

**THE
TEAM
AROUND
THE
CHILD**

**Multi-agency service co-ordination
for children with complex needs
and their families**

PETER LIMBRICK

interconnections

Back cover information –

THE TEAM AROUND THE CHILD

Multi-agency service coordination for children with complex needs and their families

Over recent years the increasing number of children who have multiple and complex disabilities has highlighted the need for new systems of service provision in which health, education, and social services and the voluntary sector join together to offer the child and the family a more co-ordinated approach. Though this need is recognised now in both local and national government, the call for service coordination is not accompanied by practical suggestions of how to achieve it or about what it should look like.

This manual describes a practical family-centred approach which provides the child with a coordinated service and gives the family more control over service provision.

Peter Limbrick taught children with special needs for many years before establishing One Hundred Hours in the early 1990s. This voluntary organisation developed and validated a keyworker-based support system for families of babies who have multiple disabilities and complex health needs. He provides a consultancy service to local authorities across the UK in multi-agency service coordination and he is Chair of The Handsel Trust, a registered charity which promotes effective support for families of children with disabilities in the UK.

A MANUAL FOR SERVICE DEVELOPMENT

interconnections

ISBN 0-9540976-0-2

£9.95

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Published in 2001 by Interconnections

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ISBN 0-9540976-0-2

This 2023 PDF version of the book is true to the original text and page numbering but does not always follow the original page design.

Acknowledgements

The parents and children I met while working for *One Hundred Hours* opened my eyes to the very real suffering caused by fragmented and disjointed services and also showed me the great damage which is caused to children and families when professionals do not listen to parents and do not acknowledge either their expertise or their central role in the service to the child. I have developed the Team around the Child model described in this manual by listening to *One Hundred Hours* parents and by in-depth discussion with professionals and parents across the UK. I would like to thank all of those people for their contribution. My sincere thanks also go to Sophie Levitt FCSP who taught me so much about the holistic approach to children and families and who first gave me the courage to run workshops for professionals and parents.

About the author

Peter Limbrick taught children with special needs for many years before establishing *One Hundred Hours* in the early 1990s. This voluntary organisation developed and validated a keyworker-based support system for families of babies and young children who have multiple disabilities and complex health needs. In this model the keyworker visits the family regularly in their own home and develops a relationship based on trust. The keyworker's role is parent-led and includes giving emotional support and helping parents get information and all relevant services. Part of the role with most families is to help parents co-ordinate all the professionals involved with their child. He is Chair of *The Handsel Trust* which promotes effective support for families of children with disabilities and is a member of the steering group of the *Care Co-ordination Network UK* which promotes co-ordinated services for children with disabilities.

Since 1995, under the name Interconnections, Peter has provided a consultancy service concerning children with complex disabilities. This work includes facilitating service-development discussions in Child Development Centres and other special units and schools, carrying out surveys of the views of parents and professionals, and leading multi-agency planning meetings in service co-ordination. At the time of writing (June 2001) he has worked with professionals and parents in over fifty different localities in England, Scotland and Wales. In 1999 Interconnections worked with Wrexham County Borough Council and North East Wales NHS Trust to stage *Sharing the Vision*, the first UK convention on service co-ordination.

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Introduction

This manual describes an approach for providing services to children with complex needs and their families by means of an individualised professional team, called here the Team around the Child (TAC). The focus in this manual is on babies and children in the period between birth and their first school years but the model is applicable in the years after that.

The manual 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.

The Team around the Child 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 the 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's and family's needs in detail and to agree a co-ordinated approach.

The model incorporates a Team Leader for each TAC who takes on the role of keyworker/co-ordinator and provides him or her with a context of multi-agency co-ordination in which to operate. The model recognises and builds on examples of good practice that already occur spontaneously in many localities in response to a particular family's needs and the interests and motivation of particular professionals around the child. This manual suggests how local services can develop such good practice into an effective system that is available to all families in their locality who need it.

Many local services wishing to offer families a more co-ordinated service think first of the keyworker model. These two approaches, Team around the Child and keyworking are complementary; the Team Leader has a defined keyworker/co-ordinator role and has a ready-made multi-agency context in which to work. In the author's experience it is unrealistic to expect family keyworkers to co-ordinate the professionals involved with the family unless there is a commitment to multi-agency working from the local agencies and some agreed processes already in place to facilitate it.

The word 'co-ordination' is often used to include the process of integration. In this manual the two processes are separated in the interests of clarity. However the Team around the Child model is designed to promote and facilitate integration of goals and programmes as well as co-ordination of services.

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.

The 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 co-ordination includes an element of service rationalisation and will bring with it the reassurance that wastage

and duplication is being minimised. However, if the TAC model were to be adopted as a way of reducing expenditure on this client group we would be doing a very great disservice to children and families whose needs have never been matched by adequate government spending at either local or national levels. While working to provide, with limited funds, the best service we can, we should also look forward to the day when adequate funds are made available for children with disabilities.

Each of the statutory services; health, education and social services, vary greatly across the UK in how they operate. Where they do attempt to collaborate on some sort of joined-up service they will differ in the place from which they start, the journey they will make and the end result they will achieve. The model offered here for the Team around the Child is an outline only and as such is intended to provide a basic plan that can be interpreted to meet the needs of each different locality. Further, the Team around the Child cannot be the complete answer to multi-agency co-ordination for any locality. Where it is adopted it is likely to be just one element in a mosaic of approaches to service co-ordination.

The Team around the Child model is based on the following assumptions –

- * the number of children who have complex disabilities is increasing
- * these children and their families require access to all the professionals, expertise and skills found in the traditional multi-disciplinary team
- * there are direct benefits to children and families when the many and various parts of services are as joined-up as possible
- * there are direct benefits to professionals and their agencies when the many and various parts of services are as joined-up as possible
- * this joining-up requires a change in the systems in which professionals work rather than a change in which professionals are involved

The Team around the Child is not the invention of the author though he has collaborated in, and worked to initiate, individualised teams for children with complex needs in school and pre-school settings during the last 25 years as teacher and, during the 1990s, as a family keyworker for the

registered charity One Hundred Hours. This independent organisation operated in West Yorkshire where there was, by and large, no multi-agency service co-ordination for children with disabilities. In these difficult circumstances an obvious first step for keyworkers was to try to get the various professionals together in a co-ordinated approach to each individual family. One exception to this was in Castleford in 1995 where the author was invited to join an existing group of multi-agency professionals who met regularly at 'Support Meetings' to review and plan services for baby Jade who was born in the previous year with complex needs. This group, co-ordinated by the Paediatric Occupational Therapist from Pontefract General Infirmary (now Pinderfields and Pontefract Health Trust) met every four months or so at the family home and included physiotherapist, speech therapist, Portage worker, member of the Community Team for Learning Disabilities, health visitor and, of course, Jade's mother.

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 who are working towards multi-agency service co-ordination for this client group. This development of the model has included discussion with many Child Development Centres as they have explored how to translate the CDC multi-disciplinary model into effective teamwork for their children and families. In this consultancy role the author first encountered the expression 'Team around the Child' at Eastbourne and County Healthcare NHS Trust's Family Intensive Support Service (FISS). This multi-agency project supports families with children with learning disabilities and additional challenging behaviour and centres on the assembly of the Team around the Child which is led by the keyworker in consultation with the family to oversee and co-ordinate all work.

The manual is divided into four sections. The first describes the Team around the Child model in detail and explains why some families need this sort of approach. The second details the benefits the model brings to children, their families and their professionals in relation to principles of an effective service. The third outlines how to build the model into an agreed system for a locality. The final section puts the model into the wider context of multi-agency service co-ordination and relates the TAC to the role of the keyworker and the role of the Child Development Centre.

The Team Around the Child Model and why it is needed

The Team around the Child is individual to each child and family. For this reason the TAC model is not the same as, for example, a 'Child Development Team' model or an 'Early Years Team' model in which one multi-disciplinary team remains more or less consistent for many children and families. The TAC can be defined as an evolving group of those few professionals who see the particular child and family on a regular basis to provide practical help in education, treatment and therapy. The members of the TAC can be drawn from education, health and social services and from voluntary and private agencies. They are probably the people who relate closely to the child and family and know most about the child's abilities and needs and about the family situation. In the case of most children with complex needs there will be many other professionals who are also involved but not on such a close or regular basis. These professionals can be thought of as the peripheral group. There will need to be effective and continuing communication between the TAC and all members of the peripheral group.

The function of the Team around the Child is to plan, execute and review a co-ordinated service to the child and family, regardless of how many agencies and workers are involved.

Working within the rules and requirements of each separate agency, the function of the TAC includes –

- * agreeing the service plan
- * delivering the agreed education, therapy and treatment
- * reviewing progress
- * making referrals to other services
- * arranging necessary assessments
- * reporting as required to review meetings, case conferences, etc.

Members of a Team around the Child are not required to adopt any working methods which are different from their usual approach nor to offer more or less regular intervention nor to work with the child at a different site from usual. The minimum commitment is the agreement to be a member of the child's TAC and to meet regularly to share observations and information and to agree and review a co-ordinated service plan. However the TAC model does provide opportunities for professionals who want to offer particular children a more holistic approach with integrated programmes.

Why some children and families need a Team around the Child

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

How a Team around the Child functions

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, perhaps averaging every two or three months 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.

It might be helpful to describe what can happen at a Team around the Child meeting. It can begin with everyone reporting on events since the last meeting. This can include sharing information about the child's health and

well-being and up-dates of work on the agreed programmes. New information might arise about the child's health and development, about changes in family circumstances and about imposed changes in service provision. There can be discussion at this point or later about any necessary changes in membership of the Team: Should it stay as it is? Have needs changed to the point that a new professional should be invited in? Is the input from a particular member not required now? How will any changes in membership be managed?

The 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 two-fold 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.

The next phase in the meeting might be to agree what each team member is going to do in the period up to the next meeting. This can be an opportunity to collectively agree goals and to share very practical information about programmes. All present can learn in detail how the child is being taught a particular new skill, for example crawling, and what language is being used in a particular situation, for example mealtime. In this way the child can benefit from a more consistent approach. Each team member, parents included, should avoid the temptation to promise more input than is realistic. This discussion should result in an agreed service plan for the period up to the next meeting detailing who is going to be involved with the child and the family, the level of their input and what they are going to be working on. The plan might also include opportunities for particular professionals to integrate their work, perhaps with joint sessions and combined programmes.

The last part of the meeting can include agreement about any new people in the peripheral group who should be added to the mailing list to receive notes of the meeting and about the next meeting's date and venue. This is a very important part of the process; if the next date is not agreed at this meeting while everyone is present with their diaries then the next meeting will be very difficult to plan and might not happen as soon as it should.

After the meeting the Team Leader will arrange for the notes to be distributed to all people in the Team around the Child (including parents) and in the peripheral group. A further task might be to follow up any agreed actions including referring the child to other services, inviting other professionals to join the Team around the Child, requesting any additional tests or assessments and chasing up anything that should already have happened but has not. It might be necessary to go through the notes with the family.

How the Team around the Child evolves

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 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 as a 'team'

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

Negotiation is an important element in the TAC model. When a family has a young child with complex disabilities there are many serious issues to face and many difficult decisions to make. The outcome of the plans the parents make will have consequences for the well-being, development and learning of the child and for the well-being and survival of the family. Given that many parents speak of having to fight and struggle to get effective services in place, it is fair to assume that any genuine partnership between parents and professionals will not always be relaxed and untroubled. From time to time there will be situations that require effective negotiation to find acceptable ways forward. Without negotiation one member of the partnership might always overrule the other. Negotiated solutions can enable the partnership to survive when there are strong differences of opinion.

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 some 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.

The 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. This chapter examines the Team around the Child model with reference to particular criteria identified by the author in his work with families.

Criteria of an effective service

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.

The Team around the Child is an ideal forum for proper negotiation of the parent's role with their child. It is usually assumed that during the pre-school years parents will co-work with therapists, Portage workers and pre-school teachers to provide specific opportunities at home for development and learning between professional sessions. This can work well but in the author's experience it is very likely to fail unless the role is carefully negotiated in advance with the parent and proper instruction and support is provided. This negotiation can happen at a Team around the Child meeting where the parent and the particular professional can also agree how necessary instruction and support will be provided. This model has the great advantage of preventing individual professionals overloading parents with co-working tasks in ignorance of what other professionals have advised and suggested.

Some parents at some times will not have sufficient resources to take on a co-worker role. Members of the Team around the Child can collectively acknowledge this and develop alternative strategies to help the child and support the parents through that period.

Some parents experience the reverse of this situation when their child starts nursery or school; whereas they were fully involved as co-workers up to that point, they might now feel sidelined, out of touch and unwanted. The Team around the Child provides them with an opportunity to remain closely informed and involved.

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.

These include in order of increasing integration –

- * a shared awareness of what each person (parents and professionals) is working towards and of the approach being used. This will facilitate a consistent approach to the child and eradicate contradictions and confusions.
- * a collective agreement about education and therapy goals. This again facilitates consistency and also contributes to a holistic approach in which the intervention is tailored to the whole child and the family. Overloading is avoided and goals can be prioritised. There can be a collective decision to focus on agreed goals in a timed sequence rather than trying to do everything at the same time.
- * the various home programmes that professionals offer to co-working parents can be rationalised and prioritised. These programmes can be integrated into enjoyable activity that is relevant to the child and his or her environment.
- * professionals can collaborate on integrated programmes that work toward goals in more than one area of development. This can, if required, provide increased options about who delivers the work to the child. For instance, a shared programme devised by a therapist and a sensory-impairment teacher could be delivered by either of those professionals and could also be adopted by nursery/school staff.
- * professionals can work towards a full transdisciplinary model with simultaneous assessment, integrated programmes, integrated goals and a ‘primary provider’. In this approach the primary provider can be thought of as a funnel directing programmes from a multi-disciplinary team to the child through one pair of hands. Very young children and children with marked sensory deficits particularly will benefit from integration which works towards this primary provider approach.

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.

Interruptions in the over-all service typically occur at transitions into nursery or school, between schools and then into adult services. The interruption can affect the child, who might temporarily or permanently lose some provision, and the parents, who might lose valuable support for themselves from their incidental meetings with professionals. This loss of support for parents can happen when the child first enters nursery or school because they suddenly lose contact with those familiar professionals who were primarily helping the child but who were also available informally to listen, answer questions and make helpful suggestions. The Team around the Child, as a whole, will remain in place during transitions and will continue to support the child and the family even though one or more of its members will change. By anticipating transitions the Team members can agree gradual changes and some overlaps where appropriate.

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. The next section of the manual discusses how the Team around the Child model can be offered to families in a uniform system across a locality.

The Team Around the Child as a system for a locality

In many localities there will be some professionals who work with some children and families in an individualised model similar to the Team around the Child. Often this will be an impromptu arrangement between the professionals and the family and not part of an agreed system in their service or in the locality. This chapter describes how the Team around the Child model can operate as an agreed system and suggests three organisational levels as follows –

1. A Team Leader for each Team around the Child.
2. A Co-ordinator or Co-ordinating Group for the Team around the Child system.
3. A Multi-agency Management Group at senior management level.

This chapter also discusses establishing a TAC for a new child and family, record keeping, confidentiality, necessary resources to run the TAC system and describes briefly an approach for establishing a Team around the Child system in a locality.

Levels of organisation in a TAC system

1. Team Leader

In a formal system each Team around the Child will have a Team Leader. In most cases this will be a professional who in addition to their usual role, assumes some responsibility for managing one or more Teams around the Child. A parent might elect to be a Team Leader. The Team Leader role will vary according to many factors including the design of the local Team around the Child system, the needs of the individual family at that particular time, the resources allocated and the roles of other professionals already helping the child and family. For instance there might be another professional acting as a keyworker for the family. (This is further discussed in the next section.) The minimum requirement for the Team Leader role includes –

- * getting to know the family well, establishing a relationship based on honesty and trust, and agreeing rules of confidentiality
- * keeping an up-to-date list of all the agencies and professionals involved with the child and family, the peripheral group
- * ensuring that meetings happen at appropriate intervals

At Team around the Child meetings –

- * guiding meetings through all the items which need discussion
- * helping Team members to be positive, encouraging and supportive to all present
- * encouraging Team members to keep the whole child and family in mind –
- * and to try to look beyond the immediate situation into the medium and longer-term
- * facilitating negotiation when differences arise or planning for negotiation of more difficult issues at another time
- * pulling the various strands together to agree the service plan for the period up to the next meeting

- * seeking collective agreement about any referrals, tests and additional assessments that are recommended by the Team members

After the TAC meeting –

- * sending out notes to TAC members (including parents) and to the peripheral group and putting a copy into the family file
- * communicating as necessary with other agencies and professionals on specific issues
- * asking the parents if they have any concerns or questions arising from the meeting
- * perhaps going through the notes with the parents
- * communicating as necessary with the TAC Co-ordinator

2. The Team around the Child Co-ordinator

The Team around the Child system in a locality will require a manager or a group of people responsible for co-ordinating the TAC system. The Co-ordinator or Co-ordinating Group will be responsible for managing the system but will not be responsible for the progress of children and families within it. The role includes –

- * managing, monitoring and reporting on the system to the Management Group
- * securing necessary resources for the system
- * keeping a record of which children have a TAC
- * taking referrals for new children who need a TAC
- * allocating a Team Leader to each new child
- * being notified that a first meeting has happened
- * arranging induction, further training and support for Team Leaders
- * supporting individual Team Leaders when difficult situations arise
- * providing necessary documentation to Team Leaders, e.g. a schema for writing TAC meeting notes
- * receiving summarised reports from Team Leaders about work with individual families

3. A Multi-agency Management Group

In an ideal system the Team around the Child Co-ordinator will report to a Multi-agency Management Group made up of senior managers from health, education and social services and the voluntary sector. The smooth running and ultimate success of the TAC system will depend on the extent to which all agencies are committed to it. Any imbalances in commitment, management and funding of the system will probably be reflected in the working of each individual Team around the Child and effective service co-ordination will be impaired at a cost to the child and family. The role of the Multi-agency Management Group includes responsibility for –

- * the over-all design, funding and resourcing of the Team around the Child system
- * setting standards and protocols
- * appointing and supporting the Co-ordinator or Co-ordinating Group
- * anticipating future demands on the system
- * being the inter-face between the TAC system and each separate agency
- * monitoring and evaluating the TAC system

The essential difference between spontaneously occurring individualized teams and a proper Team around the Child system is that an agreed TAC system is –

- * sanctioned and facilitated by senior management across the statutory agencies
- * properly documented and resourced
- * monitored and evaluated
- * available to all families who need it

Establishing a Team Around the Child for a new child

This will vary according to the design of the local Team around the Child system and the referral agreements between the various agencies. At some point a child and family entering the Team around the Child system will be

allocated a Team Leader in a consultation process with the parents. The Team Leader's first responsibility is to ensure he or she has a good working relationship with the family and a comprehensive understanding of their situation. In some localities the system might be designed so that families can choose whom to have as their Team Leader. Whether or not this is possible, Team Leaders will need to be skilled in establishing an effective relationship with families over a short period.

Once in place, The Team Leader explains to the parents how the Team around the Child model works and negotiates with the parents the level of their involvement in the first stages. If the child is already receiving some services then the Team Leader can work with the parents to identify the professionals who are working closely and regularly with them. If the system is established by multi-agency agreement then inviting professionals to attend this first meeting will be straightforward. If one or more professionals belong to agencies that are not signed up to the system then there will need to be some negotiation perhaps with the professional, perhaps with his or her line-manager.

If disclosure has been a recent event and some key professionals are not yet in place then the Team Leader will need to work with the parents to make a judgement about which few professionals to invite to a first potential Team around the Child meeting. The function of the first TAC meeting includes –

- * agreeing that the Team has the right membership for the time being or deciding to invite other people to join
- * confirming who is in the peripheral group at this time
- * discussing the needs of the child and family as far as they are known and composing an initial service plan
- * finding out what unanswered questions the parents have and agreeing an approach to trying to get answers to them
- * considering if any further tests, assessments or referrals are needed at the moment to learn more about needs
- * finding out if there are any appointments, tests, etc, which the family are waiting for and deciding which ones should be chased up
- * confirming that the child and family have been formally referred to all relevant local agencies and departments within them

Record keeping

The Team around the Child system is not intended as a heavily bureaucratic exercise. It is rather an attempt to rationalise and simplify already complicated systems. The object would be defeated if it resulted in yet another layer of complexity and in yet more time-consuming paper work for busy professionals. Keeping bureaucracy to an absolute minimum is a very great challenge for a locality establishing a new Team around the Child system.

The minimum requirement is for the Team Leader to distribute notes after each meeting to the family, fellow TAC members and the people in the peripheral group. These notes should include the agreed multi-agency service plan for the period up to the next meeting. They are kept in a family file to which the Co-ordinator and the family have open access. Depending on the needs of the family at the time, the Team Leader might arrange to go through the notes with the parents. The meeting notes might be written with the help of a schema provided by the Co-ordinator. It might be advisable to write to parents and fellow TAC members to confirm the date of the next meeting.

Confidentiality

How information about the child and the family is protected and shared within the Team around the Child system must be decided separately by each locality. Whatever policy is decided, it must be documented and explained clearly to families and to all professionals involved. Once they know what the rules are, parents and other close family members can decide what to share and what to withhold.

Resources needed by Team Leaders

Time

This needs to be stated because there are many instances when busy professionals are asked to take on an additional role without being given additional time to do it. The effect of that misjudgement on the Team around the Child system would be increased frustration for professionals

and a loss of effectiveness in the service to the child and family. It might be decided that each professional in a Team around the Child, including the Team Leader, will sacrifice a routine session with the child and family when attending a TAC meeting. The experience of the author is that the great value of the TAC model can justify loss of a routine session. Children and parents are already well used to losing sessions for a host of reasons that bring no direct benefit to them.

The Team Leader will require time after each meeting for organising the writing and distribution of notes, for making any necessary communications to other agencies or professionals and perhaps for going through the notes with the family. There might also be a need to spend some time with the family before a meeting to get properly up to date and to gain an understanding of any new or emerging issues.

It should not be the responsibility of Team Leaders to juggle their own time or negotiate priorities with their line-managers. The Team around the Child system should allow for the Co-ordinator to negotiate with line managers for sufficient protected time for each Team Leader.

Clerical help

Effective clerical help will reduce the time commitment of the Team Leader. For instance, clerical staff could type the meeting notes, from written notes or a dictation tape, and send them out to the agreed mailing list. This will be more reliable and efficient if the clerical workers are based with the Co-ordinator so that Team Leaders do not have to compete for clerical time in their own busy departments.

Training and support

The success of the system for each family will depend on how well Team Leaders are prepared for the role and supported in it. The skill requirements of the role which might be additional to the each Team Leader's professional training, include –

- * the ability to establish an effective trusting relationship with a family in a short period of time

- * the ability to manage meetings effectively
- * the ability to guide meetings so they remain positive and constructive
- * the ability to facilitate effective negotiation of routine issues and to know when to seek additional help in this
- * the ability to keep in mind the whole child and the whole family –
- * and to look beyond the immediate situation

The Team Leader will work in close contact with families and from time to time will experience great emotional demands. It is essential that he or she will be able to take some issues, both general and specific, to the Co-ordinator, or to another professional in a supervision capacity, to talk them through, to seek guidance and reassurance and to get emotional support. This emotional support should be built in to the system rather than being left to the initiative of the individual Team Leader and it must conform to the agreed rules of confidentiality.

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 –

- * 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.

- * locate parent organisations and individual parents who are enthusiastic about service co-ordination and the TAC model.
- * identify a small group of these people who will help in the first planning stages.
- * locate all examples of good practice in professional collaboration in your locality and try to build on these.
- * locate people in other localities who have established the TAC model and learn from their work.
- * 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.
- * start writing a proposal for the new system with help from the people you have identified above.
- * think about establishing a pilot project involving enthusiastic professionals and parents.

The Team Around the Child in the wider context

The Team around the Child system cannot operate independently of other initiatives in the locality towards multi-agency collaboration. If it were established in isolation then it would merely add to the mystifying service maze that already baffles parents in its complexity. The ideal in multi-agency collaboration is to achieve an integrated whole which is coherent and comprehensible to both professionals and parents. This section examines how the Team around the Child can fit into the larger pattern of a locality's service co-ordination processes and how the model integrates with, and enhances the work of, two existing examples of potential service co-ordination; the keyworker and the Child Development Centre.

Multi-agency service co-ordination in general

Multi-agency service co-ordination for children with complex needs and their families is an emerging field of work and as yet has no nationally agreed definitions, descriptions or methods. Though there is an increasing number of calls for joined-up services, these appeals are not accompanied by practical suggestions of how to co-ordinate services or by ideas of what the end product should look like.

Multi-agency service co-ordination can be defined as a holistic approach to service provision for children with complex special needs and their families that provides each family with a keyworker or co-ordinator. At the planning stage it requires local education, health and social services, the independent sector and representative parents in the locality to work together to design co-ordinated strategies for information-giving, referral, assessment, service provision and review. In service delivery to each individual family it requires professionals from the statutory services and the independent sector to work in partnership with the family to design a holistic service plan that is responsive to changing needs.

It was suggested in the Introduction that the Team around the Child is just one element in the mosaic of the locality's service co-ordination. In the author's experience the other elements in the service co-ordination mosaic can include –

- * multi-agency funding for provision of comprehensive information to parents
- * multi-agency funding for the processes of referral, assessment, service delivery and review leading towards a single care-pathway (see below)
- * multi-agency funding for one or more posts to develop and manage service co-ordination
- * multi-agency funding of a centre or unit for children and families
- * multi-agency collaboration (but without shared funding) in provision of comprehensive information to parents
- * multi-agency collaboration in the processes of referral, assessment, service delivery and review leading towards a single care-pathway
- * multi-agency collaboration in a centre or unit
- * provision of a keyworker, whose role includes co-ordination of services to the individual child and family
- * a Team around the Child approach by multi-agency professionals

A single care-pathway

Multi-agency collaboration (preferably *with* shared funding) in the processes of referral, assessment, service delivery and review, works towards the ideal of a single care-pathway. In a single care-pathway the family is guided smoothly through these essential processes without suffering gaps in provision or unnecessary duplications and without being overly aware that the pathway is constructed by separate agencies.

The keyworker

The word 'keyworker' is used by different agencies to mean different things. This can also be true within a single agency. This confusion often prevents clear discussion about whether families need keyworkers and about who can be a keyworker. When professionals are designated as keyworkers this lack of clarity can lead to general confusion about what they should be doing and about how they should be supported and resourced in the role. Within services for children with disabilities and special needs the word 'keyworker' is usually used to describe a person who performs one or more of the following functions –

1. Helping parents access information
2. Sign-posting
3. Helping parents access services
4. Being a listening ear
5. Co-ordination of services
6. Integration of programmes

1. Helping parents access information

Parents often speak of great difficulty in getting comprehensive information about their child's condition and about what services and benefits are available. In the first months and years parents are on a very steep learning curve and have the added difficulty of not yet knowing what all the relevant questions are. Without proper help parents can be largely dependent on chance encounters. A keyworker with this function knows more about the world of disability than do the parents and will help them find out what they need to know.

2. Sign-posting

A keyworker with this function agrees to be the first person the family will contact when there is a new issue needing attention. He or she will point them towards the relevant colleague, worker or service and might also make the link for them. Some Child Development Centres allocate some families a particular member of the multi-disciplinary team for this role. Some families will adopt a particular professional for this role on their own initiative.

3. Helping parents access services

Many parents feel they always have to shout to get what they need and that life with a child with complex needs is one long battle with services. A keyworker with this function attempts to smooth the way for parents by helping them get necessary services for the child and the family and when necessary does some of the battling for them.

4. Being a listening ear

A keyworker who offers a listening ear has a positive relationship with the family based on trust and honesty and has sufficient time, flexibility and empathy to be an 'active listener' when necessary. This valuable emotional support is not formal counselling but does require basic counselling skills.

5. Co-ordination of services

This keyworking function is in recognition of the difficulties that occur when many professionals from different agencies are helping the child and the family. The keyworker/co-ordinator links everyone together as far as possible to rationalise appointments, fill gaps of unmet need, avoid duplications, resolve contradictions and make sure workers know what each other is doing. He or she helps the family build a whole picture of their child's abilities and needs and helps them fit all education, therapy and treatment into a sensible daily and weekly time-table which balances the needs of the child with the needs of other family members.

6. Integration of programmes

A keyworker with this function is directly concerned with the child's play, development and learning and promotes a holistic approach. He or she can

facilitate some joining together of the various education, therapy and treatment interventions by arranging shared appointments and facilitating integrated programmes and goals. He or she might also be the primary provider or 'one pair of hands' in a transdisciplinary approach with some children or might support a parent who takes on the primary provider role.

A keyworker can then be characterised as a professional –

- * who has a positive relationship with the family based on trust and honesty
- * who is in regular pro-active contact
- * who works with the parents in an equal partnership
- * whose role is defined and acknowledged by the family, by all professionals around the family and by all the agencies involved
- * who performs one or more of the functions listed above

And an agency or a locality can be said to have a keyworking system if –

- * the role of the keyworkers is documented and resourced
- * keyworkers are available to all families who need one
- * the performance of the keyworkers is monitored and evaluated

Depending on how the locality's Team around the Child system is designed, the role of Team Leader will overlap the keyworker roles listed above. The TAC Team Leader is certainly a service co-ordinator, will facilitate appropriate integration and is probably the first person the family contacts when a new situation arises. He or she might share responsibility with the other members of the TAC for ensuring that parents have access to all necessary information and helping the family get the services they need by taking some of the battling from them.

If emotional support is not available anywhere else the family will probably look to the Team Leader for this because there is already a positive relationship with regular contact. Any expectation that Team Leaders provide emotional support must be matched with proper allocation of time and support for themselves.

The model does not assume that the Team Leader will be a primary provider for the child because this would limit the range of professionals who could become Team Leaders. (In the One Hundred Hours family support model, the keyworker could assume all of the roles listed above including the role of primary provider. This was dependent on the professional background of the individual keyworker; those who worked directly with the child in a role approaching that of primary provider were those with a teaching qualification.)

The Team around the Child and the keyworker are complementary models: The TAC system generates for each family a professional with a keyworking/co-ordinating role, establishes clearly what his or her role entails (from the list above) and provides a ready-made context in which to perform the role. In the author's experience keyworkers cannot function effectively as multi-agency service co-ordinators in a locality where statutory and voluntary agencies are happy to remain separate and where professionals are not empowered or encouraged to work together across professional or agency boundaries.

Child Development Centres

Child Development Centres and Child Development Teams in most localities are integral to services for pre-school children with continuing complex needs. Within them paediatricians, specialist health visitors and other team members have been accustomed to taking on the role of service co-ordinators to a greater or lesser extent. The environment in which CDCs function has changed in recent years as case loads, complexity of disability, parents' access to information and parents' expectations of services have all increased significantly. Among present pressures is the need to provide a wider and richer service focusing more on the family rather than just the child and the requirement to join with other local agencies to provide a more co-ordinated service. While some families will continue to benefit from the existing systems, families whose children have more complex needs will benefit from the TAC approach.

Most Child Development Centres and Teams already hold multi-disciplinary case conferences and review meetings which might also be multi-agency and which can help to co-ordinate all professionals involved. CDCs and CDTs in the UK differ greatly in their approach to children and

families. In general terms, The Team around the Child meetings might differ from CDC and CDT case conferences and review meetings by –

- * being more focused on day to day education, therapy and treatment practice
- * being more detailed about suggested programmes
- * happening more frequently
- * requiring full parent partnership
- * being less formal and more family-friendly
- * having an in-built balance between medical, educational and social needs

The Team around the Child system is designed to allow each TAC to integrate fully with the patterns of service in each of the other agencies involved with the family. There is a two-way exchange of all relevant information between the TAC and more formal case conferences and reviews held by other agencies. Until the locality has established a single care-pathway, the TAC will be one part of an agreed and coherent system involving Child Development Teams, Children with Disabilities Teams, Early-Years Teams, etc.

Child Development Centres are key agencies in most localities for young children with disabilities and have probably already established effective local networks. For these reasons, a CDC that has been able to evolve into a multi-agency Centre, in which local agencies share responsibility for funding and management, will be the ideal base for the Team Around the Child Co-ordinator and can be the administrative nucleus for the locality's multi-agency network providing, or working towards, a single care-pathway for children with complex needs and their families.

The Team around the Child model represents a low-cost approach to multi-agency service co-ordination for the child and family which will, once it is in operation, provide accurate information to service providers about the need for keyworkers and which will help prepare for a single care-pathway.

Appendix

Some relevant research

Larsson M. Organising habilitation services: team structures and family participation. Department of Psychology, Lund University, Lund, Sweden. *Child: Care, Health and Development*. Volume 26, Issue 6, 2000.

The summary to this paper is quoted here in full –

“This study is part of a project focusing on co-operation between receivers of habilitation services (families) and professionals. The study focuses on the organisation and co-ordination of the services, and compares two structures for their accomplishment. The first is the typical multiprofessional habilitation team (MHT), and the second is the individualised team (ISP). MHT teams are organised within the habilitation agency, while ISP teams span institutional boundaries. An ISP team is formed around the individual child who receives services from the habilitation centre, and includes parents (sometimes the child), professionals from the habilitation centre, and professionals from other service-providing institutions that are actively involved (for instance pre-school teacher, school teacher, etc.). The team maps the child and family needs, organises assessments and services and formulates goals that are subsequently monitored and followed up. A Questionnaire (Measures of Processes of Care) was used to assess the experiences of 385 service

receivers. The questionnaire focuses on service receivers' experiences of the family-centredness of the service, operationalised in 56 items, along with five items concerning perceptions of level of control over service provision. The experiences of families having individualised teams were compared to those not having these teams. Significant differences were obtained, suggesting the impact of the form of service organisation on the content. Families having ISP teams report both more family centred service, and a greater level of control over service provision. Results are discussed in terms of organising structures and co-ordination of services, and in terms of family participation.”

In *'How do Child Development Teams work? Findings from a UK national survey'**, the authors refer to the above study by Larsson and suggest that the multiprofessional habilitation team seems to equate to a CDT (Child Development Team).

**McConachie H, Salt A, Chadbury Y, McLachlan A, Logan S. Child: Care, Health and Development. Volume 25, no 2, 1999.*

Suggested further reading

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