

EARLY SUPPORT FOR CHILDREN WITH COMPLEX NEEDS

Team Around the Child and
the Multi-agency Keyworker



PETER LIMBRICK

interconnections

BACK COVER -

EARLY SUPPORT FOR CHILDREN WITH COMPLEX NEEDS

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In traditional approaches to children with complex needs practitioners have worked separately, providing many families with a fragmented service. This manual addresses how to join these services together and argues that effective early support can only be achieved if key practitioners take time to establish better working relationships with parents and with each other.

The author has designed the family-centred Team-Around-the-Child model (TAC) as a structure for this close collaboration and offers here an account of its philosophy, principles, outcomes and management.

Each child's TAC has a Team Leader who functions as the family's multi-agency Keyworker with a task list which is purposely limited to prevent overload. In this way, successful TAC projects have been established with only modest additional resources. The author presents a vision of effective early support for all families who have a child with complex needs and suggests that this is dependent on a significant increase in resources.

TAC principles and practice have been adopted by many health trusts and councils. This manual provides first-hand accounts of three TAC projects and parents' comments from a fourth.

Also by Peter Limbrick:

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

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

Both published by Interconnections.

Cover drawing by M Jirankova-Limbrick from a photograph of Adam with his mother Eva

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**EARLY SUPPORT FOR CHILDREN
WITH COMPLEX NEEDS**

**Team Around the Child and
the Multi-agency Keyworker**

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About the author

Peter Limbrick has a background in special education. He established the registered charity *One Hundred Hours* which worked in the 1990s to develop and validate a keyworker-based support system for families who have a baby or young child with multiple disabilities and complex needs. He now chairs *The Handsel Trust* which campaigns nationally for effective support for these families. Peter is also an independent consultant to health, education and social services in the UK and Ireland.

Peter Limbrick has written two earlier service development manuals:

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

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

Both are published by and available from Interconnections.

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All children with disabilities and their families and all practitioners who work to provide them with effective support owe a debt of gratitude, as do I, to children with multiple disabilities and complex needs. These children and their families have highlighted the need for co-ordinated support. If those of us who work in this field can find ways of joining our efforts together then all children who have disabilities and special needs will ultimately benefit.

The ideas in this service development manual, as in the two previous ones, have developed out of close contact with families and with service providers. In my role as a *One Hundred Hours* Keyworker I learned about the needs of families who have a child with multiple disabilities and complex needs. Since the mid-90s, in my role as an independent consultant in the UK and Ireland, I have learned about the challenges facing managers and practitioners in meeting those needs.

I would like to acknowledge all the children, parents, practitioners and managers in Wolverhampton, Halton, Walsall and Essex who were involved in the projects which are featured in Part II of this manual and to thank the people who found time to send me the written accounts of their work.

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Introduction

For many years parents of children with disabilities who have multiple or complex needs have been complaining about services being unco-ordinated and fragmented and about their children being treated in separate bits.

There is now a general recognition of these real problems and, in an endeavour to remedy them, service managers, practitioners,¹ parents,² and disabled young people and adults in many localities are exploring initiatives variously named 'service co-ordination', 'care co-ordination', 'integration of services', 'multi-agency working', 'joint working', 'harmonisation of support', etc. So that we can keep our focus on actual outcomes, we should think of these initiatives only as means to an end. They are not ends themselves.

The end product we are all striving for is effective support for children and young adults with multiple disabilities and complex needs. For the purposes of this service

¹ The word 'practitioner' is used as a collective noun for (in alphabetical order) dieticians, doctors, health visitors, home support workers, nursery nurses, nurses, play specialists, Portage workers, psychologists, social workers, teachers, therapists, therapy assistants, etc.

² 'Parent' denotes biological parent(s), adoptive parent(s) and foster parent(s).

development manual the desired end product is effective early support for babies and young children with complex needs and their families. An effective early support system will be multi-layered and multi-faceted and will have two essential characteristics:

1. It will empower parents and children and work to support their aspirations.
2. It will be a well organised collaborative effort.

Effective early support requires a multi-agency effort. The desired outcome can only be achieved if managers and practitioners in health, education, social services and independent agencies (voluntary and private) work closely with each other and with representatives of user families on a shared plan. For the effort to succeed it is essential first to agree a picture or a vision of what an effective early support system, or early intervention system, would look like.³ It is worth remembering though, that there are limits to what we can achieve by multi-agency collaboration. If any of the local services are incomplete or inadequate, joining them together will not in itself create effective early support. Also, some families have needs that are not addressed by their local services and joining those services together will still not fill that gap.

I attempt to demonstrate in this manual that effective early support for children with complex needs is dependent on improved partnerships between key practitioners and parents and on improved collaborative working between the practitioners themselves. Relationships based on honesty and trust are at the core of effective early intervention and are as important as improved systems. Team Around the Child (TAC) is offered as a family-centred approach which promotes enhanced relationships and which provides a simple system for collaborative child and family support.

Part I of the manual describes how the Team-Around-the-Child model contributes to effective early support, lists the outcomes the model brings to children and families, discusses how the TAC Team Leader functions as the family's multi-agency Keyworker and outlines management issues.

Part II consists of first-hand accounts of three TAC projects and comments from parents involved in a fourth.

The Appendices include various tables and diagrams relating to information in Part I of the manual.

³ See Appendix I: **A vision of effective early support**, p 86.

PART I

EFFECTIVE EARLY SUPPORT

“I’ve got a great team to help me. I like the meetings and I look forward to them.”

Spoken by a parent participating in Wolverhampton’s Keyworking Pilot Project, 2002 and 2003, in praise of her Team Around the Child.

Team Around the Child

The multi-agency Team-Around-the-Child model is offered here 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 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. There are three essential features of TAC:

- a. 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.
- b. Each TAC empowers parents by offering them a full place in the Team.
- c. Each TAC is led by a Team Leader who functions as the multi-agency Key-worker 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 new family support plans 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.

The need for parents to be fully involved

At a meeting of parents of children with impaired vision which I attended some months ago a frustrated parent commented, 'Parents are central to everything about their child, yet we are kept on the edge of things. Somehow we have to turn it all the other way up.' This comment encapsulates for me the great challenge we face to improve the support we offer families. We have to allow parents their rightful place at the very centre of all decision-making about their young children and about their family. We will only achieve this when those of us who design, manage and work in health, education and social services and the independent sector can acknowledge that we cannot always know what is best for other people and that our professional position does not give us authority over the families we are trying to support.

Over recent years I have heard many parents question the way they are treated with such comments as, 'Why is it that since I have a child with disabilities I have so many experts telling me what I must do?' This question offers us all a valuable exercise to explore how we think about families. It is a question we can mull over on our own or in team meetings. Exploring this question will bring us face to face with our beliefs about disability, about children and about families. It will make us confront our attitudes, our fears and our aspirations for children with disabilities. The question will bring into focus how we perceive our role as practitioners, our personal sense of why we do what we do, our view of our potential to offer real help.

The need for joined-up support

Many parents speak of the great difficulties they experienced during the first weeks, months and years after they learned of their child's condition. When I ask such parents what would have most helped them at that time, they often say they would have liked to have all the separate services linked together in some way.

Many parents deeply resent the confusion, repetition, gaps and chaos they experience in fragmented services. One parent spoke of her baby of nine months being spread in bits all around the city and not belonging to her anymore. She felt demoralised and helpless. Two therapists meeting for the first time in a young child's first TAC meeting discovered that one was teaching the child to stay put and use a sign when he wanted something while the other was teaching the child to go and get whatever he wanted himself. These are both valid goals: the first to promote communication and the second to encourage movement, but they cannot be used together without very careful planning. An effective joined-up service will have both co-ordination of visits, clinic appointments, etc. and integration of the young child's programmes.

How TAC began and how it has evolved

While being a Keyworker in the 1990s' West Yorkshire *One Hundred Hours*⁴ project, I became an enthusiastic advocate for the keyworking model, which in that project was single-role,⁵ and accepted invitations from services in all parts of the UK to discuss keyworking. There was not a clear consensus in those days, any more than there is now, about exactly what Keyworkers ought to do but it was loosely expected, in the light of *One Hundred Hours* experience, that they would offer parents some emotional support, help parents get information and access services, and help join services together for children who required ongoing support from a number of practitioners.

For many managers who had a growing awareness of the problems of fragmented services, the priority role for the Keyworker was service co-ordination. Practitioners and managers at those discussions could see that a local keyworking initiative would require either enough new money to employ a team of single-role Keyworkers or the addition of new tasks to the job descriptions of practitioners who were already stretched with large case-loads.

These discussions often came to a consensus that, if fragmentation was the major shortcoming to be remedied for children with multiple and complex needs, then

⁴ See **The Keyworker: a practical guide**, Limbrick-Spencer (2001), for a discussion of the role of the Keyworker in *One Hundred Hours*.

⁵ A 'single-role' Keyworker has no duties other than keyworking, while a 'shared-role' Keyworker combines keyworking with another professional role, e.g. as therapist or health visitor.

services with stretched resources could make significant immediate progress by joining key practitioners together into small individualised teams around each child. This reflected the practice of *One Hundred Hours* Keyworkers who would attempt to get key practitioners together for multi-agency planning meetings when working with children with multiple disabilities and complex needs. In this way TAC was first described almost as an interim model to enable services to provide families with a joined-up approach in the absence of new teams of single-role Keyworkers.

Since then, TAC has been recognised as good practice in its own right. The model incorporates a TAC Team Leader with a clear and limited role as a multi-agency (shared-role) Keyworker. He or she is supported in the co-ordination and integration role by the other members of the child's TAC. The establishment of a local integrated support pathway, incorporating a single-door referral system, joint assessments, collaborative teamwork and joint reviews provides the essential co-ordinated matrix in which the TAC and the TAC Team Leader can function effectively. In this manual I suggest how the role of the TAC Team Leader can be clearly defined and limited so that it can be taken on successfully by one of the child's key practitioners.

The real foundation for TAC

In writing this manual and thinking about the many TAC projects in which I have been involved, I have realised that Team Around the Child is much more than a mechanical approach to joining practitioners together and that TAC will fail if it is treated only as a new organisational system.

The real foundation for TAC lies in improved relationships between practitioners and parents and between the practitioners themselves. It is not possible for any practitioner to work effectively with children and families in regular and continuing close contact unless that practitioner is competent to develop a helping relationship⁶ with parent, child and other close family members. A helping relationship is based on empathy, respect, honesty and trust and requires the practitioner to have relevant skills and sufficient time in the first sessions to build good foundations for the relationship.

The other essential relationships within successful TAC projects are those between each child's key practitioners regardless of which service or agency they come from. As with families, these relationships must be based on empathy, respect, honesty and trust. The foundations for them can be laid in multi-agency in-service training and then further developed within individual TACs. Practitioners who are not open to working with families or with other practitioners in these enhanced relationships will not welcome the TAC approach or function effectively within it.

⁶ See *Counselling Parents of Children with Chronic Illness or Disability*, Davis (1993).

The question which TAC answered when it was first described was, ‘How can we join services together?’ The more relevant question now is, ‘How would early support be structured if each key practitioner had a genuine helping relationship with parents and was able to collaborate fully and openly with the other key practitioners also helping the family?’

This manual suggests that the answer, or one of the answers, to this question is the Team-Around-the-Child model and that the model can form a major part of effective early support for children with multiple disabilities and complex needs and their families. The TAC model, founded in genuine relationships, should provide strong reassurance to a parent I met who did not want a co-ordinated service because she feared it would give practitioners an opportunity to gang up on her. She did not enjoy a trusting relationship with any of her child’s practitioners and was anxious to preserve the fragmented approach to her child in which she could deal with her child’s practitioners one at a time.

TAC as a first step in service improvement

The Team-Around-the-Child model is now part of a response by many service providers to the above needs in early support. TAC operates directly at the level of the child and family. It puts parents at the heart of planning the service for their child and family, acknowledging their love and concern for their children, their central caring role and their expertise. It provides a safe and regular forum for sharing information and observations, for planning joined-up support and for respectful negotiation⁷ of differences of view. TAC provides a meeting of equals in pursuit of a whole approach which serves the best interests of the child and family.

TAC has evolved since 2000 in services for young children with complex needs mostly without the benefit of additional resources. The work has been undertaken by the practitioners already working in some capacity with the child and family. In this sense TAC has represented the biggest possible change towards joined-up service provision with the least impact on resources and working methods.

Perhaps in future years we will be able to adopt braver and bolder approaches in early support, but the TAC model starts where we all are at the moment, more or less, and suggests an improved approach that should be acceptable to, and within the abilities of, most of us - whether parents, family members, practitioners or managers.

⁷ See **Working with Families of Children with Special Needs: *Partnership and Practice***, Dale (1996).

TAC: Family-centred early support

An effective early support systems for babies and young children with disabilities will put the family at the centre of its practice.⁸ The Team-Around-the-Child model, designed for families of children who have multiple disabilities and complex needs, improves working partnerships between parents and key practitioners and between the key practitioners themselves. In this way TAC counters the fragmentation which is the experience of the majority of families. This is an important issue because we have in the UK an increasing population of children with complex needs and we are learning that they and their families can be damaged by the traditional fragmented approach.

The experience of many families

When families learn that their child has, or might have, complex needs, they have significant adjustments to make and a lot of learning to do. Some aspects of family life have to be adjusted very quickly:

- * family routines of work, weekends and holidays

⁸ See **Families in Context: Emerging Trends in Family Support and Early Intervention**, Carpenter (1997).

- * daily routines of meal times, play times, evening activity and bed times
- * income and expenditure
- * relationships with partner, in-laws, friends and neighbours

On a personal level family members might have to sort out their emotional response to the news, review their own attitude to people with disabilities, reassess their life plan and rethink their basic beliefs and values.

There is much that parents need to learn and the learning curve has to be steep because time is short:

- a. They will need to learn as much as they can about the child's condition. Learning all about one disability is demanding. Learning all about three or four or five disabilities and conditions, and about how each will affect the other, is a Herculean task.
- b. They will need to learn how they can best help their child. This they must do as they go along because there is no preparation time and no training programme.
- c. They have to learn quickly about what services are available and how to get them. Many parents find this extremely frustrating and can come to feel that the information they need is being deliberately withheld.

Siblings, whether children or young adults, grandparents and other close family members have great adjustments to make too. Brothers and sisters might not have as much attention as before and 'mum' or 'dad' might not be the patient, understanding, available people they used to be. Brothers and sisters of any age might feel they want to help as much as they possibly can, they might feel unwelcome responsibilities are imposed on them or they might feel both at the same time. Grandparents might feel a double anxiety; one for their grandchild and the life ahead of him or her, and one for their son or daughter and the great challenges they are facing. Whether or not they can offer any practical help will depend on how near they live, what sort of relationship they have and how fit they are.

It would be a rare family that had proper time and space to make these first adjustments, to learn what they need to learn and to think through all the issues. It is much more likely they are struggling in adverse conditions which might include fraught days, disturbed nights, anxiety about the child's health and feelings of anger, grief and guilt.

The effect of fragmentation

In the first months and years families can be very vulnerable. We cannot assume the family will survive intact any more than we can assume the child will. It is not helpful

to push and pull parents in different directions in their pursuit of effective support, to divide the child up into separate bits for treatment, to focus exclusively on the child as though he or she existed independently of the family or to deny parents a voice in how support is provided. Such an outdated approach makes life even more difficult for parents who, like the rest of us, just want to secure what is best for their child and family.

The traditional fragmented approach to these children can damage families at a time when they are very vulnerable. A fragmented service is characterised by:

- * a chaotic routine of appointments, home visits and consultations with little or no consideration of time, place and travel arrangements
- * duplications of some elements of assessment and support and a lack of others
- * conflicting diagnoses, information and advice
- * advice, suggestions and home programmes overloading parents
- * programmes and goals which are discipline-specific and do not fit together

Families suffer under fragmented services. Instead of smoothing the way for families, services which are delivered piecemeal create hurdles for them to clamber over and hoops to jump through. As a result families can experience additional and unnecessary stresses and strains. As they struggle to get their real needs met they are forced to waste valuable time, money and mental and physical energy. Their strategies for coping and their efforts to adapt are impeded. The child in this exhausted and stressed family will almost certainly be affected. He or she might, as a result, have a reduced capacity to benefit from treatment, therapy and education and consequent increased vulnerability. Practitioners, no matter how skilled and motivated they are, must face the possibility that the fragmented arena in which they operate significantly reduces their effectiveness.

The impact of a child's complex needs can be pervasive and all aspects of family life can be affected. We should acknowledge that services cannot offer total support to any family. Support will always be limited and, in some cases, practitioners will only be able to help by accompanying the family for a time on a very difficult journey. No practitioner can protect a family from all the challenges they face and, even if they could, this would not be desirable. Any family subject to such all-embracing support would lose its integrity and its opportunities for learning and development. It is important, for the sake of practitioners' mental health, to acknowledge these limitations. At the same time, it is even more important for managers and practitioners to monitor their practice to make sure they are not making life harder than it need be for children and families.

The resilience of families

The above account of what some families experience is not an attempt to describe their situation as a tragedy or to describe disabled children or adults in negative terms. My emphasis is on the great surprise, upset, and fear that many families experience when they get the news. Not getting the perfect baby will be for some families, at first, a bitter disappointment and for others a psychological trauma. This can be more so when the child's health and life expectancy are compromised. It is a rare family that accepts the news of multiple disability with equanimity and then makes all necessary adjustments smoothly and without upset or fuss.

Most families are naturally resilient and parents will eventually manage to find their feet and regain their balance after a period of confusion and fear. Many parents and family members quite quickly expand their view of normality and even become campaigners themselves for the rights of people with disabilities. I have seen many parents working hard to create networks to support other new parents when, only a few months before, they themselves were mentally and physically exhausted at the side of an incubator seeing a very black future indeed.

I would argue that effective, coherent support when parents are most vulnerable will usually enable them to regain their natural parenting skills more quickly. We should acknowledge though that families will remain vulnerable as their child grows and moves through life's stages. New crises will occur and new adjustments will be required. The TAC approach offers relevant support when it is needed and does not attempt to create dependency or to persuade families they are caught in the throes of an insurmountable tragedy.

Team Around the Child as a family-centred approach

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) 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 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 sector and the private sector 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 counter-forces.

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 all 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 well-being 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.

Who should be in a child's TAC?

It is inevitable that any discussion about the TAC model will include discussion about who should, and who should not, be in children's TACs. There is little to gain from discussing this in abstract terms. The question can only be answered in relation to a particular child and family at a particular time, and then the answer is usually clear. I see it as something like peeling an onion. We know that around any child and family there can be twenty, thirty, forty or more practitioners. On the outer layers of this 'onion' there will be practitioners who see the child and family only on rare occasions. As we peel the onion we pass through layers of practitioners whose involvement is increasingly regular and practical until we get to the inner core of a handful of practitioners who are most closely and regularly involved. These key practitioners comprise the TAC for that child and family at that time. If the onion is not peeled down to its innermost layers the TAC will be too big to be effective. In this event it will function more as a case conference, will not be family-friendly, will not empower parents and will not have time for detailed discussion of the child's programmes.

It might be that the first discussions about a particular child result in a potential TAC composed of seven, eight or more people. In this event, the first agenda item for the first meeting can ask, 'Is this the most appropriate membership for the TAC?' The parent is likely to have a view on this. The discussion might result in a decision to prioritise interventions. Any practitioner who moves out of this TAC at this stage will have more time to spend with other children.

In the middle and outer layers of the onion there will be a larger number of people whose involvement is not so close and regular. This does not mean that their involvement is less important. It just means that they are not at that time part of the child and family's close support system. As the child and family's needs change there will be some interchange between the layers. The TAC is not a permanent team, it evolves gradually so that it always reflects needs.

It would be counter to the spirit of TAC to be restrictive about whom the family can involve in addition to practitioners from local services. Many families will already have some sort of support network. Whether this comprises just members of the family or also includes members of the local community, it is a network to be encouraged, involved and informed to the extent the family wishes. There is no reason why a family should not opt for someone from this network to join their TAC.

Between the TAC and the members of the outer group of practitioners there needs to be a flow of information so that all are kept in touch with the workings of the TAC and so that members of the TAC benefit fully from the special knowledge about the child held by other practitioners. TAC cannot attempt to operate in isolation from other local systems. TAC should inform and be informed by any other meetings or case conferences which concern the child and family. However, the overriding principle is that service managers and practitioners collaborate closely with each other to avoid duplication of meetings with and about families. Where a locality has adopted Team Around the Child as its multi-agency system for children with complex needs, then all discussions, meetings, case conferences concerning those children will take place under the TAC umbrella.

Practitioners working together

TAC offers a basic plan for a joined-up multi-agency service. It requires key practitioners to meet together but does not require them to change how they normally work with the child and the family. Between meetings they are free to work separately if they wish.

There is need, when embarking on a TAC approach, to provide repeated opportunities for people from the separate agencies to get together. Managers and practitioners from one agency are unlikely to have a good understanding of the work of managers and practitioners in the other local agencies. This lack of familiarity breeds mistrust and suspicion and can prevent collaboration. A basic training need is for all workers to get together to share information about their work, their concerns and their aspirations. When they know more about each other they will begin to trust each other and when they trust each other they will be more able to work together. Without this familiarity and trust, managers and practitioners will not be able to collaborate effectively no matter how detailed and sophisticated the new multi-agency systems.

Experience shows that many practitioners, once they have become better acquainted with their colleagues from other services, will find additional opportunities to integrate their work for the child and family. This can include some softening of boundaries and some sharing of knowledge and skills. When this happens it is always a result of practitioners learning more about each other's work and learning to respect and trust each other. This exploration of collaborative working across professional boundaries will not only create new systems of joint working, it will also gradually create a workforce of practitioners with increased competencies. The process can contribute to, and be reinforced by, more imaginative multi-agency and multi-disciplinary approaches to basic training, in-service training and professional development programmes.

TAC can enhance a practitioner's effectiveness and self-esteem at another level. In the TAC model each practitioner, in his or her work with a particular child and family, is a member of a small team of people he or she trusts and who all share knowledge of the main issues and a concern for the child and family. This practitioner need not feel any dilemma or challenge has to be faced alone. TAC is a supportive team for practitioners as well as for the family.

The main practical outcomes of TAC

As a major contribution to effective early support, the Team-Around-the-Child model offers five modernising strands which provide practical outcomes for the child and family. Each one contributes to putting parents at the centre of planning and to making support well organised and joined up.⁹

1. Key practitioners work in partnership with families.
2. Support for the family is continuous and seamless.
3. Parents are fully involved in all phases of the support pathway.
4. Support for the family is well co-ordinated.
5. The child's programmes are integrated as far as possible.

1. Key practitioners work in partnership with families

Because of the child's continuing needs, the family and their key practitioners are going to be closely involved with each other over a period of months or years during which time there will be dilemmas, challenges, disappointments and joys which most other families will not experience. It is improbable these practitioners can be effective

⁹ See Appendix II: **Main outcomes of TAC for children and families**, p 87.

no matter how expert they are, if the members of the family cannot get on with them and do not trust them. The onus is on service providers to ensure that practitioners are skilled in laying the groundwork for a helping relationship with each new family during the first meetings. The aim is to establish a helping relationship based on empathy, respect, honesty and trust regardless of whether the practitioner feels he or she actually has very much in common with the parents and other family members.

Because each member has established, or is developing, a helping relationship, TAC meetings are supportive and family-friendly and can provide a safe space for parents to address emotive issues. TAC acknowledges that parents are the main carers and might remain so through the teenage years and into adulthood. TAC acknowledges that parents will have aspirations for their child and family regardless of what practitioners feel to be important. TAC acknowledges that the best interests of the child and family are served by parents and practitioners working in partnership.

Parents have a full place in their child's TAC. This place can be for one or more parents, a carer, a grandparent or an older sibling. For some families at some times this place might not be taken up. For example, some parents in the first weeks or months might be more in need of a shoulder to lean on than an opportunity to have their voice heard. The TAC place will be there for them when they are ready and most parents will want to be fully involved sooner or later.

TAC meetings are carefully managed so that parents have a genuinely equal voice. Parents are not patronised. No one pretends to listen to them while in the meeting and then afterwards ignores what they said. No one dismisses their concerns by labelling them as neurotic, over-anxious, awkward, too demanding, in denial, professional parent, etc. The TAC is a meeting of equals, a meeting of people who have different expertise and roles but who share sincere concern for the well-being of the child and the family.

2. Support for the family is continuous and seamless

Support for the family loses its effectiveness if it comes late, is fragmented, repeatedly interrupted or withdrawn too soon. Effective and seamless support will be immediately available, will appear coherent even though it is the product of a number of agencies, services and practitioners, will be continuous over transitions and other changes and will last for as long as it is needed by the child and family.

The TAC is an evolving team the membership of which changes gradually. In this way the TAC, as a team, provides continuing support even though the practitioners within it come and go. This gradual change will be caused by the child and family progressing along the support pathway, moving from one service to another or by practitioners leaving their post temporarily or permanently. If these changes and transitions are

managed badly there will be an interruption or a cessation of necessary support to the child and/or family. One example is the loss of incidental support for parents from practitioners who visit the home when the child is given a school placement.

Another major threat to seamless support is the frequent reorganising of agencies and services. TAC is not immune to this but, because it is an uncomplicated system and because it is based on the workings of practitioners in direct contact with the family, it has some in-built resistance to these administrative changes. This will depend to some extent on the commitment of the practitioners in the TAC to carry on meeting with each other—the same commitment which brought them into the TAC in the first place.

3. Parents are fully involved in all phases of the support pathway

The phrase ‘support pathway’ is used to describe the journey each new child and family makes through service provision after they first encounter one of the services. If services have worked together on a joined-up approach then it will be an integrated support pathway. There are five overlapping phases in the support pathway and parents have a central role in each of them:

- a. The Meeting Phase
- b. The Learning Phase
- c. The Planning Phase
- d. The Support Phase
- e. The Review Phase

a. The Meeting Phase

This is when the service and the family first meet each other. The phase can include:

- * a referral and/or a self-referral process
- * a system for processing referrals
- * one meeting at least between the family and one or more practitioners to exchange basic information
- * some decisions, based on what is already known about the child and family, about how the next phase, the learning phase, will be conducted

The referral process can establish which practitioners will be in the family’s first TAC or it can opt to nominate the TAC Leader and delegate to him or her the task of putting together the first TAC. Which of these options is taken can depend on local TAC protocols and on the needs of the particular child and family. Which practitioners are nominated will take into account the views of the family. Practitioners who meet the family at this early stage will be laying foundations for a helping relationship, offering some first support and listening to the parents’ hopes, fears and aspirations.

If parents are facing marked problems or stressful situations which are not yet being addressed, for instance, with the child's health, eating, sleep or behaviour, then these issues are addressed without further delay. It might well be that more information is required before they can be addressed fully, but at this stage parents will benefit from sharing their concern with practitioners, developing their understanding of the situation and getting some first practical support.

b. The Learning Phase

In this phase practitioners learn more about the child's condition, strengths and needs and about the strengths and needs of the family. The family is offered relevant support at the same time. Parents are encouraged by TAC members:

- * to provide information about their child and family in as much detail as they wish
- * to share their knowledge and skills in caring for the child with practitioners
- * to frame questions they would like answered
- * to talk about current causes of family stress such as feeding difficulties, sleeping problems and challenging behaviour
- * to say what they feel are the needs of the child and family
- * to talk about their aspirations for the child and family

c. The Planning Phase

This includes reaching agreement about the needs of the child and family and writing the first Family Support Plan (FSP).¹⁰ This should take place at the family's first TAC meeting with parents and practitioners together. Before coming to the meeting parents will have been given accessible information about their child's condition, strengths and needs and about relevant services, resources, benefits, etc. so that they can take part in the planning discussion from an informed standpoint. The resulting Family Support Plan will describe what sort of support will be provided and who is going to provide it. The FSP should also include the child's development and learning goals. The FSP will describe how family members are going to be involved in working on the child's programmes.

d. The Support Phase

In this phase the practitioners provide the support agreed in the Family Support Plan for the agreed period of time until the review at the next TAC meeting. Parents are listened to and supported in their understanding of the child's needs. They are given

¹⁰ See Appendix III: **How TAC can create the initial Family Support Plan**, p 88 and visit the Early Support Pilot Programme website: www.espp.org.uk

relevant skills and support so that they can promote the child's well-being, development and learning.

Learning and support are not separate functions in any part of the support pathway. While support is being offered there is continued learning about the child and family. Initial and ongoing assessment processes are carefully structured so that parents are supported and can increase their understanding of their child's condition, strengths and needs. In the parent-practitioner partnership there is a continuing willingness to share observations, understanding, knowledge, information and skills.

e. The Review Phase

The first review will take place at the second TAC meeting. Practitioners and parents meet to share observations about the support provided so far, to discuss relevant issues, to consider changes in needs and to write a new FSP. The cycle then continues in this way with new FSPs following each TAC meeting. Each TAC meeting combines review, discussion and planning.

Why must parents have a central role?

At this point it is worth reminding ourselves why parents should have a central role in how the support for their young child and family is planned and delivered. Everyone would agree that they should be consulted but why should they have a central role and full involvement at every stage? Services have operated for very many years on the basis that families would accept, more or less, what was offered by their local health, education and social services. What has changed?

Society has moved on. There is a greater awareness now of what families experience and of the sort of support they might need to help them survive and prosper. We understand at last that parents have their own needs and that in helping them meet those needs we promote the well-being of both parent and child. We have a deeper awareness of the rights and needs of disabled children and adults and there is a growing understanding that some aspects of disability can be seen as a product of how societies are organised. We strive to include all disabled children and adults in society rather than putting them away in institutions (while arguing about where special schools fit). Parents have access to world-wide information about disabilities, therapies, treatments and educational approaches. More babies and children with complex needs are surviving and living longer.

There is now a welcome focus by government¹¹ on how these children and their

¹¹ See **Together from the Start—Practical guidance for professionals working with disabled children (birth to third birthday) and their families**, UK Department for Education and Skills and Department of Health (2003).

families fare. The national standards which are emerging at the time of writing are welcome indeed. It is to be hoped that the government departments which set them will also arrange for the necessary resources to implement them.

In the light of these changes the old ways just will not work any more. We can no longer pretend that it is effective to provide standardised services for children with complex needs. If instead, the support is to be carefully tailored to each family then there has to be a process of learning about the family and agreeing solutions with the parents and other family members. This collaborative process recognises the uniqueness of each family, the diversity of families in each locality and the need for flexibility in service provision. These points are addressed below:

Uniqueness: There is no broad average of children with complex needs and no broad average in the nature of their families. The only characteristic they all share is uniqueness. A pre-requisite attitude of service planners, managers and practitioners wishing to provide needs-led support is an acknowledgement of this uniqueness. Many present-day services are found wanting because they were built on broad assumptions about children and about families. Many parents are exasperated about the support they receive because it does not fit their particular needs and the procedures appear to be carved in stone and unalterable.

Diversity: Acknowledgement of the rich diversity of families is necessary in pursuit of needs-led services. There are wide variations in how families are composed, the cultural traditions they follow, the belief systems they hold and the aspirations they adopt. Support services must be sensitive to this diversity and flexible enough to embrace each and every family without exception.

Flexibility: Flexibility is a necessary quality in support systems allowing appropriate fine adjustments or bigger changes of direction as the child's condition changes, as he or she grows older and as the family situation evolves.

The parent-practitioner partnership

It is valid to question here whose aims or aspirations the Family Support Plan is designed to meet. The traditional approach has been for practitioners to recruit parents' help in achieving goals set for the child by therapists, teachers and others. But if we ask parents to describe their aims for the child they might well have very different ideas. These parents would want to recruit the help of practitioners in working to *their* plan. If this mismatch is present and services proceed in ignorance of it or, though aware of it, are not flexible enough to accommodate it, then parents might fail to co-operate with suggested approaches and programmes and decide regretfully to look elsewhere for the support they need.

A tension can arise here when particular practitioners feel parents' aspirations are too low or are unrealistically ambitious. Similarly, some parents might feel one or more of their practitioners is expecting too little of their child or aiming too high too soon. This happens already in traditional services so it is not a new phenomenon. The outcome might be that parents and practitioners each perceive the other in negative terms, lose faith and then distance themselves from each other. TAC meetings will bring these differences of view out into the open so that they can be discussed and then an agreed approach negotiated.

Working in support of the family's aims does not require practitioners to do things they have never done before or forsake their professional principles and practice. But it is a different way of working. It means being willing to listen to what families are saying, respecting their views and ambitions and then exploring how each practitioners' knowledge and skills can best be used to support the family on their journey.

Team Around the Child is based in effective practitioner-parent partnership. This means that, while there is an onus on practitioners to listen to parents, there is also an onus on parents to listen to practitioners. Without this reciprocal agreement there is no real partnership. The professional members of each TAC collectively bring a wealth of skills, knowledge and experience to the child. Parents who are prepared to listen to their practitioners have the benefit of increased opportunities to develop their skills, knowledge and understanding. If they are not willing to listen, it cannot be an effective partnership.

The Team-Around-the-Child approach, in which each key practitioner has a helping relationship with the family, is an ideal forum for discussion and negotiation of attitudes, approaches and aspirations. It would represent a failure of TAC if parents or any key practitioners ultimately felt sidelined, undervalued and ignored.

A small minority of parents are guilty of neglect or abuse, regardless of whether their child has disabilities or special needs. It goes without saying that child protection procedures remain the same whether or not the TAC model is being used. It is worth mentioning that in one TAC project, the practitioners agreed that their regular contact with each other had enabled them to share concern for a particular child when otherwise each might have kept their anxieties to themselves a little longer.

4. Support for the family is well co-ordinated

Co-ordinated support is an essential part of the TAC approach. This co-ordination and outcome 5, the integration of the child's programmes, are together the main means of tackling fragmentation.

There are three main aspects to co-ordination of support:

- a. Key people know what each other is doing.
- b. Services are joined-up as far as possible in place and time.
- c. Joined-up support continues as the child gets older.

a. Key people know what each other is doing

Each practitioner who works closely and regularly with the child and family needs to know who else works with the family, what they are working towards and the methods they are using. If they do not then they have to work with the child in ignorance of other methods and goals and risk reducing or negating their own effectiveness. Parents are understandably apprehensive when, as far as they can see, their key practitioners are not talking to each other. TAC gets the key practitioners and parents together regularly to share at first hand their observations, methods, goals and aspirations.

As part of this TAC process, practitioners and parents can assemble the various jigsaw parts to see what sort of picture it makes. Are there gaps in the picture? Are there repetitions? Are services catering for the whole child and family? Is the overall plan pitched at the right level? If the level of support is not pitched appropriately, support might be too thin and expectations too low or there might be too many goals, too much work and too much rush. It is valid in early support to prioritise inputs rather than assuming automatically that the child and family need maximum input from each practitioner at the same time. Recognition of this opportunity to prioritise inputs can help keep each TAC small enough to be family-friendly and effective.

b. Services are joined up as far as possible in place and time

This co-ordination is at the practical level of where and when things have to happen. Appointments for clinics, consultations and home-visits must be co-ordinated and rationalised. I remember one mother who was waiting for two very important appointments for her child, one for shoes and one for a buggy. When the appointments eventually came they were both for the same day and in different parts of the city. She had to decide which one to rearrange knowing that this would carry a penalty of another very long wait for something the child needed weeks ago when the request was first made.

Another mother described to me how busy her life was and did this by recounting the appointments she had had the previous week. This included six visits to the home (two therapists doing a joint visit, Portage worker, district nurse, Keyworker, visual impairment teacher, health visitor and social worker doing a joint visit) and six appointments away from home (audiology clinic, twice to mobility centre, occupational therapy department for seating, hospital to meet surgeon, a nursery about a possible placement). This mother had a car. Other parents have to present themselves

for morning appointments miles from home, travelling by bus with pre-school siblings, with bulky items of equipment (oxygen cylinders, feeding pumps, etc) and with a child who might have fits and other crises on the way.

In pursuit of an effective co-ordinated service practitioners and managers will collectively make every effort to rationalise where and when their support is given. As ever, there is danger in making assumptions about a how a particular family would want to pattern their support. While one parent might want most support to come to the home where child and family are in familiar surroundings, another might be looking for opportunities to get out of the house and meet other parents. Parents who have too many home visits can feel their house is no longer a private space. While one parent might opt to meet as many practitioners as possible on a single visit to a hospital or centre, another might find this overwhelming. There is a particular challenge here when a family continues to receive some care from an acute hospital which is at a distance or which belongs to another locality.

The family's TAC can go a long way towards rationalising support but might not have the power to solve every problem. TAC members can agree with the family how they themselves should organise their sessions and the Team Leader can support the family in their efforts to rationalise other clinics, appointments, etc. Sometimes an approach from a Team Leader to another service or practitioner to ask for a different venue or a different time will have more effect than an approach from a parent. Team members can pool their knowledge and ideas to solve transport problems. This will not succeed every time but at least the family are supported in their efforts rather than having to battle alone. Sometimes two (or three or four) heads are better than one.

c. Joined-up support continues as the child gets older

Families need continuing co-ordination as they and their child progress through the various stages of support. They need a joined-up approach from the time they enter the service which first offers them support. Getting through the first door, which might itself be the result of a long struggle, should mean that other doors open automatically (or will open at the appropriate time). Many families have to knock and wait repeatedly at door after door. A joined-up approach will encompass an intelligent anticipation of child and family needs. In contrast to this reasonable ideal I recall a hospital manager admitting that in the local paediatric services parents of children with complex needs were not told of everything that could be available because the result would be too many demands on services. The system could only cope with existing resources by trying to remain hidden from the families that were entitled to it.

Families need a joined-up approach to initial and subsequent assessments. Parents have been telling us for a long time that they do not want to retell their private and emotionally charged story each time they meet a new practitioner. In TAC,

practitioners share their observations of the child with each other and collaborate on investigations so that the child is not subjected to repeated assessments. TAC provides joined-up support in which practitioners reduce as far as possible the number of places the child has to attend, the number of different visits to the home and the number of people needing to see the child separately. When it is time to review the service to each child and family, key practitioners get together in a TAC meeting with parents. Lastly, when it is time for the child to move from one service to another, transition is planned at a TAC meeting including present practitioners, parents and key practitioners from the new service. In this co-ordinated approach each transition is a gradual and seamless change in support to the child and family, not a stop-gap-start approach.

5. The child's programmes are integrated as far as possible

Integration is discussed here under four headings:

- a. Treating the whole child.
- b. Sharing skills without compromising expertise.
- c. Parents as co-workers.
- d. A consistent approach.

a. Treating the whole child

Because of the way services have evolved, we have a variety of practitioners supporting children with disabilities. Some of these only have concern for a part of the child's functioning. This fragmented provision cannot cater effectively for babies and young children with complex needs. Because professional training has divided learning and development into separate compartments it is tempting, in order to meet our needs as practitioners, to try to compartmentalise child activity. We can try but it will not work. Babies and young children operate as whole beings and every activity involves eyes, ears, hands, posture, movement, language, understanding, social functioning, and so on. It is the whole being we must cater for in our learning and development goals and in our play and work with the child. This does not mean we have to jettison our separate skills, we just need to be always aware that they do not reflect reality and to keep exploring how to join our separate efforts into a whole approach.¹²

TAC provides an opportunity to agree integrated or shared goals and to design integrated activity to help the child achieve them. For the baby or young child the activity will probably involve all parts of the body and all of the senses and will be enjoyable and motivating play or daily living activity. Learning and development goals

¹² See *Basic Abilities: a whole approach*, Levitt (1994)

will be a collaborative effort between practitioners to reassemble those aspects of the child's functioning which might have been observed and evaluated more or less separately.

Some practitioners have traditionally attempted to cater for the whole child. These include teachers, nursery nurses and Portage workers in pre-school and early-years settings. Some of these are already skilled in taking methods and goals from other disciplines and putting them all together into a whole programme for a child with additional needs. Many therapists are also already accustomed to working with others on a combined approach. TAC can build on this good practice and help establish that all babies and young children with complex needs should have the benefit of integrated working.

b. Sharing skills without compromising expertise

Integrated programmes and goals bring another benefit in their wake. Once the goals have been agreed and an integrated, or holistic, programme has been designed there is less dependence on any one particular person to actually do the work with the child. Key practitioners can be interchangeable or one can take precedence. For the child this can mean more opportunities to develop and practice new skills with fewer people handling him or her and for practitioners it can mean more flexibility in the time they spend with a particular child and family.

TAC provides an ideal opportunity to explore the validity of offering families a 'TAC Assistant' within the TAC system. This practitioner would not be a highly-trained teacher or therapist but would have necessary training in working with families and in play and child development. He or she would work with one or more families under the close guidance of their TAC. The role would be to play and work with each child on a regular basis using the agreed holistic programme and to support parents as they work to promote their child's play, learning and development. The TAC Assistant can work with the child more regularly than can the other practitioners, and in each session brings to the child the influence of each of the key practitioners.

This brings us to a common complaint from some practitioners that parents do not understand that the child can still be getting his or her therapy even when the therapist is not physically present. Some practitioners cite this is an obstacle to working in new ways and suggest that parents need to be educated about how therapists operate. I am using the word 'therapy' because it is a complaint I have heard many times from therapists and only rarely from specialist teachers and Portage workers.

In TAC there is clear information to families about how TAC will operate and this will include information about the role and methods of the practitioners. There will probably be a need to give the information more than once and in more than one

format. There will certainly be a need to discuss this fully with those parents who have other expectations and for some anxious parents there will need to be skilled negotiation with some give and take on both sides. In my experience most parents see the value of the TAC approach, trust their TAC practitioners and are prepared to accept this shared approach as being in the best interest of their child. What parents will not, and should not, accept are changes in service provision which are designed to mask the absence of relevant practitioners for their children or changes in which their children are catered for by practitioners who do not have the requisite training, experience, skills and support.

Children with complex needs require access to the skills of their key practitioners. While TAC represents an increase in collaboration and perhaps an increase in the child's exposure to relevant programmes it must never represent a reduction in the competence of people working with the child and family. When TAC members create holistic programmes for other practitioners to use, it is part of their professional responsibility to satisfy themselves that those practitioners have relevant training, support and monitoring. They will surely resist handing any responsibility over to an assistant who is not competent.

The TAC Family Support Plan can be written in a way that reinforces parents' understanding of the roles of practitioners and of how work will be delivered to the child. Alongside each integrated goal there can be a record of who has helped design the goal and then a record of who will deliver the work towards the goal. In this last section the list might include parents and other family members (who have been trained and are supported), TAC members, TAC Assistant, staff at an early-years placement, therapy assistants and others. This will help reinforce the information given to families at the start of TAC that there is a collaborative effort to provide a whole approach which has moved beyond the old idea of one practitioner catering for one part of the child's development.

c. Parents as co-workers

Effective integration requires that parents and practitioners are all supporting the young child's development and learning and using the same approaches and goals. Most practitioners will invite parents of pre-school children to become co-workers and there are clear advantages in this for the child when willing parents are properly trained and supported. Co-working parents can give their baby or young child increased opportunities to practice and perfect new skills in play activity and in the normal activities of daily living (eating, dressing, bathing, getting around the house, etc.). The fact that this happens at home makes it even more valuable because this is where the young child feels most secure and it is where the new skills will most likely be used first.

There is a danger, when practitioners work separately, that some parents are overwhelmed by these home-programmes. When tired parents do not have the time or the energy to do everything they are supposed to do they might see themselves as bad parents, have another failure to add to their list and assume more guilt. My experience over the last fifteen years or so has been that most parents do not do most of what they are asked, but I sense now that practitioners are being more realistic about what is possible. Those of us who rely on co-working in order to be effective therapists or teachers must be aware of the dangers.

I remember a family who were already busy enough with their three children, sleepless nights and home-nursing tasks. When a peripatetic teacher for hearing-impaired children visited she suggested 'mum' or 'dad' should make some simple gadget that would make a nice noise when the child moved in a particular way. Had she stayed long enough to appraise the situation she would have realised that the parents were already stretched to cater for the child's assisted feeding, the exercise regime left by the physiotherapist, the play activity to stimulate vision and general care for a very frail and delicate child. These parents could see the value in the suggestion but could do nothing about it and did not have the energy to explain this to the well-meaning teacher. They just nodded agreement and then shelved the idea. The teacher went away not knowing that she had failed to help the child and the family.

d. A consistent approach

Even the youngest children with complex needs might be played with and worked with in a number of different settings. Babies might have to accustom themselves to a child development group as well as to people coming into the home. Pre-school children might have a child-development group, a playgroup and an early-years setting, and perhaps people coming into the home as well.

Practitioners who set goals and approaches carry a dual responsibility: firstly to ensure the goals and approaches fit well with goals and approaches set by the child's other practitioners, and secondly to make sure they are used consistently in each setting the child attends. Private nurseries and other private services must be included in this. If the approach is fragmented and piecemeal the child's ability to develop new skills and understanding will be impaired. The TAC approaches to integration will start in the Learning Phase by observing the child in all the different settings and then inviting relevant staff who work in them to contribute their views. Where appropriate, key practitioners from each setting are invited into the TAC. The family support plan is then distributed to each setting and TAC members can follow this up with continued contact to share observations and skills.

The TAC Team Leader as multi-agency Keyworker

This chapter discusses the confusion we experience in the UK about what Keyworkers can and cannot do, and explains how the Team-Around-the-Child system has been designed to remove the common obstacles to keyworking. This is discussed under three headings:

1. Obstacles to keyworking and confusion about the role.
2. Planning successful keyworking projects.
3. How the TAC Team Leader functions as the multi-agency Keyworker.

1. Obstacles to keyworking and confusion about the role

It is generally acknowledged now that families who have a baby or young child with complex needs are likely to need a multi-agency Keyworker. This has been well documented over many years in research, surveys, reports and guidance and yet still the very great majority of families do not have a keyworker. It is important to try to understand why keyworking has not been widely adopted in spite of the very obvious need.

In my view there are three main reasons:

- a. Inappropriate expectations are put on Keyworkers.
- b. Shared-role Keyworkers can be overloaded.
- c. There is a lack of management and administrative support for keyworking.

a. Putting inappropriate expectations on Keyworkers

There can be pressure on Keyworkers to undertake tasks which go beyond their competence, 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
- (ii) Keyworkers trying to co-ordinate services
- (iii) Keyworkers giving advice
- (iv) Keyworkers giving significant emotional support

(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 do not have to shout and battle for everything) and the inappropriate role of supporting the family in complaints or other formal approaches to service providers. Some people like to call these two functions 'advocacy with a small a' and 'Advocacy with a capital A' respectively. When families require formal advocacy they should be linked to an appropriate advocacy service.

(ii) Keyworkers trying to co-ordinate services: Keyworkers on their own cannot create single-door referral systems, joint assessment processes or the other strategic elements of an effective integrated support pathway for children with complex needs. Multi-agency service co-ordination at this level is the shared task of senior managers from health, education, social services and the independent sector. When such a well co-ordinated matrix is in place, Keyworkers will have a favourable environment in which to keep everyone linked together as much as possible for each individual family. When local services are fragmented and piecemeal the Keyworker is very limited in what he or she can achieve for children with multiple disabilities and complex needs. Keyworking should be viewed as an essential element of service co-ordination for these children and their families but not as service co-ordination itself.

(iii) Keyworkers giving advice: Parents of children with complex needs will have to make many decisions which will impact on the well-being and survival of the whole family and on the well-being and perhaps the survival of the child. Keyworkers are not

competent to give advice. Their role is to ensure the parents have comprehensive information about the issue and perhaps to support them as they think it all through and come to their own decisions.

(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 being just an occasional listening ear to being the one person to whom family members share and offload their experiences, feelings and emotions on a regular basis. Talking to someone who is equipped to listen is a genuinely therapeutic activity which can help parents adapt to the most challenging situations and help resolve any negative emotions which stop them moving on. Emotional support at this end of the spectrum will make great demands on the Keyworker's time and this might well be unmanageable. 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, skills and support required. Families who require more emotional support than the Keyworker can provide should be helped to seek support from a relevant agency.

b. 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 some of the families they support. Depending on the nature of the practitioner's main role, keyworking might represent a set of additional tasks or just a more formal recognition of existing tasks.

Logically, when new work is added to a busy practitioner's workload, other work should be taken off them so that their job remains manageable. 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 time is allocated. 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 for future families.

c. Lack of management and administrative support

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 too few practitioners opt to assume the shared-role or when temporary funding dries up. This situation should be relatively easy to remedy by those senior managers who are committed to providing a needs-led service to families with children who have complex needs.

2. Planning successful keyworking projects

The need for Keyworkers is known but most services in the UK have so far been unable to change their working practices to meet the need. Though parents and their advocates have had little influence over the obstacles and confusions listed above, their voice is clear and unambiguous: families of children with complex needs require multi-agency Keyworkers. Faced with a large and, in the first months and years, ever-growing group of helping practitioners it is not surprising that anxious parents will look for one friendly face, one person they trust who knows more than they do, one person who can be the interface between the family and all the different services, one person who can help link everything together for them.

Keyworking can fail families and endanger the work and well-being of Keyworkers if it is not very clearly defined and limited. Whether Keyworkers are shared-role or single-role, they can only function effectively if they have very clear instructions about the elements of, and the limits to, their role. Without this clarity the role might expand beyond the available time and resources and might lead Keyworkers into areas for which they are not trained, competent, resourced or supported. It is not only Keyworkers who require this clarity, parents must also know clearly what they can expect of their Keyworker. If they do not then they might make inappropriate demands (and then be embarrassed or frustrated when refused) or might have to manage without support in some situations in which the Keyworker could have helped. Other practitioners who are involved with the family, whether from the same agency or not, must also know clearly what the Keyworker does and does not do. They will then know when to refer to the Keyworker and how best to join their efforts to the Keyworker's in pursuit of effective support for the child and family.

It is inescapable that additional resources are needed if families are to be offered either shared-role or single-role Keyworkers. This should not surprise us. Keyworkers are intended as a means of taking stress and strain off families. Families speak of a constant battle to get good information and to secure all the services they need. They tell us of many wasted hours trying to get those services joined-up with each other and

then of having to do it all over again when services are interrupted by holidays or by the child's unplanned admission to hospital. If these tasks cost families time and energy then they will inevitably impact on Keyworkers too. In the future, when services really are a well organised collaborative effort and when parents are properly involved and supported, the role of Keyworkers should be less demanding. In the meantime it is not safe to assume we can continue to provide families with shared-role Keyworkers without the benefit of additional resources.

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 expands beyond small-scale projects and is offered to *all* the 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. It is a matter of conjecture at the moment where these funds might be sought. If service managers are not given new money they will have to fund keyworking by re-prioritising existing budgets.

Developing clarity about the role of Keyworkers

We tend to use the word 'Keyworker' as though it had a single meaning and as though keyworking were just one single activity. In fact the word has different meanings for different people and Keyworkers have different functions in different settings. Even in one particular setting keyworking will probably be a mix of activities. Proper planning of keyworking systems requires that we move beyond imprecise and all-inclusive definitions.

I have found it helpful to group all the many and various things Keyworkers do under four broad headings. These cannot be used as hard-edged distinctions because the four activities inevitably merge together and overlap but the separate headings do suggest that Keyworkers will need different training, resources and support in order to be competent in each of the functions:

- a. Basic keyworking
- b. Providing emotional support
- c. Co-ordinating services
- d. Being a child's primary worker

a. Basic keyworking

This role includes:

- * being the named person who the family call when they do not know whom else to contact

- * helping the family get good information about their child's condition, strengths and needs
- * helping the family get good information about relevant services, resources, benefits, etc.
- * helping the family to understand all information
- * signposting the family to all relevant support and helping open doors into those services
- * offering *informal* advocacy to help family get all relevant support without them having to battle—this excludes formal advocacy

b. Providing emotional support

All Keyworkers have a responsibility, as do other key practitioners working closely with families, to develop a helping relationship with them. It is not possible to work closely with a family of a young child with disabilities until a helping relationship based on empathy, respect, honesty and trust has been established. All practitioners must develop the skills to lay good foundations for this within one or two meetings with each new family.

In this way each Keyworker becomes a close ally to the family and is someone parents can talk to about their joys and fears, anxieties and aspirations. This relationship, in which the Keyworker is a listening ear, can be a real asset to families and its value should not be underestimated. It is not always available. I have heard many parents complain they have never met a practitioner they could trust nor a practitioner who really tried to understand what life was like for them and their family.

When family members are in emotional turmoil or facing a particular crisis they might require a higher level of emotional support from a practitioner who has relevant skills and available time. Keyworkers who are experienced in working with families and who have learned basic counselling skills can provide this sort of emotional support if they have the necessary time and the necessary support for themselves. Family members who require formal counselling should be referred to relevant local services.

c. Co-ordination of services

The Keyworker with this role helps co-ordinate the service to the child and family to:

- * enable all practitioners to know who else is involved and what their involvement is
- * establish whether there is any unmet need or duplication of input
- * allow appointments, clinics, home visits, etc. to be rationalised as far as possible

- * ensure that the daily and weekly routines of education and therapy are in the best interests of the child and the family
- * enable services to provide collectively for the whole child and family

In my experience, this co-ordinating role is usually manageable for Keyworkers of children who do not have multiple disabilities and complex needs. Keyworkers of children who do have complex needs require a co-ordinated matrix in which to work successfully.

d. Being a child's primary worker

All experienced Keyworkers will be at ease shifting their focus continually between the child, parents and other family members. A Keyworker with the role of primary worker will focus much more on the child and will be closely involved with him or her in hands-on work and play.

This Keyworker has relevant training and experience and helps create a holistic programme of motivating activity for the child which incorporates agreed multi-disciplinary goals. This work is offered to the baby or young child as play activity or in activities of daily living. The role requires that other practitioners share their methods and learning goals with the Keyworker so that he or she can integrate them together into a whole approach.

The Keyworker with this role of primary worker can help reduce the number of hands-on sessions the child has with different practitioners. He or she can support the parent in learning how to play with the child and in learning how to help the child's development and learning.

3. How the TAC Team Leader functions as the multi-agency Keyworker

The TAC approach gives TAC Team Leaders a clearly defined and limited role as multi-agency Keyworkers. The role consists of:

- * developing a helping relationship with the family based on empathy, respect, honesty and trust
- * being a listening ear
- * keeping a list of all agencies, services and practitioners involved
- * helping the family get all the information they require (with help from other TAC members)
- * linking the family to other services, resources and benefits (with help from other TAC members)
- * helping establish the first TAC

- * leading TAC meetings
- * ensuring each TAC meeting results in a multi-agency support plan
- * ensuring the plan is typed up and distributed to the family, relevant service managers and practitioners (with clerical support)
- * supporting the family as necessary through all parts of this process

This role is a combination of basic keyworking and service co-ordination. Though a helping relationship is a prerequisite for the Team Leader, and the role includes the provision of support to family members through the phases of the integrated pathway, the role does not automatically require the Team Leader to move beyond being a listening ear and a befriender into providing regular significant emotional support. The boundaries here are inevitably fuzzy but the intention is to recognise that emotional support at this level can require more time than the typical Team Leader has available.

The TAC model recognises that families will differ in the demands they make on their Team Leaders and that an individual family will make higher demands at some than at others. For instance, helping a new family get an effective joined-up service in place can be very time-consuming at first and after that demand can quieten down considerably. A family might want to make renewed higher demands on their Team Leader during a fresh crisis or an important transition. Services using the TAC approach for their children and families will need to allow for this potential change between higher and lower demand within each family.

The TAC Team Leader's role is designed to address the common obstacles and confusions about keyworking in the following ways:

- * the tasks are very clearly defined and limited
- * the role falls to existing practitioners
- * formal advocacy is excluded from the role
- * provision of extensive emotional support and formal counselling are excluded from the role
- * the Team Leader benefits from a supportive team of key practitioners
- * the Team Leader operates within a co-ordinated matrix
- * the TAC system requires that Team Leaders are trained, supported, monitored and evaluated
- * the TAC system provides administrative and clerical support

What authority do TAC Team Leaders have?

The one remaining issue to look at in the role of TAC Team Leaders as multi-agency Keyworkers is that of how much authority they can bring to the task. How are they empowered to secure effective services for each family?

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 solution cannot be to select senior managers for this role, partly because there are not enough of them to satisfy the need and partly because senior managers do not typically work in close partnerships with families. The Team-Around-the-Child model 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, it 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 multi-agency agreement with written 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 (or both) overseeing the system and providing support to TAC Team Leaders. This person or group can support any TAC Team Leaders who are encountering difficult situations or seemingly unmovable obstacles.

Keeping the Team Leader role within manageable limits

In a flexible and needs-led service there will be room for the role of an individual TAC Team Leader to shift between the activities listed above in response to the changing needs of the child and family. This might be just a matter of changing emphasis between existing tasks or it might require some new task to be added to the role. The suggestion for this to happen might come from the family, from the TAC Team Leader's manager or from the TAC Team Leader himself or herself. The Team Leader and his or her manager must be watchful to prevent gradual change happening imperceptibly without any actual planning.

In the interests of protecting the child, the family and the TAC Team Leader, the role should only be allowed to expand if:

- * the family believes the new role will meet real current needs of the child, parents or other family members
- * the new role will help empower the family rather than create dependency
- * the TAC Team Leader is competent to perform the new role
- * the TAC Team Leader has sufficient time for the additional tasks
- * the TAC Team Leader has relevant administrative and clerical help and other necessary resources
- * the TAC Team Leader has necessary support for the new role

If the TAC Team Leader's role¹³ is allowed to expand without satisfying the above requirements the support for the child and family will be jeopardised and the TAC Team Leader will be less able to operate the shared role.

¹³ See Appendix IV: **The role of the TAC Team Leader**, p 89 and Appendix V: **Required competencies of TAC Team Leader**, p 90.

Management of multi-agency support

A multi-agency system which provides effective support in a given locality for children with complex needs and their families, which empowers parents and children and which is a well organised collaborative effort, requires commitment from the senior managers of health, education, social services and the independent sector in that locality. One of the first expressions of this commitment is the establishment of a multi-agency management group and one of the first tasks of that management group is to create a vision of an effective support system for their locality.

Each new multi-agency management group will have strategic responsibility to create effective and joined-up services for babies, children and young adults with complex needs and their families. Each will carry authority to establish policy and allocate resources. Multi-agency management groups must therefore include senior managers from health, education and social services and from relevant local voluntary agencies as well as representatives from local parents' forums or family-based organisations.

An immediate challenge is to decide over which geographical area each multi-agency management group will preside or, to put it the other way round, to decide which localities require their own multi-agency management group. Health trusts, councils and independent agencies rarely share the same boundaries. The common situation

across the UK is overlapping patchworks of unstable authorities. This makes new systems of multi-agency collaboration difficult to achieve in the first place and then holds those systems in a state of perpetual vulnerability to future re-organisations and boundary changes.

Many councils have to collaborate with more than one health trust and many health trusts have to collaborate with more than one council. The inescapable consequence is that there will need to be as many multi-agency management groups as there are over-laps. Each overlap will create a discrete shared locality and each discrete shared locality will require its own multi-agency management group.

The lack of conterminant authorities in the UK is contrary to common sense and means that managers, practitioners and families have to work very much harder to achieve an effective support system. It helps to explain why some agencies and services fail to take up the challenge to collaborate with each other or give up the effort when the obstacles become too great. It certainly explains why some families receive a very disjointed service.

The work of the multi-agency management group is discussed under the following headings:

1. A vision of an effective support system
2. The role of the multi-agency management group in TAC
3. A multi-agency referral panel
4. Keeping the focus on practical outcomes

1. A vision of an effective support system

The following questions can provide a basis for discussion by the multi-agency management group about what comprises effective support for babies, children and young adults with complex needs. The list is not exhaustive and the discussion will be informed at all stages by the views of members of local families.

- a. How are families informed about what support is available?
- b. How is information about children and families shared between services?
- c. How is information about children and families held?
- d. How are records kept about support to the child and family?
- e. How is effective partnership between practitioners and families achieved?
- f. How are children and families enabled to access all relevant services?
- g. How are children and families enabled to use and participate in all the amenities, organisations and activities of their choice?
- h. What are the mechanisms for ensuring that families receive relevant seamless support from the time when it is first required, for as long as

- long as necessary, and during all transitions?
- i. What are the mechanisms for shaping family support plans according to the aspirations of children and families?
 - j. What are the mechanisms for ensuring that all the services the family receives are properly co-ordinated?
 - k. What are the mechanisms for ensuring the child's strengths and needs are viewed as a whole and that the programmes and goals are integrated appropriately?
 - l. How are family members given opportunities to spend time apart from each other if they wish on rewarding activity?

2. The role of the multi-agency management group in TAC

The ultimate responsibility for establishing and overseeing the Team-Around-the-Child system falls to the multi-agency management group. This is true regardless of whether TAC began locally as a management initiative or as a practitioner/parent initiative. In many localities, managers who are embarking on multi-agency collaboration for children of all ages with complex needs have decided to start with pre-school children and have then decided to put TAC at the core of their new plans for this early support. The multi-agency management group's task in establishing and maintaining a TAC system includes:

- * being aware of all relevant legislation, guidance and research
- * ensuring that data is collected about current and expected incidence of children with complex needs (using agreed criteria)
- * being aware of the views of members of user families about what constitutes effective early support
- * acknowledging all local good practice in collaborative working
- * establishing policy and practice for information-sharing between agencies and services
- * establishing an integrated support pathway (for referral, assessment, family support plans, provision of support and regular review of family support plans)
- * establishing policy, practice and standards for the TAC system
- * establishing a management structure for the TAC system
- * securing funding for the TAC system
- * establishing training for practitioners working within the TAC system
- * being the link between the TAC system and each separate agency
- * nominating managers and practitioners for the multi-agency referral panel
- * monitoring and evaluating the TAC system as a whole and the performance of practitioners within it

3. A multi-agency referral panel

An integrated support pathway for children with complex needs must have a single point of entry for all children with complex needs. Without this, some children will not find their way into the pathway at the right time. One of the tasks of the multi-agency management group is to establish this single point of entry in the form of a multi-agency referral panel of managers and practitioners who have sufficient seniority to allocate resources to new families. This panel will meet regularly to accept referrals and to set the integrated processes in motion for each child and family. It will need to meet often enough to prevent families being put on a waiting list.

Either the multi-agency management group or the referral panel will have to establish clear criteria for acceptance into the integrated support pathway and these criteria must be disseminated repeatedly to all local practitioners, health clinics, G.P. surgeries, etc. This will help reduce inappropriate referrals. This information can be accompanied by a standardised referral form to ensure that the referral panel has appropriate information about each child and family referred. In an effective early support system parents will be able to refer their child to the multi-agency referral panel.

4. Keeping the focus on practical outcomes

It is essential when planning new systems of support to keep a clear focus on agreed outcomes for children with complex needs and their families. Once new services are up and running it is essential to maintain this clear focus to ensure that managers and practitioners do not let other needs gradually take precedence. Mechanisms for this must be built into initial planning because a gradual loss of focus on multi-agency working appears to be an inevitable process in the absence of very deliberate countermeasures. This is discussed here under three headings:

- a. Awareness of needs of children and families
- b. Planning change
- c. Auditing new systems

a. Awareness of needs of children and families

In any locality there will be a wide range of awareness amongst managers and practitioners of how parents, siblings, grandparents and other close family members experience having a child with complex needs, what disabled children and young adults experience themselves, what life is like for families and which needs and issues an effective support system must address. One of the first steps therefore in creating improved family-centred support is to generate a good understanding of families' needs in all practitioners and managers. Workers who have a proper awareness of need will be more able to see the shortcomings of traditional fragmented services and more

motivated to develop better systems. Managers and practitioners who remain ignorant of the experiences of families will not be properly equipped to plan a family-centred service nor to work within one. Local parent groups and family-based voluntary agencies are a valuable resource for this essential training.

b. Planning change

We should not underestimate the great challenges in creating an effective support system for children with complex needs in which managers and practitioners from separate agencies come together with representative parents in a shared endeavour. Structural changes within one service or agency meet many real obstacles and can leave some staff feeling threatened. This is more so when change requires people from a number of agencies and services to work together for the first time on a shared plan. It is important to recognise, though, that managers and practitioners in any locality will have a range of views about the challenges and opportunities of working more collaboratively. For some there will be a threat to their established practices, for some there will be appreciation that they can now develop practices which were previously barred to them and for some there will be recognition of their existing good practice.

At multi-agency planning meetings it is essential to keep the focus on outcomes for children and families. Otherwise, because workers naturally have additional concerns and interests, discussion can stray from the point. This is just human nature. A discussion about a practical outcome, for example, 'How do we give families a multi-agency Family Support Plan?' can be rapidly undermined by complaints about how other agencies operate, anecdotes about similar initiatives that have failed in the past and proclamations that a particular service's principles and practices will be unacceptably compromised by such collaborative working. The particular attributes of local parents and localities, whether real or imagined, can be used as an excuse for maintaining the status quo: parents can be 'articulate', have 'expectations that are too high', be 'deprived', have 'expectations that are too low', while the locality can prohibit change by being 'an urban area with too many children and families with complex needs' or 'a rural area in which these children are few and far between'.

Practitioners will need adequate time to air their apprehensions and to discuss working conditions in any new system. For instance, if some services are being moved to a new centre practitioners will want reassurances about staff car parking. If they are being asked to do more evening or weekend work to meet the needs of particular families, they will want to know about fair flexitime arrangements. But discussions about the needs of staff should not be at the expense of discussions about the needs of their clients. Outcomes for practitioners should not take precedence over outcomes for children and families. If discussions are not kept in focus planning meetings can easily degenerate into talking shops and if the needs of practitioners are given priority, needs-led services will not be achieved.

A recent study by the Norah Fry Research Centre at Bristol University¹⁴ examined six multi-agency services in the UK. The summary to Chapter 5 concludes, ‘...nearly a quarter of the families we spoke to felt that their involvement in the multi-agency service had made no discernible difference to their quality of life.’ The Executive Summary states, ‘Overall, the six services had worked hard to put in place structures to facilitate the process of multi-agency working. Less attention had been paid to the outcomes of multi-agency working for children and their families.’ The research report makes valuable recommendations in its final chapter.

My particular suggestions for maintaining a focus on practical outcomes for children and families are as follows:

- i. Senior managers who are overseeing the service-improvement process assume responsibility for ensuring a focus is maintained at all times on practical outcomes for children and families.
- ii. Those who chair multi-agency meetings accept, as a major part of their role, the need to keep discussion focused on real outcomes.
- iii. The question, ‘Has this meeting focussed on practical outcomes for children and families?’ is added to every agenda.
- iv. Service-improvement discussions are informed by and firmly grounded in the views of local families.
- v. Service-improvement discussions are informed by and firmly grounded in the broader body of knowledge about what UK families say about service provision.
- vi. Parents who are representative of local families are invited to attend particular meetings or to contribute to the discussions in some other way which suits them. Though this will keep discussion grounded and focused, it is not always easily achieved. A creative approach can be developed in partnership with parents and local family-based organisations.
- vii. Representatives from voluntary agencies are invited to attend particular multi-agency meetings as ‘family champions’ relaying to the meeting the voice of local parents and children and helping focus on real outcomes.
- viii. A ‘family champion’ is recruited from amongst the staff of one of the statutory agencies. Such a person would be selected with the help of parents and then allowed time to maintain good contact with local children and families to keep abreast of their needs, issues and concerns.
- ix. Audit tools which evaluate services and inform service development are designed and used with a primary focus on outcomes for children and families.

¹⁴ See **Making a difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them**, Townsley, Abbott and Watson (2004).

c. Auditing support systems

Services which support children with disabilities and their families have a duty to regularly measure their effectiveness so that they can continually develop and improve their service. This is accepted as good practice but it is not yet standard procedure. Very many services have developed out of assumptions by practitioners about children and families and have never properly tested the validity of those assumptions nor modified the assumptions in the light of research. I recall a social worker telling me that her local Child Development Centre measures its effectiveness by the number of boxes of chocolates and bottles of wine parents give them at Christmas. Many services which were probably established by people with a genuine desire to help, have fallen into a pattern of putting practitioners' needs first. These services persist doggedly in providing what they want to provide and families have to put up with it or do without.

Some managers I meet find themselves in a dilemma: they would like find out what parents think of their service but they are afraid the answer will be negative and demoralising. Some managers grit their teeth and proceed anyway while others decide to do nothing for the time being. However, the nettle must be grasped sooner or later by all managers who want to create a needs-led service. One approach is for the service manager to meet with a group of parents to invite them to help design a parent-consultation exercise. Parents will recognise the sincerity of the wish to create effective early support and some will want to be involved. Though the survey can be planned to focus on constructive suggestions rather than on recriminations, there will be a need for many parents to have an opportunity to voice their frustrations before focusing on constructive suggestions for change. Some parents will need to speak at first in angry terms and this should be anticipated, accepted and professionally managed.

I would argue that user satisfaction is central to the evaluation of any public service. In services for babies and young children, it is to the parents we must look for formal feedback. The consequence of this is that audits must focus primarily on outcomes for children and families and they must do this by asking parents for their experiences and views. Their answers and their answers confirm how far the service is successful in meeting the needs of young children and families. As children get older they are increasingly able to speak for themselves and a time will come when the views of the young adult are given precedence.

But there are other aspects of service provision to measure too. An audit will need to investigate the competence of practitioners, the protocols designed for their work by senior managers, the in-service training and support available to them, how information is shared between services and very many other organisational issues. Important though these aspects of service provision are, they can be thought of as secondary to the primary issue of evaluation by users. Training, information-handling, funding, etc. are the means by which the ends are achieved. They are the things that

have to happen to achieve desired outcomes for families. They are essential elements of service provision but they are not in themselves ends or outcomes. They are pre-requisite activity.

This has implications for how audit tools are designed, applied and interpreted, whether they are a service's own self-auditing tool or a tool used by an external inspecting agency. If the audit itself does not separate ends from means, practical outcomes from pre-requisite activity, then those interpreting the finished audit must make this separation themselves.

Why is this distinction worth making? It is worth making because the result of any audit which confuses ends with means, confuses practical outcomes for families with the pre-requisite management activity, risks losing the focus on support for children and families. There is a danger that the consequent effort to address the audit issues and improve the service might also fail to focus properly on practical outcomes and might instead dwell predominantly on administrative activity, management concerns and practitioners' interests. If this is a danger within a single service, it can be a much greater danger when two or more agencies are being merged together to form a more complex system. When such issues as training, funding and information-sharing are being discussed, it is advisable to state explicitly how this will improve one or more practical outcomes for children and families.

An audit tool¹⁵ which separates ends from means can have three sections:

- (i) Practical outcomes for child and family.
- (ii) Elements which make the outcomes possible.
- (iii) Guiding principles.

Audit tools which are designed in this way can be used diagnostically. If users report that they experience a particular desired outcome which is listed in the audit, then there is no need to explore it further. If users report that they do not experience a particular outcome, (i.e. that a particular need is not being met) then relevant parts of sections (ii) and (iii) can be explored to identify why the failure is occurring and to determine what needs to be done put it right.

This very deliberate focus on outcomes will be a significant factor in creating early support which is genuinely needs-led, which benefits children and families and which reassures committed practitioners that their efforts are demonstrably effective and are welcomed by parents.

¹⁵ See Appendix VI: **An outline structure for auditing early support services**, p 91.

PART II

TAC IN ACTION

Part II features four TAC projects:

1. Wolverhampton Keyworking Pilot Project: comments from parents who were involved
2. Halton Team Around the Child: first-hand account
3. Walsall Child Development Service: first-hand account
4. Essex Holistic Planning Model: first-hand account

Please note that it should not be assumed that the people who have contributed these accounts automatically endorse all of the ideas and views in Part I of this manual.

Wolverhampton Keyworking Pilot Project

This keyworking pilot project was established in 2002 by Wolverhampton LEA and Wolverhampton Primary Care Trust for families who had a pre-school child with complex needs. The aim was to explore the benefits of supporting a sample of these families with the Team-Around-the-Child model with a Keyworker as TAC Team Leader.

When the evaluation of the pilot was designed, it was agreed that the perceptions of parents and other family members, and only those perceptions, would determine the value of the TAC approach. It was also agreed that parent approval would not be enough to carry the pilot forward into accepted practice for Wolverhampton.

The evaluation of the pilot project therefore had two parts:

1. The views of parents about the value of the TAC approach.
2. The views of practitioners and managers about how they felt about this way of working, how it impinged on the rest of their work, what support TAC Team Leaders needed and what additional resources were required.

Parents' views were sought in structured interviews in their own homes.
Practitioners

gave their views in a questionnaire.

Both parents and practitioners spoke in positive terms and the project is now being extended to support more families. Practitioners, especially Keyworkers, highlighted time constraints and the need for clerical support. The following is a selection of parents' comments. More information is available from Wolverhampton Early Years Service.

Parents' comments about their Keyworker

'I get on with her, I have got to know her as a friend and I can tell her my problems. She has a lot of experience with children and she knows how to deal with parents.'

'I trust her.'

'She has the most information about my child.'

'She is a point of reference when you don't know who to go to.'

'She has been there at the lowest points, we have grown close.'

Parents' comments about TAC meetings

'I've got a great team to help me. I like the meetings and look forward to them.'

'We all understand each other.'

'Everybody gets to say what they want to say. We take turns to speak.'

'I like them. I sometimes feel nervous about what they might say. They might tell me I am doing something wrong.'

'Everybody gets together and shares information on my child's development. This helps me to see the development.'

'They all understand what I am going through.'

'The meetings are informal. They are important because we discuss activities and agree the next goals.'

'I am thrilled by the Keyworker project. It would have been valuable earlier... If there was a problem (in the first year) which affected everything about him we did not know whom to ask about it. It was not holistic. The first meeting was the most useful; we ironed out different approaches and agreed clear, consistent objectives...'

'We have a meeting every three months at home. All the children are here. My Keyworker is really good at leading the meetings. They last 60 to 90 minutes.'

'Doctors try to take control. TAC does not.'

'I always say what I want and they listen to me. They ask me what, as a mum, I want my child to be doing. I get on with them all and we are open as friends. They do listen and help.'

'My child has problems sleeping. She is up and down and then I usually get up with him at about five. I haven't talked to my health visitor about this or told the TAC.'

Parents' comments about the Family Support Plan and the learning goals

'Yes, I got a report. My reading isn't very good but I understand it.'

'I get a written plan, I don't know what it is called. I'm not sure where it is. It just says what was discussed so I don't need it much. It has the same words as at the meeting. They are all sticking to the plan as much as they can (when my child is not ill).'

'I get a report from the Keyworker. It is a summary with clear objectives. The Keyworker had even drawn hands to help get a point across! It is good to have something to refer back to.'

'I understand the goals.'

'I think they are the right goals, they make sense.'

'I like the goals. They are the same goals as last time. I would like more progress.'

'The goals are OK but I would like faster progress. Goals are physical now but I would like more on speech.'

Parents' comments about support for the whole family

'The team are here to help me and my child. My partner works a twelve-hour day. He has been to some appointments but he would like to be more involved.'

'The team acknowledge that I have another child and they take that into account. He comes to some of the various sessions unless they say he shouldn't. My Keyworker is mostly here for my child. My partner has met the Keyworker a few times and he gets on with her.'

'We have had lots of support. TAC is for the whole family and it meets our needs.'

In the time since this evaluation was carried out Wolverhampton has been able to use the initial comments made by parents to reshape their thoughts and approach in their Team-Around-the-Child model.

Halton Team Around the Child

The system

Team Around the Child (TAC) in Halton provides enhanced Care Co-ordination, at the level of the family, for children with complex support needs 0 to 19 years, using a 'key worker' from within the professionals already involved. This role has been given the title of Team Around the Child (TAC) Facilitator.

Eligibility criteria

1. The acceptance range is from birth to 19 years.
2. Children with complex and/or multiple health, social or educational needs that are persistent and ongoing and affect the child's functioning.
3. The child must receive, is eligible to receive or is about to receive specialist services from three or more disciplines from any agency, including the voluntary sector.
4. The child/family must live in Halton, or be registered with a Halton GP.

Families can refer themselves or be referred by any professional involved with the child/family, with their knowledge and consent.

Background

In the time before TAC there was recognition that, for many children, the services could and should be ‘more joined up’. Staff themselves wanted ‘to do better’. Some put time and effort into extra support for families where they felt a need. This was on an ad hoc basis and if that person left, families were back to square one. It often represented a special relationship between a family and professional. At worst this was well-meaning and genuine on behalf of the professional and, at best it gave the family positive help and a champion for their cause. However, nowhere in a professional’s role was this extra commitment recognised for the source of support it was to the family, or the added work-load it meant for the professional. In order to provide a reliable service a structure and mechanism had to be developed with commitment from all agencies at all levels.

The Early Support Pilot Programme (DfES) provided the funds to try out Team Around the Child in the form of a Project that ran from November 2002 to July 2003. The Project enabled development of training and support for the professionals in the use of TAC, alongside developing the scheme and supporting 13 families during that time. It is now open to a wider age band.

Team-Around-the-Child Facilitator role

The TAC Facilitator is identified by mutual agreement between the child and family and the professional. The role encompasses all elements of key working and a job/role description¹ was developed to recognise this. The Team Facilitator:

- * provides a proactive contact point for families
- * operates within boundaries agreed with families (e.g. confidentiality)
- * gives emotional and practical support
- * researches information and enables action on behalf of/with families
- * is an advocate with a small ‘a’
- * liases/negotiates with other members of the child’s team to ensure action
- * is available to families (at least at the end of a telephone) when needed during regular working hours

TAC Assistant

The original Project bid to Early Support Pilot Programme contained a generic support worker (the TAC Assistant). The rationale was to enable practitioners to relinquish some of their own uni-professional work with families in order to gain some time to dedicate to the multi-disciplinary work of a TAC Facilitator. All families have welcomed the TAC Assistant role as it seems to plug a gap in services not provided

elsewhere. Tasks include direct individual family support and indirect support such as support groups and assisting at delivery of group interventions led by a practitioner. Direct support to practitioners in terms of providing or assisting their interventions also features highly in the job profile. The remainder of the time is used for record-keeping, administrative support to TAC, training, and supervision sessions for herself. Further breakdown and investigation into the added value that families experience is currently ongoing.¹⁶

Management

The Project was ‘mainstreamed’ with minimal recurrent available resources with some additional short-term funds (Sure Start and New Opportunities Fund) to maintain the scope of support to families.

A multi-agency Management Group, including parents, meets bi-monthly to oversee Halton TAC. There is a management lead from a senior clinician, a co-ordinator (now within the CDC Co-ordinator’s role, upgraded and with some time released), clerical support and the TAC Assistant. The personnel profile is as follows:

| | |
|------------------|---------------------------------|
| TAC Lead | 0.1 WTE (Whole Time Equivalent) |
| Co-ordinator | 0.3 WTE |
| Clerical Officer | 0.3 WTE |
| TAC Assistant | 1.0 WTE |

Training

The rolling training package developed for the TAC Facilitators during the Project has been further developed and refined by use and by the feedback of participants of courses run so far. The training explores the background of care co-ordination and identifies the need, develops skills to pick up the issues from the parents’ perspectives, identifies the skills and attributes of a Team Facilitator, addresses the practicalities of working within Halton TAC (introduction to the system, the process and the personnel and ongoing support) and participants are encouraged to identify further training needs to help them to be effective TAC Facilitators. The TAC personnel, using a mixture of approaches including presentations, practical exercises, group work and discussions, deliver the package as a group effort. Following comments received from previous participants, it is now run over two half-days, each culminating in lunch to allow networking and further development of peer discussions generated during the training. A case scenario introduced during the first half-day links the two sessions. This scenario provides the basis of identifying the parents’ perspectives and is worked in, through the practical exercises, to joint goal planning at the end.

¹⁶ See *The Process*, p 64 and *Process Audit Form*, p 65.

A bi-monthly peer support group meeting allows further sharing of experience and gives support to those using the TAC model and an opportunity for the TAC personnel to gather feedback from practice. Multi-disciplinary training monies have provided further in-depth training using external consultants to develop skills gaps identified by TAC Facilitators.

Evaluation and monitoring

The Process Flow Chart and associated audit tool provides easy evaluation of standards. The Sure Start contract monitoring forms for individual children/families gives us quantitative data with regards to time spent on TAC. There is some feedback gathered by the National Children's Bureau as part of their independent evaluation of projects funded by DfES through ESPP. During the initial Project interviews were undertaken with families and professionals using TAC, and this gives a 'taster' of the impact TAC was having on them.

Future plans are for evaluation of the TAC Assistant role to include a parent questionnaire possibly through telephone interview, as well as an activity survey of the Assistant's role to identify key support needs of families and how the Assistant fulfils them. The survey will also gather parents' perspectives of the whole scheme and will be covered at the same time. Training is routinely evaluated using a standard feedback form and these have helped to 'fine tune' the package.

Barriers to Care Co-ordination

Despite care co-ordination featuring large in many recent government guidance documents, as well as many that reach far back into the past, it is still not fully funded. We have used the TAC model as a 'low-budget' option and have effected changes in working practice to re-invest time from individual interventions into TAC to provide a more co-ordinated service to families. The structure to support busy clinicians to use TAC will need ongoing resources throughout the disciplines and agencies.

The TAC Project identified the unexpected amount of time needed. Commissioners, managers or clinicians must not ignore this time element. It would be all too easy to drop TAC as 'icing on the cake' when many services are already hard pressed to even provide their 'core' bread-and-butter services. The commitment, to 'go the extra mile' for families, is inherent in many clinicians' practice but the reality of constantly striving to 'do more for less' can be destructive. Substantial changes at senior and middle management levels could also be inhibitive to schemes like this, where a shared history of development and knowledge of TAC is suddenly lost, and where organisations are under severe financial restraints. The take-up of TAC training in education establishments has been slow, possibly due to tight timetables, however commitment to the principles of care co-ordination has been good.

The future for Halton

Locally TAC has been embraced at all levels of the agencies and features in the Children with Disabilities Strategy for Halton and the Child Development Centre Action Plan. It has been heartening to see the level of commitment from front-line workers to making things better for the families they work with. TAC now features in job roles and job descriptions in several disciplines. New recruits in any discipline are being introduced to TAC as an integral system in the procedures in Halton. The training package is running three times a year to mop up existing staff volunteers and to pick up new recruits in all disciplines and all agencies.

Carol Kerry, Superintendent Physiotherapist Paediatrics and TAC Lead
March 2004

HALTON PRIMARY CARE TRUST
In partnership with Halton Borough Council
Team-Around-the-Child
Job Description

Job Title: TAC Facilitator

Context: The Team-Around-the-Child model of care co-ordination is a way of co-ordinating multi-agency service provision at the level of the child and family. The Team Around the Child (TAC) is an individualised team comprising the child's parents/carers and the group of professionals who work with the child and family. The team agrees to meet together regularly as a supportive team, to share information, review progress and agree a shared service plan for the period up to the next meeting.

Core Tasks

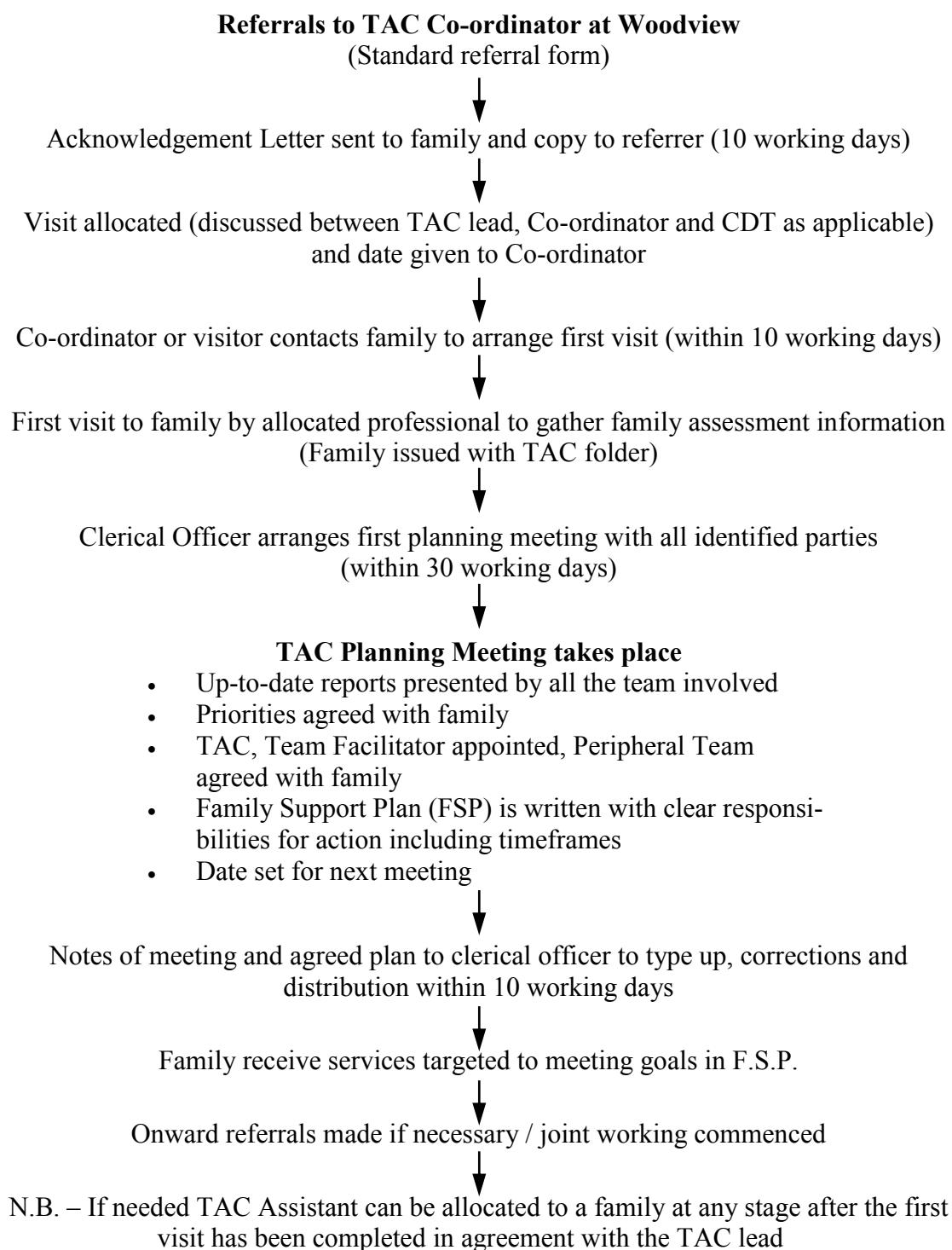
1. Develop a sound understanding of the range of services available for children with disabilities living in Halton, including benefits and welfare rights.
2. Volunteer to act as Team Facilitator for a child/children already on case-load.
3. Work with each TAC family to gain a wide understanding of their perceived priorities, including undertaking initial assessments. Make an agreement with each TAC family ensuring proactive contact is maintained.
4. Arrange and chair TAC meetings in a venue of the parent's choice.
5. Follow the TAC operational procedures to ensure the team functions efficiently, including maintaining contact with providers in the peripheral group.
6. Arrange onward referrals where indicated.
7. Monitor team goals on a regular basis.
8. Liase with the TAC Lead to utilise the TAC assistant.
9. Work with the Co-ordinator to establish a team for each child, the Co-ordinator will support the teams to become established.
10. In this role to work outside professional and agency allegiances and ensure that the TAC family's priorities are paramount.
11. Assist in identifying service gaps and duplications. Work with the families and other services to reduce these.
12. Participate in regular supervision with TAC Lead and other Team Facilitators.
13. Promote the use of parent-held records in the project.
14. Provide data as required.
15. Participate in the monitoring and evaluation of the project.
16. Act as a champion for the model and use available opportunities to raise the profile of the model.

Person Specification (E = essential, D = desirable)

- E Demonstrates the will to work in new ways to support families with a child/children with complex needs
- E Manager supports the reinvestment of existing time (anticipated average time required for TAC role with a family is 7 hours per month)
- E Ability to work outside professional and organisational boundaries to fulfil this role
- E Ability to build supportive professional relationships with TAC families
- D Knowledge of range of provision
- D Ability to take a holistic view of family's needs, ensuring that their wishes, views and feelings are respected by all
- E Excellent communication skills
- D Experience of chairing meetings
- D Negotiation skills
- D Listening skills or basic counselling skills
- D Disability rights awareness

Note: Training will be provided in all these areas for staff and parents and carers volunteering to become Team Facilitators.

THE PROCESS



**Team Around the Child - Halton
Process Audit Form**

Name : **d.o.b. :**

Referral Received (Date).....

Acknowledgement : Letter sent to parents and copy to referrer within 10 working days

Date : **Y / N** If no, how long?
Why?.....

Contact by Co-ordinator to arrange visit within 10 working days

Date : **Y / N** If no, how long?.....
Why?.....

First visit to family by allocated professional within 15 working days

Date : **Y / N** If no, how long?.....
Why?

Planning Meeting set up with all participants requested by family within 10 working days

Date : **Y / N** If no, how long?.....
Why?.....

Meeting takes place within 30 working days

Date : **Y / N** If no, how long?
Why?

Meeting notes and goal forms sent out within 10 working days

Date : **Y / N** If no, how long?.....
Why?.....

Review of goals meeting within timeframe agreed with family?

Date : **Y / N** If no, how long?.....
Why?.....

Walsall Child Development Service

The Team-Around-the-Child model

Walsall Child Development Services comprise a multi-disciplinary team of professional workers from Walsall Teaching Primary Care Trust, Education Walsall, Social Services (represented by NCH) and Walsall Resource Centre. We are currently developing an integrated multi-agency approach enabling ongoing focused child and family support using the Team-Around-the-Child model. The Service is provided to children living within the Borough of Walsall who meet recognised criteria. Currently the service is provided for children from birth to five years, although our ultimate aim is for the service to develop the TAC model in order to provide a standard that can be pursued throughout Walsall for children and young adults 0 – 19 years of age.

We aim to assess and monitor the progress of children concerned, giving consideration to the important areas of care, education, treatment, advice and support, which significantly affect the child's developmental progress, while continually acknowledging and facilitating the parent's role in all provision. Early identification of the children and families who would benefit from the service is encouraged by the maintenance of a referral system that is easily accessible to all professional disciplines and to parents themselves. Quite often children may be referred as a result of concerns

that have arisen when the child attends for routine developmental surveillance in local health centres or problems may be identified when the child attends a local nursery or group.

The earlier standard model

Prior to moving towards a Team-Around-the-Child model of working Walsall Child Development Centre (WCDC) had followed a well-established medical standardised model of service. When children were initially referred to the Centre, they were usually required to attend for a medical appointment before they could be referred to other members of the team. This often resulted in unnecessary delays in receiving provision. In many instances it was considered appropriate for the child, accompanied by an adult carer, to attend for a two-week block assessment followed by a formal Case Conference.

This process may have met certain requirements and deadlines for professionals but it was often unnecessarily daunting for the families concerned.

How and why the project started

In many ways the groundwork for developing our particular model of Team Around the Child (TAC) was already established with the Child Development Centre at its hub. Team members had already set up effective systems of communication and liaison with other professionals working in various departments and networks with other community provision such as local Family Centres and Sure Start groups. This provided a continuity of services for the children and families concerned.¹⁷

In June 2002 some of our team members attended a Handsel Trust conference regarding 'Integrated Working Practices in Children's Services' held in Birmingham. This planted the seed. We became enthusiastic about the idea of moving towards establishing a Team-Around-the-Child model of working in Walsall. Later that year, in October 2002 we set aside three separate days in which to consider the possibility of change.

- Day one - for parents
- Day two - for all team members
- Day three - for managers at a strategic level

Day one. The focus group of parents involved with these discussions highlighted their desire for more direct participation and control over the planning and decision-making stages, recognition of their expertise and the need for a Key Worker to guide them through the confusing terminology and processes.

¹⁷ See *The Hub and Spoke Model*, p74.

Day two. The team members learned more about the Team-Around-the-Child model and considered the options available, including the viability of taking on a Key Worker role with their individual families in addition to their existing role. It was agreed that many of them already functioned as a Key Worker with the families concerned and the discussion was a means of recognising this and defining their practice more clearly.

Day three. In this facilitated group discussion the strategic managers of all the services involved welcomed with enthusiasm the principle idea of adopting the TAC model, as most participants were already convinced of the need to move towards more integrated working practices.

As a conclusion to these sessions we agreed to completely adapt our service provision towards the Team-Around-the-Child model of working, to place children and families at the centre of care and to include more recognition of the Key Worker status. A 'Statement of Intent' for children with complex needs was defined to rationalise the various groups that have a responsibility for children 0 – 19 years.

Starting out

In January 2003, having taken three months to write protocols and establish paperwork, we began, with a degree of trepidation, our initial Team-Around-the-Child Panel Meetings.

The Panel consists of practitioners from each discipline involved at an operational level, thereby including representation from health, education and social services. Gradually, as the word spread, we have been pleased to welcome other key representatives of complementary services onto the Panel. Because the Walsall project is relatively early in its evolution, the team have found it necessary to have regular planning meetings in order to continually formulate the process, to tailor it to the local area, to begin the process of audit and to meet ongoing training needs.

Planning meetings by necessity create additional deadlines, which may have to be squeezed into an already busy working schedule. We have been fortunate in having an Operational Group who have driven the project and been totally committed to this change.

The child's journey

Our Panel meets on a weekly basis to consider all new children being referred to the service and to review the ongoing provision for children to meet their individual needs. Education Services and Speech and Language Therapy may already have had some involvement with the child. Referrals to the panel will have previously been discussed with their operational manager who is a member of the referral Panel. When a referral

is received, the Specialist Health Visitor will screen the information for any presenting acute medical concerns that may need more urgent attention, whilst administrative staff collate the records. The child is then discussed at the Panel meeting to establish that the referral meets the recognised criteria for our involvement and to consider how best to proceed. The referral details usually direct the Panel in allocating the two services most relevant to the child for the Initial Assessment. The two Panel members carry out a home visit during which one team member discusses and documents the child/family story using a detailed Initial Assessment Form whilst the second team member engages in play with the child. Afterwards their initial findings are noted in the 'Home Visiting Observation Record'.

In the past parents/carers have often complained of having to repeat their story to professionals. In our model, when the family are asked to provide their detailed story it is explained that they will not be required to repeat it all again when they subsequently meet other members of the team. The two members then report back to the Panel as formerly agreed and at this point allocation of appropriate services, medical follow-up and any other provision tailored to the individual child and family's needs can be arranged.

Where the child is deemed to have more complex needs requiring two or more services to be involved in their care, the Panel appoints an immediate Team Around the Child consisting of other appropriate members from the wider team. One of the initial visiting professionals known to the family is appointed as Initial Co-ordinator.¹⁸

The role of the Initial Co-ordinator

The Initial Co-ordinator's role is to set up the first meeting of the Team Around the Child. Ideally this happens within 4 to 6 weeks to ensure the establishment of the team and to give the team members, one of whom will become the Key Worker, some initial support in establishing their relationship with the parent/carer and in gaining an understanding of the needs of the child. The Co-ordinator begins to prepare the Family Service Plan (FSP) with the family by exploring the needs of the child and the initial concerns of the family about the level and type of support they want from the team. The Family Service Plan is based on the Early Support Pilot Programme (ESPP) Tool Kit. The Family Service Plan is owned by the family and contains their personal thoughts and feelings and includes information they require in a way that is considerate of their needs. It puts them at the centre of planning and delivery of the services.

At the initial review the plan is used to outline how the multi-agency team aim to work with the child and the family, and to establish the targets and aspirations they have for the child by providing information and practical support at a pace that is acceptable to

¹⁸ See *The Referral Process*, p75.

the family. The venue for this meeting may be in the family home or any other venue chosen by the family so long as privacy can be ensured.

The team members strive to provide a relaxed, non-threatening atmosphere to reduce the risk of stress to the child and the family.

The Key Worker to be appointed must be approved by the family. At this stage, the Co-ordinator will pass over responsibilities to the appointed Key Worker.

The role of the Key Worker

The following points inform the role of the Key Worker:

1. Key Workers may be drawn from any of the disciplines involved with the family.
2. They aim to ensure the family continues to receive the type and level of support that is needed. Consideration is given to other family commitments, the needs of siblings, time limitations and whether the family would prefer their support to be provided at home or at other centres.
3. Parents should be treated as equal partners and have significant influence.
4. Some parents may choose to act as Key Worker for their own child and this progression would be encouraged.
5. The Key Worker is required to be aware of the network of social and family support that is available locally and nationally. They often access information from within the services or from existing information resources.
6. They need to be aware of cultural and religious aspects which may impact on the choices made by the family.
7. Walsall has a large ethnic minority group and it is often necessary to ensure that interpreters are available for assessments, medical appointments and Team-Around-the-Child reviews.
8. It may be necessary for the Key Worker to rationalise appointments for the family. Often at critical stages the parent/carer becomes overwhelmed by too many demands.
9. Key Workers assist the family by co-ordinating the work of all team members, ensuring that the family has a good understanding of both medical and education issues.
10. The Key Worker is expected to have a proactive rather than reactive style of working and, at the same time, to be aware of the limitations of their role. Key Workers are advised not to give difficult information alone and to refer to their mentor/line manager when situations become difficult to handle.
11. The Key Worker will co-ordinate review meetings with the wider team at

which the Family Service Plan is updated. The Key Worker can call upon their mentor/line manager or another member of the team to take on a specific role at the review meeting, e.g. chairing or minute-taking.

12. They may need to ensure continuity of support for the family throughout periods of transition for the child. Eventually the Key Worker may reach a point where they no longer represent the lead agency or are no longer involved with the child. A new Key Worker will then be approved at a review meeting with the family.
13. A new Key Worker can also be appointed if the current one requests a replacement for reasons of incompatibility.

Training of practitioners

All practitioners involved in the changing process have accessed ongoing training and learning opportunities which advance their practice. The Operational Group (who make up the Panel) have arranged training days on a termly basis to involve the wider team in all of the new developments and to further the knowledge and awareness of Key Workers. These have taken the form of presentations by local/national support services, including:

- * Sure Start
- * Home Start
- * NCH Project, Walsall
- * The Benefits Agency
- * The Citizens Advice Bureau
- * The Family Fund

In addition, team members have participated in multi-disciplinary awareness training on the following topics:

- * Policies and procedures
- * Group work—roles and responsibilities
- * Chairing and minute-taking—guidelines

All participants were armed with their ‘A to Z of Key Working’—a handbook of useful information explaining the role of the Key Worker and containing valuable local and national information pertinent to the role and a ‘Protocol for Team Around the Child’ which aims to share information and formulate principles involved.

Management and funding

The Operational Group launched the change to Team Around the Child with the encouragement of strategic management but without the benefit of any additional resources. It has become evident that in order to move forward it is essential to have a Strategic Management Team for the Team Around the Child to which the Operational

Group reports on a three-monthly basis. This helps steer the change to multi-agency strategic planning for Team Around the Child. One particular aim is to develop service provision beyond that currently available for children under five years of age.

The Strategic Management Group has recently been established with agreed terms of reference. The Groups consists of one key representative from each agency involved. It will steer the team providing clarity on local and national policy and current developments and will represent Walsall CDC Team-Around-the-Child service at a local planning level.

Monitoring and evaluating the change

In truth we are at a very early stage in the process of auditing and evaluating the change. Practitioners have collaborated to offer training and support to others working in locality. We are currently exploring the ESPP multi-agency evaluation tool for qualitative evaluation whilst providing an information technology audit to track the process and numbers of children moving through the service.

Waiting lists for initial discussions, initial assessment, physiotherapy and detailed assessment are all significantly reduced.

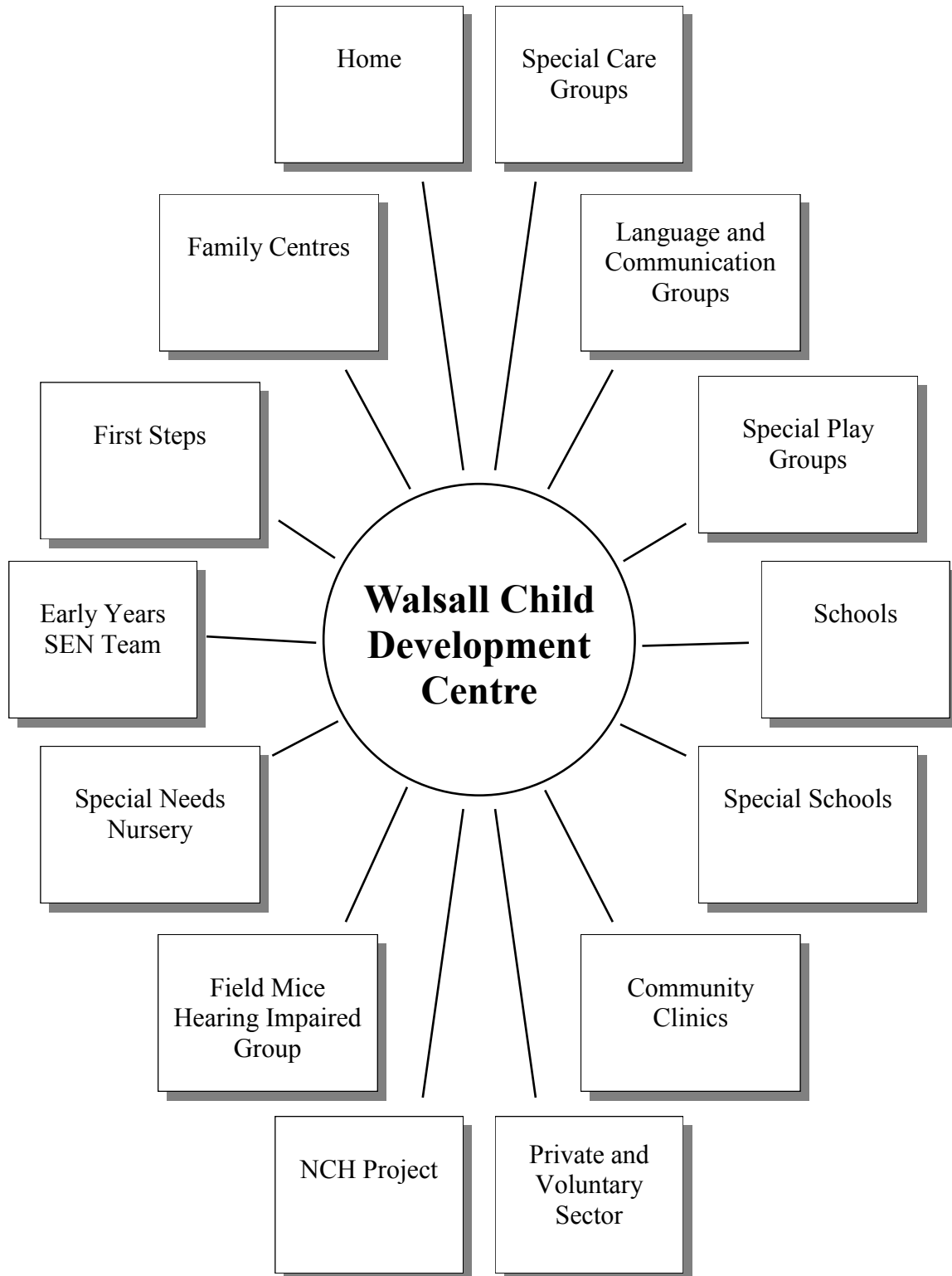
Aims and values which reflect a shared vision of a family centred service are now agreed. Services have joined together to agree clear policies for an integrated referral process including a single point of entry and a multi-agency referral panel.

A Parent Focus Group is being established to monitor parental views and gather user involvement news regarding information and services.

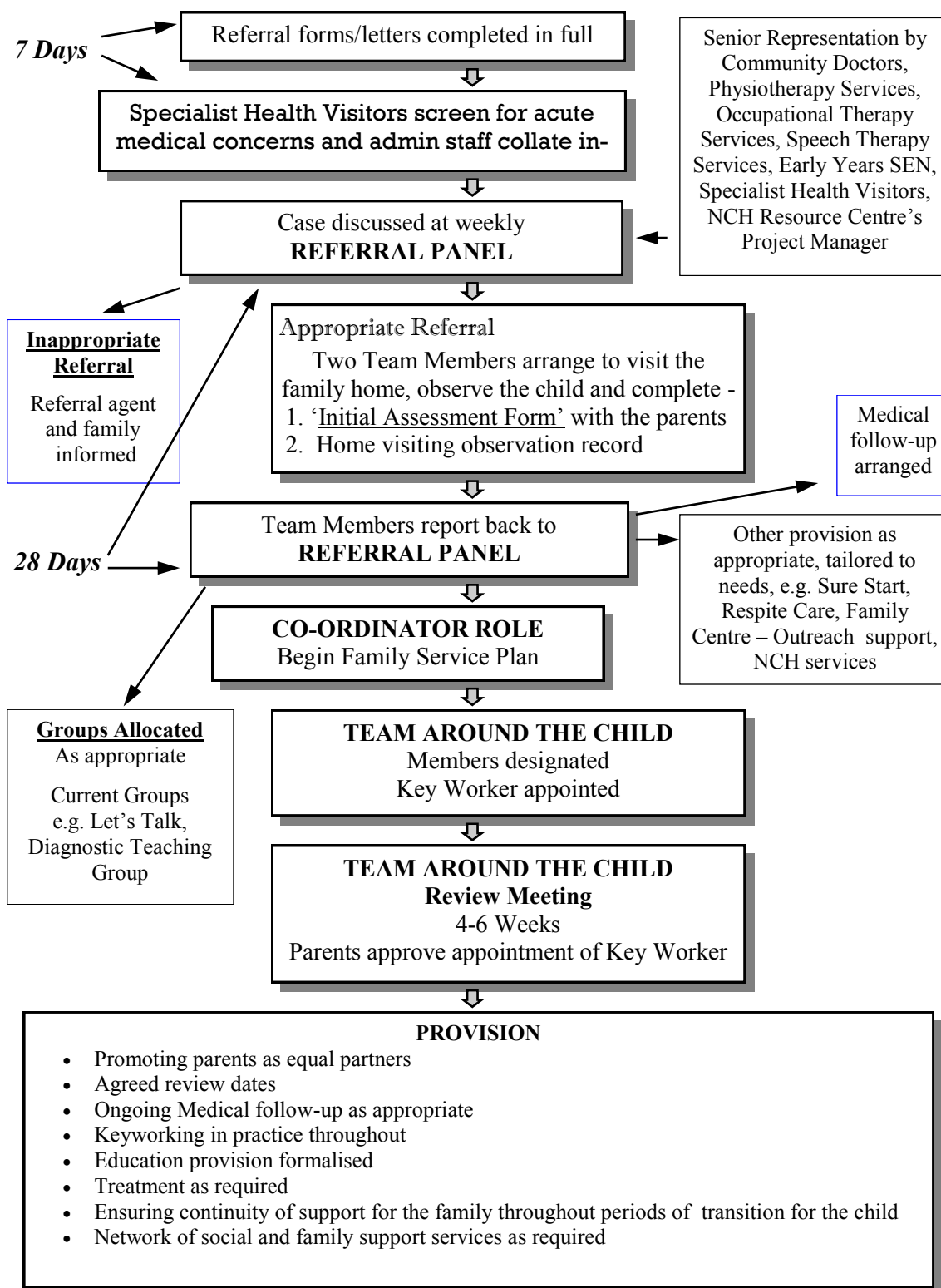
All new referrals are presented at the Panel within seven days. This means children and families have earlier access to support services and dates are agreed for reporting back to the Panel and the establishment of Team Around the Child.

Members of Walsall CDC Team-Around-the-Child Service

Walsall Child Development Service: Hub & Spoke Model



Referral process for children with complex needs to Walsall Child Development Service



Essex

Holistic Planning Model

In Essex, a group of professionals from Education, Health and Social Care met to discuss the future provision for children with complex needs. Their prime concern was how services should plan together a way forward which would offer children and young people with disabilities and their families a seamless and co-ordinated service. A pilot project was initiated and through tripartite funding from Education, Health and Social Care a project co-ordinator's post was established in 2001.

There were two special school sites dedicated to pilot the project. The children were aged between three and nineteen years old, and their needs ranged from having severe to moderate learning disabilities (with and without profound physical impairment), severe autism spectrum disorders and complex medical conditions.

The purpose of the project was to work towards setting up multi-agency resource centres that would bring together education, health and social services and the voluntary agencies, to provide integrated and holistic support for children and their families.

A county multi-agency steering group provided the strategic direction with representation from all the statutory and key voluntary agencies, and included parent

representation. Local steering groups, whose multi-agency membership mirrored that of the county steering group, developed the operational practices and designed the holistic planning model.

The framework offers the opportunity to deliver more co-ordinated services and address the needs of the family collaboratively.

During the project most aspects of the holistic planning model were piloted, evaluated and refined. The evaluation also sought to clarify current and preferred working practices and this information had an influence on the development of the model.

The Holistic Planning Model

The holistic planning model supports the person-centred approach to child and family focused planning, the Team Around the Child concept, the role of the key worker and the preparation of one plan for the child and family. It provides the structure for joined-up planning and working practices.

It has key elements that include:

1. Placing the child and family in the centre of all planning
2. Developing the Team Around the Child concept
3. Providing a process for joined-up planning
4. Establishing the shared goals
5. Addressing the shared goals or next steps
6. Establishing one holistic plan
7. Designing a role for a 'key worker' and a 'lead practitioner'

1. Placing the child and family in the centre of all planning

The child and family are placed at the centre of the planning and, with the identified Team Around the Child, develop shared goals or next steps. These give the strategic direction to all planning.

2. Developing the Team-Around-the-Child concept

The different disciplines and agencies work together as the Team Around the Child. Families and practitioners identify this team and clarify who is part of the 'close' or 'extended' team. The 'close' team is defined as those most involved with the child and their family. This distinction between the two is important. Identifying who is directly involved and then the links with the extended team make good use of resources when planning or reviewing. For children with complex healthcare needs, the school nurse or children's community nurses could be 'close' members whilst the paediatrician or specialist at a tertiary centre may be identified as members of the 'extended' team. Alternatively, the specialist teacher for children with visual impairment could be a member of the 'extended' team whilst the child's teacher is a member of the 'close'

team. Each family will have a different Team Around their Child to match their individual needs. Some teams may be very small, just two or three people including the family, whilst others may be larger and represent the greater number of people who are directly involved. The Team Around the Child will change as the child's situation alters and some members may move between the close team and the extended team depending on their role and the need for their more direct or indirect involvement.

3. Providing a process for joined up planning

The opportunity for a joined-up planning meeting is key to holistic planning and crucial for effective communication. This part of the process brings together the 'close' Team Around the Child, including the child and family. The purpose of the meeting is to establish shared goals or next steps and identify actions. Actions also include agreeing a date for when the plans are to be reviewed. The meetings are scheduled to take approximately forty minutes and require good chairmanship and clarity of purpose. Families have the opportunity for support from the 'key worker' or 'lead practitioner' during this process.

4. Establishing the shared goals

Families and children and the Team Around the Child share their own goals or next steps with each other at the joined-up planning meeting and the discussion results in shared goals being established and agreed. The Team Around the Child works together to identify how they will contribute to each shared goal or next steps and what actions need to be taken. The different agencies and services will have varying priorities but all the shared goals are addressed.

The shared goals are key to holistic planning. They should give the directional lead to planning. They belong to the family and the Team Around the Child and are not service or discipline specific.

5. Addressing the shared goals or next steps

Many of the shared goals will require the acquisition of key skills that may be addressed in smaller steps. An example of this could be '*Lucy to be able to make herself understood to those who do not know her*'. This is a shared goal that probably requires the acquisition of smaller targets towards effective communication that can be addressed in part through the child's learning plan, and as an integral aspect of the curriculum. The strategies to support the achievement of many of the shared goals may involve several disciplines, agencies and settings. There may be a need for joined-up assessments. For some goals the emphasis may be on actions as well as key skill development. The Team Around the Child will have different priorities relating to each shared goal. They will also have the opportunity to share the responsibility for their acquisition. The goals or next steps can be revised at each planned review meeting.

6. Establishing one holistic plan

The one holistic plan is called the 'Unified Plan'. This should be considered a working document, accessible to everyone supporting the child and available to all settings. It is written following the joined-up planning meeting as the shared goals and agreed actions are crucial to its preparation. The child's Unified Plan should be central to the planning for all Statutory Reviews. The family, including the child, agrees to the Unified Plan being shared with all involved in its implementation.

Key features of the Unified Plan include:

- The introduction of the child through a pen portrait. Families and children, with support from the Team Around the Child, prepare this in language that encapsulates the perspective of the child.
- The shared goals or next steps for the family and the Team Around the Child are clearly expressed, and there is evidence that they are central to the direction of the planning. They are written in common, jargon-free language.
- The key skills to support the acquisition of the shared goals are identified in the learning plan. This is essential to support the child's learning opportunity and ensure their curriculum entitlement. There should be shared recording mechanisms to enable the Team Around the Child to record progress and identify successful learning outcomes.

For some children there may also be:

- A quick reference guide that highlights behaviour that should be encouraged or discouraged, written from the child's perspective.
- A communication guide that interprets the meaning of the child's communication, written from the child's perspective.
- Practical support plans to facilitate learning, positive behaviour and leisure activities.
- Practical support arrangements with an emphasis on the social care aspects to support the family through practical assistance.

7. Designing a role for a 'key worker' and a 'lead practitioner'

There is a need for a designated support worker or 'key worker' whose dedicated role is to support the child and their family at home, school and in the community through the implementation of the plan. There is also another role described as a 'lead practitioner' or 'plan co-ordinator'. The Unified Plan should be co-ordinated by one key professional as identified by the Team Around the Child, the child and their family. This person may be from any of the agencies involved and should be identified from the Team Around the Child. Within the school setting, the plan co-ordinator may be a teacher. However, this should not be assumed and may need reconsidering, especially during the school holidays, or if another professional has a significant role in the child's life. Parents and children are involved in this decision-making process.

The holistic planning model is based on the principle of placing the child and family at the centre of all planning, the concept of the Team Around the Child, the one holistic plan and a designated person within that team whose role is to support the co-ordination of the plan. The model should be considered to be cyclic with implementation and review being integral aspects.

What makes it possible is the idea of the shared goals or next steps. They give the Team Around the Child a common denominator from which to work and each team member has the opportunity to use their specific skill and knowledge base to support the achievements of the various shared goals or next steps. The model also supports a very effective and efficient means of communication through the joined-up planning meetings.

Recent feedback from the Teams Around the Children is encouraging. The feedback included the following:

Health and social care staff reported they felt:

- *their contributions were more accepted*
- *the process was beneficial and good use of time*
- *it resulted in joined-up planning around common themes / shared goals*

Families reported they felt:

- *listened to*
- *the plan was more meaningful*
- *pleased with the attendance and contribution of the Team Around the Child*
- *involved with the planning*
- *it made the annual review process more relevant*

Teachers reported they felt:

- *they learned a great deal from the Team Around the Child,*
- *the resulting unified plan was more appropriate to supporting the child's needs*

Essex Children and Young People's Service and Health Services within Essex continue to sign up to this model. This ensures joined-up working practices continue using existing resources. The holistic planning model is being adopted by other special schools across Essex as they work towards becoming multi-agency resource centres, or New Model Special Schools, for children and young people with disabilities.

Acknowledgements

The MARC project would like to acknowledge and thank the school staff, parents and children involved in the two project sites. Their participation and feedback has been much valued and has influenced the design of the holistic planning model. The project would also like to acknowledge the time and commitment of all those involved in the county and local multi-agency steering groups. Their contribution, wisdom and enthusiasm have resulted in the development of the holistic planning model and all its supporting processes.¹⁹

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Multi Agency Resource Centre Project Co-ordinator

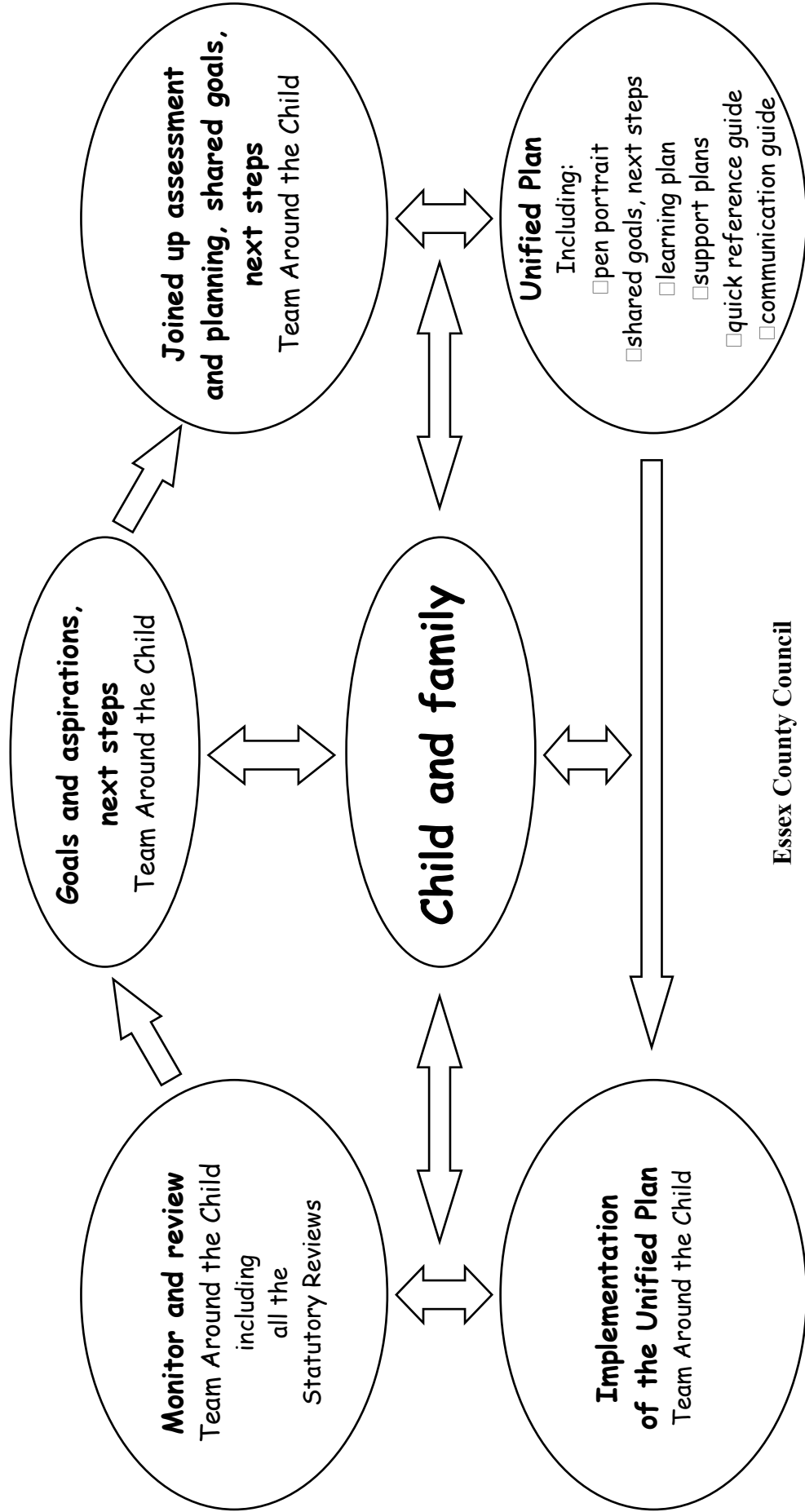
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Team Manager
Provision Development and Interagency Links
Essex County Council

September 2004

¹⁹ See *Holistic Planning Model*, p 83
and *Team Around the Child Proforma*, p 84.

Holistic Planning Model

Person centred approach to child and family focused planning



Essex County Council

Appendices

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| | Each locality must create its own vision of an effective early support system. This diagram is offered as an aid to discussion. | |
| II | Main outcomes of TAC for children and families | PAGE 87 |
| III | How TAC can create the initial Family Support Plan | PAGE 88 |
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| V | Required competencies of TAC Team Leader | PAGE 90 |
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| | This chart is offered as a guide for services | |
| | * which are designing a self-auditing tool | |
| | * which are analysing the results of an internal or external audit | |
| | * which are using information from an internal or external audit to create a service development plan | |
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A vision of effective early support

Parents' central role is acknowledged and facilitated. They:

- * receive all information, sensitively given, about the child's condition, strengths and needs
- * receive information about all available support
- * are helped to access all relevant support
- * are invited to share their knowledge and skills with their practitioners
- * are fully involved in planning support to the child and family
- * are given a Family Support Plan
- * are helped to acquire all necessary skills and knowledge to help them promote the child's well-being, play, development and learning
- * are offered a family-held record

Parents and children have good opportunities for short breaks to recharge their batteries in rewarding activity

Waiting times for all elements of support for child and family are eliminated or minimised

Families have named people as multi-agency Keyworker and as TAC members, all of whom develop helping relationships

A
VISION
OF
EFFECTIVE
EARLY
SUPPORT
FOR
FAMILIES
OF
CHILDREN
WITH
COMPLEX
NEEDS

The child and family receive effective support as soon as needed, for as long as needed and over all transitions

Child and family are well supported in accessing all local services, facilities and amenities

Parents have opportunities to give informal and formal feedback about all elements of the support for the child and family

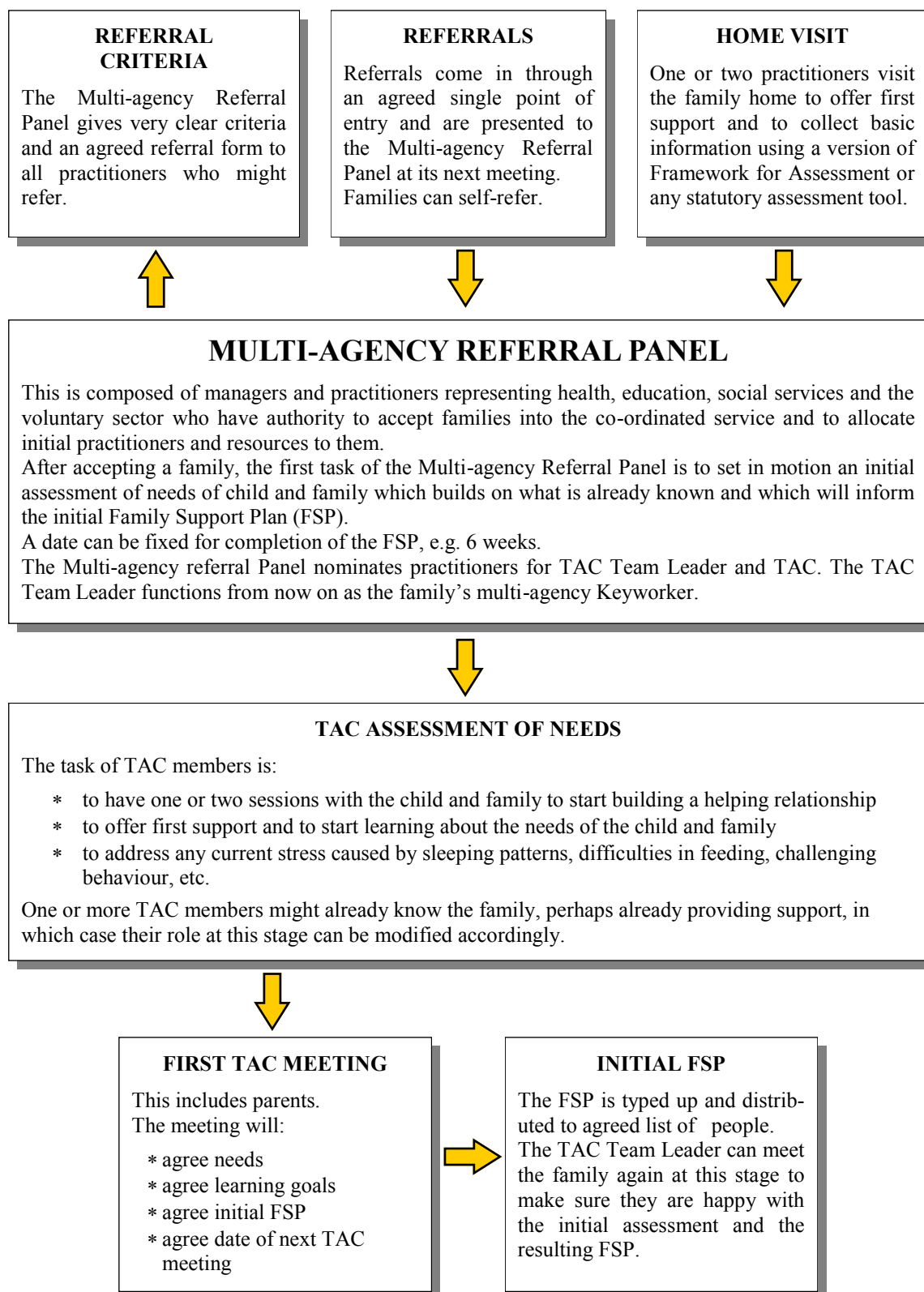
Children and families receive seamless support along an integrated multi-agency pathway through:

- * **The Meeting Phase** with the referral process
- * **The Learning Phase** with the initial assessment of need
- * **The Planning Phase** resulting in the Family Support Plan
- * **The Support Phase** in which services are well co-ordinated and the child's programmes are integrated
- * **The Review Phase** which reviews progress and creates a new FSP

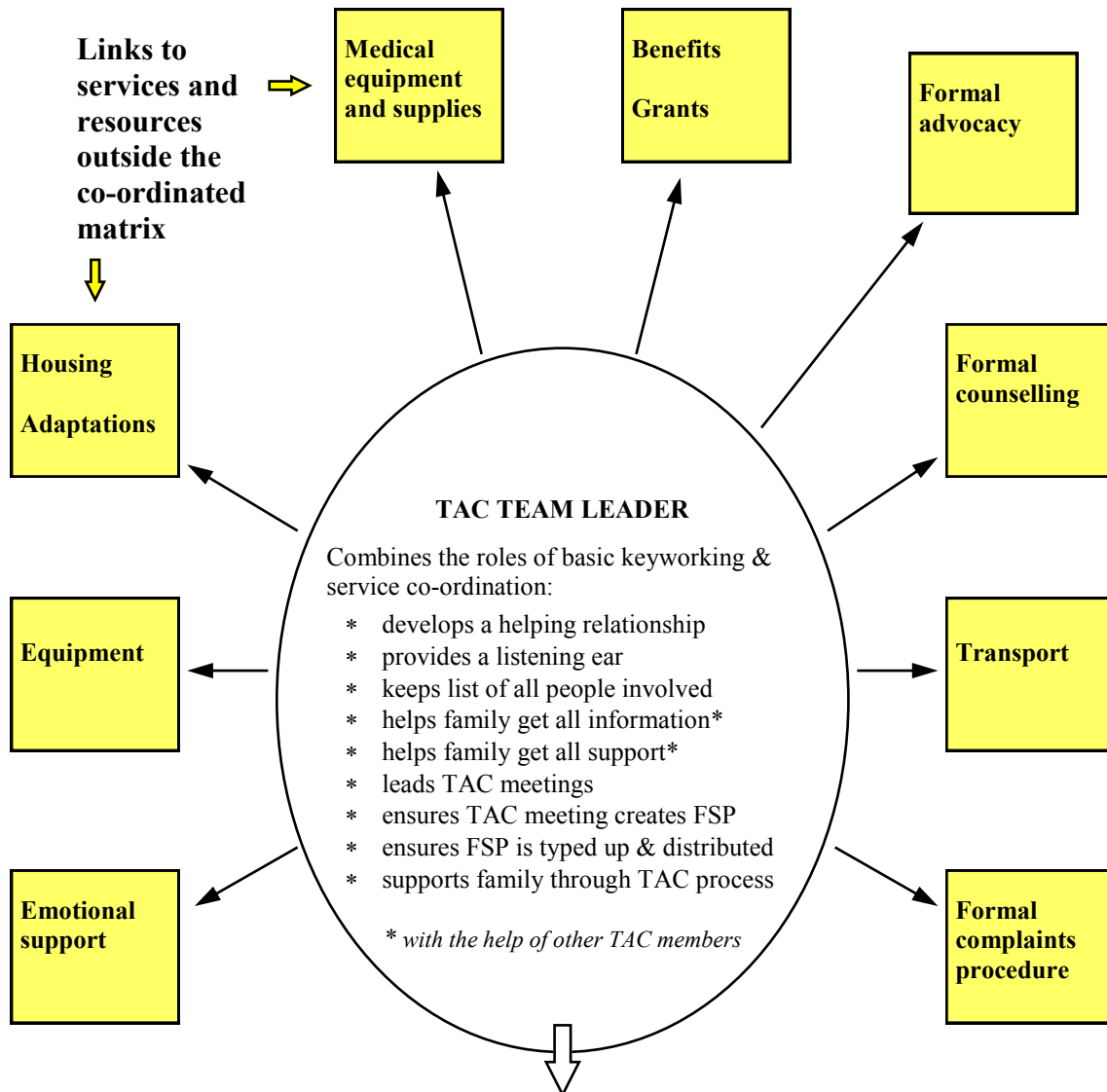
Main outcomes of TAC for children and families

| <p>In principle: Parents have a central role in planning support for the child and family. The family is supported by a well organised, collaborative effort.</p> | | |
|--|---|---|
| | OUTCOME | DETAIL |
| 1 | Key practitioners work in partnership with families | <p>The family has named key practitioners as TAC members and TAC Team Leader.</p> <p>These key practitioners work with the family in a helping relationship based on empathy, respect, honesty and trust.</p> <p>Parents' expertise, caring and central role are acknowledged.</p> |
| 2 | Support is continuous and seamless | <p>Support is immediately available, continues for as long as it is needed, continues over all transitions, persists during and after admissions to hospital, and has some immunity to staff changes and organisational restructuring.</p> <p>Support appears to be coherent even though it is the product of a number of agencies.</p> |
| 3 | Parents are fully involved in all phases of the integrated support pathway | <p>In the Learning Phase (when practitioners are first learning about the child and family) parents share their knowledge and skills with key practitioners, help frame questions to be answered and describe the needs of the child and family.</p> <p>In the Planning Phase (when the Family Support Plan is being agreed) parents are given good information about their child's condition, strengths and needs and good information about all relevant services, resources, benefits, etc. so that they can make informed decisions and be fully involved in creating the Family Support Plan.</p> <p>In the Support Phase parents are supported in understanding their child's needs and are given knowledge, understanding and skills so that they can help promote their child's well-being, play, development and learning.</p> <p>In the Review Phase parents contribute their views about how well the Family Support Plan is working for the child and family, describe their current needs and help create the next Plan.</p> |
| 4 | Support is well co-ordinated | <p>Separate service are co-ordinated as far as possible to eliminate duplications, to ensure all needs are being addressed, to rationalise appointments, clinics and home visits, and to consider transport needs.</p> <p>Practitioners are linked together so each knows who else is involved and what they are doing, can share observations and information, and can agree a joined-up approach.</p> <p>Advice, suggestions and home programmes are co-ordinated to eliminate contradictions and confusion and to ensure that what is being suggested is in the best interests of the child and family.</p> |
| 5 | The child's programmes are integrated | <p>Where possible, programmes are integrated together into a holistic programme with shared methods and goals.</p> <p>The child's programmes are consistent in all the places where child spends his or her time.</p> |

How TAC can create the initial Family Support Plan



The role of TAC Team Leader



EXPANSION OF ROLE

The TAC Team Leader's role is only allowed to expand if:

- * the family believes the new role will meet real current needs
- * the new role will help empower the family rather than create dependency
- * the TAC Team Leader is competent to perform the new role
- * the TAC Team Leader has sufficient time for the additional tasks
- * the TAC Team Leader has relevant administrative support and other necessary resources
- * the TAC Team Leader has necessary supervision for the new role

Required competencies of TAC Team Leader

| | COMPETENCE | DETAIL |
|---|---|--|
| 1 | To develop a helping relationship with family members and to work in partnership with them | The developing relationship is based on empathy, respect, honesty and trust and requires from the TAC Team Leader: <ul style="list-style-type: none"> * a positive attitude to family members * a positive attitude to other practitioners about the family * ability to encourage and empower family members * to take great care to not create dependency * willingness to learn from the family and with the family * punctuality and reliability in doing what has been agreed * confidentiality within the rules set by the TAC system and agreed with the family |
| 2 | To provide a listening ear | The TAC Team Leader is skilled in 'active listening' (see App. VII: Davis, 1993) and is strong enough to provide a shoulder to cry on when needed |
| 3 | To help parents get all information about the child | The TAC Team Leader: <ul style="list-style-type: none"> * supports parents' right to know everything about their child * adjusts to parents' level of knowledge and understanding * can support parents as they pursue information themselves * co-ordinates the efforts of TAC members |
| 4 | To help parents get all information about services, equipment, benefits, grants, etc. | The TAC Team Leader: <ul style="list-style-type: none"> * supports parents' right to know about all relevant support * has good and expanding information about local resources * can support parents as they pursue information themselves * co-ordinates the efforts of TAC members * keeps a record of information given to parents |
| 5 | To lead TAC meetings and manage the Family Support Plan process | The TAC Team Leader can lead TAC meetings so that: <ul style="list-style-type: none"> * they are family-centred, family-friendly, supportive and constructive * progress to date is reviewed, current issues are discussed and coming phases are anticipated * the child is viewed holistically and as a member of a family * agreed agenda items are covered in the agreed time * each member feels they have been listened to * no one dominates the discussion * a Family Support Plan is agreed (and then typed up and distributed by clerical staff after the meeting) |
| 6 | To promote effective negotiation of differences of view | The TAC Team Leader is equipped with basic skills so that he or she: <ul style="list-style-type: none"> * can openly discuss difference of view with family members * can support parents in discussing differences of view with other practitioners and services * can lead TAC meetings through discussion of differences of view to agreement about the way forward |
| 7 | To know the limits of the role and the limits of personal competence | The TAC Team Leader has a clear understanding of the tasks included in the role and knows when and how to seek support in carrying out any of those tasks |

An outline structure for auditing early support services

| PRACTICAL OUTCOMES FOR CHILD & FAMILY (THE 'ENDS') | ELEMENTS WHICH MAKE THE OUTCOMES POSSIBLE (THE 'MEANS') |
|---|--|
| <p>1. Parents' central role in supporting child and family is acknowledged and facilitated. They</p> <ul style="list-style-type: none"> * receive all information, sensitively given, about the child's condition, strengths and needs * receive information about all available support * are helped to access all relevant support * are invited to share their knowledge and skills with their practitioners * are fully involved in planning support to the child and family * are given a Family Support Plan * are helped to acquire all necessary skills and knowledge to help them promote the child's well-being, play, development and learning * are offered a family-held record <p>2. Families have named practitioners as Key-worker and TAC (depending on level of need), all of whom develop helping relationships.</p> <p>3. Waiting times for all elements of support are eliminated or minimised.</p> <p>4. Child and family are well supported in accessing all local services, facilities and amenities.</p> <p>5. The family receives support as soon as needed, for as long as needed and over all transitions.</p> <p>6. Children and families with complex needs receive seamless support along an integrated multi-agency pathway through</p> <ul style="list-style-type: none"> * The Meeting Phase with the referral process * The Learning Phase with the initial assessment of need * The Planning Phase resulting in the FSP * The Support Phase in which services are well co-ordinated and the child's programmes are integrated * The Review Phase which reviews progress and creates a new FSP <p>7. Parents and children have good opportunities for short breaks to recharge their batteries in rewarding activity.</p> <p>8. Parents have opportunities to give informal and formal feedback about their support.</p> | <p style="text-align: center;"><u>A: MANAGEMENT PROCESSES</u></p> <p>1. There are unambiguous statements of policy and practice for each of the desired outcomes.</p> <p>2. Services are planned in the light of</p> <ul style="list-style-type: none"> * current incidence and anticipated incidence of disabled children * legislation, guidance, research and surveys * the views of local families <p>3. Local services agree a system for storing and sharing information about children and families.</p> <p>4. Practitioners are selected, trained and supported so that they can support children and families effectively. Practitioners from separate services can learn <i>with</i> each other and <i>about</i> each other.</p> <p>5. Funds are available</p> <ul style="list-style-type: none"> * so that support is available to all families that meet the agreed criteria for that support * for the management processes listed here * so that new projects which have proved their worth receive long-term funding * so that particular outcomes which require multi-agency collaboration are funded jointly <p>6. A multi-agency management group oversees support for children with complex needs and designs an integrated support pathway for them. This will include a Multi-agency Referral Panel.</p> <p>7. Support services are continually improved in the light of regular formal monitoring. Family members are consulted and fully involved at all stages.</p> <p style="text-align: center;"><u>B: GUIDING PRINCIPLES</u></p> <p>1. Children are respected and treated holistically.</p> <p>2. Parents are respected and treated as equal partners.</p> <p>3. Practitioners bring a positive attitudes to families.</p> <p>4. Practitioners bring a positive attitude to the challenges in their work with each family.</p> <p>5. Support services accommodate to the social, religious and cultural diversity of local families.</p> <p>6. Support services accommodate to the uniqueness of each child and family.</p> <p>7. Support services respond flexibly to the changing needs of each child and family.</p> <p>8. Support is available equally to all families who require it.</p> <p>9. Support services are designed and resourced for sustainability.</p> |

Further reading

- Beresford B (1994) *Positively Parents: Caring for a severely disabled child*. SPRU.
- Beresford B (1995) *Expert Opinions: A national survey of parents caring for a severely disabled child*. The Policy Press.
- Berry T, Dawkins B. *Don't count me out: The exclusion of children with a learning disability from education because of health needs*. A Mencap publication.
- Britton C (2001) *Telling it how it is: Researching families' perspectives—what is it really like for families managing their child's serious condition at home?* The Handsel Trust*.
- Carpenter B (ed) (1997) *Families in Context: Emerging trends in family support and early intervention*. David Fulton.
- Council for Disabled Children (2004) *The dignity of risk: A practical handbook for professionals working with disabled children and their families*. National Children's Bureau.
- Crown Copyright (2003) *Together From The Start—Practical guidance for professionals working with disabled children (birth to third birthday) and their families*. Department for Education and Skills and Department of Health. (See also Early Support Pilot Programme. www.espp.org.uk)
- Dale N (1996) *Working with Families of Children with Special Needs: Partnership and practice*. Routledge.
- Davis H (1993) *Counselling Parents of Children with Chronic Illness or Disability*. British Psychological Society.
- Davis H, Day C and Bidmead C (2002) *Working in Partnership with Parents: The Parent Adviser Model*. The Psychological Corporation.
- Glendinning C, Kirk S (1999) *The Community-Based Care of Technology-Dependent Children in the UK: Definitions, numbers and costs*. Research report commissioned by the Social Care Group, Department of Health. National Primary Care Research and Development Centre.
- Kirk S, Glendinning C (1999) *Supporting Parents Caring for a Technology-Dependent Child*. A study commissioned as part of the Department of Health's Supporting Parents Research Initiative. National Primary Care Research and Development Centre.
- Lacey P (2001) *Support Partnerships: Collaboration in action*. David Fulton.
- Levitt S (1994) *Basic Abilities: A whole approach*. Souvenir Press.
- Limbrick P (2001) *The Team Around the Child: Multi-agency service co-ordination for children with complex needs and their families*. Interconnections**.
- Limbrick P (2003) *An Integrated Pathway for Assessment and Support: For children with complex needs and their families*. Interconnections.
- Limbrick-Spencer G (2000) *Parents' Support Needs: The views of parents of children with complex needs*. The SOFTY Survey. The Handsel Trust.
- Limbrick-Spencer G (2001) *The Keyworker: A practical guide*. WordWorks in association with the Handsel Trust.

Ratcliffe J (2003) *Listening to Siblings: The experiences of children and young people who have a brother or sister with a severe disability*. The Handsel Trust.

Townsley R, Abbott D and Watson D (2004) *Making a Difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them*. The Policy Press.

Tozer R (1999) *At the Double: Supporting families with two or more severely disabled children*. National Children's Bureau Enterprises Ltd.

Watson D, Townsley R, Abbott D and Latham P (2002) *Working Together? Multi-agency working in services to disabled children with complex health care needs and their families—A literature review*. The Handsel Trust.

West S (2000) *Just a Shadow: A review of support for fathers of children with disabilities*. The Handsel Trust.

Every Child Matters. Department for Education and Skills Green Paper
www.dfes.gov.uk/everychildmatters

National Service Framework for Children, Young People and Maternity Services. www.dh.gov.uk or www.teachernet.gov.uk

Parents have needs too! The role of counselling services for children with special needs and disabilities. An Ealing Mencap publication.

Removing Barriers to Achievement. The Government's Strategy for Special Educational Needs, www.teachernet.gov.uk/senstrategy

* 2023 note: The Handsel Trust has closed down. Enquiries to Interconnections

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