TAC for the 21st Century

Nine essays on Team Around the Child

Peter Limbrick



interconnections

TAC for the 21st Century Nine essays on Team Around the Child

Written and edited by Peter Limbrick

The TAC system, accepted as good practice in several countries, offers opportunities to radically re-appraise how practitioners use time and resources in pursuit of effective support for the increasing population of infants who have multifaceted conditions and disabilities. *TAC for the 21st Century* will inform and inspire managers, practitioners and families in the struggle to match limited resources to increasing needs.

The nine TAC essays, written over the last eight years and published in various places, show the evolution of TAC philosophy from its foundation at the start of the decade to the present day. TAC began as a straightforward approach to multi-disciplinary joint working and has become the vehicle for genuine child and family-centred support.

THE ESSAYS

- The Foundations of Team Around the Child
- Keyworkers are an essential part of a quality service for families. So why do most families not have one? Is Team Around the Child part of the solution?
- Principles and practices that define Team Around the Child
- Team Around the Child Helping to Keep Families Strong
- Integrated Programmes and the Primary Interventionist in Early Childhood Intervention
- Team Around the Child: The small collaborative team in early childhood intervention for children and families who require ongoing multiple interventions
- The Team Around the Child approach for assessment of needs within a local multi-agency integrated pathway
- Team Around the Child in Early Support being genuinely child and family centred
- TAC for the 21st Century: A unifying theory about children who have multifaceted disabilities

---- A TEXT FOR SERVICE DEVELOPMENT ----

interconnections ISBN 978-0-9540976-4-6 £19.95

TAC for the 21st Century

Nine essays on Team Around the Child

Published in 2009 by Interconnections

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ISBN 978-0-9540976-4-6

Cover drawing © Martina Jirankova-Limbrick, 2009

For Martina

About the author

Peter Limbrick has a science degree from Liverpool University and has enjoyed a career in which senior management in special schools has been mixed with management of voluntary sector organisations. At the beginning of the 1990s Peter established the charity One Hundred Hours to explore and validate keyworker-based family support for new families whose baby had neurological impairment. At the end of the decade One Hundred Hours became the Handsel Trust (www.handseltrust.org) which is working nationally at the time of writing to alleviate sleep deprivation in families with a disabled member. Peter chairs the Trust.

Peter had a younger brother, Nicholas, who had cerebral palsy. He was born during Peter's later years at secondary school and died at the age of forty. Although Peter has this long experience as a sibling, he feels it is his experience of One Hundred Hours families that has provided the major impetus for his present work as writer, trainer and independent consultant to health, education and social services in the UK and Ireland. In this role Peter has developed and promulgated the Team Around the Child system (TAC) to meet the needs of statutory services that want to create joined-up support within very limited resources.

Peter, under the name of Interconnections, publishes the online Interconnections Quarterly Journal (IQJ) for practitioners who support children and young people with disabilities and special needs. He also publishes the free monthly Interconnections Electronic Bulletin.

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Introduction to the essays

Team Around the Child, variously described as a *philosophy*, an *approach*, a *model* or a *system*, and often abbreviated to *TAC*, became an identifiable entity when it was named as such at the beginning of this century with the publication of *The Team Around The Child: Multi-agency service co-ordination for children with complex needs and their families*. It was the right idea at the right time and seemed to crystallise the concerns and aspirations of very many people. For a small minority, TAC described the way they and their colleagues had always come together for a limited time around a child and family when there was a challenging situation – either an ongoing situation that had frustrated their separate efforts or a sudden crisis that called for shared action. For some practitioners, even before reading the book, the words *Team Around the Child* offered an immediate solution to worrying fragmentation. For very many parents it sounded like the answer to a prayer for a joined-up service. TAC has the appeal of 'just common sense' and many parents would expect TAC on the basis of 'Why would my child's practitioners *not* want to work together?'.

TAC was first conceived in the One Hundred Hours project (which is described in these pages) and then given birth in response to demands of multi-disciplinary practitioners, service managers and parents around the UK who could see how One Hundred Hours brought joined-up support to children and families, but could not see how to muster their own team of keyworkers in emulation of the One Hundred Hours approach. In my consultancy work with health, education and social care services in the UK and Ireland since 1995, TAC is welcomed as the most achievable system for getting each child's practitioners to work together across agencies and disciplines. One Hundred Hours itself was informed by my teaching work since the early 1980s with children, parents and therapists in which I learned that the small collaborative team around each child brings good outcomes for child and family and provides practitioners with valued support and reassurance in their work.

TAC philosophy argues for a small collaborative team of just two or three key practitioners around each child - a team in which the parent has a full place and an equal voice. Any process which excludes or belittles parents is not TAC. Any meeting which is large and not parent and child-friendly is not TAC. Any organisation that labels traditional case conferences as TAC is cheating.

I hope you will enjoy these essays. In them you will also see how TAC has evolved into what I would want to call now the TAC system. The word *system* is used because in the later essays TAC is described as a logical response to adopting a systems perspective to children, to their disabilities and to their interventions.

1

The Foundations of Team Around the Child

Introduction

The Manual from which this paper is adapted, *Team Around the Child: Multi-agency service Co-ordination for children with complex needs and their families* (Limbrick, P. 2001)¹ is intended for managers and practitioners in the statutory services, workers in parent organisations and the voluntary sector and individual parents (and other family members) who want to respond to the call for co-ordinated or joined-up services for children with disabilities and special needs and who are looking for practical ways to do it.

Team Around the Child (TAC) is an approach to multi-agency service co-ordination at the level of the actual service to the child and family. In this model the handful of professionals who already work closely and regularly with the child and family, offering practical input in education, treatment and therapy, agree to meet together regularly to share observations, to agree a joined-up service plan and to review progress. The essence of TAC is that professionals from the different agencies and the child's parent(s) come together on equal terms at regular family-friendly meetings to discuss the child and family's needs in detail and to agree a co-ordinated approach. Each individual TAC has a team leader or TAC facilitator who can be the child and family's keyworker or lead professional.

There is very great need for reform of services to children with complex needs (who can also be defined as children who require a complex service) so that they are co-ordinated *for* the family and not *by* the family. The general picture in the UK is that when there is some degree of service co-ordination for a child it is because the family have used their own time, energy, and money to achieve it themselves.

TAC is offered as a first approach for service providers (from statutory, voluntary and private sectors) who wish to remedy this situation and assume the responsibility for joining services together for these children and their families. It is a low-cost model but does require commitment from senior managers, effective planning at all levels in the various agencies and some resources. Disjointed and fragmented services are wasteful of valuable time and energy for individual professionals and the agencies in which they work. In this sense service coordination includes an element of service rationalisation and will bring with it the reassurance that wastage and duplication is being minimised.

¹ References are listed at the end of the book.

Why some children and families need TAC

Some children and families require regular and frequent services over many years from a large number of professionals coming from two or more agencies. There is not a tradition of professionals or their agencies working together to provide all of these separate services as a co-ordinated package. The task of co-ordinating and rationalising services falls to parents, making yet one more demand on people whose resources are probably already severely stretched.

There is a growing acknowledgement that fragmentation of services can cause families great additional stress. In the author's experience, the harmful effects on families of fragmented services can include the following:

- parents are not given comprehensive information about all local services
- parents have to encounter each professional and each agency separately
- parents are not given the reassurance of seeing professionals communicate with each other about their child
- the pattern of appointments, clinics, therapy sessions, home visits, etc might be chaotic and wasteful of energy and time
- the child's daily and weekly routine might not be in the best interest of the child –
- and might not represent a workable balance between the needs of the child and the needs of other family members
- the service to the child and the family might have gaps of unmet need and some duplications
- the child and parents will have to undergo repeated interviews, assessments and reviews
- there might be unresolved contradictions in diagnosis, treatment and advice
- parents and child might be overloaded with activities and programmes to carry out at home.
- parents will have to pass essential information from one professional to another
- parents will not have one professional with whom they can discuss all aspects of their child's daily life, condition, development and learning –
- and no one to help them arrive at a whole and integrated picture of their child's abilities and needs
- the child and the parents might lose valuable support when one particular professional is ill or changes post –
- or when services and professionals change at a transition
- parents will have no opportunity to comment or influence the situation when they feel they are being helped by too few or too many professionals

The harmful effects of fragmentation of services on professionals and their agencies can include:

- each professional might be unaware of who else is involved with the child and the family –
- or of what their involvement is
- therapists, teachers, Portage workers, etc might have no opportunities to arrange joint sessions –
- and no opportunity to rationalise and integrate home programmes, helpful advice and suggestions
- the professionals will have no opportunities to share information, observations, and ideas

- the professionals might have to rely on the parent remembering what another professional has said or done
- a particular professional might feel isolated and unsupported in her work with a particular child or family –
- and must face some very difficult situations alone
- the professionals will have no opportunities to integrate their approaches with joint visits, shared goals and holistic programmes
- wastage of effort, time and money as some services are duplicated or even triplicated

The Team Around the Child model is designed to remedy the above ill effects of fragmented and disjointed services. In essence, the model consists of the small number of people who are most involved with the child and family agreeing to meet regularly at meetings which are smaller, more frequent, more detailed and more family-friendly than formal reviews and case conferences. Parents have a full place on the TAC and the child might be present at the meeting. The venue, frequency and timing are decided by general agreement. The venue can be nursery, school, Child Development Centre, clinic, home, or elsewhere. The frequency is determined by needs at the time with greater or lesser frequency depending on how quickly needs are changing. The choice of daytime or evening, weekday or weekend is likely to be a compromise between family routines, the needs of working partners and the flexibility of the professionals. The tone of meetings is honest, positive, respectful, encouraging, and supportive to all present. The meetings are not rushed and might require one to two hours depending on what needs to be discussed. One person, probably one of the professionals, will be acting as team leader to guide the meeting and keep notes.

Team Around the Child provides a needs-led approach. It is important to check at each meeting that services in general and intervention programmes in particular are matching needs as far as possible. There is a twofold advantage in this. Firstly, by identifying any needs which are not being met and any former needs which no longer exist, the over-all service can be rationalised. Secondly, parents and children will probably have greater motivation to collaborate on any agreed approaches that are designed specifically to meet real needs they have identified.

As the child's needs and the family's circumstances change the membership of the Team Around the Child will change. This is a gradual process so that the child and the family continue to receive support from the Team as a whole even during a major transition. As needs change, particular professionals in the peripheral group (i.e. the professionals in the wider circles around the child) can become members of the Team Around the Child and particular members of the Team Around the Child can move to the peripheral group. It might be appropriate for an entirely new professional who is not in the peripheral group to be invited in. After a major transition (not before or during) it might be appropriate for a new professional to take on the role of team leader. It is important that the Team Around the Child remains small and manageable. It would lose much of its value if it had more than a handful of people.

The Team Around the Child should operate as far as possible as a team rather than as a group of individuals. This will vary depending on how long the Team Around the Child has been running and how frequently its membership has changed. The skills of the team leader will be an important factor in this. The ideal to work towards is a team:

- which is encouraging and supportive to all members
- in which all members have an equal voice

- which can arrive at collective agreements
- which can acknowledge differences of view –
- and negotiate workable solutions

The Team Around the Child, once a level of trust and shared concern for the child and family has been established, can provide an effective and supportive forum for negotiation of difficult issues. This might be when the professional view differs from the parent view or when there are differences of view between professionals. It can be reassuring both to parents and professionals that important issues have been discussed by the group and have resulted in a collective agreement about how to proceed. It is important that the Team recognises when a very difficult issue requires outside help.

Benefits of the Team Around the Child model

An effective service for children with complex disabilities and their families must meet particular criteria regardless of which agencies are involved or which disabilities are present. These criteria determine both the effectiveness of the service and its sustainability against the common threats. In the author's experience, an effective service for children with complex needs and their families requires that:

- professionals work in partnership with parents
- services are co-ordinated
- programmes are integrated
- support is continuous
- the service is stable
- the service is flexible
- provision is uniform across the locality

Partnership with parents: Parents are likely to be closely involved in their child's health, wellbeing, development and learning during the pre-school years, while the child is at school and perhaps for many years after he or she leaves school. Their involvement should be acknowledged as the major resource and any multi-disciplinary team supporting the child and the family should be considered incomplete if it does not offer a place to the parents. The Team Around the Child includes the parent but recognises that the parent's preparedness to participate may vary from time to time. For instance, in the traumatic days and weeks after first disclosure the dominant need of some parents will be for understanding and support. Later on, most parents will want to be involved in planning the service to their child and some can take a lead role.

Service co-ordination: The effective co-ordination of services is the prime motive for offering children and families a Team Around the Child. This model ensures that services are co-ordinated where it most matters – at the 'grass roots' with the child and family. The Team Around the Child model:

- enables professionals to know who else is involved and what their involvement is
- establishes whether there is any unmet need or duplication of input
- allows appointments, clinics, home visits, etc to be rationalised as far as possible
- ensures that the daily and weekly routines of education and therapy are in the best interests of the child and the family

• enables services to provide collectively for the whole child and family

By co-ordinating services in this way the Team Around the Child model reduces the time, energy and money that parents have to waste pursuing disjointed services and lessens the stresses and strains that many experience as a consequence. The demanding and time-consuming role of service co-ordination is taken from the shoulders of those parents who are very happy to be relieved of it.

Integration: Child development and early learning does not happen in the separate disciplines of movement, posture, hand function, language, social skills, independence skills, etc and neither children nor parents naturally divide their activity into these compartments. The distinction between therapy and education is also often artificial. For young children with complex needs it is preferable to work towards the ideal of integrated activity for the whole child. Such activity should be both motivating for the child and appear relevant to the parents. The Team Around the Child offers a spectrum of integration opportunities that can match the particular child's abilities and needs and the preferred working style of the professionals.

Continuity: Support to the child and family should be seamless, continuing without interruption from the time around disclosure for as long as required. Some parents will need support from the time they first have cause for anxiety about their child, whether or not disability is yet confirmed or labelled. For some children it will be appropriate to provide the first intervention programmes based on a functional diagnosis while waiting for a medical diagnosis.

Stability: Services to complex children are always vulnerable to such inevitable events as a professional leaving their post or taking sick leave and the upheaval of periodic reorganisations of statutory services. The child's illnesses and periods in hospital will often cause a break in services that lasts much longer than the actual episode. It can happen that any one of these events will bring to an end a complicated pattern of interventions which the parent and others have spent much time and energy organising and which will now have to be organised again. In the Team Around the Child model the team persists as a whole, as it does over transitions, and over-all support can continue during these events. When there is advanced warning of such an event the team members can plan for it.

Flexibility: No two families are the same and children with complex needs are each unique in their abilities and needs. For a service to be effective it must be tailored to the individual child and family. An effective service must also be able to adapt as the child's needs and the family's situation change, whether the changes are expected (e.g. the child getting older) or unexpected. Because the Team Around the Child offers a needs-led approach and works in a close relationship with the child and family it can adapt quickly when necessary and plan ahead for expected changes.

Uniformity: Good practice should be uniformly available to all families in the locality. In the present situation, even across one locality, the service can be patchy, depending on the family's address, which professionals they happen to have encountered and whether or not the parents have learned to shout. The Team Around the Child model should be available to all local families who have a child with complex needs in a system which is fair and seen to be fair. This will help remove the common perception that the only families who get a good service are those who make a fuss. (If this is true, it is not parents who have created the situation.) It will also help reduce the requirement on otherwise gentle and reasonable people to become fighters.

Establishing a Team Around the Child system

Individual statutory services operate complex systems in obscure hierarchies from elected members at the top down to practitioners who work directly with children and families. Any major change to a new type of system requires very careful planning and negotiation. The task is greater and even more complicated when the proposed change encompasses two or more agencies. But it is never impossible and the needs of families dictate that local agencies should collaborate to find ways to move towards such multi-agency initiatives as the Team Around the Child.

As conditions differ in each locality the following general points are offered only as the briefest of guides. Once the process is begun the sequence will largely be imposed by events but there is some advantage in starting with a combined bottom-up and top-down approach as follows:

- a. Make contact with all the professionals at all levels in all services who are enthusiastic about service co-ordination and the Team Around the Child model.
- b. Locate parent organisations and individual parents who are enthusiastic about service co-ordination and the TAC model.
- c. Identify a small group of these people who will help in the first planning stages.
- d. Locate all examples of good practice in professional collaboration in your locality and try to build on these.
- e. Locate people in other localities who have established the TAC model and learn from their work.
- f. Work out where to place this initiative for change within existing planning structures. Ideally this will be a multi-agency committee or a manager with some responsibility for multi-agency collaboration.
- g. Start writing a proposal for the new system with help from the people you have identified above.
- h. Think about establishing a pilot project involving enthusiastic professionals and parents.

In recent years the author has worked to develop the Team Around the Child model in consultation with many health, education and social services, parent groups and voluntary agencies in the UK and Ireland who are working towards multi-agency service co-ordination for this client group.

2

Keyworkers are an essential part of a quality service for families. So why do most families not have one? Is Team Around the Child part of the solution?

Introduction

It is generally acknowledged now that a multi-agency keyworker should be offered to each family who has a baby or young child with complex needs. This has been documented over three decades in research, surveys, reports and guidance and yet still the majority of families do not have one. It is interesting to speculate why keyworking has not been widely adopted by service providers in spite of the obvious need. In my view the reasons include:

- 1. Overloading practitioners who agree to add keyworking to their main professional role.
- 2. Inappropriate expectations of what keyworkers can achieve.
- 3. A general failure to treat keyworking seriously within organisational systems.

The Team Around the Child (TAC) approach is offered as a remedy to some of the problems.

1. Overloading shared-role keyworkers

The great majority of keyworking services have relied on existing practitioners agreeing to become keyworkers for a number of families and then dividing their time between the main professional role and keyworking tasks. This is because funds have not been available to provide new teams of single-role keyworkers. The typical situation is that these practitioners are already busy enough with their present case-loads but are willing to 'go the extra mile' because of their acute awareness of the needs of the families they support.

Logically, when new work is added to a busy practitioner's workload, other work should be taken off them so that their job remains doable. In my experience shared-role keyworkers are not always given this consideration. If the practitioner has one manager for the keyworking role and another for the main role, tensions and disagreements can arise about how much time is allocated to each role. If the practitioner is relieved of some duties to make room for keyworking, it can leave the line manager with no option but to share that work out amongst other members of the team. Assuming that these people were already busy, they will become overloaded with this additional work. This in turn will reduce their capacity to take on shared-role keyworking.

It seems inescapable that additional resources are needed if families are to be offered either single-role keyworkers or shared-role keyworkers. A test of this need for additional resources

is for service providers to project ahead three, five and ten years to anticipate the probable demands as keyworking is offered to an increasing number of families in their locality who require it. Services which expand their shared-role keyworking service to the point where they have no more practitioners to call on for the shared role will have a choice of rejecting new families or seeking funding for more practitioners.

2. Inappropriate expectations

There can be pressure on keyworkers to undertake tasks which go beyond their training, their status and their available time. The pressure might come from the family or from the keyworker's employer or it might come from the keyworker's own commitment to doing as much as possible for the family. Four examples are:

- (i) Keyworkers trying to be advocates. This role can require keyworkers to attempt to exert an influence over service provision which goes well beyond their status and the power invested in them. Advocacy can compromise a shared-role keyworker's relationship with his or her employer. A distinction must be made between the appropriate keyworking role of helping families get what they need (so they don't have to shout and battle for everything) and the inappropriate role of supporting the family in complaints or other formal approaches to service providers. When families require formal advocacy they should be linked to an appropriate advocacy service.
- (ii) Keyworkers trying to co-ordinate services. Keyworkers cannot create strategic multiagency collaboration, single-door referral systems, joint assessments or integrated pathways. This is the task of senior management from health, education, social services and the independent sector. When an effective co-ordinated system is in place, then keyworkers have a favourable environment in which to keep everyone linked together for the family. When services are fragmented and piecemeal the keyworker is very limited in what he or she can achieve. Keyworking should be viewed as an important element of service co-ordination but not as service coordination itself.
- (iii) Keyworkers giving advice. Parents of children with complex needs will have to make many decisions which will impact on the wellbeing and survival of the whole family and on the wellbeing and perhaps the survival of the child. Keyworkers are not competent to give advice. Their role is to ensure the parents have good information about the issue and perhaps to support them as they think it all through.
- (iv) Keyworkers giving significant emotional support. Many parents need emotional support from time to time. This might be a priority for new parents. Provision of emotional support by keyworkers varies between just being an occasional listening ear to being the one person to whom family members offload their experiences, feelings and emotions on a regular basis. Having someone to talk to is a therapeutic activity which can help parents adapt to the most challenging situations and help resolve any negative emotions which stop them moving on. This can make unrealistic demands on a keyworker's time. Most shared-role keyworkers, like most practitioners anyway, do have time to be an occasional listening ear but should only offer more than this if they are sure they have the time and skills required. Families who require more emotional support should be referred to a relevant agency.

3. Lack of proper systems

Keyworking has mostly slipped informally into service provision without job descriptions, training, protocols, standards, career structure, management, support systems, monitoring, clerical support or proper funding. Keyworking projects, like the families they are trying to help, are very vulnerable. They can collapse when a particular enthusiastic practitioner or manager moves on, when practitioners opt not to assume the shared-role or when temporary funding dries up.

The Team Around the Child (TAC) approach

This provides each family with an individualised and evolving team (of just three or four or five) multi-agency practitioners who meet every half-term or so to review the child's progress, to discuss pertinent issues and to update the Family Support Plan including the child's development and learning goals. Each TAC includes parent or parents and has its own team leader (with a shared-role). The team leader functions as the family's multi-agency keyworker. In a real sense, the TAC approach provides an effective response to the need for keyworkers. It keeps the role within manageable parameters until such a time as funds become available to develop keyworking further. The basic role consists of:

- developing a helping relationship with the family and being a listening ear
- keeping a list of all agencies, services and practitioners involved
- ensuring the family has all the information they require
- ensuring the family has access to all relevant services, resources and benefits
- leading TAC meetings
- ensuring each meeting results in a multi-agency support plan
- ensuring the plan is distributed to other agencies, services and practitioners
- supporting the family as necessary through all parts of this process

This can be seen as minimal approach to multi-agency keyworking. But we have to acknowledge that children and families are all unique in their needs and that TAC team leaders come from a variety of professional backgrounds and working conditions. In response to these varying conditions there might be pressure from the family, from the keyworking service or from the TAC team leader him or herself to expand the role. This should only happen if the TAC team leader is competent to perform the new role, has sufficient time for the additional tasks and has all necessary resources and support.

The design of the TAC team leader's role overcomes the common obstacles and negative perceptions around keyworking. The role is very clearly defined and delimited, it falls to existing practitioners (from local statutory or voluntary services) and the TAC team leader is part of the supportive team rather than being an additional person grafted on to it. Formal advocacy is excluded from the role as is extensive emotional support. TAC team leaders operate within a supportive and co-ordinated matrix and are trained, resourced, supported, monitored and evaluated.

TAC team leaders must carry some authority, as must other keyworkers, if they are to be effective intermediaries between families and their local services.

The TAC approach empowers TAC team leaders in the following ways:

- (i) In dealings with the agencies and services around a family, the TAC team leader is a spokesperson for the TAC and does not just speak for himself or herself. As the TAC by definition comprises the handful of practitioners who are most closely involved with the child and family and who collectively hold the most rounded and detailed information about them, the Team collectively carries authority and status which equals or surpasses that held by anyone else involved with the family. This authority is invested in the TAC team leader.
- (ii) Each TAC team leader operates within a system which is established by multiagency agreement with principles and protocols about how TAC team leaders and local services will collaborate with each other in pursuit of effective support for children and families.
- (iii) Within this system there is training and support for TAC team leaders to enable them to be effective communicators and negotiators.
- (iv) The TAC system and the TAC team leaders within it are monitored so that lessons can be learned when TAC team leaders find themselves unsuccessful in representing the needs of children and families to other services and agencies.
- (v) Within the TAC system there will be a senior manager or a management group overseeing the system and providing support to TAC team leaders. This person or group can support any TAC team leader who encounters difficult situations or seemingly unmoveable obstacles.

Services for children with disabilities and their families have never been adequately funded. I expect that this will not always be so and that funds will be made available to local councils, health services and voluntary agencies to enable them to provide families with a choice of single-role keyworkers or shared-role keyworkers. In the meantime, the TAC approach can represent the best attempt we can make to give families multi-agency keyworkers who are empowered to support families within a system which is well organised, co-ordinated and accountable.

3

Principles and practices that define Team Around the Child

Introduction

A Team Around the Child or TAC is defined as:

An individualised and evolving team of the *few* practitioners who see the child and family on a regular basis to provide practical support in education, therapy and treatment.

Team Around the Child has gained acceptance during the last few years in many parts of the UK as a way of working with children who have multiple/complex needs. The TAC approach provides continuing joined-up support for the child and the family. Part of the success of the approach might be accounted for by the name 'Team Around the Child' which appeals to parents and to practitioners (therapists, teachers, nurses, doctors, social workers, etc) as an uncomplicated, easily understood and non-threatening concept. Most parents feel the approach is just common sense. For me, it represents the way we might all have always worked if we did not belong to separate health, education, social services and independent (voluntary and private) agencies.

TAC is not a new method or a new idea comparable to, for instance, conductive education or neurological patterning, which were both new methods arising from new theories. TAC merely embodies particular elements of good professional practice, which, though largely accepted as such, have not yet become standard procedure for all services in all parts of the UK.

The following account of those particular elements of good practice which are promoted and fostered within the TAC approach is offered so that everyone involved with children with multiple/complex needs (parents, practitioners and managers) can be very clear about what they are committing themselves to if they adopt the TAC approach.

Elements of good practice in TAC

1. Each child's key practitioners agree to work as a closely collaborative and individualised team

The model requires those practitioners who offer, or who are going to offer, a child and family regular practical support to collaborate closely with each other regardless of which service or agency they work in.

With or without TAC, I would argue that good practice demands of any practitioner meeting a child with multiple needs for the first time that they:

- find out who is already supporting the child and family
- ask them what they are doing
- work together with these other practitioners to ensure that all interventions are part of a coherent whole

This is the beginning of a collective effort by a collaborative team that contrasts with the support many families have experienced in which, in the words of a group of parents I met recently, 'everyone does their own sweet thing'.

TAC is a collective response to children and families who have multiple/complex needs which fits well with UK provision in which we do not have, and would not give credence to, practitioners who were trained to meet all the needs of these children and their families. TAC joins each family's key practitioners together into a cohesive and continuing team that can:

- arrive at a collective view of strengths and needs of the child and family
- provide a collective response to those needs and to the aspirations of the child and family
- speak with a collective authority about the strengths and needs of the child and family to other practitioners and services

An essential feature of the Team Around the Child approach is that the number of people in each TAC is kept down to 3, 4 or 5. This allows the TAC to be family-friendly and to guarantee that the parent's voice will be properly heard. For each family this means that they will not be asked to attend large case conferences – unless, of course, they clearly elect to do so.

The plurality of needs of these children and families, and the influence these needs have on each other disqualify any single practitioner, no matter how well trained, experienced and motivated, from acting alone in the provision of support. No practitioner who is part of a family's support system can continue to do 'their own sweet thing' and hope to be effective for the child and the family. TAC is not a compromise in the absence of some sort of new specialist practitioners: TAC is the forum for the collective effort that provides the only valid service-provider view of the child and family and the only valid service-provider response to their needs and aspirations.

2. Parents are equal members of the team

If those key practitioners who offer the child and family regular and practical support are going to work as a team, then this team should also include the parent or parents (and perhaps other family members nominated by parents). This is the antidote to parents feeling they are left on the periphery in decision-making about their child and family. In this way TAC informs, involves and empowers parents as truly equal partners. Putting parents at the centre of planning for their child and family is now established as good practice — with or without TAC.

3. A keyworker (or lead professional) facilitates each individual team

Families who have a child with special needs should have a keyworker or a lead professional. (For the time being, I take these two roles as meaning the same thing. I can imagine much confusion if a family has a keyworker *and* a lead professional.) Provision of a keyworker is accepted now as good practice – but is far from standard procedure.

There is a growing consensus (see Penny Lacey Support Partnerships: Collaboration in Action, 2001, and DfES Early Support's Professional Guidance)¹ that keyworkers or lead professionals can help children and families of children with disabilities and special needs get a joined-up service at three levels according to the plurality and complexity of need. (As needs change the child and family can move between the levels in both directions.) My version of the three levels is as follows:

- (i) At the lowest level of complexity, the keyworker functions as a *named person* who helps families get information, helps ensure the local networks function effectively for the child and family, helps families access relevant services when they need them and is available as required to help address new situations.
- (ii) When there are several separate elements of intervention, the keyworker can be the *co-ordinator* who helps keep everything well organised, preventing clashes of dates, duplication of elements of support, makes sure the family can get to the places they need to get to, and ensures that support as a whole is delivered in a way that protects family life and the wellbeing of the child.
- (iii) For children and families with the most multiple and complex needs (because of the child's condition and/or because of the additional needs of the family) good practice requires key professional to join together in a collaborative team or Team Around the Child. Each Team is then facilitated by one of those professionals as the TAC *team facilitator* who then functions as the multi-agency keyworker or lead professional for that family. The tasks within the role are kept to a minimum to prevent overload.

Each family's TAC, with its facilitator/keyworker/lead professional, assumes a collective responsibility to provide joined-up support at each of the three levels above. This includes ensuring:

- parents are fully informed, involved and empowered
- the family accesses all relevant services
- essential information is shared appropriately
- all separate interventions are co-ordinated as far as possible
- the family is supported in each new situation that arises
- key professionals work in close collaboration with each other

In my view, good practice for children who have multiple/complex needs and their families requires heath, education, social services and the voluntary sector in each locality to work together to construct a multi-agency integrated pathway. This will have a single point of entry, a multi-agency referral panel, joint assessment of need, joined-up support systems and joint reviews.

¹ References are listed at the end of the book.

According to the above analysis, children and families who require their multiple interventions to be well co-ordinated will not be well served if they are provided only with a named person. Children and families who require their key practitioners to work in close collaboration with each other will not be well served if they are provided with only a keyworker/co-ordinator.

The expanding population of children whose needs are multiple and complex each require a small individualised collaborative team around them which operates within the supportive matrix of an integrated pathway.

4. The child's development and learning programmes are integrated as far as possible

I would argue that good practice dictates that babies and young children with multiple/complex needs should have development and learning programmes which:

- do not work against each other
- support each other and form part of a coherent approach
- are consistent in all the settings the child attends and between all the people who play and work with the child
- do not overwhelm the child and family by their number and complexity
- do not require the child to adapt to and accept more professionals than he/she is comfortable with

The people in each TAC can decide to what extent they want to deliver separate programmes or move towards a transdisciplinary model by integrating the child's development and learning programmes.

5. There is a pro-active effort to ensure that each TAC is founded in effective relationships

No practitioner can expect to be effective in providing regular, practical support to a child and family until she or he has developed a helping relationship with the members of the family. Professor Hilton Davis has developed the Family Partnership Model (formerly entitled the Parent Adviser Model) which he contrasts with the more usual expert model. It is a relatively simple and explicit theory that attempts to enable all workers to have a clear understanding of the process of helping and the skills and qualities involved. The process is seen as beginning with and founded upon a relationship between parents and workers in the form of a partnership where the partners work together respectfully, communicate openly, explicitly negotiate and agree what they will do together and how, and share different but equally important knowledge and skills. (see Davis, H. et al. 2002)

Other aspects of the theory include outcomes to be expected, the steps in the helping process and the adaptive processes in which parents are involved. Professor Davis goes on to discuss the qualities and skills of the 'helper' and lists fundamental attitudes as respect, genuineness, humility, empathy, personal integrity and quiet enthusiasm. He also argues that all workers should be selected for these qualities, trained in the helping processes and supported in their work by skilled supervisors – who should also work in partnership with them.

Dr. Naomi Dale has developed the 'Negotiating Model' for working with families. She says:

The definition of partnership which I have developed for the Negotiating Model is of 'a working relationship where the partners use negotiation and joint decision-making and resolve differences of opinion and disagreement, in order to reach some kind of shared perspective or jointly agreed decision on issues of mutual concern'. (Dale, N. 1996)

If effective support requires key practitioners to develop helping relationships with families, the TAC approach requires that practitioners also develop effective relationships with each other. Practitioners from separate agencies and services will not be able to collaborate closely with each other unless they trust each other. They cannot develop this trust unless they are facilitated to get together with each other, to get to know each other and to learn about each others' job descriptions, professional practice, aspirations and frustrations. Familiarity, empathy, respect, honesty and trust are just as much desirable elements of the practitioner-practitioner relationship as they are of the practitioner-parent relationship.

The arena in which TAC operates

1. Time constraints

Service improvement plans that conform to Together from the Start, NSF for children Standard 8 and Every Child Matters (all in England) are not going to succeed as viable systems in the longer term if they add to the workload of practitioners who are already fully occupied or even over-burdened. The collective effort cannot be an add-on to present systems. If practitioners are going to work together effectively, with parents and with each other, there needs to be a reconfiguration of how each practitioner and each service provides support to these children and their families.

In the absence of significant increases in personnel, requirements for workers to take on new tasks must be balanced with release from some existing tasks. Joint planning in the TAC approach will require some practitioners to spend more time meeting with each other and with parents. On the other hand, any collective decisions an individual TAC makes to prioritise or integrate the child's separate development and learning programmes can create flexibility in how much time each practitioner spends working with the child. Also, if separate services and agencies can agree to conflate some separate processes then some time can be saved – for the child, for the family and for practitioners. There is a need to achieve a careful balance in which time is found for collaborative teams to meet together and in which professional standards are created or maintained at the highest level.

2. Training constraints

It is not usual practice for practitioners to receive training in how to develop helping relationships with family members nor is it usual practice for practitioners to receive multiagency or multi-disciplinary training to help learn about each other and about how to work with each other. Both of these needs must be addressed as part of a TAC initiative. Experience indicates that training in basic counselling skills is a real asset. The involvement of a practitioner in a child's TAC itself provides opportunities to learn about other practitioners and to share some skills with them. However, real progress in joined-up working requires training opportunities on a bigger scale.

Summary

TAC embodies the following elements of good practice:

- 1. Each child's key practitioners agree to work as a closely collaborative and individualised team.
- 2. Parents are equal members of the team.
- 3. A keyworker (or lead professional) facilitates each individual team.
- 4. The child's development and learning programmes are integrated as far as possible.
- 5. There is a pro-active effort to ensure that each TAC is founded in effective relationships.

If this good practice were established as standard procedure by practitioners and managers in the statutory and independent sectors, then each child and family would automatically benefit from the appropriate level of joined-upness. Named persons, keyworkers/co-ordinators, and facilitated collaborative teams would arise in response to each family's needs at that time. TAC, as a model for joined-upness and as a movement for improved provision, is one amongst many current initiatives working to bring accepted good practice to all children and families.



Team Around the Child: Helping to keep families strong

Introduction

There are two assumptions implicit in this title. The first is that families are strong before the arrival of a child with profound and multiple learning difficulties (PMLD). Logically, this must be no more or less true for this minority of families than for families in general. The second assumption is that having a baby or young child with PMLD might pose a threat to a family's strength. The title also asserts that the Team Around the Child (TAC) approach, when used as the core of an early intervention strategy, can help counter some of the common threats. This essay will explore how the strength of a family might be jeopardised and the potential for TAC, as a collective effort, to help.

In addressing the second assumption, I must avoid the danger of describing the arrival of the new family member in wholly negative and tragic terms. This would be a disservice to people with disabilities and special needs who are no more tragic than the rest of the population. Of course, some babies are born with conditions which leave them with continuing serious illness and some will have short or uncertain life expectancy. This fits within most people's definition of a tragedy within a family whether or not the child also has a disability and special needs.

So what is it about the arrival of a child with profound and multiple learning difficulties that might threaten a family's strength in the first months and years? In my experience the threats can be grouped under the following headings:

- 1. Changes in relationships within the family and beyond.
- 2. Stresses and strains in looking after the child.
- 3. The practicalities of running a home and a family.
- 4. Ineffective support for the child from local services.

Changes in relationships within the family and beyond

If two parents are living together, their relationship is likely to change. For some couples the relationship can be strengthened. For others it might deteriorate quite quickly. If it deteriorates significantly one parent might leave. The relationship can falter because of differences of view about the cause or seriousness of the condition or about the validity of the diagnosis (if there is one). There might be differing attitudes to disability and differing willingness or ability to alter long-held views. A partner can be overwhelmed and disempowered by such negative emotions as guilt or anxiety about the child's wellbeing and

future prospects. A partner might have ideas and aspirations which cannot embrace a child with these needs.

Other relationships in the family can be affected too. Siblings might feel things are not the same any more and see their parent or parents as less available, less tolerant, less loving. While this impacts on the children themselves it is also likely to be a further reason for parental guilt. Relationships with parents' parents, in-laws, brothers and sisters can all be tested. Friends and neighbours might turn away because of their own attitudes to disability and because they are afraid they will not know what to say or how to help.

Stresses and strains in looking after the child

A family can be subjected to continuing stress when a child is unable to eat or drink enough, is subject to persistent and unexplained crying at all hours, is repeatedly ill or fails to thrive. Some infants are subject to all of these. Stress and anxiety might be increased when the child's health and wellbeing depend directly on a complicated regime of medications and nursing procedures carried out by a parent at home. Not only does the parent have to know what to do, she has to observe the child skilfully to know when an intervention is required. If she gets it wrong there will be consequences. Other causes of stress in the family home can be lack of sleep for everyone and few or no opportunities for family members to get a break from these tensions and from each other.

The practicalities of running a home and a family

Each family grows and thrives within a set of practical conditions including finance, accommodation, work, transport and leisure. Each of these can be at risk of a more or less severe downturn in the first months and years. Expenses are likely to increase significantly, the family home might no longer fit everyone's needs, paid work might become less manageable (and the income from it reduced or lost), there will probably be many more occasions when children and equipment need to be transported to clinics, consultations and centres beyond the neighbourhood (with perhaps reduced access to private transport), and lastly, there are likely to be reduced opportunities for evening and weekend leisure time, and holidays away from home might become very difficult or impossible.

Ineffective support for the child from local services

Ineffective support for the disabled child can add to the family's anxiety and stress, impede their adjustment to the new situation and spoil their coping strategies. The major reasons why support from the statutory services can be ineffective include:

- the absence of relevant support (still the experience of many families in the first months)
- parents feeling they are not allowed to be involved in decisions about their child
- inflexible provision which is offered on a 'take it or leave it' basis with no reference to actual needs
- fragmented support in which appointments and home visits are chaotic, disruptive and unmanageable
- delivery of development and learning programmes to the child on a piecemeal and disjointed basis

If we are prepared to credit families of children with PMLD with being initially just as strong as other families, then perhaps we can also have faith that the majority of families, if given timely and relevant support will, after a period of uncertainty, confusion and floundering, regain a more even keel and a sense of purpose and direction. The child with PMLD will gradually stop being so 'special' and will assume his or her place in the family from which he or she benefits and to which he or she contributes. This positive outcome must be a major aim of family-centred early support services.

How can the Team Around the Child approach help keep families strong? TAC is not a brand name nor should it be thought of as another fixed system into which children and families must be persuaded to fit. The principle behind TAC is merely that when a few practitioners are working closely with a child who has PMLD they should agree to collaborate closely with each other and with the parent or parents. This joined-up approach appeals to most parents as just common sense. So what can TAC, as a collective approach, do to help keep families strong and to counter those threats which are frequently consequent on the arrival in a family of a child with multiple and complex disabilities?

The Team Around the Child is defined as an evolving and individualised collaborative team of the *few* practitioners who see the child and family on a regular basis to provide practical support in education, therapy and treatment. It offers a full place to parents (and other family members if the parents wish) and it ignores all agency boundaries. Its contribution to effective support is as follows:

- 1. Each TAC comprises just a handful of people whom the family know well and trust. Members join and leave as needs change. Because only one or two people change at a time, the family benefits from a continuing support system which remains seamless even over major transitions.
- 2. Parents have the reassurance of seeing their key practitioners meeting together, every half-term or so, to share observations, iron out contradictions and learn what each other is doing. This collaborative effort allows parents to contribute to and share in an agreed and balanced collective view of the strengths and needs of the whole child and the family.
- 3. Parents, as full members of their TAC, are informed, involved and empowered in all aspects of the child and family's support. This is *genuine* partnership with a straightforward process and a visible practical outcome.
- 4. TAC sits with the child and family at the centre of their support network providing joined-upness at whatever level it is currently required. Penny Lacey (Lacey, P. 2001)¹ argues that liaison, co-ordination and collaboration 'can be conceived on a continuum, with liaison indicating the least degree of communication between agencies or professionals through to collaboration indicating the most'. Each TAC, as a collective effort for a child and family with multiple needs, will liaise as necessary with other services (for example, housing, benefits and transport), will ensure that such interventions as clinics, assessments and home visits are co-ordinated in space and time as far as is possible, and can facilitate close collaboration on the child's development and learning programmes. For those practitioners and parents who are willing, the TAC is a forum for a full transdisciplinary approach with unified assessments and fully integrated education/therapy programmes.

¹ References are listed at the end of the book.

Walsall Child Development Service has recently asked parents how the TAC approach has helped their families. The main response was that by having TAC, there was more focused and effective communication. Parents found that they did not have to do everything for themselves, but that when a problem arose they contacted their keyworker and the TAC responded as a whole. Parents found that things happened more quickly and appropriately so that they did not have to expend time and energy on chasing appointments and actions. Parents valued that any family member could attend reviews – which is very different to the conventional 'medical' appointment system which expects only parents to attend. By actively involving extended family members in this way parents felt their support network had been extended. Walsall CDC gives two examples of how TAC helps keep the family strong:

- 1. Child X is eight months old and has complex physical needs. His mother, a single parent, has an older daughter of four. Her concerns initially were not only related to child X, but also focused around the impact of her son's disability on her daughter, who, she felt, was being left out and not being given the time and attention she needed. Her main concern, as documented in the Family Service Plan, was to have some free time to spend with her daughter and also for herself. Her TAC, which includes professionals from health, education and social services, focused on obtaining an early nursery placement for her daughter, an additional place at her local SureStart Nursery and a place in the SureStart crèche for her son (where all staff were trained by the TAC in his particular Physical Management Programme). These arrangements were completed by the TAC and keyworker within one month. This has allowed mother time to dedicate to her daughter and to herself. She has also found she has more structured time now to deal with her son's needs and issues.
- 2. Another family that uses TAC had concerns regarding acceptance and understanding of their child's condition by the paternal grandparents. Also, initially, the father was finding it very difficult to come to terms with his son's disabilities. The TAC was therefore set up with an objective that father could be fully involved in all aspects. To this end reviews were held to fit in with father's work shifts. Appointments at home by the physiotherapist and Early Years worker were also booked for when father could be present in order that he could fully participate in programmes of intervention. These programmes were videotaped so that other family members could be involved in the child's care. This led, at the parents' request, to involving grandparents in appointments and reviews and to supporting them in the child's Physical Management Programmes. These parents value their TAC for facilitating more open dialogue between the various members of the family.

There is no average UK family. There is wide and welcome variation in composition, circumstances, culture and beliefs. Responses to a child with profound and multiple learning difficulties will vary as will the strengths of family members. Different families have different needs and these will change with time within each family. Effective early intervention for a family whose child has PMLD must be a collective effort which empowers parents, helps keep the family strong and responds flexibly to the needs of each individual child and family. TAC provides a forum for this collaborative family-centred approach.

5

Integrated programmes and the Primary Interventionist in early childhood intervention

Summary

There is significant benefit to babies and pre-school children with profound and multiple learning difficulties (PMLD), to their families and to their practitioners when all interventions for development and learning are pulled together into an integrated or whole-child approach. Integrated programmes will cater for children who are not yet ready to compartmentalise activity. Provision of a Primary Interventionist will protect the child from exposure to more practitioners than they can accommodate. Both models offer practitioners opportunities to work together in a transdisciplinary approach and create flexibility in how they use their time.

Who needs an integrated programme?

I would suggest that all babies and pre-school children with PMLD will benefit from some integration of their development and learning programmes, whether provided by teachers, therapists or others. Though practitioners might specialise in the separate disciplines of perception, movement, communication, understanding, etc, it is a mistake to assume babies and young children can compartmentalise their activity in the same way. Infants with PMLD are likely to bring their whole being into each situation they encounter, each activity requiring some integration of posture, movement, language, dexterity, perception, emotions and social skills. It is the whole child we must have in mind when we plan interventions – just as parents of young children do naturally.

What would an integrated programme look like?

It is probably best to think in terms of providing activity for the child which is natural, meaningful and enjoyable rather then puzzling out how to join various discipline-specific activities and goals together into some composite multi-disciplinary programme. This approach follows the principle of starting where the child is rather than starting from where we are as separate practitioners. The integrated education/therapy activities then will be part of the daily routine (mealtime, bath-time, bedtime, dressing, moving around the house, socialising, playing, etc).

The task of each practitioner is to incorporate their required work into these activities so that it fits naturally and becomes part of a routine which is always developing. Practitioners' goals might have to be prioritised to keep the amount of new work within the child's capacities and care must be taken to ensure that each activity includes elements in which the child is already competent, elements he still needs to practise and elements which require new learning. The

aim is to provide new opportunities for development and learning at the child's pace and which maintain or enhance his enjoyment and involvement.

Who needs a Primary Interventionist (PI)?

A Primary Interventionist is a practitioner who, by agreement, does more work with the child and parent than do the other practitioners who are also involved with the child's development and learning. In early childhood intervention the child, parent and PI will work together in a threesome. The PI has validity for babies and children who are not yet able to form multiple relationships or accommodate a number of people handling and working with them. In my experience, this group of children would include babies (whether premature or not), infants with significant sensory impairment and infants who are generally ill at ease, or fearful, of the world around them and the people in it. Readers will be able to add to this list. The PI will be the first practitioner to carry on and extend the work begun by the parent, and is the main person providing the baby or young child, in partnership with the parent, with development and learning opportunities as prescribed by the other key practitioners involved with the child and family. For some families the first task of the PI will be to help the parent and baby relate to each other.

Obviously, it is expected that for most children with PMLD the need for a PI will be a phase that will lead, sooner or later, to acceptance of a widening group of people. As the child gets older a widening group is inevitable, but for some infants, the PI represents the best response services can make to the child's needs in early intervention.

Who can be a Primary Interventionist?

Any of the child's practitioners can, by agreement, become the PI for a specified period. If one of the teachers or therapists is chosen, then the other teachers and therapists will benefit by gaining time to spend with other children. This can help compensate for the additional time spent in coming to agreement about integrated programmes and PI. If the person chosen as PI is a practitioner who can see the child on a daily or weekly basis, for example a nursery nurse or a Portage worker, then it is probable that the child will have more frequent exposure to each practitioner's work than would otherwise be possible. A practitioner who can see the child only once every few weeks will have the reassurance that the child is benefiting from her intervention on a regular basis – even if the intervention is indirect most of the time.

What responsibilities do practitioners have when working with integrated programmes and Primary Interventionists?

The primary concern is to ensure that these models of working result in the child having increased exposure to the development and learning opportunities prescribed by the key practitioners, and that each practitioners feels her skills, knowledge and experience are impacting on the child and family more effectively than in the traditional model of separate interventions and multiple programmes. Babies and pre-school children with PMLD have a right to support from the full team of highly trained and experienced therapists, specialist teachers and play specialists. Integrated goals and PI are means to bring all of this expertise together into a whole approach.

Integrated programmes and Primary Interventionist approaches both invite practitioners to work within a consultant model, exchanging skills, knowledge and understanding with colleagues. Boundaries are softened and there is willingness for sharing both general and child-specific information between disciplines. Each practitioner gradually widens and deepens her knowledge base and range of skills, and by doing so enhances her own specialism and practice. To maintain standard at the highest possible level, each practitioner who provides part of her programme to a child through a PI can apply a code of practice. My suggestion for this is:

- 1. Ensure the PI is competent to take on the work.
- 2. Ensure the PI has necessary time and resources.
- 3. Give necessary instruction and training with written or video notes if required.
- 4. Provide ongoing support as necessary.
- 5. Monitor PI's performance, give helpful feedback and ask for feedback from PI.

Training

Any council department or health trust, or integrated health/education/care service, that expects its practitioners to adopt these practices must provide for their training and support needs and for the smooth transition from traditional separate working to new collaborative activity. The foundation of this training must be a multi-agency effort to facilitate multi-disciplinary practitioners getting to know each other and learning to respect and trust each other. In this in-service training, practitioners can learn about each other at the same time as they are learning with each other. Until these inter-practitioner relationships are established all plans for close collaboration will come to nothing.

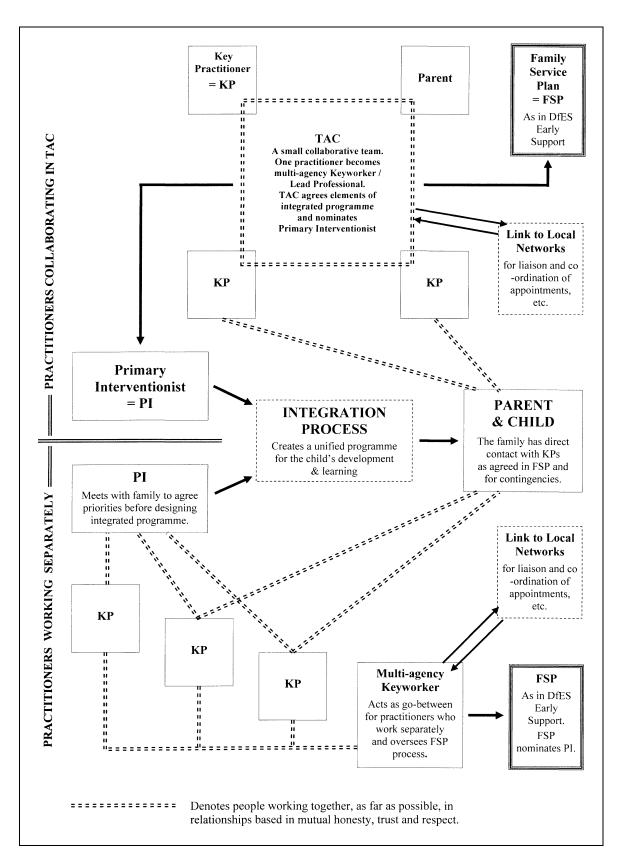
The One Hundred Hours (OHH) experience

During the 1990s One Hundred Hours (OHH) provided keyworker-based support to families of neurologically impaired babies and young children. This was a voluntary organisation in Yorkshire, established to develop and validate the keyworker model of child and family support. Each keyworker was a trained and experienced professional (nurse, social worker, teacher, health visitor, etc) who was then employed by OHH with the single role of keyworking for one or more families.

Having at that time no useful guidance about what keyworkers should do, OHH allowed the role to develop during the decade in a tripartite partnership between families, keyworkers and OHH management. A full account of OHH can be found in *The Keyworker – a practical guide* (Limbrick-Spencer, G. 2001)¹, but I will focus here only on how the keyworker could, if the family wished, generate integrated programmes and become the Primary Interventionist. I shall refer to the diagram overleaf in which I have used *Primary Interventionist* and *Team Around the Child (TAC)* though neither of these expressions was used at that time within OHH.

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¹ References are listed at the end of the book.



Two approaches to programme integration in the One Hundred Hours model

The diagram shows that the keyworker had two options when the family were looking for some integration of interventions. In the first and far less satisfactory option, the keyworker would assume the role of go-between amongst the child's key practitioners (usually therapists and pre-school specialist teachers). The keyworker's task was to invite them to provide some part of their intervention as consultants. The keyworker would then integrate these separate activities and goals into an integrated programme. This approach was used when key practitioners were working separately from each other in the traditional approach. If practitioners did not choose to adopt a consultant role with the keyworker, then the keyworker could integrate whatever home programmes practitioners had given to the parent.

The much more successful option was for the keyworker to invite key practitioners to work together in a TAC, or, as happened in one instance, to join an existing TAC-type meeting. The clear benefit of this option is that key practitioners, parent and keyworker are in regular and close collaboration and can modify and adapt their interventions as they learn at first hand what the other people are thinking and doing.

The first option requires the keyworker to carry the responsibility to integrate interventions, while in the second option, the key practitioners assume a collective responsibility to integrate their interventions. In my view, this is common sense and obvious good practice for children and families who require multiple and complex interventions.

Two further points are worth making. The first is that each practitioner who works as a consultant must come to a decision with each family about what direct contact she will continue to have for review, assessment and any specialised interventions. Secondly, therapists might be involved in some form of treatment as distinct from helping the child's development and learning (e.g. chest drainage). This article does not concern itself with such treatment.

In conclusion

There is an increasing population in the UK of children who require on-going multiple interventions. In my experience there have always been some families whose practitioners have worked together under their own initiative to provide a coherent and integrated approach. There are many other families whose children have had reduced learning opportunities because of confusion, contradictions and inconsistencies. My appeal would be for new multi-agency systems which provide all young children with PMLD with integrated support by facilitating practitioners in a collective and collaborative response to the child's needs.

A significant move in this direction would be for service providers and practitioners to adopt a code of practice for each practitioner to apply when first meeting a family with a baby or pre-school child with PMLD. I offer the following suggestions as a starting point for developing a code of practice:

- 1. Ask the parent which other services and practitioners are already involved.
- 2. Check that the family and the child are ready for another practitioner to be directly involved. If not, decide if the new work can be offered on a consultant basis.
- 3. Find out what approaches, programmes, goals, etc are already in place.
- 4. Ensure that any new work offered fits well with these existing interventions.

5. If there is already a TAC operating, make contact with it, and if there is not, suggest establishing one.

Neither integration of programmes nor the provision of a Primary Interventionist require busy practitioners to add to their workload. Both developments can be part of a radical reconfiguration of service provision for children and families who require multiple interventions. To succeed, this must be an initiative at strategic level, with full involvement of families and practitioners, in which fresh decisions are agreed about how practitioners' time and skills are best employed.

6

Team Around the Child: The small collaborative team in early childhood intervention for children and families who require ongoing multiple interventions

Introduction

Effective early childhood intervention for all babies and young children with disabilities requires joint working between all the practitioners involved and between practitioners and parents. Varying degrees of joint working are applicable to children and families according to need. The Team Around the Child (TAC) approach facilitates the highest degree of joint working for children and families with complex needs. The approach enables each child's key practitioners and parent to collaborate with each other to achieve collective competence and provides them with an opportunity to operate a transdisciplinary model in which practitioners act as consultants to a primary interventionist.

The Team Around the Child (TAC) approach

The description of a TAC meeting in Figure 1 below is offered as a practical illustration of how the approach works. The imagined scene can be happening in the family's home, in a local centre, in a health, education, social care or independent sector base or in another venue which suits the family's needs for place, date and timing.

There are six people present: a baby (with his mother when he is not asleep in his buggy), the baby's mother, the physiotherapist, the speech & language therapist, the pre-school visual impairment teacher and the family's keyworker (or lead professional) who is also the baby's health visitor. These comprise the child and family's present TAC and it is the third TAC meeting since the baby was discharged from the Special Care Baby Unit some months ago. Everyone is smiling at the moment because, for the first time, the baby has just appeared to visually track a moving toy.

Most of the meeting so far has been taken up by a detailed discussion of feeding. As keyworker, tasked with leading the meeting through its agenda, the health visitor is the only one with an open file on her lap. She is sitting on the sofa with the mother and was thus in a good position to offer some warm support and reassurance half an hour ago when the mother shed tears of frustration about the baby's weight. The two therapists are kneeling on the floor because they were working with the baby to explore feeding positions. The mother, visual impairment teacher and the health visitor were all able to contribute fully to the discussion using their own expertise

and knowledge of the baby. The result was a detailed whole-child plan for mealtimes including positions, choice of spoon, cup and dish, type and quantity of food, oral functions and use of language, signals and prompts. The mother was reassured to have a group discussion on this important issue with a clear consensus on how to proceed. The broader discussion which followed addressed the following issues:

- i. Possible interventions should the feeding problems continue.
- ii. How to get the older child to school leaving the mother free to give the baby breakfast without rush.
- iii. The forthcoming routine appointment with the consultant paediatrician. It was agreed the health visitor would accompany the mother to help in a discussion about the baby's nutritional status.
- iv. The forthcoming appointment with the dietician. It was agreed that the speech and language therapist would approach her to see if she (the dietician) could join the session with the consultant paediatrician instead of having a separate session which the mother could not easily attend.

After agreeing the various elements of the plan of action, the meeting ended by fixing a date, time and venue for the next TAC meeting in a few weeks time. Because the baby's father had said he would like to start coming to TAC meetings when he can, the next meeting was fixed with his work pattern in mind.

Figure 1: TAC in action

The baby in the above scene can be described as having 'complex needs'. He has neurological impairment and consequent difficulties in posture, movement, hand function, vision, eating, drinking, sleeping, vocalising and communication. Time will tell if he has any learning or hearing disability. Very many practitioners have become involved since birth but the ones above are those presently offering the most regular and practical interventions.

A group of practitioners from services who have pioneered TAC in England and Scotland have agreed the following working definition of TAC:

The Team Around the Child approach has been designed to provide effective, timely and seamless support for children and young people with complex needs and their families ('family' being defined by each child's circumstances). It supports child- and young-person-focused family-centred planning and provides each child and young person with their own individual, collaborative team of practitioners.

Minutes of meeting

The phrase 'complex needs' is in common usage but has no nationally agreed definition. My description of this client group suggests that problematic complexity is to be found as much in service provision as it is in the child and family:

Children and families with complex needs are those who require ongoing multiple interventions – and for whom those interventions are, or are likely to become, burdensome to the family and counterproductive to the child.

Figure 2 below outlines this problematic complexity in service provision in terms of the potential ill effects of fragmented service provision on the family and on the child who requires ongoing multiple interventions. Once the situation is described in these terms, some practical approaches to resolving the complexity become obvious.

For parents and siblings

When there is no attempt to co-ordinate and rationalise the pattern of home visits, assessments, education/therapy interventions, meetings, etc or to help with child care and travel for the various clinics, centres and hospitals, the result can be:

- i. An almost impossible and escalating daily and weekly routine which the parent struggles to maintain so that the child is not denied anything which could be valuable.
- ii. No opportunities for the parent to work, study or socialise activities which could be a welcome respite from the daily round.
- iii. An overload of separate items of advice, suggestions and separate discipline-specific home programmes. Parents can be ambivalent about these, feeling they should do them but really preferring just being a parent to becoming a sort of teacher/therapist.
- iv. Unresolved contradictions in advice about helpful approaches, treatment, medication and surgery.
- v. Siblings being sidelined within the family.

The result can be an exhausted family suffering a gradual erosion of time, money, energy and spirit with no prospect of any sort of normal family life. Such a family is made more vulnerable by these fragmented services.

For babies and pre-school children

When practitioners, whether from health, education, therapy or care services, keep their interventions separate from each other:

- i. The child might have to relate to, and accept 'hands-on' interventions from more people than he is comfortable with.
- ii. Interventions are piecemeal rather than whole-child as though language, movement, cognition, socialising, etc could operate independently of each other.
- iii. Discipline-specific programmes might not be compatible with each other. For instance, a child will be confused if in a speech & language therapy session he has to sit and sign for a toy while in a physiotherapy session he has to move in some way to get what he wants.
- iv. Attitudes, approaches and programmes might be quite different in each place where the child regularly plays and works, e.g. nursery, centre and home.
- v. Practitioners have no opportunity to consider how one condition or disability, e.g. sensory loss, will impact on others, e.g. cerebral palsy and/or ASD, or to plan strategies in which all strengths and needs are integrated.

The result can be that the child's opportunities for development and learning are reduced or nullified.

Figure 2: Problems which can arise when there are ongoing multiple interventions

TAC comes indirectly from the work of One Hundred Hours (Limbrick-Spencer, G. 2001). This voluntary organisation pioneered keyworking during the 1990s for families of babies and young children with complex needs. The model was then refined in my consultative work with service providers across the UK who wanted to achieve joint working but did not have funds for full-time One-Hundred-Hours-type keyworkers. These managers and practitioners, with children who require ongoing multiple interventions in mind, considered TAC to be a better fit with their existing resources and practitioner roles.

The TAC approach is designed as an antidote to the following:

- 1. **Fragmentation of support:** This includes an unco-ordinated and often chaotic pattern of appointments, meetings, assessments, etc with the possibility of duplication, gaps and mismatches in provision.
- 2. **Parents who are sidelined:** Many parents complain that they are not allowed to be equal partners in decision-making for their child and family.
- 3. A piecemeal approach to the child's development and learning: This comes from the mistaken view, in my opinion, that we can cater for babies and young children as though such functions as posture, movement, language, play, cognition, socialising, etc operate in isolation from each other.

TAC and joint working

This section discusses how TAC facilitates joint working in early childhood intervention. There are five headings:

- 1. The need for joint working at appropriate levels.
- 2. TAC: a collective effort within a matrix of shared responsibilities.
- 3. Collective competence.
- 4. TAC and transdisciplinary teamwork.
- 5. TAC and keyworking.

1. The need for joint working at appropriate levels

Dr. Penny Lacey (Lacey, P. 2001) describes how people can work together at increasing levels of closeness according to child and family need. She suggests that collaborative teamwork is necessary when needs are complex:

Liaison, cooperation, coordination and collaboration are often, erroneously, used inter-changeably. These terms can be conceived on a continuum, with liaison indicating the least degree of communication between agencies or professionals through to collaboration indicating the most (Lacey, 1995). Payne (1993) defines liaison as making contact with other organisations and sustaining this contact. This seems to be the first step towards cooperation which denotes the minimum manner in which two organisations or professionals can work together. They take specific steps to ensure that they do not cut across each other's work or otherwise hinder each other.

¹ References are listed at the end of the book.

The next stage is coordination, where organisations and individuals 'work together when this is necessary' (Payne 1993, p.4) by streamlining services and timetabling so that children and their families receive a well thought out package of care and education. The final point on the continuum, collaboration, includes processes such as sharing, trusting and handing over skills, joint assessments and mutual training. Professional boundaries are crossed naturally in the effort to meet a complexity of needs.

Lacey equates collaborative teamwork with transdisciplinary teamwork and says of both:

... the importance of a keyworker and a small team in direct contact with children and their families can be appreciated. This helps to prevent a multiplicity of personnel overwhelming families with alternative or even conflicting advice. Most contact with the child and family is through the keyworker and small team, although direct contact with others may be desirable, especially if needs change dramatically and specialist assessment is required.

Deborah Chen (Chen, 1999) in speaking of the situation in the USA, champions collaborative teamwork as follows:

In the transdisciplinary model, service providers of various disciplines collaborate to conduct assessments to plan and implement interventions. Families are active members of the transdisciplinary team, and interventions are integrated into the daily routines....the transdisciplinary approach is essential for providing effective early intervention services to families and their infants with disabilities, especially those with significant disabilities.

There is consensus here that effective support for children and families with the most complex needs requires a small individualised collaborative team as offered by both TAC and transdisciplinary approaches.

2. TAC: a collective effort within a matrix of shared responsibilities

Each TAC is defined as much by the practitioners who are not members of it as by those who are. In a TAC system it is essential to maintain the involvement of those practitioners who provide essential interventions to a particular child and family on a less regular or less close basis than do those in the TAC at that time. For each child, these are the ten, twenty, thirty or more 'peripheral' practitioners (Limbrick, P. 2001, p.5) or the 'network of people in intermittent contact' in Lacey's terms (Lacey, P. 2001, p.12). Each practitioner involved in some way with a particular child becomes part of a collective effort and assumes a professional responsibility to joint work at appropriate levels with the others. This matrix of shared responsibilities is the antidote to what Lacey terms 'benevolent chaos' (Lacey, P. 2001, p.141) and is a complex pattern in which practitioners switch as necessary between the modes of liaison, co-operation, co-ordination and collaboration in pursuit of effective support for each individual child.

There has always been a need for practitioners to work together but, without any agreed structure, joint work has been largely left to the discretion of individual practitioners working under their own initiative. For many families support resembles an attempt at a symphony by musicians without a conductor—and with sections of the orchestra in separate concert halls. There is much work to be done by health, education and social services and the independent

sector at strategic level in pursuit of seamless early support and *Together from the Start* (DfES and DOH. 2003), *DCSF Early Support* and *Every Child Matters: Change for Children programme* have set the scene for this in England (see references at the end of the book).

In practical terms, we can construct this matrix of shared responsibilities and facilitate the collective effort within it at two levels in each locality:

- Each child's TAC practitioners and their line managers can help orchestrate support, for they sit with the family at the centre of the network, understanding the whole picture of child and family strengths and needs, and being aware of all the current and planned interventions. Whilst TAC members are collaborating closely with each other they can facilitate and encourage appropriate joint working between other services and practitioners.
- 2. At the strategic level, each agency, whether a children's service, health trust, education department, social service department, voluntary organisation or private agency, could promote shared responsibility and collective effort by agreeing a code of practice. Figure 3 below offers a starting point for this:

It is the responsibility of each practitioner who is supporting a child and family who require ongoing multiple interventions, or who is meeting such a child and family for the first time, to consider:

- With whom do I need to network/liaise?
- With whom do I need to co-ordinate my interventions?
- With whom do I need to collaborate closely?
- With whom do I need to work to achieve collective competence? (see next section)

To construct and maintain the network of shared responsibility, such a protocol would have to apply to every practitioner at every level in each local agency or service. The aim of the protocol would be for shared responsibility to become eventually part of local professional culture.

Figure 3: A code of practice to promote shared responsibility

3. Collective competence

This concept, which I have termed 'collective competence', asserts that when a child has more than one significant disability no practitioner can be fully competent while operating independently of others (Limbrick, P. 2007). To illustrate collective competence we can imagine a blind baby with cerebral palsy whose key practitioners are a paediatric physiotherapist and a visual impairment home-visiting teacher and whose main carer is her mother.

We can consider the separate competencies of the baby's mother, the physiotherapist and the teacher to provide effective whole-child interventions for the baby. The mother in this scenario knows all about her baby's growing personality, habits and preferences, is developing a mother/baby relationship with communication and affection, is encouraging some early play and independence and has already learned much about how to care for her baby's everyday needs. However, she cannot be competent on her own to meet the child's development and learning needs because at this stage she has a tremendous amount to learn

herself about blindness, about cerebral palsy and about what she can do to help her new baby manage these conditions. She will surely become very knowledgeable about these disabilities eventually, but during these first months she is inevitably a learner. The paediatric physiotherapist knows how to promote posture and movement in sighted children, but how will she encourage a blind child to lift her head while lying on her tummy? Can the baby be encouraged to roll when she does not 'know' yet if the floor will still be there when she moves? The visual impairment teacher knows how to promote play, communication and independence in sighted infants but how will she achieve this when the baby cannot sit or hold her head up and has only limited use of her hands? The answer must be that competence in a whole-child approach to this baby can only be achieved by all three working closely together – collective competence.

Another factor in this argument for collective competence is the lack of research into effective interventions for children with multiple disability. Practitioners cannot reach for textbooks of good practice for every possible combination of two, three, four or more conditions and disabilities – and will never be able to do so. While we have to resort to trial-and-error approaches and learn about each child 'as we go along', it is surely good practice to aim for collective competence in small collaborative teams rather than trying to get by on our own.

For these children two (or more) heads are likely to be better than one and it seems fair to assume that a plan coming out of a shared knowledge of the child and with shared concern and expertise is going to be superior to any strategy devised by a lone operator. TAC ideology argues that this collective competence can only be fully expressed and exploited when each child's key interventionists meet regularly face-to-face in TAC meetings to share observations, aspirations and skills and to agree a joint action plan.

4. TAC and transdisciplinary teamwork

In my experience, there can be a continuum of collaboration between practitioners within the TAC approach, and the term 'transdisciplinary' only applies to those individual TACs in which practitioners have agreed to collaborate most closely. The following descriptions illustrate how practitioners can collaborate at the two ends of this continuum:

Lesser collaboration: In the TAC meeting practitioners and parent share views on the current needs of the child and inform each other about the approaches they are using and the goals they are working towards. Collaboration might then include the following processes:

- 1. Any instances of contradictory views, approaches or goals are ironed out.
- 2. If the whole picture of interventions, when constructed at the meeting, appears to be either overloading child and/or family or not providing enough opportunities to the child or support for the family, then adjustments are agreed. This might include prioritisation of interventions and agreements about involving additional services or practitioners.
- 3. Agreement about consistency in such basic functions as positioning, communication, hand function, etc which are integral to everything the child does.
- 4. Agreement to promote each other's goals when appropriate. As an example, if the physiotherapist is promoting rolling on the floor, a sensory impairment teacher will encourage the child to roll when playing on the floor with the toys she is using in her programmes. In turn, the physiotherapist will integrate the same toys into her work

and use them with the child in the same way as the teacher does. This obviously depends on a willingness to share information.

Greater collaboration: Orelove and Sobsey, (Orelove, F. P. & Sobsey, D. 1991) describe the transdisciplinary team model as follows:

Originally designed to serve infants at high risk for disabilities (Hutchinson, 1978; United Cerebral Palsy Associations, 1976), the transdisciplinary model has been embraced by programs serving children with multiple disabilities. The model is characterised by a sharing, or transferring, of information and skills across traditional disciplinary boundaries. In contrast to multidisciplinary and interdisciplinary approaches, the transdisciplinary model incorporates an indirect model of services, whereby one or two person(s) is the primary facilitator of services and other team members act as consultants (Albano et al., 1981).

In the illustration above of lesser collaboration the people in the child's TAC agreed to promote each other's efforts. The members of the well-established TAC, when they know and trust each other sufficiently, can go much further by agreeing to radically modify how their interventions are presented to the child (Limbrick, P. 2006). The two main possibilities are as follows:

- 1. **Integration of separate programmes:** Education and therapy interventions for the child's development and learning (which, in my view, lose their traditional distinction with these children and would both be better described just as 'education'), instead of remaining as separate discipline-specific programmes which are perhaps offered to the child at separate times and venues, are integrated as far as is appropriate into the child's daily routine of mealtime, bath-time, bedtime, dressing, moving around, socialising, playing, etc. This approach recognises that all of the child's functions are interconnected and interdependent and results in interventions which appear relevant and meaningful to both child and parent and which they will feel are worth doing.
- 2. The primary interventionist: The primary interventionist is a practitioner who, by agreement within the TAC and for an agreed period of time, does more work with the child and parent than do the other key practitioners. The role has validity for babies and children who cannot yet form multiple relationships or accommodate more than one or two people handling and working with them. In early childhood intervention the primary interventionist works in a threesome with child and parent and becomes the main person providing the baby or young child, in partnership with the parent, with those development and learning opportunities prescribed by the other key practitioners. Any of the child's practitioners, for example, specialist teacher, therapist, nursery nurse or Portage worker, can become the primary interventionist for a specified period. Figure 4 on the next page shows how the primary interventionist functions within the TAC system and, importantly, how the other key practitioners maintain their contact with the child and family. This level of contact is agreed with the parent by each key practitioner and is written into the Family Service Plan.

This transdisciplinary approach with its integrated programmes and primary interventionist is intended to give the child increased exposure to development and learning opportunities and must be validated by each practitioner and parent perceiving that everyone's skills, knowledge and experience are impacting on the child and family more effectively than in the traditional model of separate interventions and multiple programmes. Practitioners are invited

to soften (but not eliminate) their professional boundaries and to work within a consultant model, sharing skills, knowledge and understanding with trusted colleagues.

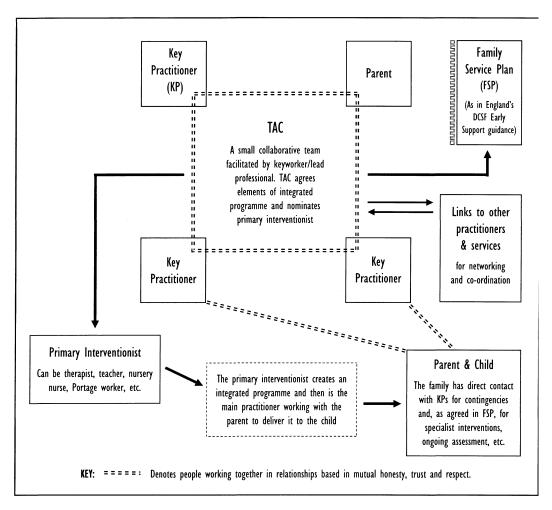


Figure 4: The primary interventionist within the TAC system

Though each individual TAC must come to its own decision about integrating programmes and nominating a primary interventionist, a prerequisite of success is a multi-agency commitment at strategic level to training in the transdisciplinary model and establishing a code of practice to ensure standards are maintained at the highest level. Figure 5 below offers a starting point for a such a protocol. (The same protocol could well be applied to practitioners who hand over some aspects of their work to parents in traditional approaches.)

It is the responsibility of the practitioner who is handing over some work to a primary interventionist to:

- satisfy herself that the primary interventionist is competent to take on the work
- ensure that all necessary training and instruction has been given to the primary interventionist—with notes or video to refer to when necessary
- ensure the primary interventionist has all necessary time, space and equipment
- be available to provide ongoing support as necessary to the primary interventionist

• monitor the primary interventionist's performance, give constructive feedback and be willing to receive constructive feedback about the support offered.

These protocols should apply whether the handover is to a practitioner of equal professional standing, to a practitioner who has a lower level of training and experience, or to a practitioner with a higher level. This is the essence of the transdisciplinary approach in which skills are shared within equal partnerships based on mutual honesty, trust and respect.

Figure 5: A code of practice for practitioners acting as consultants to a primary interventionist

5. TAC and keyworking

The guidance *Together From The Start* (DfES & DOH, 2003) recommends that all children with complex needs and their families should have a keyworker and begins its definition of the role with:

A keyworker is both a source of support for the families of disabled children and a link by which other services are accessed and used effectively.

DfES Early Support's Professional Guidance (DfES, 2004) acknowledges the need for practitioners to work together in escalating degrees in response to increasing levels of need in children and families and, focusing on the keyworking role, describes a spectrum from less need for a keyworker or lead professional (when there is a single agency in contact with family and a single, relatively mild or transitory condition in child) to more need (when there are many individuals or agencies in contact with family and multiple/relatively severe conditions in child). They recommend three levels of provision on this escalating spectrum as follows (with numbers inserted for clarity):

- 1. 'Befriending service' helpful. Community-based information services. Contact for more information clearly identified.
- 2. Some keyworking or care co-ordination required. More regular contact with family needed to ensure continuity of care.
- 3. Full 'Team Around the Child', keyworker or lead professional service required.

Together From The Start (DfES & DOH, 2003) refers to Himmelman (Himmelman, A.T. 1996) who offers a continuum of co-ordination from networking, through co-ordination and then co-operation to collaboration. This is clearly a different interpretation of these individual processes from that in Lacey's sequence of liaison, co-operation, co-ordination and collaboration. The experience of One Hundred Hours suggests a practical application of the continuum of increasing joint working which might simplify the issue. The One Hundred Hours keyworker in the 1990s facilitated joint working on an escalating continuum with three recognisable stages described as follows:

1. **Keyworker as Named Person.** This practitioner befriends the family, provides some emotional support, helps the parents with information and access to services and ensures the child and family are properly embedded in the local networks. In my experience, most families of disabled children will benefit from this support.

- 2. **Keyworker as Co-ordinator.** When there are multiple interventions this practitioner works with the family to achieve the best possible co-ordination and rationalisation of the separate appointments, meetings and assessments with careful consideration of the family's routines, finances, travel needs, other children, etc.
- 3. **Keyworker as TAC facilitator.** This practitioner is a member of the TAC with the specific role of supporting the family through the TAC process, making sure each TAC meeting runs smoothly, pulling TAC decisions together into the multi-agency action plan or 'Family Service Plan' (in England's DCSF Early Support terms) and arranging for the plan to be sent out to the practitioners on the agreed distribution list.

In this tiered One Hundred Hours model, which is built on a three-part joint working sequence of networking, co-ordination and collaboration, each level of keyworking embraces the previous levels and the keyworker becomes the agent who facilitates the gearing up and the gearing down through the levels of joint working to accommodate changes in the child's condition and the family's situation. The majority of keyworkers and lead professionals in the UK are practitioners who take on this new role alongside their main role as therapist, teacher, health visitor, etc. To avoid overload, the additional tasks in the keyworking role at whichever level must be kept to a minimum. In the TAC approach, the keyworker is supported by the other TAC members who share the workload with her – as might be expected in a genuinely collaborative effort.

TAC, systems thinking and plain common sense

The TAC approach can form the heart of a locality's multi-agency strategic plans for effective early childhood intervention for children who have more than one condition, disability or need. The approach conforms to the discipline of systems thinking and appeals to most people's common sense.

Systems thinking

Systems thinking emerged during the last century as an attempt to describe how the world works. The people who developed systems thinking then, and those involved in it now, come from many disciplines including biology, engineering, sociology and physics. Their creed is that everything we can think of is part of a system and does not function on its own. This applies to systems themselves which are comprised of smaller systems and which join together into more complex systems. Whether we are thinking about a brain cell, a kidney, a baby, a family, a supermarket, a car factory or a multi-national bank, we are not going to get very far in diagnosing problems or designing helpful interventions if we focus on individual parts and ignore how each part relates to the other parts. The functioning of any system depends on interconnections and relationships. Each part depends on the other parts and nothing exists on its own. For an introduction to systems thinking see Bertalanffy, L. (1968). For a longer account of a systems approach to children with multiple disabilities see Limbrick, P. (2007).

A systems-thinking approach to a child and family who have complex needs would require service providers to:

• perceive the child as whole and not as a collection of discrete parts with separate functions

- acknowledge the child as part of a family and then to consider child and family within their support network and community
- consider the child and family's practitioners to be interconnected and interdependent and to join them together into a collective effort or 'intervention system'
- consider each of the child's conditions and disabilities to be interconnected and to consider how each impacts on the others

Systems thinking suggests to me that an individual practitioner working with a child who has multiple needs cannot function effectively on her own—just as her car engine cannot function to get her to work in the morning without the wheels, body, control pedals, etc that make up the whole functioning system of her car. With these children, rather than thinking we can carry on *doing our own sweet thing*, we have to discard the idea of individual competence and accept in its place the concept of collective competence. While we lose some independence we benefit from being in a supportive team. While we lose some autonomy we develop a broader understanding and acquire new skills.

Common sense

Most people who are not yet initiated into disability issues would expect that the key practitioners supporting a child with multiple needs would meet to share opinions and agree a plan of action. When new parents of children with disabilities become frustrated and disillusioned with their support (and very many do) it is often, at least in part, because they are very disappointed and worried to discover that their key practitioners, in the words of some parents I met recently, are each 'doing their own sweet thing'. For many frustrated practitioners I have met who feel disempowered by their local fragmented services, the phrase 'Team Around the Child' itself evokes a possible solution to fragmentation even before they learn more about the approach.

This is a fitting note on which to conclude: TAC is a common sense approach and there should really be no need to muster a collection of educational, psychological, sociological or philosophical theories to argue that, when a number of practitioners are helping the same child and family, they should talk to each other.



The Team Around the Child approach for assessment of needs within a local multi-agency integrated pathway

Summary

The Interconnections Manual An Integrated Pathway for Assessment and Support for children with complex needs and their families (Limbrick, P. 2003)¹ describes how health, education, social services and the voluntary/private sector can work together to provide children who have complex needs and their families with an effective service. This essay is adapted and updated from particular sections of that Manual and will touch first on the integrated pathway and will then focus on assessment of needs. In pursuit of the earliest possible support to child and family, I suggest two strategies for the assessment of needs: the simpler and more immediate TAC assessment, or first level assessment, and the more explorative second level assessment which involves more practitioners and is relevant to a minority of children.

The Integrated Pathway

For a child with complex needs, who might need specialist care and nursing support and specialist help to develop motor, perception, communication, social and cognitive skills, and for the family, who might need counselling, financial advice and help with equipment and housing, there can be many practitioners, services and agencies which might operate more or less separately from each other. Each service can have its own referral system, waiting list, assessment procedure and working method, and each can have different terminology, criteria and rules. The result is the service maze which mystifies parents, practitioners and service managers alike. These children and their families require an integrated pathway that reflects collaboration between agencies, services and practitioners and which describes a coherent, seamless and responsive service for the child and family. A multi-agency integrated pathway will have five major phases:

1. The Meeting Phase. In this first phase the integrated service and the family first encounter each other, probably through the intermediary of one of the participating services. All referrals for children that potentially meet the agreed criteria come through a single door and are processed by a multi-disciplinary intake panel that meets regularly enough to prevent a backlog, or waiting list, building up. (In an integrated service, a practitioner meeting a new child and family will see herself as a representative of the integrated service rather than of a single service. In this way she will apply joined-up thinking to what she sees and hears and will be the very beginning of a joined-up response.)

¹ References are listed at the end of the book.

- 2. The Learning Phase. This is when the integrated service and the family learn more about each other so that a first plan of action can be decided. It is important in this phase to listen to parents' views and questions, and to give them clear information about how the integrated service is designed to offer them effective support. How the learning phase is structured will depend on how much is already known about the child and family. The assessment of needs might coincide with, and be linked to, a medical investigation of the child's condition.
- **3. The Planning Phase.** The child's TAC will be in place by now and should consist of just the two or three key practitioners (defined by their close involvement with regular and practical interventions) and the parent. The TAC will consider the whole picture of child and family strengths and needs, and will make an action plan. The plan will last until the next meeting of the TAC when the support is reviewed and the plan refreshed.
- **4. The Support Phase.** Support is now provided to the child and family according to the action plan. In the TAC approach learning about the child and family and providing support (or *assessment* and *intervention*) are continuous processes that happen naturally together and should never be separated. Accordingly, everything that a practitioner does with or to a child and family should be supportive. This is true from the first minute of the first meeting.
- **5. The Review Phase.** The TAC reconvenes on the agreed date to review the action plan and agree a new one. Each new action plan can include agreed decisions about new referrals, tests, investigations, etc and can suggest a second level assessment of needs if appropriate.

The Learning Phase and the assessment of needs

I am aware of a range of approaches to the learning phase that can be ranged on a spectrum between 'a formal child assessment event' at one end and 'a family-centred assessment process' at the other. At the formal end of the spectrum assessments will be designed by practitioners with an emphasis on their own, or their service's, questions and will probably focus primarily on the baby or child. Formal assessments, in my view, can be problematic. They are often delivered as an event over one or more days during which the child and family encounter practitioners they have not met before. Each practitioner might ask the parents to retell their story. After what can be a very stressful time, parents might be further frustrated to see an atypical snapshot of their child being taken as representative. On the positive side, some parents are reassured to have their child looked at thoroughly by the whole team in one place at one time.

At the family-centred end of the spectrum the assessment process is a more drawn-out process in which the child is observed on several occasions in familiar settings where infant and parents are relaxed and supported by practitioners they know and trust. Parents are involved in framing questions to be addressed and the assessment process is designed with them to explore approaches to the immediate challenges they are facing at that time as well as to more long-term and general issues. In my view this approach is the more family-friendly and child-friendly option. It is much more likely to provide some relevant and timely support at the same time as gathering reliable information.

In the TAC pathway an effective assessment of needs, at either level, is defined as a flexible process which is respectful to the child and family, which gives primacy to the needs expressed by the parents and which considers the abilities and needs of the whole child and

family. It requires practitioners to develop a helping relationship with the child and family. The process includes:

- answering parents' questions as fully as possible
- learning about the child's condition, abilities and needs and about the family situation
- listening to the parents' views about the needs of the child and family in order to agree a plan for intervention
- addressing any immediate stressful situations the family is currently facing

By this definition the assessment process is *not* effective if it is not grounded in helping relationships in which the family and the practitioners know and trust each other, and if it fails to result in timely and relevant intervention.

The need for earliest possible intervention

The ideal is that families will not have to wait for support once they have been accepted into the integrated service. The reasons include:

- 1. Early intervention and waiting lists are not compatible.
- 2. For many conditions early diagnosis and intervention improve the prognosis.
- 3. During the first months after becoming aware of the problem, parents are likely to be very vulnerable, confused, anxious and in need of effective support for themselves as they adapt and develop coping strategies.
- 4. The child and family might be experiencing great stress and increased vulnerability because of the child's health, behaviour, sleep patterns or nutrition and will welcome early acknowledgement and practical help even if the full answer cannot be provided yet.

Waiting times are often associated with procedures at the formal end of the spectrum. These assessments, which often combine a medical investigation with an assessment of needs, require a large number of people to be in the same place at the same time. Usually they happen within a fixed schedule which caters for a fixed number of children per week or per month. Families have to wait their turn for this expensive resource and in my experience many have gone without relevant support of any kind while on the waiting list. The TAC pathway allows the majority of families to be given a first action plan without waiting for a formal assessment, and provides some relevant and timely support to families waiting for a formal assessment.

Assessment of needs in the integrated TAC pathway

This is represented diagrammatically on page 53. There are two levels of assessment of needs available to families: the TAC assessment of needs and second level assessment of needs. Both are designed to be family-centred and both can be fully integrated with any one-off or ongoing medical investigations happening at the same time. The two models are described below after some discussion of the intake process.

The intake process in the Meeting Phase

The Intake Panel is multi-disciplinary group of practitioners and managers that meets regularly to process referrals in the Meeting Phase. Part of its task with each new referral is to decide how best to learn more about the child and family so that a first family support plan

can be agreed. There are two options:

- 1. The Panel will feel that the first level TAC assessment process is adequate and appropriate at this stage. The Panel can then designate the members of the TAC or they can designate just the TAC facilitator (who then works with the family to assemble the first TAC).
- 2. The Panel will feel that a second level assessment of needs is the most appropriate way to proceed. The Panel can arrange some 'first-aid' support if the family is facing particular challenges and they can discuss how other relevant support can be offered to the child and family during any waiting period before the assessment begins.

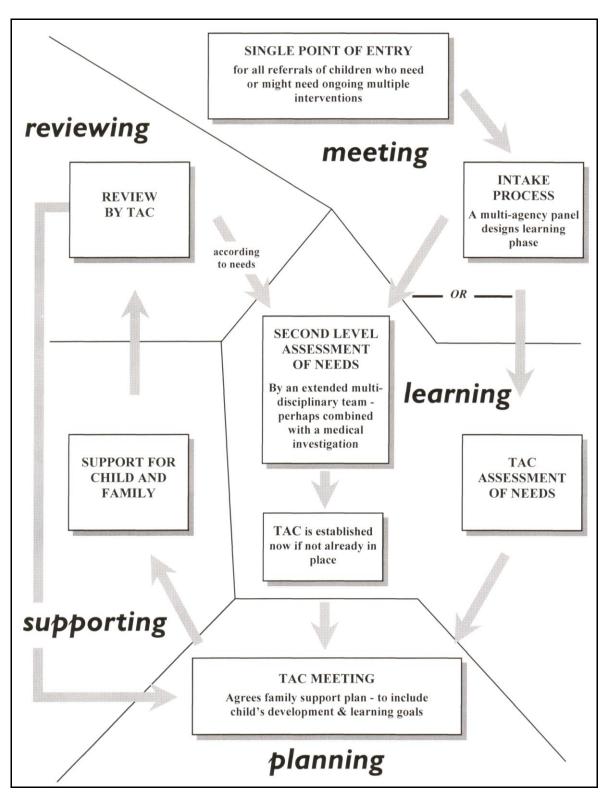
The initial home visit

Parents might already have waited a long time to get to this stage, they might be upset and anxious, they might be angry about delays, they might have no support systems yet and they might know little or nothing about the integrated service that is now considering offering them support. A home visit by one or two practitioners is essential during the Meeting Phase. If no visit is made before the meeting of the Intake Panel, parents will certainly need some communication after the meeting to tell them their child has been accepted and to invite them to participate in the next part of the pathway. They will need clear information about what is being offered and they will have many questions at this stage. The home visit provides an opportunity to:

- start building a trusting relationship with the family
- begin the combined assessment/support process
- be positive about the child and about the care the parent has provided so far
- be clear and reassuring about the integrated service and what it will entail
- answer, as far as possible, all questions
- learn about what has happened to the family
- find out what particular challenges they are facing at the moment
- start learning about needs in general

Most parents will have a story to tell and will probably welcome talking to an empathetic practitioner who has good listening skills and time to offer. Listening at this level is itself a therapeutic intervention and this home visit might be the first opportunity the parent has been given. It is essential to agree rules of confidentiality so that the parent will know what to say and what not to say.

This family story will include the child's history, medical and otherwise, and this should be recorded in detail so that it can be typed up afterwards. It is then passed back to the family for alterations before it is used. This record can then be passed to other members of the TAC and other practitioners by agreement so that they do not have to ask those first questions again. The home visit is an opportunity to start filling in any locally agreed multi-agency assessment forms. If two practitioners do the home visit together, as happens in Walsall Child Development Service (see Limbrick, P. 2004, p 67), one can occupy the child (supporting and learning) while the other talks to the parent (supporting and learning).



Outline of multi-agency integrated pathway for children who require ongoing multiple interventions

TAC assessment of needs

To take this option means that the members of the Intake Panel feel enough is known about the child and family to be able to identify which two or three key practitioners need to be closely involved at this time as the first TAC. The Panel can set a date for completion of the written Family Support Plan – perhaps in six or eight week's time.

The task of the TAC facilitator now is to co-ordinate an initial assessment/support process during which each TAC member organises one or two first sessions with the child and family to start building helping relationships, offer support and learn more about the child and family's strengths and needs. These sessions can happen at home or elsewhere by mutual agreement. They can take place in any nursery or group setting where the child is placed and will collect observations from the people in those settings. TAC practitioners can arrange to do these sessions on their own or they can do joint sessions with other TAC members.

Second level assessment of needs

This process involves a wider group of practitioners who represent additional disciplines or bring increased expertise and experience. It can be made available to children and families as required and can be triggered by the intake panel or later by the TAC at review stage. The second level assessment of needs is appropriate when it is felt that much less is known about a particular child's condition, abilities and needs than is usually known at this stage, that there are uncertainties about the family's situation, strengths and needs, that the TAC is unlikely to find all the answers on its own, and that more needs to be known before an effective action plan can be written.

Because it brings in a wider group of practitioners, some of whom might be based elsewhere, it might not be as flexible and as adaptable to each particular family's situation as the TAC assessment. For this reason it will be necessary for the assessment co-ordinator (perhaps the TAC facilitator if already nominated) to offer additional support to the family and to work with colleagues to make the process as well co-ordinated and family-centred as possible.

In an integrated TAC pathway the assessment co-ordinator works with the parent to agree membership of the first TAC, if there is not one in place already. Obviously, membership will reflect what has been learned in the second level assessment process. The first responsibility of the TAC now is to meet to write the Family Support Plan – the first plan if the second level assessment of need followed initial referral, or the next plan if the extended assessment occurred later in the pathway.

The TAC meeting in the Planning Phase

Whether the TAC is meeting for the first time following the referral, or for the first time after a second level assessment, the discussion will include the following:

- 1. Sharing general observations about the child's condition, abilities and needs and about the family's situation.
- 2. Agreeing a list of the child and family's needs. This will probably comprise:
 - needs which can be met by the present TAC members
 - needs which require involvement of, or referral to, other practitioners (who might become TAC members if they will have a regular involvement)

- needs which involve other agencies (e.g. housing, counselling)
- needs for which local agencies have no remedy at present
- 3. Agreeing the content of the written Family Support Plan. This should include agreed development and learning goals for the child.
- 4. Agreeing the date, time and venue for the next TAC meeting to review progress.

The meeting can be arranged to accommodate a working parent or any other person the parent wants to include. The discussion will address the situation of the child and family as it is now and anticipate changes during the period up to the next TAC meeting. There will be an emphasis on listening to parents' views with some focus on the particular challenges the family are facing at the moment. There will need to be agreement about any role parents will have as co-workers in the work with the child and decisions about the support they will be offered to help them succeed in this role. There can be decisions about involving other practitioners at this stage and the need for any additional tests and investigations.

Practitioners can agree who will chase up any appointments for clinics, tests, etc which should have happened by now but have not. Such follow-up does not have to be the task of the Team facilitator if one of the other TAC members is more appropriate. The TAC facilitator's tasks must be kept to a minimum to avoid overload and TAC is designed as a collective effort. The initial Family Support Plan will include:

- a list of TAC members with description of their role and contact details
- a list of other involved practitioners with role and contact details
- the TAC facilitator's contact details with times when he or she can be contacted and the agreed timescale for replying to messages
- what contact the family can expect from TAC members if the child is admitted to hospital and how the normal service will resume after discharge
- how often and where TAC members will see the child and family
- the learning and development goals
- referrals to be made to other practitioners and agencies and who will make them
- the involvement of parents in working towards agreed goals
- any integration of interventions, e.g. joint sessions and/or integrated programmes
- the agreed rules for confidentiality
- procedures for giving feedback about the integrated service and for making a complaint

In conclusion

TAC can only ever be described in general terms as a set of ideas or principles that must be adapted to each locality and there will never be two identical integrated TAC pathways. Nor should TAC be yet another system into which families have to be shoe-horned against their will. TAC is a family-centred philosophy within which individuality, adaptability and flexibility are essential elements. It brings to the child and family the incontrovertible benefits of child- and family-centredness, joined-upness and clarity. To the practitioner there are the benefits of a supportive individualised team, a forum for sharing ideas and plans about the particular child and family, and opportunities for extending professional skills in close collaborative teamwork with other practitioners. For service managers there can be the dual satisfaction of providing an integrated approach and making the best use of practitioners' time and skills — which might otherwise have been squandered in the traditional fragmented scramble.

The managerial effort to agree an integrated pathway for children who need multiple

interventions itself brings the great benefit of getting multi-agency managers (and some representative parents) together to see local provision in its entirety and to begin to understand why frustrated parents talk of mazes and jungles. As the discussions proceed towards a pathway diagram, there will be many occasions when duplications, overlaps and logjams are seen for the first time and immediately solved.

There are more children needing multiple interventions year by year and finite resources will be stretched ever thinner. The integrated pathway described here with its simple and straightforward TAC assessment of need provides an opportunity to get effective support to children without unnecessary and bureaucratic delay.



Team Around the Child in Early Support: Being genuinely child and family-centred

Introduction

The multi-agency Team Around the Child model is offered as a significant contribution to an effective early support system which will empower families and join services together. The model was designed for babies and young children with complex needs and their families and has since been adapted in some localities for older children and for children with other needs. At its core is each family's Team Around the Child (TAC) which is defined as an individualised, evolving and collaborative team of the few practitioners who see the child and family on a regular basis to provide practical support in education, therapy and treatment. There are three essential features of TAC:

- 1. Each TAC has a multi-agency membership bringing together the practitioners who support the child and family regardless of which agency they work for. This can include health, education, social services and the voluntary and private sectors.
- 2. Each TAC empowers parents by offering them a full place in the Team.
- 3. Each TAC is led by a Team facilitator who functions as the multi-agency keyworker for the child and family with a very clearly defined and limited role.

The TAC approach is designed to:

- facilitate sharing of detailed observations and information about the child and family
- provide a safe forum for the discussion of all pertinent issues
- create successive multi-agency Family Support Plans which include agreed goals for the child
- provide seamless support to the child and family as agreed in the current Family Support Plan
- regularly review progress and create a new Family Support Plan at each review

This TAC approach for young children with complex needs and their families addresses two major needs: the first is the need for parents of babies and young children to be fully involved in all decisions about support for their child and family. The second is the child and family's need for joined-up support regardless of how many practitioners, services and agencies are involved.

TAC: promoting seamless support when needs are complex

The Team Around the Child model acknowledges parents' central role in planning for their baby or young child and provides joined-up support to the family. TAC has been used mostly, but not exclusively, with young children with multiple disabilities and complex needs who need long-term practical support on a regular basis from a number of practitioners. Which practitioners are involved will depend on the changing needs of the child and family and can include teachers, therapists, nursery nurses, health visitors, nurses, social workers, Portage workers, home support workers, therapy assistants, and others. The child and the family need support from a number of different practitioners because they have a number of different needs and because there are no multi-skilled or 'complex' practitioners. TAC addresses the difficult question:

How do we provide seamless support to families of children with complex needs when so many practitioners have to be involved from different services and agencies?

There is not yet an agreed definition of 'complex needs'. In the context of many services who have adopted the TAC model, a definition would include babies and children who have needs in more than one developmental area (motor, sensory, communication, learning, social skills, etc) and who might also:

- have continuing health needs, frequent illnesses, home-nursing needs
- be dependent on technological support, e.g. oxygen, assisted feeding
- have uncertain or short life expectancy

Even though we cannot refer to a universal definition for these children we do know that they are an expanding group in the UK. There is a valid argument that says the definition is not very relevant because the test of whether to include a child and family in a TAC service is more about how many practitioners need to be involved to meet child and family needs rather than about how complex the child is. By this standard many other factors can come into play alongside the needs of the child. These can include family language and culture, additional needs of parents and other family members, family finances, transport and housing. The list in the figure below illustrates how diverse early intervention needs might be and is offered to show that, frequently, there can be a mismatch between what a particular practitioner can offer and what a family are needing at that time:

Speaking from my own experience as a keyworker with the One Hundred Hours organisation in the 1990s, parents, during all of the early years, might be seeking any combination of the following elements of support when they encounter a new practitioner or a new service. (For an account of One Hundred Hours see Limbrick-Spencer, G. 2001.¹)

- 1. To find out what is wrong with the child.
- 2. To find out why this happened.
- 3. To find out if there is a cure or a medical treatment.
- 4. To find out the implications for any siblings.

1

¹ References are listed at the end of the book.

- 5. To find out if it is safe to have more children.
- 6. To find out what the diagnosis means for the child's health, survival, wellbeing, happiness, education, adult life.
- 7. To acquire an understanding of the condition.
- 8. To find out what can be done to help the child.
- 9. To find out what services and support are available.
- 10. To acquire necessary skills to help in the child's treatment, care, play, development and learning.
- 11. To get practical help from practitioners in the child's treatment, care, play, development and learning.
- 12. To find words to use to explain the condition to strangers, neighbours, friends and relatives.
- 13. To get support in helping partner, grandparents, siblings and friends understand the condition.
- 14. To get support in encouraging and facilitating partner, relatives and friends to offer practical help.
- 15. To get help in balancing the needs of the child with the needs of partner and siblings.
- 16. To get support in maintaining the relationship with the partner.
- 17. To get relevant services so that employment can be continued.
- 18. To get help in remedying an immediate problem or cause of stress such as disturbed nights, the child's feeding, the child's constant crying or other challenging behaviour.
- 19. To get such support as 'baby-sitting', childcare or short breaks to help in coping with stressful and difficult situations.
- 20. To have someone to discuss issues with and to help parents come to informed decisions.
- 21. To have someone to be a listening ear and a shoulder to cry on.
- 22. To have counselling to help sort out emotions and to develop coping strategies.
- 23. Help with getting benefits, applying for Family Fund and other grants, securing money for items of equipment, managing the family budget.
- 24. To get more appropriate housing by moving house, getting adaptations, equipment, etc.
- 25. To get practical help with household tasks.
- 26. To get opportunities for family members to spend valuable time apart from each other on rewarding activity as happens naturally in most families.
- 27. To get help in taking the child to such local facilities as mother and toddler groups, playgroups, nurseries, swimming pool, football matches, etc.
- 28. To get help in keeping family life as normal as possible in relation to outings, socialising, leisure activities, holidays, etc.
- 29. To be helped to make informed choices about the shape of the whole package of support so that it is a coherent whole which does not make family life impossible and which enhances aspirations of all family members.
- 30. To have an adviser and advocate to help remove barriers to the parent's aspirations.

The list is long and wide-ranging because the challenges in caring for a child with sensory and multiple needs can affect every aspect of family life: finances, housing, leisure, employment, relationships, emotions, beliefs, etc. A parent who has all or many of the needs listed above and who might or might not have articulated them into

clear ideas and wishes, can easily become frustrated when services and practitioners are found to have a narrow remit and when no services are found which are designed to meet particular needs. Many practitioners who perceive needs which are beyond their own job description will do as much as they can to help. This might mean they put extra hours in and it might mean they have to distort the records they submit to their managers about how they have spent their time with clients. Such practitioners are often described by parents as saints and life-savers. This sort of under-the-counter support can help keep desperate parents going and help vulnerable families stay together.

The above list of elements of support is taken from Birmingham University's School of Education Distance Learning Module: *Early Years Sensory and Multiple Needs:*The Child in the Family, Unit 3: Evaluating the Work of Services, written by Peter Limbrick and edited by Linda Watson.

Figure 1: What a parent might be looking for when she meets a new practitioner or a new service

The need for the TAC approach arises because these children and families require a joined-up approach and have to seek it from practitioners, services and agencies which are not, by and large, joined up. We cannot blame practitioners or their managers for this situation. The main agencies, which comprise statutory health, education and social services, the voluntary and private sectors have all evolved separately. The practitioners within them have trained separately, belong to different professional bodies, work more or less separately from each other, are accountable to different managers and are funded by separate budgets. While a growing population of children with complex needs has taught us the need for well-planned and detailed collaboration, all the major influences on service provision continue to promote fragmented and piecemeal working. Herein lies the tremendous challenge, first to design joined-up initiatives and then to build into them sustainability against the prevailing counterforces.

Returning to the issue of defining 'complex', we can, instead of referring to the complexity of any child and family, argue that the problematic complexity we need to resolve lies in the way multi-agency and multi-disciplinary support is provided. Presenting the problem in this way reminds us that children are still whole children regardless of their diagnoses, and provides us with a clear responsibility to do as much as we can to resolve confusion and fragmentation in service provision.

TAC as a family-centred approach

The basic TAC approach is intended to be simple and straightforward. It requires that the handful of practitioners who already provide regular practical support to the child and family agree to meet together every half-term or so (more often if necessary) to talk with the parents about how the child is getting on, to share information and ideas and to agree a joined-up support plan to last till the next TAC meeting. Parents who do not have a child with special needs (and many parents who have just discovered that they do) would naturally expect this approach anyway. They would ask justifiably, 'Why would practitioners who are all helping the same child *not* meet together to co-ordinate their efforts?' They would wonder how on earth the child could be properly helped in separate bits. And yet separate bits is what too many children and families get. Working 'blind' with a child in ignorance of what support other practitioners are offering is what many practitioners have to tolerate.

TAC provides a way to put the bits together towards a whole approach for the whole child and family. It is an uncomplicated idea that is easily understood by parents and practitioners. In its basic form TAC requires no new technology and relies on the practitioners who already work with these children and their families. TAC acknowledges that we have practitioners in the UK with appropriate specialisms and that children with complex needs require all of their skills and expertise. Team Around the Child provides an improved system in which these practitioners can enhance their effectiveness and increase their influence on the wellbeing of child and family.

The TAC approach confers enhanced status and responsibility on those practitioners who are most closely involved. This will usually be a small and manageable group of between two and six people who have established helping relationships with the child and parent. This means that meetings can be informal, non-threatening and family-friendly. TAC reduces the number of people required at planning meetings to a number with which parents can cope comfortably. The child's TAC is not a fixed entity. As the needs of the child and family change so will the composition of the Team. Because each TAC is managed to ensure membership changes only gradually, even at transitions, the child and family have a continuing support system. This continuity is an essential feature of seamless support and I have accumulating evidence that TAC provides effective support to families and practitioners (pre-school and school) when the child is being admitted into school.

The long list in Figure 1 above demonstrates a wide range of potential needs in a family from the time when the child's condition was first confirmed or suspected, from when the family first had good cause to be anxious. This list can inform service providers about what family-centred support might involve but in my experience most of us, because of our training and because these children are still relatively new on the scene, still focus on the child. When practitioners are asked what the term *family-centred* might mean they will often think only about the quality of their relationship with parents.

The table below offers a structure with three categories of family need and might provide a starting point for discussions about family-centredness in any locality and then the basis for a local audit tool. Support for families is a collective effort within which overall responsibility is carried by the multi-agency integrated service. Within that local system each separate agency or service will carry some responsibility as will individual practitioners.

| Category of need | Some elements within the category |
|---|--|
| 1. Shaping interventions for the child in consideration of the family situation | To be an effective co-worker, does the parent have sufficient understanding, energy, space, time, calmness of mind, to do the home programmes? |
| | Does co-working take the parent away from her other children? |
| | Can the parent get her child to the places we specify at the times that we fix? |
| | Can the family accommodate increasing numbers of practitioners getting involved? |
| | What does the totality of provision mean for 'normal family life'? |
| | Other elements? |

| 2. Supporting the family with the consequences of the child's disability and needs | Does the parent need short breaks away from the child? Do family members need breaks from each other? Does the family needs breaks & holidays together? |
|--|---|
| | Is the family suffering from stress? |
| | Does a parent need significant emotional support or counselling to help in adapting and coping? |
| | Is there a need to discuss fostering / adoption? |
| | Is the family sleep-deprived? |
| | Is the family becoming poorer? Is advice needed for money/debt management? Is advice needed about benefits and grants? |
| | Does the main carer need support to stay in, or get back to, work? |
| | Do two parents need help with their relationship? |
| | Can a working partner be considered when appointments, meetings, etc are planned? |
| | Do siblings need someone to talk to? Do siblings need help to maintain peer-group activity? |
| | Do grandparents need support or training in how to care for the child? |
| | Is accommodation satisfactory? Is housing advice needed? Are adaptations needed? |
| | Other elements? |
| 3. Supporting the family with needs that do not arise directly from the child's disability and needs | 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 a learning disability? |
| | Does a parent have mental health needs? |
| | Other elements? |

Table 1: A structure for planning and auditing family-centred support

Being genuinely child-centred in the TAC system

The term *child-centred* can lack any real meaning for service providers as can the term *family-centred* discussed above. They are often mere token phrases that do not reflect any real effort to move beyond traditional approaches nor to create any improved outcome for children and families.

I would argue that babies and infants who have multiple disabilities and conditions deserve a better thought-out response than just piling on multiple practitioners with their separate discipline-specific programmes and goals. In this traditional approach vulnerable pre-school children are required to relate to, and tolerate being handled by, a number of teachers and therapists who might be using inconsistent communication, positioning, motivations, etc.

This 'scatter-gun' approach, in which each discovery of a new need is followed by provision of yet another practitioner, is applied without any consideration of how the child might feel about it. I would argue that it would not be thought good practice for children who do not have disabilities, yet it is applied thoughtlessly to our most vulnerable babies and infants. Opportunities for development and learning can be lost if the child is overloaded with practitioners and programmes. Their plight is made even worse if the child has difficulties in forming multiple relationships and if the programmes used do not fit well with each other. Such practitioners as child psychiatrists, child psychologists and psychotherapists could help pre-school teachers and therapists address these important issues of child-centredness.

The following table suggests a strategy for addressing the issue and applying relevant remedies within the TAC system. The suggestion here is that it is a major TAC responsibility to keep checking that support is child-centred and to agree creative remedies when it is felt the child is being overloaded with too many practitioners and programmes.

Addressing any overload

TAC discusses at each meeting whether the totality of early support is appropriate to the child's needs at that time or is overloading, or in danger of overloading, the child. The discussion can also consider the impact on the rest of the family of this number of practitioners and programmes.

If there is an effective relationship with the family with mutual honesty, trust and respect, then parents might be prepared to disclose any 'non-statutory' help they are receiving from voluntary and private agencies. In the child's interests these too should be brought into consideration of any overload.

When it is felt that support is not child-centred, or is in danger of becoming counterproductive, then the following options can be considered:

1 | Preventing overload

To help prevent overload in the first place, TAC could consider the following questions each time a new practitioner or service is suggested. (This could be adopted as local multi-agency protocol for all of these children when a new practitioner is suggested.)

- Is the family ready for another practitioner?
- Is the child ready for another practitioner?
- Will the new intervention fit with the current interventions?
- Will the new intervention fit into the child's day and the family's routines?
- Could the new intervention be postponed for a time?
- Could an existing practitioner offer some or all of the new intervention?
- Are there other creative solutions?

2 The consultant model

Can the consultant model be usefully applied by the child's therapists, pre-school teachers, etc? In this model, practitioners hand over some aspects of their intervention to one of the other practitioners for a period of time. Practitioners who have handed over some of their work remain on the scene for support, ongoing assessment and any crises. The practitioner who is taking on some work in this way will need good initial instruction, support, refreshers, relevant equipment, and adequate space and time.

3 | The primary interventionist

The primary interventionist is one practitioner who, by TAC agreement, does most of the hands-on work with the child and parent for a specified period of time. Her role can only succeed to the extent that she is supported by the other therapists and preschool teachers acting as consultants. There are many babies who would benefit at first from a primary interventionist to support the mother as she gets to know her baby.

4 The integrated whole-child programme

This is an amalgam of the separate discipline-specific therapy and education programmes and is integrated into the child's daily activities (at home or elsewhere) of play, getting around, socialising, mealtimes, bedtimes, etc. Rather than attempt to bring unwelcome 'work' into every aspect of the child's life, the integrated programme is a creative effort to translate discipline-specific interventions into meaningful and enjoyable activity that enhances each child's experience of life. This is an important factor when one considers that some of these children have very uncertain futures. It is a TAC responsibility to agree which parts of which programmes can be integrated in this way.

5 Building these approaches into the Family Service Plan (FSP) process

Any TAC decisions to address overload with such remedies as the consultant model, primary interventionist, integrated programme, etc must be built into the FSP that is distributed after the TAC meeting. An important part of this plan will be information for parents about how practitioners are remaining available even though they have handed some work over to others for a period of time.

6 Involving parents

The child-centred approach outlined here offers individual TACs ideas for preventing or remedying any overload. It would be advantageous for practitioners and families if they were supported in this by local multi-agency protocols, in-service training and support. As with other developments in early support, the local discussions must include parents.

Table 2: Preventing or remedying child overload within the TAC system

Can the TAC approach continue in school?

Pre-school provision and school provision differ greatly in environment, culture, history, legislation, etc. We cannot yet assume that effective pre-school practice with regular, multi-disciplinary TAC meetings and a family-centred approach will automatically be available in school. Head teacher and staff attitudes will be significant factors amongst others. But in my experience, parents can be disappointed, frustrated and angry when valued elements of local pre-school provision are abruptly ended. Some particular children and families will need additional and tailored support for a limited period of time to help them over the transition into school.

Effective transition can be designed at both the multi-agency strategic level in the locality and at the level of the individual school. Discussions will need to involve pre-school practitioners, school staff and parents and must address issues raised by any of those people who have experienced children or families losing valued aspects of pre-school provision. The list in the table on the next page gives some common anxieties parents have voiced to me about transition into school. None of them present insuperable problems for pre-school practitioners and school staff who are willing to work together to find creative solutions.

1 Will I have someone I can relate to – • with whom I can form a relationship • whom I can grow to trust • who can listen to me • who can link things together? Will the 'special person' I have now have to change abruptly, or can there be an overlap? 2 Will I be properly involved in the plans for my child – or just informed? Pre-school practitioners were often available to give me reassurances and to 3 answer my questions. Will this informal support still be available or will it come to a sudden end? 4 Will the practitioners be flexible in agreeing a two-way communication system with me – or will there be just one system that I am expected to fit into? 5 Will I be judged harshly if I do not attend the school when invited – or will someone ask me why I cannot attend? Will the programmes and plans that are already happening continue and will the 6 existing bank of information and assessments be trusted and used – or will the new practitioners want to start with a clean sheet? 7 Will there be a chance for the new practitioners to talk to the present ones who already know my child and family? 8 Will the new practitioners wrongly assume that I am relieved to have the child 'off my hands at last'? - and are the new practitioners secretly expecting my child will do better once he is 'away from his mum'? 9 Will the new practitioners want to learn from me about how I help my child with the most challenging situations? When the new practitioners have learned new ways to help my child in 10 challenging situations, will they come and show me? 11 Will there be a whole-child approach in which therapy and education are integrated as appropriate? If my child's 'specialists' operate as consultants to school staff, will there be an 12 appropriate code of practice to guarantee a high standard?

Table 3: The anxieties of some parents on transition into school

The work in Walsall by Wassall, Rimmer, and Boulter (2008) demonstrates how TAC facilitated a very careful and successful transition into a mainstream school for a child of two and a half years who had been supported by TAC since he was 8 months old. Work in which I am involved in another Midlands city (but which is not yet published) reinforces this message about TAC facilitating transition into school. In this case transition was into three of the city's special schools and a mainstream school. The emerging picture is that TAC provides effective child and family-centred support in the pre-school years and during the transition into school, but then might naturally evaporate after a term or two as the child and family become embedded into the school's systems.

Rather than strive to transplant TAC into special or mainstream schools, a better approach might be to remind ourselves what TAC attempts to remedy in early support and then examine whether these problems recur for children and families in the school setting. For preschool children and their families TAC is an antidote to:

- 1. Parents feeling they are not informed, involved or empowered.
- 2. Teaching and therapy interventions remaining inappropriately separate from each other for a particular child.
- 3. A lack of awareness of and attention to the child's family.
- 4. Education, health and social services not being joined up around a particular child and family.

Once the school has audited itself on these characteristics of effective support for its children and families, staff and other local practitioners and managers can begin to address any shortcomings. One aspect will be to discuss to what extent the school's planning for the child can become more like Early Support's Family Service Plan. Any requirement for a school to become genuinely family-centred will bring with it significant issues of time and resources. Families who are content to see their TAC support evaporate during the first few terms are probably in a school that has already addressed the four elements above to some extent. Families in schools that have not addressed those elements might wish their TAC system could continue in school.

Conclusion

This article has outlined the merits of the TAC approach for children and families who have complex needs or, turning the situation around, for children and families whose needs are such that service provision can become problematically complex. When the totality of support is disjointed and inconsistent the family can be made more vulnerable and the child's opportunities for development and learning can be spoiled. TAC can promote genuine child-centred and family-centred support during the pre-school years and over the transition into mainstream or special school.

9

TAC for the 21st Century: A unifying theory about children who have multifaceted disabilities

Summary

We have in the UK an increasing population of children with neurological impairment and consequent multiple disabilities or 'multifaceted disability'. There is a danger of these children and their families being overloaded in the first years by too many practitioners with too many discipline-specific programmes. This comes from the well-intentioned, traditional practice of providing a new practitioner for each of the disabilities as they emerge.

The result can be a fragmented approach to the infant's development and learning with some young children being required to relate to, and accept being handled by, more people than they can cope with. The Team Around the Child (TAC) approach adopts a systems perspective and enables service providers to move from thinking about multiples to thinking about wholes – whole children, whole conditions, whole intervention systems.

Introduction

This article is about how support is provided in the UK to the increasing population of babies and children who have a 'multifaceted disability'. This phrase, though not in common usage, is, by the logic of this article, more appropriate than such phrases as 'multiple disabilities', 'requiring multiple interventions', 'complex disabilities' and 'complex needs'. The article will suggest that a systems perspective can reduce multiples to manageable wholes and that any problematic complexity is more likely the product of outdated service provision than an inherent feature of any child. (Readers who prefer not to use *disability* could think of children with a 'multifaceted condition'.)

When Michael J. Guralnick (2005)¹ lists the principles of early intervention relevant to his Developmental Systems Model he gives as the very last one: 'A *systems perspective* is maintained, recognizing interrelationships among all components.' (p 6)

The systems perspective is the subject of this article for it is my belief that systems thinking provides the way out of the cul-de-sac that UK services find themselves in with this growing population of children who are relatively new kids on the block – 'growing' because more and more are surviving birth and the vulnerable first two years and 'new' because in the UK they used to be excluded from education on a spurious IQ assessment and often incarcerated in 'long-stay mental handicap hospitals' from infancy to grave.

¹ References are listed at the end of the book.

It is my contention that these new kids need new services and that in stubbornly trying to make the old ways fit we are failing children, families and hardworking practitioners.

When new children are failed by old thinking

While there has been a wealth of creative, scientific thinking and revolutionary advances in molecular biology, genetics and medical technology since the middle of the last century, there has been no corresponding progress in education, therapy or care for the generality of children who have multifaceted disabilities. It feels as though we are stuck in the age of the steam engine and telegraph as though quantum theory, space travel and the World Wide Web are all still waiting to happen.

So what happens in the UK to an infant who has a multifaceted disability? The traditional and still current approach is to add a new practitioner for each condition, disability or need that we discover. For a child with neurological impairment from birth there could be paediatrician, outreach nurse, health visitor and physiotherapist at the head of the procession, closely followed by speech and language therapist, teacher for visually impaired children, occupational therapist, teacher for hearing impaired children, play therapist, psychologist and so on. The list and the sequence will be different for each child but the dangers are the same. The family can be overloaded by multiple appointments, clinics, assessments and reviews, and by the travel and childcare costs incurred (for any young siblings), and will inevitably encounter duplications, contradictions and gaps in this dangerous mêlée – all adding to their stress, confusion and anxiety. The child can be overwhelmed by the requirement to relate to so many people – far more people than we would impose on a non-disabled child, and might have a daily and weekly routine crammed with discipline-specific programmes. Pre-school practitioners suffer too with increasing demands on their time as they try to meet parents' aspirations for regular sessions of this or that.

We learned in the last century that individual practitioners, whether specialist teachers or therapists, can help children who have an individual disability. We now blindly assume that the answer for children who have multiple diagnoses is simply to multiply the practitioners. This scatter-gun approach has happened by default and, in my view, is not tenable within the resources available in the UK. Nor should we perpetuate it when we give some thought to what is fair to children. Some infants, because of prematurity and/or disability have not yet bonded with their mother. Other infants have communication difficulties. Others are just plain nervous and fearful. For these babies and young children it is illogical to impose ever more practitioners just on the basis that each one has expertise in this or that disability – while we could be asking instead, 'Is the child ready for another practitioner?' or 'Is the family ready for another practitioner?'. For some reason children who have a multifaceted disability manage to creep under our 'child-centred' radar and fail to evoke our empathy, sensitivity or professionalism. Could this be because we remain stuck in an overly medical approach and see the disabilities under the microscope but not the child under our nose?

A systems perspective

Ludwig von Bertalanffy (1969) tells us that General Systems Theory is founded on the understanding that there are models, principles and laws shared by different fields of human endeavour, for example, physics, chemistry, biology, economics and sociology. Speaking of the various entities that we encounter in any of these fields (e.g. atoms, molecules, bacteria, humans, factories, supermarkets) he says, '...the entities concerned can be considered in

certain respects, as "systems", i.e. complexes of elements standing in interaction.' (p 33) He goes on to say:

The meaning of the somewhat mystical expression, 'the whole is more than the sum of the parts' is simply that constitutive characteristics are not explainable from the characteristics of isolated parts. The characteristics of the complex, therefore, compared to those of the elements, appear as 'new' or 'emergent'. (p 55)

I take this to mean that if you add four wheels, an internal combustion engine and a steering wheel together you get a means of getting to work. If you add boiler, thermostat and radiators together you get heat all round the house. If you add cerebral palsy, blindness and learning disability together you get a multifaceted condition that is very much more than the sum of its parts. I also take it to mean that we cannot understand cars or central heating unless we learn how the bits fit together, how the bits relate to each other. And that we cannot help a child who has a multifaceted condition by focusing on the separate disabilities as though they were not 'standing in interaction'. Here is a story about how I see the problem:

A group of five pupils in a school in Japan, or China or on another planet, are given the English word 'CHILD' to decipher. The busy teacher designed this as a group activity but instead, each child takes a letter to their desk to work on individually and eventually each comes proudly back to the teacher with their answer. The first reports that the first letter says 'see', the second 'aitch' and so on. The teacher, seeing the misunderstanding and knowing that, as far as words are concerned, the whole is more than the sum of the parts, asks them to work as a group to decipher the whole word – to find out what meaning is created in English when these five letters are strung together in this order.

Are we not in a similar position with children who have multifaceted disabilities? Do we not by tradition, as therapists or specialist pre-school teachers, examine separate bits without ever getting to the whole 'CHILD'? Do we not report our individual answers back to the parents in pieces for them to fit together themselves?

Presumably our teacher in the above story had already given her pupils instructions in how to join English letters and sounds together to make whole words. If we want practitioners to join all their discipline-specific interventions together then there has to be some sort of science that tells them how to do it – hopefully with effective training, resources and support. In my experience these skills do not come naturally to practitioners who have by training moved their focus from the whole child to this or that specialism. If we do not commit ourselves to a scientific approach with a systems perspective for the education, therapy and care of children who have multifaceted conditions we will remain fumbling in the dark with last century's trial and error strategies.

Some implications of a systems perspective

There is not space here to describe all the implications of a systems perspective on children who have multifaceted disabilities and their families so I will restrict myself to four headings:

- 1. The Team Around the Child system
- 2. Collective competence

- 3. Integration of development and learning programmes
- 4. Disabilities interacting with each other to create new, emergent disabilities

1. The Team Around the Child (TAC) system

If the multiple conditions, disabilities and needs interact with each other as a system within the larger system of the whole child (who has *very many* more separate parts than just the disabling conditions), and if the child forms part of the larger system of the family (which exists within the larger systems of extended family, community, society, nation, etc), then it seems to me to be logical to support the child and family with an intervention system in which the separate parts stand in interaction with each other rather than functioning as isolated entities. This is the thinking behind the TAC system (Limbrick, P. 2004) in which a small team of key practitioners around each child communicate and interact with each other within the larger system of a multi-agency integrated service for these children. (The phrase 'key practitioners' refers to the practitioners who have most regular and practical involvement with the child and family at any given time.)

TAC philosophy dictates that a young child's parent or carer has a full place in their child's TAC and that disabled young people have increasing presence in their TACs as they get older (see Middleton, N. 2009). The child's TAC can organise initial assessment, planning, intervention and review processes along each child's multi-agency integrated pathway (Limbrick, P. 2003).

TAC philosophy argues that practitioners cannot be effective for these children if they remain in isolation from each other. The TAC is a forum in which the separate elements of key practitioners, parent/carer and older child can stand in interaction with each other to produce outcomes that are greater than the sum of the parts. In the TAC system the child's wholeness is recognised and honoured with a whole approach.

2. Collective competence

The concept of collective competence acknowledges that competence in providing these children with a whole approach to their development and learning has to be a collective effort. For these children my understanding and skills are relevant but they are not enough on their own. Your understanding and skills are just as relevant but risk being similarly ineffective if they do not stand in interaction with mine. Consider a deaf infant who has cerebral palsy. The mother, the physiotherapist and the teacher for deaf children all risk failing in a whole-child approach if they persist in standing alone rather than standing in interaction.

Competence is only achieved as a collective effort. Everyone's understanding and skills must be offered to the child within a system in which separate competencies are joined into a whole which becomes more than the sum of the parts. The physiotherapist can help the mother and the teacher find positions in which the child can observe signs and copy them. The teacher of the deaf can help the mother and the physiotherapist improve how they communicate with their child. The mother teaches the other two about effective strategies the family has developed already, about the child's motivations, personality, likes, dislikes, habits, etc. Of course, the child is teaching all three about his or her strategies for learning so we have four people in this competence collective!

3. Integration of development and learning programmes

There are degrees of integration and how far to go will be agreed by each child's TAC in consideration of the child and family's needs and circumstances at that particular time. Integration for the deaf child envisioned above can begin with all three people (mother, teacher for deaf children and physiotherapist) just listening to each other talk about what they are doing and what they are working towards. Even this most basic level of integration would come as a great relief to those parents who fear their practitioners do not know what each other is doing. This process will resolve any mismatch in approaches and goals.

The next stage can be each of the three in the TAC agreeing to take on some of the work of the others. In this way the physiotherapist will use the same signs, the teacher will incorporate the same posture and movement into her sessions and both will adopt successful approaches the mother has developed. Now we have education, therapy, play and the daily activity of family life integrated into a learning system which reflects and supports the child's natural integration of understanding, communication, posture, movement, dexterity, daily activity, play, relationships, memory, motivation and so on.

Two more steps in the integration process might be appropriate:

1. TAC members can each contribute some or all of their approaches and goals to a whole-child programme in which education, therapy and family activity are melted together to become part of the child's meaningful and enjoyable daily experience at home and in the settings he or she goes to. In this way learning can become more relevant, more regular and more consistent. Specialist teachers and therapists would need to make their own professional judgement about any parts of their intervention that they must keep to themselves for whatever reason. This is not a new requirement; specialist practitioners already have to judge what they can hand over to parents of pre-school children and to school staff for school children (Limbrick, P. 2007, p 70).

It is worth emphasising, in pursuit of genuine child-centred interventions, that there is no intent here to make vulnerable babies and children's lives miserable and onerous by loading endless targets into every part of their day. The trap for practitioners to avoid is integrating their interventions and then making the child do more and more work on the 'integrated programme'. TAC philosophy suggests that practitioners might explore how to integrate their programmes into the child's natural activity – for the infant, either rewarding play and socialising or the meaningful daily routines of dressing, mealtimes, bath time, etc. If our interventions are of a high standard then they will enhance the child's experience. This is a key part of the TAC system – to acknowledge each child's right, no matter how many conditions and disabilities are emerging, to be a child, to have as little pain and discomfort as possible and to have the best possible experience of being alive on each day – no matter how many days there might be ahead.

2. The second of these two further integrative steps, is to check whether the number of people directly and regularly involved with the child represents good child-centred practice. This question should arise at the first and all subsequent TAC meetings and one of the first TAC tasks might be to address whether the child has too few or too many hands-on practitioners.

Because TAC is a creative and collective intervention system, each TAC team can find its own creative solution when there are, or soon could be, too many people making too many demands. The options include:

- i. Prioritising interventions so that they do not all have to happen at the same time.
- ii. Using a consultant model in which a necessary new intervention is offered by one of the current TAC members for the time being.
- iii. Appointing a primary interventionist for an agreed period who becomes the practitioners doing most of the hands-on work (Limbrick, P. 2007, p 69).

4. Disabilities interacting with each other to create new, emergent disabilities

A systems perspective suggests that a child's various conditions and disabilities will stand in interaction with each other and that the resulting, emergent condition or 'multifaceted disability' will be greater than the sum of its parts. The disability resulting from any complex of single disabilities will have new or emergent characteristics that the separate elements do not have. (Please note that *complex* as used here is a noun and not an adjective.)

Let us imagine a child whose diagnosis includes autism and blindness. As a developing infant he has to endure, celebrate, learn and accommodate to, all the things other autistic children are also dealing with. But he has to do it without the advantage of sight. At the same time, he is striving to meet all social, psychological and educational challenges of blindness but with the additional challenges of being autistic. I would suggest the interaction between the two conditions significantly affects the neurological processes and outcomes in his development and learning.

It seems fair to assume that his condition is a lot more complicated than autism plus blindness (A+B) but is in fact an emergent disability which we will have to call autistic blindness (AB) or blind autism (BA). People who have an interest in autism will opt for the latter while people with an interest in blindness will opt for the former. In actual fact they are both the same 'new' disability.

When a child's diagnosis includes autism, blindness and cerebral palsy her developing brain has the task of establishing neural pathways for posture, mobility, co-ordination and dexterity without the advantages of sight and within the constraints of autistic perceptions and social interactions. A, B and now C merge together into a new complex which is much more than A + B + C. Whether we call the emergent disability ABC or BCA or CAB will depend on our primary interest, but whichever we opt for, we are dealing with a new disability that is greater than the sum of its parts.

The children in the increasing population of neurologically impaired infants invite us to add D for deafness to the complex and then E for epilepsy – and so on. These emergent disabilities of ABCD and ABCDE (and all other possible combinations of disabilities, conditions and needs) at first seem to offer an impossible challenge in which practitioners need access to a bank of computers in order to find a way forward. Not so. The child growing up with ABCDE is still just a child, no more, no less, and the emergent condition is just like any other condition that requires us to carefully observe the child's strengths and needs and then agree a collective intervention plan.

The pitfall for parents and practitioners to avoid is to think A + B + C + D + E and then provide a practitioner and a programme for each element as though the conditions and

disabilities were not standing in interaction with each other. The approach for therapists and teachers is again the TAC system in which expert observations are shared and a whole-child programme is agreed. TAC philosophy does not argue for multi-skilled, 'jack-of-all-trades' practitioners because that would inevitably lead to a reduction in standards. On the contrary, TAC is the forum for highly skilled practitioners to find creative solutions for delivering their expertise to the child and family in joined-up, child-centred practice.

Sharing information about emergent conditions

But do not these emergent conditions impose a greater responsibility on all of us, whether we are family members, teachers, therapists, medics or academics? Should we not be developing a bank of information about AB, CBD, EBCA, etc so that we do not have to offer each child a trial and error approach? While I am not advocating putting vulnerable children under a microscope, I am suggesting a careful collection of data from interventionists about what has been effective and what has not. Such an international library would enable all of us to make the best possible start with a new child, bringing effective intervention sooner rather than later or never. It would help over time to remove the discrepancy between those (single) conditions and disabilities that have established interventions and those emergent conditions that do not – and that are treated as a new mystery each time they appear.

Conclusion

If our thinking remains clear we can offer effective interventions to these children regardless of the label we attach to them. But we cannot be effective if we remain in last century's discipline-specific ruts. We need radical reforms that echo the change from steam train to air travel, from telegraph to e-mail. Just like the TAC system, this radical change has to be a creative and collective effort – in this case between families, practitioners, senior managers, training bodies, academics, professional associations and government departments. We must move from thinking about multiples to thinking about wholes – whole children, whole conditions, whole intervention systems. Then we will be ready for the 21st century.

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^{*} England's DfES has been renamed DCSF.

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