KENT ADULT FGC DEVELOPMENT RESEARCH

FINAL REPORT: AUGUST 2007

OUTLINE OF REPORT
This report covers the developmental research undertaken with Kent Family Group Conference Service in 2006/7. The work was designed to contribute directly to the early development of the service, in particular noting issues which were arising which were different from, or additional to, those encountered in connection with children’s FGCs. It provides some preliminary answers to the following questions:

• Is it possible to carry out high quality FGCs in adult services, for older people at risk, for people with learning difficulties, and for young physically disabled adults making the transition to adult services?
  Is the service high quality (in comparison with other FGC services)?
  Are there similar implementation challenges as in other FGC projects?
  Are there additional co-ordinator skills needed for the work?
• If so, will such a service prove popular with families, carers and professionals?
• What impact might be likely from such a service in connection with multi-agency work, and the budget of Adult Services Division?

The project builds on the substantial body of research covering children’s FGCs, aiming to add knowledge specific to FGCs for adults. It has involved an analysis of planning and policy documents, interviews with key policy and practice staff, engagement with the implementation group, detailed discussions with Adult FGC co-ordinators, and case studies of six representative FGCs, covering learning difficulties, older people, and young adults with a physical disability (involving 20 interviews with service users, family and friends, and 15 interviews with professionals). All names in the case studies are anonymised.

The research has been carried out by KCC staff under the overall direction of Professor Peter Marsh, who developed the design with the FGC service, carried out the analysis, and wrote this report.

The report provides:
AN EXECUTIVE SUMMARY

DISCUSSION
Quality of service
Implementation hurdles
Co-ordinator skills
Popularity of service
A service for carers
Multi-professional teamwork contribution
Service efficiency.

CASE STUDIES
Six Family Group Conferences

IMPLEMENTATION SEQUENCE AND POLICY ISSUES

FINANCIAL DATA
EXECUTIVE SUMMARY

The FGC service for Adults has been notably successful: delivering high levels of satisfaction from service users, carers, families, and professionals, while providing over two years around £85,000 of savings which could be re-invested in other services.

• Kent FGC service can provide high quality FGCs for Adults, but there is now an urgent need to move on from a pilot to a wider service, with mandatory trigger points for referral.

• The FGC service works very well. Within high levels of satisfaction from all parties it is notable that carers make a strongly favourable contrast with previous experiences of service, and that professional co-ordination is much improved.

• The families in this study will have a better service, and save ASD, on a conservative estimate, around £85,000 over two years (a saving of around £7,000 per FGC)

• The FGC service delivers directly into or within Kent policies, in particular providing substantial support for:
  In Control, notably via the planning of care package
  PCP, via the family network generated in the FGC process
  Alpha, via better customer experiences
  Transition planning, via co-ordinating professionals across services
  Active Lives, via developing services with users and carers

And in connection with the overall policy of ‘Our Health, Our Care, Our Say’, it clearly meets major central Government objectives, especially concerning ‘more choice and a louder voice’, and ‘more support for people with long term needs’.

• To maintain success the project should move on from a pilot to a widespread service, and implementation needs to include wider publicity and mandatory referral triggers.

A Kent FGC service, covering children, adults and schools, with relevant training can help to provide better and more efficient services. Mandatory triggers for referral are needed, and in the first place should be introduced with transition service users, but other groups should also be considered as the service develops.
DISCUSSION

This report examines the implementation of the FGC service for adults, providing a view of the early period primarily through the eyes of the participants in the FGCs. Based on the substantial literature covering children’s FGCs, the design of the study involved interview with a wide range of staff, and a series of case studies, with data provided by records and interviews with all participants. The case studies covered a representative group of with learning difficulties, older people and young physically disabled adults. In all 20 interviews with service users, family and friends and 15 interviews with professionals were carried out. The case studies are integral to the arguments outlined in the discussion section and should be read alongside that discussion. A series of three reviews of progress was also held with the implementation group for the FGC development, enabling a time line to be outlined and some key policy issues identified with them. Financial data was gathered via service records and analysed to identify broad cost effects of the new service.

The evaluation was carried out by KCC staff under the overall direction of Professor Peter Marsh, who developed the design with the FGC service, carried out the analysis, and wrote this report.

1. A HIGH QUALITY SERVICE FOR ADULTS
   A high quality service can be delivered across the project service user groups (older people, people with learning difficulties and young physically disabled people).

   It is possible to carry out high quality FGCs in adult services in a broadly comparable way to children’s FGCs (for older people, for people with learning difficulties and for young physically disabled people). There are some factors which may affect quality and the service will need to continue to address some differences in approach that are required, the potential for quite rapid changes in the health of some participants, and access and care issues.

   There is a clear difference between these FGCs and the children’s ones in that there is normally not a focus on repairing and remaking family and friendship bonds. For children and young people the family that comes to the FGC has been disrupted in some way, and elements of repair and reconciliation are often important. For the adult FGCs there are also problems of the relationships between people, but given the passage of time, and the adult status of the main client, there is unlikely to be a family ‘repair’ process. A number of the case studies show this clearly, with splits between key family members being accepted, such that people who would be very likely to come to the children’s variant (close blood related family members for example) not being invited on the express wishes of the older person.

   The adult FGCs often face difficulties of existing care, brought about by:
   - Changes in service users, and/or
   - changes in carer capacities, and/or
   - changes in status for specific services (eg eligibility changes).
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There are important access and care issues in most of the FGCs, with some very careful provision being needed to support the physical and mental health needs of participants. Advocates have an important role, and will be central to the successful outcomes for many of the FGCs.

GP attendance is non-existent, and family and friends find this quite unacceptable.

Many of the Conferences involve large numbers of professionals, who have clearly not co-ordinated their work. This means that the 3way advance meetings are especially important. It is most evident at times of transition between services.

The ability of a Conference to take important decisions, and for the participants to see that it has the power to do so, is limited by the attendance in adult FGCs of professionals who, for a variety of reasons, do not have the power to agree financial decisions.

The project will need to continue to address the following areas to maintain quality in this new area of work:

1.1 Premises and support: continue to develop knowledge of suitable accessible premises, and the pool of appropriate advocates.
1.2 GPs: develop a strategy to tackle the non-attendance of GPs in the light of their perceived key role by service users, family, friends, and carers in particular.
1.3 Taking decisions about services at the FGC: examine ways to encourage those professionals attending FGCs to have the ability to take, at least in principle, budgetary decisions at the Conference.
1.4 Transition problems between services: provide material for Children and Adult services management on issues of transition, concerning for example differences in procedures and budgets.

2. MAJOR HURDLES FOR IMPLEMENTATION

Implementation work to get these FGCs established has been difficult. There have been long time scales (many months) to get referrals at any substantial level, and the added complexity of trying to obtain support for FGCs from health services that see it as relatively marginal to their mainstream business, will continue.

The project has taken around four years to reach fruition. This is a longer timescale than in children’s projects and reflects the complexity of multiple agencies, and multiple budgets in health.

Achieving ‘buy-in’ from all groups is a lengthy and time consuming process, and the project has hit a problem of the reality of much community health practice being based around secondary acute models which do not emphasise user control and involvement. Clear policy objectives are likely to be met in health, but from the health practitioner point of view the project requires significant effort, and to some degree a change of culture.

Now that it has been shown that very successful Adult FGCs can be run by the FGC service the project needs to to bear in mind the following issues as it moves on:
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2.1 The implementation work takes time: planning will need to recognise that it may be one or two years before health systems can respond well to FGCs, in the light of the complexity of health systems, the relatively low volume of FGC work, and the perception of too many new projects and initiatives hence a certain weariness and wariness of work such as FGC development. With hindsight it is clear that the project should have been regarded as a new development in FGC work, not an extension, as there were more implementation barriers to overcome in this project than most new Children’s FGC projects and these heavily outweighed the advantage of having the infrastructure for co-ordinators in place at the start of the project. Previous studies, for example Marsh and Crow, 1998, showed that a minimum of eighteen months, and usually more than 24 months, was needed for the implementation of an FGC project. These studies also show the need for a senior level champion who can devote considerable effort to implementation, and in particular to awareness raising. The latter has been a key challenge in health with wide ranging staff, and with priorities clearly drawn to other areas.

2.2 Presenting the work such that health colleagues see the benefit to their service aims: for example emphasising a contribution to the issues of customer choice and customer satisfaction. Working with some health colleagues to develop this presentation, and using their advice as to how to disseminate, may be a good way forward. Again in hindsight, the preparation necessary for health professionals needed a higher input than it could be given. The assumption that health professionals are likely to see, quite quickly, the FGC as a positive means of planning for their clients was not supported. Dealing with this, and finding ways to present work such that health colleagues can see the benefits, has implications for both the training of Co-ordinators and the training offered to professionals outside Adult Social Services.

2.3 Focussed work with selected health groups, either geographically or by service may be worthwhile: bearing in mind the likely saving to Adult Services budgets of FGCs (see below, section 7), some investment in more time to work within health systems would be worthwhile, for example by visiting existing team meetings, surgery sessions, training sessions and so on.

3. SKILLED CO-ORDINATORS
A generic FGC service can clearly be provided across children and young people, schools and adults. Co-ordinators require the same skills as those needed for children’s FGCs, but there are also additional skills needed, primarily due to the physical and mental health problems of service users, the nature of family involvement at this stage, the importance of the needs of carers, and the multiple agencies involved.

Overall it is clear that co-ordinators require the same skills as those needed for children’s FGCs. But there are additional skills needed, primarily due to the physical and mental health problems of service users, the nature of family involvement at this stage, the importance of the needs of carers, and the multiple agencies involved.

Five key skill areas are emphasised in adult FGCs, alongside those in children’s

Gaining professional involvement requires some understanding of the differences between health and social care practice(s).
Co-ordinating professionals is often a key issue prior to the Conference and the FGC will not work well if it has to engage in too much of this work during its session
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(and family and friends rightly feel aggrieved that professionals have not got themselves reasonably organised…)
Engagement of family and friends may be particularly complex, as the type and nature of the relationship can be very long standing.
Changes in the pre-conference period are likely to occur as health deteriorates, and co-ordinator need to have an approach that may accommodate such changes.
Handling the process and length of Conference for frail individuals is often difficult.

Future development should include the following:

3.1 Training: the co-ordinator training will need to take account of the additional skills needed.

3.2 Adult FGC case discussions: it would be useful to hold a review morning around practice skills for co-ordinators, focussing, amongst other topics, on care needs of service users, nature of family involvement, the importance of carer needs, and ways to handle multiple agency involvement.

4. A POPULAR SERVICE
The FGCs are just as popular with the participants as in the children field, and the results are thought to be very positive for all concerned. The service clearly contributes directly to Kent policies concerning the central role of service users and carers, and provides support for a wide range of Kent initiatives.

The FGCs are very popular with all concerned, just as in children’s services. The case studies provide a range of quotes showing this from all parties, despite the great difficulties that faced some of the FGCs.

Future developments could include:

4.1 Publicity for the positive views of FGCs as a Kent service: they could be incorporated into annual reports, and publicity, in a wide range of areas. The FGC philosophy and principles, as directly experienced by the users and carers, support the values and beliefs underpinning KASS (Kent Adult Social Services) 10 year vision- 2007-2016-‘Active Lives’. They also directly support Adult Social Services in delivering a number of its key policies especially In Control (planning of care packages), Person Centred Planning (family networks generated via the FGC), Alpha (better customer experiences), and Transition planning (co-ordinating professional services).

5. A SERVICE FOR CARERS
The FGCs clearly met the needs of carers as well as users, and fulfilled a supportive role that carers felt had been neglected in the past. In common with children’s FGCs it was felt by family and friends that voices were heard, and a ‘seat at the table’ provided. This could be in some contrast to earlier experiences. Professionals may also gain more insight into both the strengths and the limitation of carers.

The role of friends is important in adult FGCs, and they can outnumber family and/or be more relevant than family. The nature of the connection between key user and the participants may therefore be somewhat different from the children’s work. Crucially it is evident that adult FGCs support the carer network, including friends, in ways that
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most existing services struggle to do, and in ways that the carers in the case studies had not experienced before. This is a very important contribution of adult FGCs.

The project should consider the following:

5.1 **Continuing to analyse the contribution to Kent policies regarding carers:** the additional strengths of the FGC from the point of view of carers, via better communication and involvement, need to be continued after the FGC, in due course the project should examine ways of making sure this happens (for example via the proposals in the children FGC planning study).

6. **A CONTRIBUTION TO MULTI-PROFESSIONAL TEAMWORK**

The adult FGCs, in common with the children’s FGCs, can reach sensible service decisions which are agreed by service users, family, friends, and professionals. They make a particular contribution to multi-professional teamwork which directly supports Kent policies in this area.

The FGCs clearly provide for the ability to plan and provide a less reactive service, bring together the right people in the right way. They provide an incentive for professionals to co-ordinate work which probably should be stronger in everyday practice.

The project should consider the following:

6.1 **Publicise and document the ability to plan and provide a less reactive service:** For example the outcome of one case study: great family involvement and family agreement with LA of semi-independent living arrangements for the service user post FGC. Prior to the FGC the family had expressed the view that they would “barricade the doors” to stop the service user from being moved from respite care in a residential unit.

6.2 **Publicise and document the opportunity to help with the co-ordination of multi-professional services:** the FGCs clearly aided the complex issue of co-ordinating multi-disciplinary services, and from user, carer and professional viewpoint they removed muddles, cleared up communication, made services more efficient, and where there were genuine problems in delivery made those shared rather than resented one side to another.

7. **AN EFFICIENT SERVICE**

Overall the trend in the FGCs was clearly to reduce the budget expenditure of Adult Services, on average by around £7,000 per FGC. There may be some relatively small additional costs for health (the examples were increased use of CMHT and a small amount of respite care). If other cases manage to avoid care proceedings then costs to other parts of the public services (for example CAFCASS and legal aid) will be reduced. The notable increase in partnership working, between family/friends and services, and between different services, will also lead to greater efficiency in service provision.

The financial data has been gathered for services before and after the FGC, and estimates made on the basis of professional judgements of what would have happened if the FGC had not been held. A time period of two years was chosen for the estimates because beyond that changes in health status would be likely to impact on services.
Estimates were deliberately conservative. Overall there is a significant gain to ASD budgets, and probably a small increase in the budgets of other services.

The project should note the following:

7.1 An expansion of the service is likely to generate savings which can be re-invested in services: a generic FGC service is needed to deliver the project, to provide efficient co-ordinator training and support, with, as noted earlier, suitable training and development.
CASE STUDIES

All names are anonymised, and some details changed to enhance anonymity. The financial data section outlines the model used to estimate financial costs.

1. ANNE
Anne is female, white British, and in her 90’s. She was a new client to Adult Services. The referrer wanted to plan for her safe return home from respite care and to address difficult family dynamics. These dynamics were around the fact that Anne’s sister felt guilty that she had reached the point where she could no longer manage to provide care, although at that time Anne was wanting to return home. The family consisted of an elderly sister, her stepson and his wife.

Apart from the above family two other people were identified as being part of the family group – a friend who was also the Crossroads Carer and a neighbouring friend.

Anne was quite isolated. As the ‘family’ explained she had lived with her sister for nearly 50 years. She had never been married so the other ‘relatives’ that came to the FGC were the stepson of the sister and his wife as well as the family friends. The stepson and his wife were clear that while there was some concern for the identified client their main concern was around the sister who had provided the care up until now. The outcome: a plan was agreed, endorsed by referrer Care Manager and family, with no planned review.

THE FGC
The co-ordinator began preparing for the FGC by initially visiting Anne and determining from her who she wished to invite. She also prepared the sister for the FGC and visited the stepson and his wife. During this preparation time Anne, herself, decided that she could not return to the care of her sister and informed the co-ordinator of this. All family members attended. However one of the invited friends did not attend due to a recent bereavement. Family and friend attendance was:
Stepson
Wife
Sister
Friend

The following professionals were invited to the FGC:
The Care Manager from Eastern House.
A Community Psychiatric Nurse from the Hospital
The Manager of the Residential Home – a carer attended in her place
A professional who gave information on sheltered housing from the Community Housing Association
A District Nurse
An Advocate for the service user
An Occupational Therapist from an Intermediate care team.

The GP (who told the co-ordinator he was unable to attend)

The FGC was held at the Surestart building and all agreed this was a suitable venue. The family members did feel that the meeting was over-catered for and they felt no
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need for the food although they did state that for a family that had travelled maybe it was more important. They felt tax payers money was better spent on providing services.

This was the first FGC for this particular coordinator. The co-ordinator felt that while this could perhaps have been resolved at a Pre Conference Resolution level (by the time she visited Anne had decided she wished to remain where she was), this would not have achieved the positive connections and relationships that were clearly developed between family members.

This was an FGC where there was a mutual interdependence between the two sisters that was probably not fully recognised by the professionals involved in the FGC. There was a high degree of vulnerability of service user and carer, and the co-ordinator had to handle this with sensitivity, and also make sure the FGC was not too tiring or inaccessible. The stepson clearly also felt some further information might have been helpful prior to the FGC. This may be related to people's learning styles in that some people may need more time to ‘reflect’ on information prior to making decision whereas the activists want to get on and do it. For older persons the concept of ‘family’ may have a different meaning in that their own birth families may not necessarily have survived them, particularly in this situation where there was also no real younger generation. However, it appears that family relationships were improved and that no ill feeling remained between the sisters due to the decision that Anne was to remain in the residential home, an outcome that is probably very important to both of the sisters concerned, as well as the family and friends involved.

The financial effects of the FGC were difficult to calculate for this case study due to major difficulties in obtaining previous service data. The predicted service costs without FGC were thought to be similar to the FGC outcome, and so the overall finance appears to be cost neutral.

2. BETTY

Betty is 84, white British, and had been living with one of her sons. Her situation involved adult protection issues following admission to hospital and then a rehab unit with pneumonia. Bruising was noticed on her and she alleged her son had hit her. He denied this but agreed he could not care for Betty any longer. The Care Manager said that he had mental health issues. Betty by the time of the FGC also seemed to have ‘forgotten’ these issues. She had become isolated from the rest of the family due to behaviours exhibited by the son and his partner. The extended family had not been in regular contact with Betty. The family, as identified by Betty, consisted of three sons and their partners/wives. She also identified one granddaughter, and the co-ordinator thought there were other younger granddaughters as well, but Betty did not identify them as family. In addition Betty wanted to invite a friend who had been helpful, and she had known through the Salvation Army and dances. All family and friends lived in the East Kent area. The outcome: a plan was agreed, endorsed by referrer Care Manager and family, with no planned review

THE FGC

The initial work with Betty identified the seven family members and the friend. All were invited, but the friend did not come, sending apologies some three days afterwards. All attended except the family friend who sent his apologies three days
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after the FGC. One son participated by telephone as he was agoraphobic, Betty felt he should have been there in person.

Family and friends attendance was:
Three sons (one by telephone)
Three partners/wives
One granddaughter

The following professionals were invited, and came, to the FGC:
The Care Manager from Westbrook House
The Occupational Therapist from Westbrook House, Integrated Care Centre
The Housing Assistant from Thanet District Council.

The GP was invited but did not attend – the Care Manager expressed concern in a follow up interview that Betty had previously made allegations regarding her son’s treatment of her to the GP and it appears that he did not follow these up. However the co-ordinator had been able to follow this up during the preparation period for the FGC, when Betty had made it clear that in her view nothing had happened.

The FGC was held at Westbrook House. This was the home that Betty was currently resident in and its location was convenient for everyone. It was also less stressful for Betty as she had limited mobility at that time. Food was provided at the FGC.

The two professionals involved in making the referral were strongly of the view that Betty should not return to her current accommodation on discharge. While the adult protection concerns were essentially unsubstantiated there were still concerns that Betty was isolated and that the son and his partner’s lifestyle meant that she was not being well cared for and was unable to care for herself. There were also concerns about Betty’s mobility on the stairs and Betty claimed that the flat was ‘damp’. They hoped the FGC would provide information to the family; that suitable accommodation would be found and, that family relationships would be improved with support being provided.

Everyone involved hoped to find a safe housing solution for Betty where she could be well cared for. The family in their interviews were positive about getting together instead of trying to deal with the situation separately. One family member who wasn’t able to be interviewed wrote a positive letter regarding the FGC. One of the family felt a meeting of the professionals prior to the FGC may have resolved some issues or given the family more relevant information.

Good information from the Housing professional and the Care Manager was vital to the decision making. The housing assistant provided the family with information regarding warden assisted flats. The Care Manager from Westbrook House was able to provide suggestions to the family for future resources such as a care package, cooked meal, check call, lifeline, family visits/input and the Salvation Army. The family were clear they could not provide care but that once they knew where she was living they would work out a support package. The Care Manager was very positive about the outcomes from this FGC stating it was a ‘textbook case’

Although Betty had had no services prior to the FGC it was strongly predicted that she would have needed residential care without the FGC, due to lack of support for her in sheltered housing. The saving to ASD was predicted as £23,258.40 over a two year period.
3. CHRIS

Chris has a rare form of dementia with symptoms very specific to the illness. He is white British, aged 68. He was referred for the possibility of an FGC because both his care manager and his family felt that he was not coping at home. He was quite isolated but had some supportive friends. His main companion is his dog Jessie. He wanted to remain in his current accommodation.

The only known birth family was a son from whom Chris was estranged. He was adamant he did not want his son contacted. He also alluded to an older sister. Again he did not give permission for this sister to be contacted. Therefore his ‘family’ consisted of Chris, four family friends and a neighbour. Other than his sister and his son it is not known if Chris had any other living blood relatives. A crucial part of his family was his dog, Jessie. One couple from the friends seemed to be carrying much of the responsibility for Chris.

Chris lives in the Margate area and the friends came from there and London. The three friends from London visit Chris regularly and one couple in particular seemed to be proactive in trying to get Chris needed services. The outcome: a plan was agreed and endorsed by the referrer Care Manager.

THE FGC

In this case there was both an initial FGC and follow up FGC. The friends of Chris were invited to participate in the FGCs.

Four family friends and the neighbour were invited, and all but one friend did attend both FGCs.

The following professionals were invited to the first FGC:

- Care Manager, East Kent Adult Team
- Domiciliary Care Manager for Margate area, Choice Care

The Carer from Choice Care attended although she did not receive a formal invitation.

The GP, was invited but did not attend.

The Care Manager when interviewed the first time said there had been confusion and a lack of communication between herself and the co-ordinator, and due to this the Occupational Therapist was not invited to the first FGC. Both she and the Sheltered & Support Service Co-ordinator from the Thanet Community Housing Association were invited to, and attended, the Follow up FGC.

The family commented that they found the Follow up FGC more beneficial as the ‘right’ people were there. The Care Manager was interviewed again after the second FGC and she also felt that the Follow up FGC was better and that the right people were there to answer the family’s questions and queries. The Housing Association were able to provide and explain to the family the process for getting some of the needed items and time frames for these.

From other comments from the Care Manager it is clear she was new to this process and did not feel adequately prepared. The preparation had been done by e-mail which
Kent FGC Service and Professor Peter Marsh, Sheffield University led to some of the confusion over who should be invited. The carer who received an informal invite through the CM also clearly felt unprepared and wasn’t sure why she was there, and felt the need to apologise to Chris the next day.

The co-ordinator arranged for the first FGC to be held at the Surestart building in Margate. However this did not turn out to be appropriate as Chris arrived with his dog, Jessie. He refused to part from her for the time of the FGC. The venue equally was not prepared to have Jessie in the building due to health and safety regulations. A compromise was reached and the FGC was held outside – fortunately the weather was fine, although there was the problem of traffic noise. The Care Manager clearly felt the concern over the dog was not conducive to Chris’ active participation.

The second venue, the Baptist church, led to a much more positive meeting where everyone was more relaxed. The church agreed the dog could be brought indoors so long as she remained in the main hall.

Food was provided at both FGCs although again it appears there were some problems with the 1st venue with no available kitchen. This according to one of the professionals led to FGC staff appearing stressed. The family however, said the lunch made it easy.

The Care Manager was very keen for Chris to be able to participate actively in decisions and she was worried about one of the friends taking over. At the same time she wanted Chris to acknowledge that there would be future problems and for him to make some decisions while he was able to. The family members wanted Chris to be reassured that he could stay in his home but wanted practical issues e.g. the bathroom and hygiene in the kitchen addressed. They had previously felt that they were doing caring work all on their own.

Chris himself said he couldn’t see the point of it but acknowledged it may have been more important for those around him. In his words “It may have been important to other people present. I like my dog – I’m not a people person”. This is borne out by one of the family friends stating – ‘it didn’t feel as if we were alone any more’. He did say he wanted the issue of the bathroom resolved as he couldn’t currently have a bath.

Day to day questions about helping Chris in his flat were the main focus of the FGCs.

There was some additional expenditure for ASD after the FGC, costing £8,103 over a two year period, on some items of capital refurbishment in his flat, and some additional personal care.

4. EMILY

Emily is a woman in her 60’s who has learning difficulties and mental health issues. She is white British, and has Parkinsons and is now suffering falls. She had been in some sort of care all her life. Her mother had died 10 years earlier. At the time of the referral she had been admitted to hospital due to being unwell. While in hospital she made it clear she did not want to return to the residential home she had been in.

Her family consisted of a maternal aunt and her husband, a maternal uncle, a cousin by marriage and another maternal aunt. The family all lived in the Dartford area. One
elderly member of the family was also in hospital and so was unable to attend the FGC. The outcome: a plan was agreed and endorsed by the referrer, however a range of financial decisions had to be made later.

THE FGC
There were some difficulties in the preparation for both the initial FGC and follow-up FGC because there were periods in which Emily was seriously unwell. The co-ordinator went ahead with the planning for the initial FGC on the basis that Emily had previously given permission to her Care Manager for the meeting. However, she was not well enough to have a discussion around who she wanted at the FGC and this information was provided by her aunt. All the identified family were invited (except the aunt in hospital).

The aunt and her husband, one uncle and a cousin by marriage attended the initial FGC. The aunt and her husband attended the follow up FGC. There was a two month delay in the scheduling of the follow up FGC due to Emily being extremely unwell at the point preparation began for this. While it is not clear why not all family members attended the follow up the ones that attended did show some initial reluctance as they felt Emily was not doing her part of the FGC plan.

The professionals that were invited were:
Care Manager/Referrer, CT Learning Disability Team, Brook House, (who attended both FGCs)
Psychiatric Nurse from the Community Integrated LDN Team (who attended both FGCs)
The Clinical Psychologist from the Community Integrated LDN Team was invited but did not attend either FGC
Two Psychiatrists from the Learning Disabilities Directorate – one of these attended the initial FGC and a Senior House Officer attended the Follow up
A staff nurse from Littlebrook Hospital attended both FGCs.
A Care Manager Assistant from the Dover Mental Health Team attended the initial FGC but not the follow up.
An advocate from the Mid Kent and West Kent Advocacy Scheme attended both
The Acting Residential Service Manager and a Director of MENCAP – one of these attended the first FGC but the family requested they not be invited to the follow up.

A community venue close to the family was used for the first FGC but the co-ordinator wasn’t entirely happy with it and the follow up FGC was held in a venue in the hospital grounds which was better for Emily because of her mobility difficulties.

Food was provided at both FGCs. Emily described the FGC as her ‘party’.

The advocate was used during the information giving time and again at the planning stage in order to ensure Emily understood what was happening. The advocate was not present during private family time. From the professionals point of view the FGC was an opportunity for Emily to think and plan for her future in a way that would also involve her family.

The financial effect of the Conference was an overall saving to ASD of £59,696, as all concerned were clear that Emily would have moved to full time care without the FGC. The original plan had agreed half time respite care for Emily, but this did not
occur due to changed circumstances. There are some increased costs for CMHT as a result of the FGC.

5. DOREEN
Doreen is 64, and has been a long term ASD client. She is white British, has major learning difficulties, and has lived in institutions for a good period of her life. At the time of referral she had been living at home with her parents, but she was suffering both mental and physical health problems such as depression, gout, arthritis, high blood pressure and obesity. When SS visited they arranged an admission to hospital as she was so unwell but she was discharged from hospital with support put in place over the weekend. She was then referred to the community Mental Health team and the psychiatrist’s assessment was that she was still very unwell and an admission to Seaview Lodge residential home for those with learning disabilities was arranged. This was for an initial two weeks but was later extended to a 6-month placement. In the meantime a referral was made for a Family Group Conference as it was unlikely Doreen was going to be able to return to her parents address given their own care needs. The outcome was a plan agreed by the FGC and endorsed by the Care Manager/referrer. The wish of the family that Doreen remain in her current respite placement for a further 6 months could not be finalised on the day as this required agreement of the Social Services Panel which was meeting the following week. Other decisions centred around ensuring that Doreen went to all medical appointments, activities and attendance at church and occasional weekends at home. There was also a decision about life skills training through the respite home and from the social services OT once one was appointed.

The identified family consisted of:
Doreen’s parents
A sister and brother-in-law
Two other sisters
A niece
A brother and sister-in-law
Two friends

In this instance the Care Manager provided the information regarding the family contacts. Doreen was then asked who she did and didn’t want to attend. There was discussion around the provision of an advocate – initially it looked as if a brother-in-law would fulfil this role but in the end it was decided to use someone from outside the family group – this was one of the FGC Service’s trained volunteers.

All family members except the niece were invited to attend, and came to the FGC. The two friends (from the Lodge) identified by Doreen had their own health issues so instead of attending they made a tape for the FGC.

The professionals invited to the FGC were as follows:
The referrer/Care Manager
Care Manager from the Learning Disability Team, employed by KCC,
Community Nurse from Brook House, employed by KCC
Adult Placements Officer
Accommodation Officer
Care Manager/owner of Seaview Lodge
Kent FGC Service and Professor Peter Marsh, Sheffield University
Senior Nurse – provided nursing care for Doreen while at the FGC only, from Seaview Lodge
Floating Support Team member from KCC

Learning Disability Psychiatrist – provided a report but the family would have liked him to be present in person.

The GP – he did not attend although the family felt he should

THE FGC
Although the speech and language therapist did not attend the FGC advice was sought from the therapist as to how to best manage Doreen’s thought processes during the meeting.

Doreen also required nursing assistance during the meeting particularly around toileting. The co-ordinator was mindful that Doreen would only be able to cope for short periods so regular breaks were made. The meeting lasted 3 ½ hours but with these breaks Doreen coped well. Another family member did however, comment on the length of the conference for her parents and Doreen. They suggested the conference either needed to be condensed down or be held over a couple of days where people have short attention spans.

The FGC was held at a sheltered accommodation facility in Herne Bay and the co-ordinator felt this was a good venue with disabled access available (Doreen’s mother is in a wheelchair). Both Doreen and her parents wanted to visit the venue prior to the FGC. Unfortunately another appointment came up for Doreen on the scheduled date so this did not go ahead. A buffet type meal was provided and one of the professionals felt this was a good opportunity for the family to sit down over a meal and talk.

The co-ordinator and Care Manager felt it was important for Doreen’s view to be heard and not just the family’s view. They were a vocal family and the Care Manager commented on how well the co-ordinator managed the process.

The Care Manager hoped that the FGC would move things forward. Doreen doesn’t meet the criteria to remain where she is in the long-term and the Care Manager wanted a good workable plan but also that Doreen would have a voice that would be listened to by the family. The professionals and the co-ordinator hoped that Doreen would be able to express her views and that the family would recognise that she was a person in her own right. The family equally wanted for Doreen to well cared for and to be happy.

The Family Group Conference helped put all the options for future care forward – some family members felt some of these were not viable. The family and Doreen were also keen for her to be involved in some activities and it was seen that a period of time was needed in her current situation in order for her health to improve and for her to learn some skills to become more independent.

The Care Manager provided some background information that suggested that the family had had difficulty in working with Social Services due to their involvement with another disabled family member who had died six years previously. She felt that the FGC process would enable the family to realise that they weren’t working on opposite sides but that in fact they were all working together and had Doreen’s best interests at heart. This hope was met, and family members appreciated that the FGC
Kent FGC Service and Professor Peter Marsh, Sheffield University service was independent from Social Services and that Doreen’s views were central to the process. The family felt the process was ‘better organised, open and everyone was informed of what was going on’. Other family comments included comments that in the past Social Services ‘did not inform them of anything up front, and that they often felt that social services were doing things behind their back’. In addition one of the family members commented that the advocate ‘was very effective at putting across Doreen’s views, thoughts and feelings.’

Both professionals in this case stated that they were unhappy that they had been asked to change/reword some of their report. One of them stated ‘It was my report and my manager had approved it …this created a lot of anxiety and extra work for me’. The three way meeting would be a crucial element in helping to reword reports, and clearly the professional staff were new to FGCs. In addition the Care Manager expressed some concern that the owner of the residential home portrayed Doreen as being more disabled than was the case. The Care Manager believed that Doreen did not meet the criteria for long-term residential care. The co-ordinator was clear that there were some quite serious inter-professional disputes in this case, and was worried that some of the behaviour was not of a very high professional standard.

Despite the immense complexity of this case all those interviewed were extremely positive about the process and it was clear that Doreen’s needs on the day were also met through the provision of the nurse and the advocate. All said they would recommend the FGC service for similar types of situations.

The major financial costs both before the FGC, as predicted without an FGC, and post FGC all fell on the health budget. The ASD cost change was neutral.

6. FRED
Fred is a white British young physically disabled adult, whose disabilities include severe global delay epilepsy. He is in a wheelchair with very limited communication. He used to live in a residential school and either go home or into another residence for weekends. However he finished school and was returned to his parents’ care with 42 nights respite care arranged and an agency worker. The carers weren’t going in every day and his mother was unable to cope. Fred became ill and was hospitalised – there were concerns his needs weren’t being met. Fred’s father has uncontrollable diabetes and has brain damage so there were also concerns he was being violent towards Fred. The case was being worked by a social worker with the Children and Families team and they were planning on seeking an Interim Care Order and plans were needed to help transition Fred into adult services.

The family consisted of:

Fred’s mother
Fred’s father – he assaulted Fred’s mother after the referral was taken and was imprisoned followed by a hospital admission due to mental health issues
An aunt had recently reappeared on the scene but there was concern she was exerting control over the mother
A cousin
A maternal grandmother
A family friend of the mother
3 maternal aunts and uncles
Kent FGC Service and Professor Peter Marsh, Sheffield University

A paternal uncle

It is recorded on the referral that the maternal grandfather either lived in Doncaster or may be dead. Fred had a twin that died at birth. There had also been another sibling that had died.

The outcome of the FGC was that plans that were developed for Fred’s main care to be in a foster placement with continuing respite and a lot of contact and communication with Fred’s mother. There was also provision for Fred’s mother and friend to have further training in meeting Fred’s health and feeding needs.

THE FGC

An initial and a follow up FGC have been held for Fred. Fred’s mother attended both FGCs. His father was unable to attend either FGC due to his hospital admission. It had been hoped to have an advocate meet with him to represent his views but unfortunately in the process of organising this his mental health again deteriorated and he was transferred to another hospital.

The initial FGC was attended by Fred’s mother, cousin, grandmother an aunt and the family friend. The family from Doncaster were unable to come. It was hoped they would attend the follow up FGC but they didn’t come to this one either. Attempts were made to contact the paternal uncle without success. Fred did not attend the FGC as arrangements were unable to be made to support his high care needs.

The following professionals attended:
The referring social worker from the Children with Disabilities Team, employed by KCC
A transitional worker and a Care Manager from the Adult Learning Disability Team, employed by KCC
A social work assistant from the Children with Disabilities Team, employed by KCC
Fostering Social Worker, employed by KCC
An advocate for mother from Advocacy Works, Vanguard House.
The manager from the respite care home employed by KCC
A support worker from the Direct Payments scheme
A consultant paediatrician

Information was provided at the initial FGC by the following but they didn’t attend the FGC in person:
Community Children’s Nurse from the Children’s Assessment Unit at Kent and Canterbury Hospital
Dietician
Deputy Head, Aspen 2, Archers Court School
The GP – the family said they would have like the GP there in person
Maternal aunt

The co-ordinator began preparing for the FGC by making initial contact with the family members and the social worker. Fred’s mother needed an advocate due to having learning difficulties and also a concern that her sister can dominate her. There was a poor relationship at that time between Mum’s sister, the grandmother and Social Services. It is clear this changed over the preparation time and during the FGC as can be seen by this family member’s comments:
Kent FGC Service and Professor Peter Marsh, Sheffield University

“The FGC has given the family and Gail a better understanding of their rights. The family and Gail feel more empowered after the FGC and have gained a better understanding of what other agencies/services are available. All other meetings (Social Services), Kay and Mary had attended up until the FGC had been negative and they felt apprehensive and on the defensive when attending. The FGC was much more relaxed and made the family feel more at ease and helped them understand that the other professionals were not the enemy…”

This view was endorsed by the referrer – “the FGC gave them ownership. It helped me work with the family, particularly with one family member who had been angry with me regarding some decisions…”

The first venue used was a Community Centre but a Family Centre was used for the follow up. The co-ordinator felt both venues met the family’s needs. However one of the professionals said that she felt some of the venues can be a bit cold and unfriendly. She was in favour of neutral venues as she felt SS buildings can give the wrong message. Food was provided for the family. One of the professionals commented that it nice for the family to have refreshments when they needed it and to take as much time as they needed. This same professional said that she liked the way participants are welcomed and introduced and that they are given space.

The FGC needed to decide where Fred should live both immediately and in the long-term, how his relationship with his mother could continue (they were close) and what contact needed to be in place for his father. His medical needs had to be taken into consideration in any plan. Participants felt that Fred would be happiest in a family-type environment and it was equally important that his mother be fully involved in his life. The family hoped for the following from the FGC:

“Information from all professionals, on what support and services are available, Mum to retain PR and gain input into Fred’s future, to include the family, so there was support for all, and all had their say, and a better understanding of what’s available and being able to plan for the future”

The referrer wanted the family to take ownership of a long term, safe plan that would put Fred’s needs first. The 2nd professional that was interviewed was a fostering officer who was crucial in helping find future carers for Fred. She hoped that Fred’s best interests were met but also that he would be able to maintain relationships with his wider family network and to ensure that Fred’s future would be secured.

Unfortunately Fred’s father was unable to participate in either FGC, however the family did make some plans for contact once he was well again – this to be done in a way that was safe.

The family commented on the role of the co-ordinator that she ‘was extremely helpful, listened and never rushed or pressured us, was very open, non-judgemental, independent and a neutral ally’.

One of the professionals commented that the FGC process has given her more confidence in the family – she can see where the family network fits and why people in the family can or can’t do certain things. She continued and said that if she was recommending an FGC to a family she would say that: ‘it gives you the chance to talk feely about how we can help and support you. It helps us to plan with you and not for you. It is a forum that we can go back to review the plan’.
Kent FGC Service and Professor Peter Marsh, Sheffield University

Services changed quite substantially post FGC, and there were predictions of significant costs regarding court and legal aid if an FGC had not been held. Overall there was an ASD saving over two years of £14,062.
IMPLEMENTATION SEQUENCE AND POLICY ISSUES

October 2003
Initial FGC development within Adult Services, from Bron Henry following meeting with Mike Doolan.

Summer 2004
Discussion paper requested from Cathy Shannon on policy formulation of Adult Services FGC and identification of funding source/stream.

Early 2005
Funding stream agreed with Area Management Team, original remit to leave hospital earlier rather than later.

May 2005
Paula Moyle appointed as FGC team leader, Adult Services.

September 2005
Later remit agreed to include adults with learning disability.

October 2005
Launch with Mike Doolan, adult protection included in remit. Good response from broad base of social workers and managers within Health, but disappointing response from medical professionals and strategic policy makers.

Autumn 2005
Formal partnership with AshfoRd PCT as lead partner, wider remit of promoting independence with target clients at risk of going into care, in line with PSA.

Late 2005
Canterbury district learning disabilities team become key champions of FGC.

Early 2006
Second PCT partnership.

Mid 2006
A slow referral process, with clear evidence that it is not high on the agenda of potential referrers, discussion of the need for a mandatory process.

Key issues in policy identified:
The FGC project clearly fits within Kent’s 2010 vision, and person centred planning including independence measures such as Direct Payments and the principles underlying the ‘In Control’ and citizenship policies.

FGCs meet policy objectives very well, but they are not part of the mainstream social care service, and they impact on budgets of partners, where at present there is no budget pooling.

FGCs have hit problems in health with an emphasis, in practice, on secondary acute care models, while FGCs need an emphasis on primary preventive approaches.

Positive influence in health is needed, for example building the incentives for GPs to participate via QOF (Quality Outcome Factor) targets.

Four key benefits in policy terms can be seen, and could be promoted:
Cost effective professional partnerships.
Better integrated commissioning and planning for clients
Positive engagement for their families
More positive day to day experience for clients.
FINANCIAL DATA

Figures are for a two year period (the maximum term that is likely to be stable), all are conservative, and based on actual ASD or other service figures (care proceedings based on DfES/DCA Child Care Proceedings Review 2006). Predicted figures are based on care manager and co-ordinator views.

1. ANNE
   Poor records of services pre FGC
   Residential services post FGC: £32,532.24
   Predicted without FGC: as above
   ASD neutral costs

2. BETTY
   No services pre FGC
   Domiciliary services post FGC: £13,041.6
   Residential services predicted without FGC: £36,400
   Gain to ASD £23,358.40

3. CHRIS
   Direct payments pre FGC: £4,914
   Additional personal care post FGC: £7,644
   Share of capital cost of new facilities post FGC: 2/3x£8,000=£5,333
   Direct payments predicted without FGC: £4,914
   Additional ASD £8,103

4. EMILY
   Care services pre FGC: £59,696
   Support package post FGC: £3,120
   Care predicted without FGC: £59,696
   Gain to ASD £56,576
   NB increased CMHT costs for health

5. DOREEN
   In patient health care pre FGC
   Permanent care post FGC: health funded
   Permanent care predicted without FGC: health funded
   ASD neutral

6. FRED
   Taxis, pre FGC: £5,200 (+£37,987.04 foster care, planned before FGC)
   No taxis post FGC (+£37,987.04 foster care)
   Taxis predicted without FGC: £5,200
   Speeded up process of move from care, assume by 6 weeks, saved £8,862
   ASD gain £14,062 (not allowing for care proceedings saved) NB Care proceedings predicted without FGC, save £6,250 ASD (or CSD?) and £18,750 for Court, CAFCASS, legal aid. Health may have additional costs from respite care.

   ASD gain across six cases (two of which were financially neutral) £85,893.40

   Per FGC per year, therefore an average gain to ASD budget of £7,157.79