist model

In this chapter, answers are offered to the following questions:

- Why do we need a more modern approach?
- What is a multifaceted condition?
- What is early childhood intervention?
- What causes problematic overload?
- What is the TAC approach?
- Who or what is a primary interventionist?
- What does a primary interventionist do?
- Who supports the primary interventionist?

Why do we need a more modern approach?

During many decades of work in the UK, I have repeatedly heard parents assert that they get more stress and strain from fragmented and disorganised patterns of service delivery than from the consequences of their child's condition.

I heard parents say this in the 1980s when I worked with pre-school children who had cerebral palsy with associated conditions and I hear it now from parents I meet in my 'Early Childhood Intervention without Tears' seminars. I have also heard it in my work in other countries – mostly countries with strong enough economies to offer families well-resourced support.

Long-term stress and strain in families can surely contribute to later mental ill-health for children, parents and other family members. These mental states should not be underestimated. Coupled with anxiety about the child's future and a feeling of being out of control of the family, they can overwhelm parents, keeping them awake into the small hours and bringing up dark thoughts.

Unhelpful patterns of service delivery that add to stress and strain come from practitioners and managers who are trying to help. So, what is going wrong? A big part of the answer is overload of children and parents with just too many practitioners and programmes. In outdated support, this overload comes as an inevitable response to the baby or infant's multifaceted condition. There is a problem to address here needing all our creativity and willingness to change.

What is a multifaceted condition?

In discussing development and learning in babies and young children, I have stopped using phrases that refer to multiple disabilities and instead describe each child as having a single unique multifaceted condition. We can then plan an integrated unique multifaceted intervention approach for each child, escaping the multiples that lie at the heart of the problematic overload.

In terms of development and learning, it is my understanding that no baby or infant can have multiple separate disabilities. We can imagine a baby or infant with a dual diagnosis of cerebral palsy and vision impairment. In her development and learning each of these conditions will impact on the other. Limited vision will impact on hand skills. Difficulties in posture, head control and movement will impact on the development of vision. The two conditions are in interaction and from that interaction arises a new condition with characteristics neither of the separate conditions has when it exists singly in other children. This conforms to systems theory – the whole is greater than the sum of the parts.

A boy with a dual diagnosis of autism and hearing loss is another example. He must develop skills in verbal communication in the context of the features of autism. While learning to relate and communicate with others, he has to contend with hearing loss. The two conditions impact on each other. This boy does not have hearing loss and autism as conditions in isolation from each other any more than the young girl has separate conditions of cerebral palsy and vision impairment. One has 'autism/ hearing loss' and the other has 'vision impairment/cerebral palsy'. The separately labelled conditions or impairments cannot be found in the new neurological networks established as the child develops and learns.

This concept of a multifaceted condition, in which two, three or more disabilities interact with each other, is offered to support parents and practitioners in early childhood intervention as they plan coherent whole-child programmes for development and learning. It belongs to the educational component of early childhood intervention rather than the medical. I assume it is not such a useful concept for physicians and surgeons.

What is early childhood intervention?

This is first support for a child and family when the baby or infant has on-going special needs for development and learning. It can last between birth and admission to school. In some circumstances, parents are offered special support during pregnancy.

There are three interconnected components: medical treatment, education for the child and support for the family. A very wide range of people can be involved in early childhood intervention either as the whole or only a part of their duties. Included are doctors, nurses, social workers, occupational therapists, speech and language therapists, physiotherapists, therapy assistants, teachers, specialist teachers for children with sensory impairments, psychologists, keyworkers, family support workers and play specialists. Practitioners who work in early childhood intervention services can be termed early interventionists. Sadly, despite the great value of the work, early childhood intervention is not a separate profession in the UK with its own training and qualification. Early childhood intervention is termed 'early support' in some localities. My preferred term for an up-to-date service is 'early child and family support'.

In some parts of the UK there is no well-organised system of early childhood intervention. Instead, babies and infants will be offered some therapy sessions either intermittently or in short blocks. Parents have to fight for anything additional to this.

It is counterproductive when parents have to sit on a waiting list for weeks or months for early childhood intervention. Service providers should offer some relevant first support as soon as the family comes to them for help. The modern system I am suggesting creates flexibility in how early interventionists spend their time so waiting lists can become a thing of the past.

What causes problematic overload?

For children who have a multifaceted condition, there is a persistent and inappropriate additive approach. Each of the child's separate diagnostic labels, for instance cerebral palsy, intellectual disability, vision impairment, hearing impairment, autism, brings its own early interventionist and they pile up on top of one another. In traditional services, each of them will need to see the child regularly in their centre or clinic or at the family home, each has assessment and review procedures, each delivers their own programme and might ask parents to help them with it. Each might or might not know who else is already involved with the child and they might or might not have established practice for integrating their work with them.

It is easy to see how children become fragmented and how parents experience disorganisation and even chaos. Perplexed service managers, trapped in this outdated additive approach, might hear appeals from parents to have fewer interventionists and, at the same time, complaints from their team members that they have too many children on their case list. It seems to me that the trap comes from a medical mode persisting long after it would be better supplemented with an educational one.

A medical mode is appropriate when a child has a diagnosed medical condition that requires help from a single clinician. It is not appropriate when it results in a child having six clinicians for six diagnoses! Nor is an exclusively medical mode appropriate when helping a family in the longer term with their child's development and learning. The more appropriate response is an educational approach to the whole child – alongside any necessary medical interventions and family support.

Persisting with the additive approach for children who have a multifaceted condition in the face of parents' appeals for less disruptive support and in stubborn opposition to plain common sense, brings significant disadvantages including the following:

- Vulnerable babies and infants are required to relate to and accept being handled by a host of non-family adults.
- Parents and other family members are kept too busy and suffer added stress, strain and exhaustion.
- Baby and infant attachment to parents and other family members is made more difficult.
- Early interventionists' time and energy is wasted.

While intending to be helpful, this outdated style of early childhood intervention can put unnecessary and clumsy obstacles in the way of the child's attachment, wellbeing and learning, detract from child and parents' quality of life, impede parents' adaptation to their new situation and slow the family's progress towards a new version of liveable family life.

As part of a modern system for early childhood intervention or 'early child and family support', I suggest offering some families a primary interventionist within a TAC approach.

What is the TAC approach?

TAC is a commitment by the few early interventionists who have the most regular and practical involvement in a child's development and learning to meet together to share observations and agree a unified plan of action. Its primary aim is to reduce fragmentation and disorganisation. Its mode is always to support parents in their upbringing role. It is a defining feature of the approach that parents have a full place in their child's TAC. The approach is for everyone who wants to use it, but some agencies that adopt the label 'TAC' are a long way from up-to-date early child and family support.

At the core of this approach are regular TAC meetings for each child and family. These are very different from case conferences. Membership is deliberately small so that parents and other family members present feel free to speak openly without being intimidated. The tone is informal, warm, sensitive, supportive and positive. They have a flat power structure in which people work in horizontal relationships characterised by empathy, honesty, respect, trust and genuineness. TAC meetings are led (not managed) by a keyworker or facilitator. These small TAC meetings can deal with issues in closer detail than can large case conferences in which a large number of people need to contribute.

The regularity of TAC meetings is decided by each TAC. They might be held every month, every two months or every three months. They will be more frequent when a lot is happening with the child and family. Each meeting ends with a decision about when and where to meet next time. Usually, they take place in the family home unless parents prefer another place. They might last an hour or two, ideally without any sense of rush. A keyworker or TAC facilitator leads the meeting through topics agreed at the beginning and keeps notes as discreetly as possible – or there might be a clerical assistant for this. TAC members try to not be encumbered with files. The baby or infant might be present (asleep or awake) and young siblings can be present too if they are at home. This avoids them feeling excluded. I have been at more than one TAC meeting where a therapist involved a sibling in the activity she was demonstrating with the infant.

Each child's TAC will work best when it is supported within a local TAC System created in collaborative planning between local agencies. Such a system will:

- provide relevant information about the TAC approach to new families
- select new staff members for their competence in collaborative teamwork
- offer in-service training in such skills as developing helping relationships, facilitating TAC meetings, being a primary interventionist and working indirectly with children through a primary interventionist
- provide support and supervision for early interventionists

The Australian Early Childhood Intervention Association describes the TAC approach in their *National Guidelines: Best Practice in Early Childhood Intervention*. In their words:

> *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).*

In the context of this essay, it is important for TAC meetings to consider whether the child and/or parents are becoming, or are likely to become, overloaded with too many appointments, too many interventionists and too many programmes to work on at home. While parents might feel life is too busy and tiring, they might not mention it to the people supporting them. They might assume it is inevitable and cannot be remedied.

It is also important for TAC meetings to help parents find a workable balance between meeting the needs of the child and meeting the needs of the rest of the family. If some pressure can be taken off parents, there will be more time and energy for young siblings – and for each other when there are two parents.

When it is felt the baby or infant has too much to cope with and parents are overloaded, stressed and exhausted, their TAC can consider moving towards the primary interventionist model.

Who or what is a primary interventionist?

Within the TAC approach, primary interventionists are not a defining feature. They are an option for a TAC to adopt if it is felt necessary for the child and family. A primary interventionist is the person chosen in TAC discussion to work with a child and family for a period of time when TAC members (remember parents are fully involved) feel there should only be one person offering most of the direct support. The reasons for coming to this decision include the following:

1. The baby or infant does not have the capacity at this time to relate comfortably to a number of interventionists or to accept being handled by them. This can be true for all new babies and for babies and infants who have sensory impairment or anxiety, fear of strangers and a general apprehension about the world they find themselves in.
2. The parent or parents do not have the capacity at this time to relate comfortably to a number of interventionists or to

develop effective working relationships with them. It is felt the regular calm threesome or foursome of parent(s), infant and interventionist will provide the best conditions to support attachment between parent(s) and child.

3. It is felt the child will have the optimum chance of success in each chosen learning task when supported by a single early interventionist who can integrate all facets of infant activity including communication, movement, vision, hearing and understanding.
4. It is felt parents needing support in helping their child learn basic baby and infant skills (for instance baby games, playing with toys, moving around the room, managing first undressing skills, using a spoon and cup) will have optimum chance of increasing their confidence, competence and self-esteem when they are regularly supported by just one person they get on well with and trust.

The primary interventionist model can be the first TAC option for supporting parents with their new baby or it can be a remedy when child and/or parents become, or are likely to become, overwhelmed with too many people and too much going on.

What do primary interventionists do?

The foundation of the work is the relationship between the primary interventionist and the child and parents (empathy, honesty, respect, trust and genuineness). Working this closely with a family in their own home is a privilege calling for sensitivity and humility. Sensitive partnership replaces an expert mode in which parents can be undermined. Parents take the lead in saying what they want help with. This can be with any aspect of the child's care, socialising, play, sleep, development and learning – from the first baby-care tasks to the infant cruising around the furniture, from nursery rhymes to establishing a bedtime routine.

Support in any activity starts with what the parents know and do already. Then suggestions are made to help parents help the child move along the necessary small steps towards the desired goal. In this way, parents are bringing up their child with relevant and timely support from someone they know well and trust. It is important that support is in response to parents asking for this help. If it is imposed, parents are undermined.

Who supports primary interventionists?

Baby and infant natural activities are always multifaceted. For instance, using a spoon at breakfast time involves hands, eyes, ears, sitting skills, communication, relationship, oral skills, intention, an understanding of the whole situation, some impulse to learn an important and relevant natural skill and, probably, some satisfaction when the cereal is tasted in the mouth and swallowed. This new skill brings increased self-esteem as it is mastered.

All the necessary expertise, knowledge and skills for teaching these multifaceted activities reside not in the child's primary interventionist, but in the whole TAC team – practitioners and parents. It is the TAC members who fully brief and support the primary interventionist to become competent in supporting parent and child in the chosen activity. This involves team observation of the starting situation (perhaps with film), detailed discussion of all aspects of the task, TAC members handing over necessary skills to the chosen primary interventionist and then being available to offer further support as necessary. Progress can be filmed for discussion and TAC members can, if necessary, see the child and parent on joint visits with the primary interventionist. How this operates with a child and family is always by TAC decision. Principles in adopting the primary interventionist model include the following:

- TAC members feel a primary interventionist is the best way to support the child and family at this time.
- The chosen primary interventionist is competent to take on the role.
- TAC members can provide necessary on-going support to the primary interventionist.
- No TAC member feels their professional standards and responsibilities are being compromised.
- Child and family needs are held paramount when planning how the primary interventionist will work.
- The primary interventionist has a flexible working day, so can be with a family occasionally at a mealtime or in the evening.

Sensitive and timely support from a primary interventionist will feel comfortable and unexceptional to many parents while it will represent new thinking for many early interventionists.

2

Four families

This chapter relates stories inspired by four children I have known that I am calling Jamie, Adam, Tuyen and Megan. Jamie's family story illustrates the persistent worries and exhaustion that many parents experience during the first months and years while adapting to the new and unexpected situation. Adam, Tuyen and Megan's stories are representative outlines to show the evolution and practice of the TAC approach with its potential for a primary interventionist. The work with Adam preceded publication of the TAC approach in 2001. The work with Tuyen began in a TAC pilot project early in the 2000s. Megan and her family had TAC support in a local TAC System between her first months and admission into a nursery.

Jamie's family

Bridget is sitting with a cup of tea at the kitchen table. It is three in the morning and she is wide awake – again. She always lies in bed wondering whether to get up or lie in the dark worrying. Getting up might mean disturbing her partner, Patrick, or waking Jamie in the next room. Jamie is two years old and hardly ever sleeps through, so waking him is to be avoided. Tonight, she had dozed off eventually and then woke in a panic remembering the evening TV news of young adults with special needs being badly treated in a care home in London. This is by far her biggest worry: about what will happen to Jamie when she dies. Patrick won't talk about it yet.

Her own health is an issue for her now. She is always stressed with one thing or another and she is sure that is causing her weight gain. The doctor said she is not quite obese yet and prescribed antidepressants. Antidepressants! She knows full well she needs some practical help more than pills.

Help with Jamie's sleeping would be a good start. A psychologist had given her a programme but it didn't do any good. She thought it would have been better if he had come round one or two evenings to see the problems first hand. Then he might have been able to help. Trouble is, Jamie screams if they try to put him down at a proper bedtime. So he stays on the sofa till Bridget goes to bed and then she has to stay with him until he drops off. Then she lies in her own bed knowing that at any minute he might start screaming and wake the whole house. Neighbours have been round to complain. The other person complaining is Kiera's teacher who says Kiera keeps dozing at school and 'should go to bed at a proper time'. Something else to worry and feel guilty about.

She knows Patrick is not happy. Will they stay together? When they were told Jamie had a genetic problem, Patrick's mother said in a very spiteful way there had never been anything like that 'on our side of the family'. Bridget has been wondering ever since if Patrick blames her for Jamie's disability. He lost his last job because of Jamie. In the early days, the boss gave him time off to go to some of the appointments, but that couldn't last and they sacked him. In his new job he has to work all hours and he cannot do that without a good night's sleep.

Bridget feels Patrick is torn. He loves Jamie but wants life to be possible again with his career back on track. She doesn't know how she will manage if he leaves. She might have to cope on benefits and Jamie costs a lot more than Kiera ever did. Just getting to regular sessions at the hospital and therapy centre needs two buses each way and costs even more in the school holidays when she has to take Kiera with her. Debts are mounting up already – something else to keep her awake at night.

The doctor asked her what her social life was like. Social life? That was before Jamie came along! Friends have fallen by the wayside. Their children are all doing so well and this makes a barrier Bridget has not overcome. They cannot understand what life is like with Jamie. Kiera suffers too. Her friends don't come round anymore (probably because the house is so disorganised) and there's no money for clubs or sports in the evenings or weekends. Kiera doesn't complain though, she dotes on her little brother and loves to help look after him. That is the positive side. Jamie is so loveable and Bridget can't imagine being without him. Being without him – more fuel for the small hours.

Jamie's family are experiencing the same worries and stress as do many other families whose child has special needs. Tiredness and anxiety about the future seem to be ever present. Many parents say that lack of sleep makes everything harder to manage.

Adam and family

Adam's first weeks were in a neonatal intensive care unit (NICU). He had loving parents and an older sister. His multifaceted condition included cerebral palsy, sensory impairment, inability to suck and swallow, respiratory problems, epilepsy and sleeping difficulties. Adam was fed by tube and had an oxygen supply available at home. During the first difficult year at home the most regular support came from the hospital's speech therapist and paediatric nurse. There were frequent readmissions to hospital.

Realising more support was needed, towards the end of Adam's first year, the parents contacted a voluntary agency and were allocated a keyworker who could visit the family regularly with a focus on both child and parents' needs. Soon after this, a handful of practitioners appeared on the scene to begin work with the child. Parents thought this was probably the result of an assessment some months earlier. Included were a physiotherapist, a therapy assistant, a social worker and two teachers – one from a sensory-impairment service and one from a home-teaching service. The child was offered a place in a special children's centre. Two of their staff started getting to know the child at home in preparation.

Parents who had survived months feeling unsupported now felt confused, overwhelmed and overloaded. The keyworker suggested getting everyone together in an informal conference to make a coherent plan. This became a meeting of more than twenty people.

The parents asked for the following:

- Fewer appointment away from home and fewer home visitors. They needed time to be a family and more time to spend with their daughter.
- Fewer demands on Adam so that he would have a better quality of life.
- One person to bring enjoyable and relevant activity to Adam instead of so many separate people and programmes.
- Better co-ordination of appointments and interventions so that less time, energy and money would be wasted.
- Access to a children's hospice but no further involvement with the children's centre for the time being.
- One person to help the family 'keep everything together'.

It was agreed that both teachers and the therapy assistant would withdraw for the time being. The speech therapist would continue work on oral skills and communication. She and the physiotherapist would work closely with the keyworker to share understanding and skills and gradually hand over to her appropriate parts of their programmes in communication, posture and movement. Their intention eventually was to need to see Adam less often.

The keyworker would take on a dual function: firstly, to visit the family once or twice a week for a couple of hours to support both parents and spend productive time with Adam. This activity would be enjoyable for him and, at the same time, incorporate the approaches and goals suggested by the other interventionists. It would respond to Adam's condition, mood, interest and responsiveness on the day. The visits could be to the ward when Adam was in hospital.

Secondly, as far as appropriate, the keyworker would be the link between the family and all practitioners to support parents in keeping all appointments as well-co-ordinated as possible. This would mean two-way communication via the keyworker between the family and all practitioners involved.

This plan worked smoothly because everyone had understood the child and family's needs and because early interventionists trusted each other sufficiently to replace some direct work with indirect work through the keyworker.

Tuyen and family

Tuyen's parents had moved to the UK from Asia some years ago. The mother had started studying for a degree but then had to put it on hold when the baby arrived. The father was holding down two jobs with occasional night shifts. After a difficult birth, Tuyen was found to have neurological damage and vision impairment. He stayed in the special care baby unit (SCBU) for three months and was fitted with a nasogastric tube. He needed regular suction to keep his airways clear and had an array of daily medications.

Local services were piloting the TAC approach and, in anticipation of Tuyen going home, a team gelled around him with a specialist health visitor, a community-based paediatric nurse, a physiotherapist and, as keyworker, an experienced teacher of vision impaired pre-school children. The hospital paediatrician played a key role in getting this first TAC together.

Though hospital staff felt Tuyen would soon be ready to go home, the mother was convinced he would die without doctors and nurses on hand day and night. Both parents wanted their baby son home, but the mother could not imagine she would manage all of his needs and keep him alive. She had nightmares of finding Tuyen dead in his cot in the morning.

The keyworker took on a central role of being the most regular interventionist, visiting the family at home and on the SCBU with the dual aim of learning all about Tuyen and forming a familiar and supportive relationship with parents, especially Tuyen's mother. After about four weeks, Tuyen went home. By TAC decision, practitioners would see Tuyen as often as they needed to. The keyworker would make home visits two or three times a week for ninety minutes or so. As often as possible, a visit would be planned with the father at home. Parents had phone numbers to use day or night if they needed help.

Within this pattern, the keyworker was the primary interventionist with the primary role of 'being there' for the mother. This included emotional support, being an active listener and helping get answers to all parents' questions. Alongside this, she helped the mother spend quality time with Tuyen: getting to know him, forming first bonds of attachment and becoming relaxed and confident in caring for and playing with him. TAC meetings were held when group discussion was necessary, sometimes with the paediatrician in attendance. By mother's choice, these were kept to a minimum.

During two years of this work, with the pattern of visits reducing to one every week or fortnight, the mother's natural parenting skills grew as her anxiety reduced. She became a strong and articulate advocate fighting for his future schooling needs. She felt that, for the time being, a second pregnancy was too much to think about. The primary interventionist formed strong bonds with the family and learned much about their culture.

Megan and family

Megan was born in a locality where a TAC System was becoming embedded. Both parents said they had been slow learners at school and were surviving now on welfare payments. Megan was soon found to be delayed in general development. The paediatrician predicted intellectual disability and there was talk of cerebral palsy but with no formal diagnosis. The maternal grandmother was caring and supportive to the point of exhaustion while trying to hold down a part-time job. This caring family treasured the new baby. Megan's paediatrician organised a first TAC meeting in discussion with parents and grandmother during the first months.

At the TAC meeting in the family home were parents and grandmother, Megan (enjoying the attention), physiotherapist, occupational therapist, speech therapist and the TAC facilitator/ keyworker from an early education service. Therapists brought relevant information from the paediatrician. All of these practitioners had already met Megan to make initial individual assessments and had then met together to share observations and build a rounded picture. The TAC facilitator had established a positive relationship with both parents and the grandmother and was now a familiar non-threatening adult for Megan.

Many issues were discussed about the general family situation. These included: the mother's apprehension about whether she was a good enough mother to look after her baby properly and help her learn; the grandmother's deep concern for the family's wellbeing and her own lack of time and energy to help as much as she would like; the father's preference for sometimes not being fully involved with the child; and whether Megan's name should be put down for one of the local nurseries. The occupational therapist reported she was organising some bathroom aids and would put the family in touch with a local toy library.

The outcome of the meeting, and therefore the first multifaceted TAC action plan, was to treat as a priority the mother's nervous apprehension and low self-esteem as a mother. The plan was for the TAC facilitator to become the primary interventionist visiting the home weekly to support parents (primarily the mother) in playing with Megan and teaching the mother baby-care skills. In this there would be time to offer the mother and father emotional support and to occasionally meet the grandmother to listen to her concerns. The grandmother felt relieved that now there would be someone she trusted to share her concerns and efforts.

The TAC facilitator as primary interventionist was well briefed by the therapists in managing the child's communication, posture, mobility and hand function needs and, bringing his own teaching skills, could involve the mother in baby games and infant activity. This provided opportunities to answer questions and to explain how infants develop and learn. Activities progressed to first undressing skills (pulling socks off and pushing pants down) and managing cup and spoon. In their work to support the primary interventionist, therapists were guided by Sophie Levitt's book *Basic Abilities: A whole approach* that shows how to integrate therapeutic activity into the child's natural daily activities.

While working indirectly with Megan, the therapists would visit the child when they felt it necessary and be available to answer any questions from the family or primary interventionist. These visits were sometimes arranged jointly with the primary interventionist. From time to time, sessions were filmed for the therapists to see and comment on and for the family to keep.

There were three local nurseries with varying capacities to cater for children with special needs. A TAC decision was for the occupational therapist to visit each of them with the parents. The primary interventionist worked with the family on an 'All About Me' book to accompany Megan to the chosen nursery. At the mother's request Megan would have just a part-time place initially. Before admission, a member of the nursery staff attended two TAC meetings at Megan's home. Up to this time, TAC meetings had settled into a pattern of every eight or ten weeks.

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Additional considerations in modern early child and family support

None of the four children, Jamie, Adam, Tuyen and Megan, nor their families conform to any stereotypes. Each child and family is unique. It follows that no TAC approach to a child and family can be planned in rigid terms. Support for Adam and his family began chaotically and for Megan there was no clear or formal diagnosis. Jamie's story and Tuyen's to an extent highlight anxiety, stress and strain that parents might suffer – with or without added stress from fragmented and disorganised patterns of support. With these children in mind, it will be helpful to say more about:

- How individual TACs get started
- Focusing interventions on natural activity
- Assessment of needs in the TAC approach
- TAC assessment for a natural activity using film
- Time issues and training needs

How individual TACs get started

Even within a TAC System there will be variation in how interventionists come together in TACs around individual children. For

Megan, the paediatrician called key people together for the first TAC meeting basing the selection on what was known of child and family needs. For other children, a case conference can identify key people for a child's TAC. This happened for Adam in the large meeting organised by the keyworker when the problematic number of interventionists was distilled down to a much smaller TAC. For some children, a concerned interventionist can work with the family to invite two or three interventionists of their choice to form a TAC. This was the case for Tuyen when it was suggested the family be invited into the pilot project. Similarly, there might be a keyworker in place first who then promotes and facilitates a TAC. Parental choice in membership is important because an interventionist whom the parents do not get on well with will not be able to work in a helping relationship.

When there is a prevailing local TAC culture, every interventionist who meets a new child and family will ask who else is already involved, will attempt to integrate interventions with a whole-child mindset and will consider whether a TAC would be appropriate if not already in place.

No TAC System in any locality can have hard and fast rules of operation because each situation is different. It is best to see case conferences (if any are necessary), keyworkers, TACs and primary interventionists as interdependent options, as parts of a pattern that can be reconfigured for each child and family.

Focusing interventions on natural activity

In the TAC approach interventions are designed to support parents in their role of bringing up their child. This includes parents being helped to support their child's learning at home or in other familiar places in the course of the natural activities of each day. In this way, new understanding and skills have direct significance and relevance to the child and family's daily life. All learning tasks within natural activity are multifaceted rather than discipline specific and allow each child to develop and learn gradually at their own pace. Children are treated as whole children and are respected and valued. Young siblings are included in the activities if they wish.

Assessment of needs in the TAC approach

In my experience, 'assessment' in early childhood intervention can have confusions and problems. I have seen many assessment events in a medical mode that take place over one or two days. Child and parents are confronted with a sequence of interventionists whom they might not have met before and who frequently ask the same questions. They conclude with a professional meeting to compare notes and then a meeting with the parents to offer conclusions. These assessment events have two integrated functions:

- To decide what the child's condition is, attach a name if possible and prescribe any available treatment.
- To decide what the child's needs are for development and learning and start putting together an action plan involving relevant interventionists.

Parents and children can be overwhelmed by meeting so many people, telling their story repeatedly and perhaps being given a list of negatives at the end. Typically, in these traditional assessments there is no consideration of the child's routine of wakefulness, sleep, play and feeding.

This sort of assessment event has given way in many localities to less formal processes but, perhaps, with the same dual function and medical flavour. Though coming to a diagnosis and exploring a child's learning needs are interlinked, assessment in TAC focuses on the latter, integrating observations with support.

Adam's parents reported to the keyworker that there had been some sort of assessment day when he was about ten months old. This was in a local child development centre separate from the hospital. They had tried to put it out of their minds because it had been so unpleasant and could not remember who had been present. Adam had reacted negatively to each person, cried, screamed and then slept. The discussion at the end was full of negatives. Both parents left the centre feeling extremely angry. The day had achieved nothing as far as they were concerned; they had been patronised and unfair judgements had been made about Adam based on activities in which he was unsettled, unhappy and afraid. If a report of the day had been sent to them, they had not kept it. When interventionists did begin work with the child some time later they were not the same ones they had met at the assessment as far as the parents could remember.

Essential first information about Tuyen came from his time in the SCBU under the care of doctors, nurses and therapists. When the vision impairment teacher became involved, she made her own observations during repeated visits to the SCBU.

In the case of Megan, with the paediatrician taking a co-ordinating role, the baby and mother had been seen informally by relevant interventionists either in their clinics or at home. Helping relationships were begun and first assessments of need had been made. In this way, the first TAC meeting had no strangers and no shocks for the parents. This is an example of TAC assessment at its best.

While there might well be need for a more or less formal event to explore and pool information about the child's medical condition, likely diagnosis and possible treatment, this is not an appropriate start to an educational approach to the child's learning. In contrast, TAC assessment of a child's character, preferences, learning style, abilities and strengths are observed while working and playing with the child. Assessment and relevant support to the child and family go hand in hand in an on-going process.

Within the TAC assessment process, each TAC member carries a professional responsibility to learn what they need to learn before beginning any development or learning programme with a baby or infant. For some this might mean going through their preferred assessment schedule while for others it might mean a quick whole-child appraisal in a matter of seconds.

The TAC assessment process has the following main characteristics:

- It is an on-going process and not a single event.
- It is sensitive to the emotional needs of child and family and always respects the child's routines for feeding, changing, playing and sleeping.
- It keeps attachment and quality of life in mind at all times.
- It attempts to answer parents' questions as well as interventionists' questions.
- Learning about the child and family and offering relevant support both happen at the same time in informal sessions, preferably in the child's home.
- Parents' observations about their child are respected and treated as a valid part of the assessment process.
- Each TAC member abides by their professional standards.
- Each TAC member applies their preferred assessment routine with standardised measures or informal methods, either individually or with colleagues.

TAC interventionists can share observations with each other if they wish independently of TAC meetings when parents are present. This integrated TAC assessment/support process begins when work with a child and family begins and builds a first broad picture of abilities and needs. It is also used to focus on an activity parents have asked for help with, perhaps because they are encountering difficulties. The following section gives an example.

TAC assessment for a natural activity using film

Video film is a great asset in the primary interventionist model as illustrated in the work with Megan. In the task of supporting the mother to teach her daughter to drink from a cup while sitting at the table or in her chair with a tray (a task the mother had asked for help with), the primary interventionist began by filming Megan at home being helped by her mother to have a drink. The camera had remote control and was set on a tripod so that it would not intrude. The film was then viewed in a meeting with the therapists and TAC facilitator but with parents not present. The mother had said she was happy to see the film later when there were suggestions to offer. Sensitive conversations avoided the mother feeling she was being observed and judged.

Taking a drink seated at a table is a natural multifaceted infant activity. It begins with the cup being reached and grasped. It finishes with drink being swallowed and cup returned to the table or tray. On the way are many steps: seeing the cup, grasping the handle or handles, lifting to the mouth, positioning at the lips, taking a small amount of liquid, closing lips and swallowing. Underlying this sequence is an understanding of the drink-at-table situation, communication with the parent about wanting a drink and perhaps choosing which sort. Hopefully, there will be enjoyment of the drink and satisfaction with success in a relevant meaningful task.

There is much for TAC members to think about in this: Is it the right sort of cup with appropriate handle or handles? Is a non -slip mat needed? Should the drink be thickened? Is the chair at the right height and angle? Is extra padding needed? Should the parent support at the shoulder, elbow or wrist? Should help initially focus on the first steps or the last steps?

We can see that when a child has a multifaceted condition, managing a cup and drink while seated at a table or tray cannot be the sole province of any individual therapist or teacher.

Because all interventionists present knew Megan well, they were able to make constructive suggestions. The speech and language therapist had already helped with oral skills but would see the child again if the primary interventionist thought it advisable. The physiotherapist decided to make a home visit to check on the posture and mobility aspects of this task and would refer to the occupational therapist if necessary. At the next TAC meeting the mother, well-used by now to seeing herself on film, was pleased to hear positive comments about how she was guiding her daughter and about her daughter's present skills. The mother realised during the film that she ought to clear the table to remove all distractions. She accepted suggestions for developing Megan's drinking skills with support as necessary from the primary interventionist.

With film as the medium, reporting back to the supporting TAC interventionists can happen as necessary. Whether they view a film individually or as a group will depend on the situation.

Time issues

Time will always be an issue when discussing changes to local early childhood intervention practices. A major benefit of the primary interventionist model, as well as taking pressure off children and parents, is to take pressure off busy interventionists. When interventionists feel they are no longer compelled to always work directly with each child on their case list, they have more flexibility in time management. At agency level, the model makes the most efficient use of the practitioners around each child.

Early childhood intervention services were established with a clear purpose of supporting children with disabilities and special needs. It is illogical therefore to persist in traditional working practices that detract from child or family's wellbeing. Discussions about time must put the needs of children and families before the needs of interventionists and the agencies they work for but flexibility and compromise have their part to play.

Families do not run on a 9 to 5 timetable. There can be a need for one or more TAC members to visit a family out of normal hours. This means a working partner can be included, the child can be seen at a mealtime and parents can be supported in establishing a bedtime routine.

Flexibility in interventionists' time is also necessary in school holidays. When they coincide with agencies' holidays, parents are left unsupported. This gap in support comes at a time when the family might be under increased stress with siblings at home.

Training needs

This different way of working in which children's TACs can opt to work through a primary interventionist brings training needs.

Each TAC provides opportunities for interventionists to learn from each other and gradually improve their whole-child awareness and skills. What they learn in one child's TAC about multifaceted intervention will be transferrable to other children and families.

A TAC System will need to provide in-service professional development programmes in which interventionists from public, private and voluntary agencies come together to develop familiarity, trust and respect for each other. Part of this is to generate trust across the usual boundaries between interventionists in health and education services and between those with a professional qualification and those without.

At another level, I look forward to the day when there is a professional qualification for early interventionists providing a foundation in a whole-child approach with later opportunities to specialise in one or more aspects of child development. If such a qualification also included work with families, then we would have practitioners well prepared for up-to-date early child and family support systems.

Last thoughts

To achieve modern early child and family support when a baby or infant has a multifaceted condition, the TAC approach is essential while the primary interventionist model applies only under particular conditions. The TAC approach counteracts fragmentation and disorganisation with a well-organised whole approach. The primary interventionist model prevents actual or potential overload of child and/or parents.

Agencies that adopt these approaches might choose other names for them, but there are clear guiding principles that have been offered in this essay.

A primary interventionist supported by TAC colleagues, applies whole-child awareness and skills to support parents in their task of bringing up their child. This approach respects parents' rights and responsibilities and fits as closely as possible to how all babies and infants do their first learning at home with their parents in natural daily activities.

In my Foreword to the essay I put three concerns in order of their priority when a baby or infant is found to have very special needs: firstly, the new child's survival, health and freedom from pain; secondly, the new child's attachment to the mother or other primary carer; thirdly, meeting the needs of both new child and family together while keeping their quality of life as a continuing concern.

Bonds of attachment, essential for the child's neurological development, depend on child and parent sharing unhurried stress-free quality time. Awareness of this means paying attention to conditions for the parent-child relationship from the first.

In most traditional approaches, the child's on-going needs in development and learning take precedence over whatever needs the family might have. In modern early child and family support the new family is supported in having a quality of life with necessary periods of undisturbed 'family time'. Meeting family members' emotional needs is a continuing priority for interventionists during the first months and years. In this way family wellbeing and all relationships are protected and nurtured. This family-centred mode becomes the setting for interventions for the new child and continues over the pre-school years.

I hope the essay with its children's stories inspired by families I have known has shown that moving towards a primary interventionist model does not mean moving very far from the best of existing good practice. In fact, some early intervention teams will realise they are already moving in this direction, but perhaps not using the words I have used and perhaps not with my strong focus on attachment and the quality of family life.

Neither the TAC approach nor the primary interventionist model should be applied to any child or family as a rigid way of working. Sensitivity, respect, adaptability, creativity and imagination are valuable qualities for agencies and their practitioners just as they are for family members.

I hope this essay will raise discussion in early childhood intervention services and university departments about these two related issues of attachment and family stress. When babies or infants who have very special needs and their families are suffering from long-term emotional and physical stress their future wellbeing, quality of life and mental health are compromised. Primary interventionists in the TAC approach are a first antidote to problematic overload in modern early child and family support.

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