



ASPzRe

A SHARED PLANNING AND INFORMATION RECORD
for children with additional and complex needs

Evaluation Report





**EVALUATION REPORT
DUNDEE CITY**

**ASPIRe (A Shared Planning and Information
Record)**

**and CARE CO-ORDINATION
for**

**CHILDREN WITH ADDITIONAL AND
COMPLEX NEEDS**



Liz Irvine - Clinical Governance Facilitator
Gill Simpson - Development Officer for Children with Additional and Complex Needs
Ann Hogg - Development Officer for Children with Additional and Complex Needs

September 2006



CONTENTS

Executive Summary	4
1. Introduction	5
2. Outcomes for children and families	6
3. Legislative Context	6
4. Proposal for Pilot	7
5. Development of Pilot	7
6. Additional Resource	8
7. Evaluation of ASPIRe	8
8. Analysis of Information Gained from Evaluation	9
9. Conclusion	11
10. Summary of Recommendations for Future Development	12
11. Appendix:	
11.1 Independent Evaluation of Parents Views	14
Independent Evaluation of Lead Person's Views	19
11.2 Definition of Complex Needs	26
11.3 Flow Chart of Care Co-ordination	27





EXECUTIVE SUMMARY

This report discusses the way in which shared information and planning for children with additional and complex needs has been developed in Dundee. It gives an overview of the legislative drivers behind a change in providing services for children, and explores the key themes to continue integrated working between families and professionals in this initiative. The report focuses on the evaluation of the pilot ASPIRe document and Care Co-ordination process.

The Evaluation highlights the good practice of the Lead People in supporting parents, listening to their views and working to meet the child's identified unmet needs. It also acknowledges the value of parents being empowered to plan for their children alongside the professionals, as never before. Both the parents and professionals have endorsed the use of ASPIRe, but some professionals identify the need to condense some of the sections, enabling the time spent collating the information to be reduced.

Parents endorse the continuing use of ASPIRe, seeing it as a "valuable resource that has made a difference" to their child. Parents/Carers feel more central in decisions made about their child. They see ASPIRe as "understandable and comprehensive." One parent said their Lead Person was "fabulous" and "has taken a lot of the pressure off" them, as the relevant information was available in the one place. One of the parents, who moved out of Dundee City whilst in the Pilot, would like to see the system extended throughout the rest of Tayside.

Lead People saw the peer supervision sessions delivered to support them as positive. One commented "peer supervision sessions were beneficial, as it allowed us time to share experiences and problems we had encountered, as well as ideas we had about possible solutions." They also saw the need for clerical/ administrative support to formulate and update the ASPIRe, as it was quite time consuming, depending on the level of their keyboard skills.

Action points will be executed and progress updates circulated to the Multi-agency Steering Group, Parents/Carers and Task Group in Dundee, and, as requested, The Scottish Executive.

Following the Evaluation it is the intention that the Initiative will be extended for all pre-school age children with additional and complex needs. The multi-agency Steering Group will continue to steer the focus of the ASPIRe and Care Co-ordination process and champion the Initiative across Dundee to mainstream it into the Early Years System.



1.0 INTRODUCTION

- 1.1 This report follows the Independent Evaluation of the Pilot of ASPIRe and the Care Co-ordination process in Dundee City. A Trial, of the ASPIRe document only, was undertaken at the end of 2004.
- 1.2 Eleven children with Additional and Complex needs (definition in appendix 1), from ten families, were selected for inclusion in the Pilot. Unfortunately, before completion of the documentation, one family moved to another Local Authority in West Scotland and another child, who had been in the Trial and Pilot, died. Eight Parents/ Carers of nine children, therefore, participated in the entire Pilot of ASPIRe and the Care Co-ordination process, through to the Independent Evaluation.

Child's age (January 2006)	Diagnosis	Number of current listed professionals	Comments
3 yrs 3 months	Cerebral Palsy	10	Attends Armitstead Child Development Centre
5 yrs 2 months	Infantile Battens Disease	16	Attends Armitstead Child Development Centre
5 yrs 2 months	Infantile Battens Disease	16	Attends Armitstead Child Development Centre
5 yrs 1 month	Autistic Spectrum Disorder	8	Attends Council Nursery School
4 years	Autistic Spectrum Disorder	8	Attends Council Nursery (specialist unit)
5 yrs 1 month	Autistic Spectrum Disorder	7	Attends supported unit Primary School
3 yrs 10months	Cerebral Palsy	9	Attends Council Nursery School
3 yrs 5 months	Cerebral Palsy	12	Attends Armitstead Child Development Centre & local supported Nursery (1 session weekly)
5 yrs 5 months	Autistic Spectrum Disorder	6	Supported in PI placement
3 yrs 3 months	Cerebral Palsy	12	Died December 05

- 1.3 This Independent Evaluation was carried out by Liz Irvine, Clinical Governance Facilitator with Dundee CHP. The purpose of the evaluation was to ascertain the views of the Lead People trained in the use of ASPIRe and Care Co-ordination, and the families from the Pilot.



2.0 OUTCOMES FOR FAMILIES

1. A trained and supported lead person to support and guide them through services in a more co-ordinated way. The families choose someone they trust and can share information with.
2. An ASPIRe which allows them to share information regarding their child with new professionals coming into contact with them for the first time effectively.
3. A basic information pack which will allow the parent to gain information about the professionals they may meet in the future, and resources they may wish to draw upon. Providing consistent information for all families.
4. Professionals effectively working together on one plan for the family to be met, and being aware of all the other professionals input, avoiding confusion, and professionals focusing only on their role.
5. A Shared Plan produced with the family at the centre of planning instead of 'being told what will happen to their child.'

FOR PARENTS

- Less intrusion;
- Easier access at any point in time.
- We are listened to;
- Our opinions are valued and taken into account.

FOR CHILDREN

- My family is less stressed.
- People who work with me are consistent
- People who know me and what I need and want
- I have a better chance of achieving my potential
- I get the services I need when I need them where I need them
- People ask my views and listen to me (same language)

3.0 LEGISLATIVE CONTEXT

- 3.1 The development of an Integrated Assessment Framework (IAF) for children with Additional Needs was part of a drive from the Scottish Executive towards more integrated service planning and provision across all agencies.
- 3.2 The provision of integrated systems for children with additional and complex needs continues to be developed in Dundee by Health, Education, Social Work and the Voluntary Sectors. The agenda to share information has been highlighted from various legislation/reports such as For Scotland's Children, 2001; The Additional Support for Learning Act 2004; Every Child Matters 2005; Its Everyone's Job to see that I'm Alright, 2005; Kerr Report 2005; Health for All (Hall 4) ; and The Integrated Assessment Framework (Getting It Right for Every Child. Consultative Paper 2005).
- 3.3 Other driving forces to change practice came from the recommendations in the Caleb Ness Inquiry 2004 and the Bichard Inquiry 2004, to share information and provide families with a Key/Lead Professional to co-ordinate care. A local research study undertaken in 2002 "Partnership Working: Rhetoric or Reality" J. Tocher 2002, also highlighted the need for lead people and information for children with additional needs.
- 3.4 In Dundee City an integrated approach was proposed in 2003, with the development of a shared assessment/information process. The ASPIRe document and the Care Co-ordination process was produced from this, to provide a framework for pre-school age children with Additional & Complex Needs, leading to this Pilot.



4.0 PROPOSAL FOR PILOT

The successful bid proposal for Changing Children's Services monies led to the creation of this Post. Development Officers (2 x 0.5 WTE job share) were employed to work as 'change agents' across Health, Education, Social Work and Voluntary Sector, to develop new systems of assessment, information sharing & planning and writing protocols and guidelines for children with additional and complex needs and their families.

1.1 AIMS

- 1 To have a single document which records children's details and needs, which is shared across Social Work, Health, Education and the Voluntary Sectors. It is easy to use and appropriate for Children with Additional and Complex Needs. (ASPIRe).
- 2 To provide parents with a trained and supported Lead Person to guide them through services as their child develops, providing preventative support and continuity.
- 3 To co-ordinate a "Team around the Child" to work for the needs of the child to be met in a holistic way.
- 4 To use the ASPIRe as a recording tool where additional information is collated behind, for example, Personal Passport, All About me, Co-ordinated Support Plan.
- 5 Reduce duplication of questioning, visiting and recording information regarding children giving professionals more time to support families. To build trust between professionals, departments, sharing skills and professional development/practice. Training lead people and supporting them using peer support groups and continued training programme in co-ordination and ASPIRe.

5.0 DEVELOPMENT OF PILOT

- 5.1 The Development Officers have been in post since 2003 and have consulted with families and professionals to devise new ways of joint working, introducing an integrated framework of assessment for children with additional and complex needs. The multi-agency Steering Group gave the focus to the Post and continue to monitor its progress and advise the Development Officers. The multi-agency Task Group gave frontline professionals the opportunity to assist in developing the ASPIRe (A Shared Planning and Information Record) (available on request) and Care Co-ordination. The ASPIRe document was refined through consultation with this Group, and the process of Care Co-ordination (Flow chart in appendix 2), introduced.
- 5.2 ASPIRe is a tool used to gather and record information, sharing the relevant sections with new and existing professionals as appropriate. The ASPIRe contains the core information about the child, with more specific assessment documents annexed (i.e. IEP, Care Plan, CSP, individual specialist assessments e.g. feeding plans etc).
- 5.3 Confidentiality blocks will be placed on many sections once an effective Shared I.T system has been developed. At present the sections each family feels to be "sensitive" will be identified and through discussion with the family, it will be decided which sections should not be carried around with the child on a daily basis.
- 5.4 Care Co-ordination in Dundee involves having a Lead Person who co-ordinates the entry of data to the ASPIRe document, supports the family through the services, and ongoing review process, co-ordinating all the professionals involved in the team around the child.



6.0 ADDITIONAL RESOURCE

- 6.1 An Information pack for parents/carers has also been developed. This Pack is for parents/carers of pre-school age children who have recently been diagnosed as having additional and complex needs. The pack is available online at dundeecity.gov.uk/pub. And in A4 Hard copy from gill.simpson@dundeecity.gov.uk and ann.hogg@dundeecity.gov.uk. Copies are also available from Barnardo's FST, Parent to Parent and Armitstead Child Development Centre.

7.0 EVALUATION OF ASPIRe

- 7.1 This Evaluation Report informs the reader of the development of ASPIRe and Care Co-ordination in Dundee City. It was piloted with children aged 0-5 years, who had additional and complex needs.. Having developed the ASPIRe document it was trialled with 4 children of varying ages from 0-14 years. This was independently evaluated with focus groups for the Lead People and individual interviews for the families. The views were recorded and the ASPIRe document amended as we moved into the Pilot Phase. It was decided by the Children's Services Executive Group to establish the Pilot with pre-school age children only, to enable good practice to grow with the children.
- 7.2 For the Pilot, professionals from all agencies put forward the names of children, fitting the criteria (appendix 4), who they thought would benefit from an ASPIRe. For most families the choice of Lead Person was their own, but in 2 cases the Lead Person of their choice was not available and another professional's name was suggested to them.
- 7.3 For some Lead People the completion of the ASPIRe documentation with the family was achieved in a single visit as they had known the family for some time, but for other Lead People it involved two or more visits. In general, information requested from professionals was returned to the Lead Person within 4 - 6 weeks, but there were some incidences of it taking 2 - 4 months, from first being requested. The Medical section was initially delayed, as a new template was being developed to produce a report that met the needs of ASPIRe and the newly developed Co-ordinated Support Plan in Education.
- 7.4 The inputting of the data onto the computerised form was undertaken by some of the Lead People and others, due either to time constraints or lack of confidence in their IT skills, had clerical support to do this. The ASPIRe was integrated into the Care Co-ordination process where all the information was gathered, and the Shared Planning Meeting was convened, pulling together the team around the child. Ten children were in the pilot, three of whom were pre-school age children from the Trial. At the Shared Planning meeting the unmet needs were discussed and an action plan (Shared Plan) drawn up to try and meet these. Solution Focused Therapy techniques are used to look forward and encourage involvement from the parents, presenting their view of what works and what they would not like to stop. The review meeting was then timetabled to review progress of the recommendations made in the Shared Plan.



The Lead People in the Trial and Pilot were:

- * Pre School Home Visiting Teachers
- * Social Work Staff
- * Educational Psychologists
- * Nurses
- * Voluntary Sector Staff
- * Physiotherapists.

The Lead People undertook a 3 half-days training programme on:

- * Welfare Rights
- * Advocacy
- * Care Co-ordination
- * Consent
- * Carers assessments
- * ASPIRe ethos and documentation
- * Legalities of sharing information
- * Empathy & Ethics of working with families
- * Communication Aids & their use to establish the child's views
- * Person centred approach - deciphering needs and wants

7.5 After running for 7 months, the Pilot was Independently Evaluated by Liz Irvine, Clinical Governance Facilitator, from Dundee CHP. The views of the Lead People and families are reported in appendices 1 & 2 of this report.

Several professionals, mainly from Health professions, have stated they believe there is a place for ASPIRe to be introduced at the discharge-planning stage for children identified as having additional and complex needs. If ASPIRe is introduced at this time, involved professionals will appreciate recording all the necessary information within a single document prior to the child's discharge home.

8.0 ANALYSIS OF INFORMATION GAINED FROM EVALUATION

8.1 POSITIVE COMMENTS

It was clear from the Independent Evaluation of the Pilot that the ASPIRe document and the supporting Care Co-ordination process with a Lead Person, has been effective in reducing duplication of resources.

- 1 Eight Parents endorsed its continuing use, seeing it as “ a valuable resource that has made a difference”.
- 2 The document was seen as “understandable and comprehensive, with the process encouraging the sharing of relevant information”.
- 3 Six Parent/Carers stated they previously hadn't felt involved in decisions, but with this new system felt more “central & involved” in decision-making about their child, with their child seen “as a person, not a diagnosis”.
- 4 One parent said of the process “It was the first time that I felt included, and the whole picture was looked at”.
- 5 Another Parent/ Carers reported “I felt more supported by this new process, and would like to see the whole Initiative developed and made available to all appropriate children”.
- 6 One parent said “It felt like it had taken a lot of the pressure off me, as the necessary information was easily available in one place & didn't need to constantly be repeated”.
- 7 The Lead Person was seen by Parents/carers to have met their expectations of the role - “ My Lead Person has been effective in taking things forward, needs previously unmet have either now been met or are now being addressed”.



8.2 CHALLENGES

1. The ASPIRe Document.

Lead People's negative views summarised: "Too lengthy, time consuming and too intrusive in parts, Unwieldy - areas of duplication".

2. How will the ASPIRe be kept up to date?

3. Choice of Lead Person

Parents' views: Two Families in the Pilot felt the choice of Lead Person had not been entirely their own choice. This, for one parent, led to an unwillingness to openly discuss some issues.

4. Continuation of ASPIRe into Primary School with child

Parent's view: One parent/carer felt uncertain as to whether now her child had reached school age, he/she would continue to be part of the ASPIRe Initiative, as it was for Pre-School age children.

8.3 MEETING THE CHALLENGES

1. In response to this, a sub-group of the ASPIRe Task Group reviewed the "other" relevant tools presently in use. The template of the ASPIRe document (on IT) is being re-formatted to provide drop-down boxes which will allow selection of only the relevant sections. This will provide a more compact document containing only the relevant sections.

Clerical support worker, when in post, will input the data gathered by the Lead Person onto the template and distribute copies to all the relevant people. This will be accessible to all relevant agencies.

2. The ASPIRe is kept up to date by the Lead Person, with the family and team around the child. Additions will be made between the shared planning meetings and these will be written in the Green Changes page in the ASPIRe so that all professionals can see where the updated information has been inputted. The Child will hold the definitive copy in his/her bag and this will go to appointments with them for professionals to update. Before the Shared Planning meeting the Lead Person will contact the team around the child and ask if there are new pieces of information to be added to the ASPIRe. The Clerical support will enable the lead people in updating the ASPIRe if this is problematic
3. In the future the Development Officers will ensure, as far as is reasonably possible, that the parent/carer has the opportunity to select an alternative Lead Person, if their initial choice is unable to take on the role. Professionals will only make a "suggested choice" after the parents/carers have been unsuccessful in their choices.
4. As part of the Lead Person Training Programme, the Development Officers will ensure that Lead People inform parents/carers that once a child has an ASPIRe it will continue to be their main "shared information-giving, recording, and future planning" document.

There will be a few exceptions, where the child's needs will be met adequately within their IEP (Individualised Education Programme) or CSP (Co-ordinated Support Plan), once these are established for their Educational provision. Unfortunately at this time we can't guarantee the continuation of ASPIRe after March 2007, as future funding is not yet assured. Indications, however, are very positive about its future development.



9.0 CONCLUSION

- 9.1 The ASPIRe document and supporting Care Co-ordination process with a Lead Person, has been effective in reducing duplication of resources in process time and visits. In some cases Professionals were unaware of the input of others, and the information gathered previously, therefore it was more effective use of time finding resources for the families. Parents appreciated the joint approach for their children, and the emphasis placed in Shared Planning Meetings to look at the whole families needs with community resources. Parents used the ASPIRe to let new professional groups learn about their child before meeting them in a new nursery, or GP for example. This gave parents the space to spend more time with their child and only be asked the questions necessary for the new setting.
- 9.2 The child and the family are now central in discussions and decision-making. Many parents said that they felt more included in the planning process and integral to decision making. The parents/carers have reported feeling more supported by this new process and would like to see the whole initiative developed and made available to all relevant children. The support from one professional has proved to bring continuity, trust and direction for both parents and professionals alike.
- 9.3 Lead People have changed systems for children and families. Parents have acknowledged the change this has made.
- 9.4 Lead People have been recognised as the first point of contact by the 'team around the child', collating information. The Lead People have taken pressure from the professionals around the child, in their focus to be holistic and this has also been appreciated.
- 9.5 Through peer support, Lead People had an opportunity to maintain regular contact with each other to sustain their continuous learning, and appreciation of methods of good practice and problem solving skills.



10.0 SUMMARY OF RECOMMENDATIONS FOR FUTURE DEVELOPMENT

Outcomes for Children	How	When
1. A co-ordinated early response to emerging needs	Offer ASPIRe and Care Co-ordination for all children aged 0-5 years with additional & complex needs.	July/August 06
2. Ensure provision of skilled Lead People for children and families of children with A & C Needs	Continue to train Lead People to support children.	September 06 onwards
3. Children at the centre of planning	Collaborate with all agencies to use the Shared Plan format and condense the number of meetings.	September 06 onwards
4. Continuity and Consistency for families.	A more user-friendly document Clerical support for Lead People.	September 06
5. Improved planning process for children with A & C Needs	Collate unmet needs to project the direction of service planning for children in future.	September 06
6. Fewer appointments for children and families to attend	Encourage joint appointments.	June 06 onwards



**INDEPENDENT EVALUATION REPORTS
UNDERTAKEN BY Liz Irvine
for the ASPIRe INITIATIVE
JANUARY 2006.**

**Parents / Carers Views
Pages 13 - 17**

**Lead People's Views.
Pages 18 - 22**



EVALUATION OF PILOT ASPIRe Project

Parent/Carer Views January 2006

The remit of the interviews was to obtain parent/carers views and opinions on the ASPIRe pilot.

This involved carrying out individual interviews using a standard question set and allowing time at the end for general comments and views. This was done by a mixture of one to one interviews and telephone interviews.

To this end 7 parents/carers were interviewed (3 in person and 4 by phone), and their responses to questions collated under each main heading below, as well as general comments about the ASPIRe document and process.

In summary

In general, the feedback from parents and carers was very positive. It was viewed by them as being a valuable resource that had made a difference to them and their child. Most felt that it had benefited their child by making the process more centred on them as a “person and not just a diagnosis” and concentrating on the positive things they could do or enjoy rather than what they could not.

In general they liked the fact that all information was in one place to share with other professionals and services so that they did not have to keep repeating things. However it appears that some parents/carers are still not making full use of the documentation by taking it to meetings and reviews.

Parents and carers believed they were now more involved in the process and had their views taken seriously when decisions were being made.

Problems had arisen for one family that had moved out of area and no longer had the support of the full ASPIRe pilot. They felt that it was more of a “loss to have had something that they felt worked well and then to lose it as you were aware of how much benefit it had been.”

Documentation and Process - ASPIRe Lead People

Despite the short time you have been in the ASPIRe project have you felt supported by the system and people around you?

All said they felt supported by the ASPIRe lead people. They found them in general to be approachable and supportive and willing to take on board their problems and provide useful suggestions in an understanding manner. The participants felt that within the ASPIRe system their concerns were taken seriously and efforts were made to get the right people to engage in sorting things out.

One parent stated that since moving out of area they no longer felt supported or able to access similar system for their child and this was a real loss for them.

Was the introductory information for parents sufficient for you to understand the concept of working together in Care Co-ordination?

All felt that the general information they were given was sufficient and appropriate for their needs. It was considered to be in a format that was understandable and clear. One of the participants had the information gone over with them at the child and family centre and that was deemed to be useful for them. They also felt it was useful to have for future reference.

It was felt by one participant that other more specific questions would probably come about as you used the system, but these could be addressed at the time by the Lead Person.



Have you begun to use your ASPIRe by taking it to appointments and reviews for updating?

Five of the participants stated that they had begun to use the ASPIRe. They stated that they had shared it across Armitstead, Glenlaw House, Barnardo's, nurseries and school, depending on which areas they are involved with. It was felt by the parents and carers that it was very useful as it saved duplication and had all information on hand for reviews or new professionals who became involved.

Two parents stated that they have not used it as yet. This was partly because it was sometimes forgotten but the parent thought it could be made more use of at Armitstead if it was taken there. The other didn't use it but knew others had copies of it.

Do you perceive the ASPIRe to avoid duplication in sharing the same information in the future?

All participants felt that it would cut down on duplication and prevent them from having to repeat information every time they engaged with new professionals or services. It was felt it made sharing of information easier and more reliable as you did not have to try to remember all the details every time.

How do you think having a co-ordinated approach amongst professionals will help your family?

It was felt that professionals across different areas would have a better understanding of the child's problems and be more aware of what was happening in response to the child's needs.

It was also felt by the majority of parents/carers that they were more involved in decisions and aware of what was being put in place. One parent said, "it was the first time that they felt included and that the whole picture was looked at." Another respondent felt that it had been really useful to be involved as it had allowed co-ordination of social worker for both of the children instead of having two separate people involved.

Are there any changes you would make to the ASPIRe document?

It was felt by the majority that the documentation was fine as it stood. It was perceived to be understandable and comprehensive. One parent felt that it could be a bit overwhelming as there was a lot of information to check over, and another parent stated that they had no views on it.

The only suggestion for an alteration was that one parent suggested that a diary and planner would be useful to keep track of meetings and appointments.

Are there any changes you would make to the process of Care Co-ordination?

Five of the participants felt that they were happy with the process as it is and did not feel that there were any changes necessary. They stated that it was working well for them. One participant felt that they were still unsure about timing and method of reviews being carried out. They also felt that those involved should be realistic about what can really be achieved as regards levels of input from various services. One other participant felt it needed to be more inclusive of areas outside Dundee as it had worked well for them whilst they lived there.

Would you like any more information on the ASPIRe or Care Co-ordination?

Five of those interviewed felt that they had sufficient information on both areas at present and were not looking for anything further.

One participant said that some feedback as to how it has performed and what it has achieved so far would be useful. Another participant felt that they still needed more information on the general process and what their expectations of it should be.



Would you like the system to continue, and this to be rolled out for all children with additional and complex needs?

All participants felt that the system should be continued and made available to all appropriate children.

It was felt by one parent that it should be extended outwith Dundee to Angus and other areas.

It was felt that the system was proactive on behalf of the child and family and provided someone central who can take forward unmet needs in a co-ordinated way. One parent felt that it had taken a lot of pressure off of them as the necessary information was easily available in one place and didn't need to be constantly repeated.

It was also felt that it provided good support for parents and carers by having someone that they could talk problems over with.

One parent also stated that they wished it had been available for their older child as it has made so much difference.

From your previous involvement with Health, Education, Social Work, Voluntary Sector did you feel that there was a clear outline of action planning?

Five of the people interviewed felt that in the past there was a lot of uncertainty about who was doing what in different sectors. These participants felt that since the use of ASPIRe things had become clearer and more structured as previously it had been a bit disjointed. One of them stated that previously things had to be constantly repeated.

Of the other two participants one was unsure about how things had seemed previously and one had no previous involvement.

Did you feel key to the planning of your child's care in the previous system?

Six of the participants stated that they did not feel involved in decisions in the previous system but now they feel central to decision-making and believe they have a real input to the process.

One parent stated that care provided outwith the home had made her feel involved but previously care that was to be delivered within the home setting needed to be improved.

Do you see the planning process in Care Co-ordination helping you to be more central to and "in control" of developments?

All the people interviewed felt that they were now more in control and involved in developments for their child. They felt that this was much more positive both for them and the child as it gave them a "voice, which was listened to."

Do you now feel that the needs of the whole family are considered?

The majority felt that the needs of the whole family were taken into consideration. However, it was stated that not all needs could be addressed and some unmet needs were highlighted: -

Support group for older child where they could talk over their fears and problems with peers – sometimes older child felt left out.

One participant thought that some agencies thought in silos and were unwilling to change.

One participant said that just the child's needs were covered but they felt that was what it should be.



Lead Person

How effective was your Lead Person in taking unmet needs forward?

Five participants felt that their Lead Person had been very effective and efficient in taking forwards a range of unmet needs. These covered a range of areas including how child could be integrated into leisure activities, housing issues, special dental care, DVLA mobility issues, nursery placements, care at home, care packages and manual handling training.

One parent felt that they had managed to take most things forwards on their own.

One parent still felt they had unmet needs about placement at Glenlaw House but that this had been discussed at last review meeting and hopefully would be addressed.

Are you able to talk about your feelings with your Lead Person?

Six of the interviewees felt that their Lead Person was very easy to talk to and that they could discuss anything with them. They felt that they could discuss problems with them, either in person or on the phone without any awkwardness. It was felt that the Lead People provided help and support, and also helped you to see problems from other angles and perspectives.

One interviewee felt that they were not able to discuss things freely with their Lead Person as they had not been able choose who they wanted.

Was your Lead Person appointed to you or did you choose them?

Four participants had chosen their own Lead Person. These were usually people that had been involved with the family before and the parents/carers felt they could relate to.

Three had their Lead Person allocated to them. One parent did not realise that they could choose their Lead Person but it had not been a problem. The other felt that they would have been much happier if they had been able to choose the person they wanted, and one felt that as they knew the person before she was quite happy with her being appointed.

Have you the amount of contact time with your Lead Person you would like?

Six of the participants felt that they have sufficient time with their Lead Person. All of them felt that they could phone the Lead Person if anything cropped up unexpectedly and it would not be a problem for them to visit. One however felt that they had not established a relationship with a lead person since moving to Angus but that their previous Lead Person was “fabulous”.

Have your expectations of your Lead Person been met?

Four parents/carers said that their expectations had been fulfilled and that they had no problems or issues with this. They felt that the Lead Person had been effective in taking their needs and problems forward, and several of their previously unmet needs had now either been resolved or were in the process of being addressed.

Two participants said that they didn't know what to expect from their Lead Person so they had no expectations of what could be achieved, however they had no problems. One other participant said that their Lead Person had ensured ASPIRe documentation was completed prior to her move out of area, but that there was now no-one to take it forward.



Comments

Happy with process feels it works well.

Needs to be extended across borders so that it can work outwith Dundee.

Only problem is that social work contact has changed 4 times in a short period of time.

Uncertain if project is to continue once child at school – this sort of information is needed.

School and SLT now kept informed and documentation updated.

Sometimes knowing who to contact for specific queries is difficult.

Documentation took a long time to gather but once done it has been really useful and has helped at meetings and reviews enormously.

Mrs Liz Irvine

Clinical Governance Facilitator

10th February 2006



EVALUATION OF PILOT ASPIRe Project

Lead Person Views January 2006

The remit of the interviews was to obtain Lead People's views and opinions on the ASPIRe pilot. This involved carrying out individual interviews using a standard question set and allowing time at the end for general comments and views. To this end eight Lead People were interviewed and their responses to questions collated under each main heading below as well as general comments about the ASPIRe document and process.

In summary there are mixed feelings across the Lead People as to the usefulness of the ASPIRe process in its current form, however, in general it is felt to have its merits and to put the child at the centre of the process. It appears there is a will amongst most of the Lead People to make the process work, as they can see benefits to the parents and child, as well as professionals. The principle of providing shared information is generally seen as worthwhile and beneficial for clients and professionals alike.

As can be seen from the individual questions there are issues that still need to be taken into account and clarified for the documentation and process to be successful. Not least of these is the amount of time involved in collecting information and completing the documentation. Communication across some agencies is also still a drawback to the smooth running of the process. It appears that there is still a need for the profile of the pilot to be raised in order that agencies are aware of and understand its potential benefits.

Several Positive and Negative comments have been pulled together at the end of the report and these should help to inform any alterations planned to the documentation or process in the future.

This report is intended to be read in conjunction with that obtained from the parents/ carers involved in the project, as their views need to be considered in tandem with those of the Lead People.

Mrs Liz Irvine
Clinical Governance Facilitator
2nd February 2006



Training

The training seemed in general to be fairly well received but there were some issues that fell out of delivery and gaps that participants felt existed.

Did you feel that the training you received prepared you for being a Lead Person and filling in the ASPIRe?

Six Lead People thought the training was useful at least in parts, one did not and one did not attend training sessions. In general the feeling was that the training was useful and provided information which was pertinent to fulfilling the role of Lead People. Some Lead People did not get to the full training sessions as they joined the programme part way through and they felt that this left them feeling at a disadvantage as they were not wholly clear as to the way the process was meant to function in its entirety. The fact that it covered issues such as legal aspects and how the process should flow was considered very useful.

It was felt by some of the above participants that there were gaps in the training especially around confidentiality issues regarding who should have copies of the ASPIRe documentation and if indeed everyone should have access to all sections. There was also an issue regarding what action should be taken if the information requested was not forthcoming from specific agencies such as health or social work. It was also felt more time could have been spent on documentation and IT issues.

Two participants felt that some of the training was quite useful but other parts were not appropriate for them due to their current working knowledge.

One participant felt that the training was a little patronising and not really of a level that was useful.

One Lead People did not participate in training but did have 1 to 1 sessions and didn't feel that this was a barrier for her.

Is there any further training you would like that would enhance your role?

There was a variety of suggestion about further training that might be useful.

Two participants felt that half-day updates looking at problems that have occurred and how to address these would be useful. They felt that these could be used as a networking opportunity by all.

It was suggested by one participant that for some Lead Person training to highlight empathy for the families could be useful depending on the role that they normally fulfil. Another Lead Person suggested that how to manage parental expectations was important, and also how to create awareness of the differences that the parents/carers might expect from the process.

Training on confidence building, advocacy, joint working, cultural issues were suggested as possible areas that would be useful to have further training on.

One participant felt that the ASPIRe process falls out of their normal way of working so there was no need for further training.

Another participant felt that they had a fundamental difficulty with the assessment, as it appears to sit separate from the rest of the work going on rather than be a central part of the process.



Support

There appears to be a mixture of professional and peer supervision across the participants. The feelings that were expressed suggested that all supervision had been beneficial whether it had been Peer or professional supervision. As far as admin support is concerned the majority of participants feel that this is something that would have to be considered for the future, as the ASPIRe documentation is time consuming to complete and the format is unwieldy.

Do you receive supervision?

Two participants had Peer Supervision but no formal Professional Supervision, four had Professional Supervision but had not attended Peer Supervision and two had both.

In general the supervision received was deemed to be supportive and beneficial.

Have you attended the Peer Supervision Sessions? What has been beneficial in these sessions?

Four participants stated that they had attended some of the Peer supervision Sessions. They found it beneficial as it allowed them to share experiences and problems they had encountered as well as ideas they had about possible solutions. It was felt that getting different perspectives on problems was always useful.

General information on The ASPIRe project was passed on this kept people updated with the progress of the pilot study.

It was also stated that support and advice could always be obtained by phoning the project leaders.

For two of those who did not attend, the timing of sessions was problematic, but they felt they would have liked to be able to join in with it.

Do you receive professional supervision? Does this allow you to discuss the issues raised in your lead person role?

Six participants had access to Professional Supervision. All of them found this to be very supportive and beneficial. It was felt that to allow discussion about the project with colleagues who did not know much about the process, and in passing on information to them helped the participants to clarify the ASPIRe role for themselves. They also felt that it was beneficial to be able to discuss issues with those from other backgrounds and areas.

Did you receive support from Administration Staff to complete your ASPIRe? Is this something you would need in the future?

Four participants completed the documentation themselves, three had support from their own admin staff to complete it and one set of documentation is not yet completed.

The majority felt that admin support would be needed in future, as it was very time consuming to complete the documentation. It was suggested that the documentation needed to be put into a proper template form so that it was more easily completed.

One participant felt that if this was done the ASPIRe documentation could be more easily completed on a laptop by the Lead Person.

One participant felt that it would take too long to explain to admin what the notes meant so it would be just as easy to complete it themselves.



Process

Who did you give copies of the ASPIRe to once completed?

Four of the interviewees had given copies of the ASPIRe documentation to others. These were given to parents, nurseries, educational psychology, respite centre, Armitstead, Occupational Therapist, Speech and Language Therapist, Glenlaw House and school as appropriate. They felt that the documentation should be shared over all the appropriate agencies involved with the child's care.

Three participants had only given a copy to the carer but not to any other agencies and one participant has still to complete the documentation but would intend to share it with Barnardo's once parents have agreed it.

Have your family been using the ASPIRe and bringing it to appointments/Nursery?

Of the eight participants, the four who had given copies to other agencies three stated that the families were using the documentation routinely on a daily basis. One participant was unsure how much the family used it but thought it was to be taken to the school meeting that was due soon.

Two participants stated that the families were not using the documentation, as they did not see any real benefit or use for it.

One participant stated that the family did not engage with other services so never really used it and the final participant still has to complete the documentation.

Have the family informed you of changes to input in the ASPIRe between reviews?

One participant stated that family informs them of changes, but only some of the time.

One stated that the family would update it themselves, but not specifically inform her of the changes.

Two stated that no alterations had been made outwith the planning meeting, so there was nothing to update.

Three participants stated that the family was not really using the documentation as they did not feel it was of value to them and one participant has still to complete the documentation.

Have professionals informed you of changes they have made in the ASPIRe?

Two of the participants said that professionals had informed them of changes. The professionals were Occupational Therapists and Speech and Language Therapists. However, getting information from Social Work was still presenting problems.

One stated that information was received from nursing staff but only in an ad-hoc manner.

Two participants stated that they had not received any information as yet from professionals for updating of the ASPIRe documentation.

One participant said that as there was no real involvement with other professionals nothing had been changed, and two said that as the family did not use the documentation, no changes had been notified.

Did you read the guidance before completing the ASPIRe?

Seven of the participants read the guidance before completing the documentation.

Of these, two felt that it was helpful and informative and was useful for them.

One felt that it was very convoluted but that the summary elements were helpful.

The eighth participant did not read the guidance notes.



Was a Shared Plan made and were the actions assigned to the team around the child?

Seven Lead People said that a shared plan had been made.

Of these seven, five stated that actions mainly around unmet needs had been assigned to individuals including physiotherapy, lead worker, parents and social work. They would be checking to see how well these actions were being taken forward.

One stated that planning meetings should fit in with meetings already agreed with the school and not be an extra piece of work.

The eighth participant said that formulating a plan had not happened yet.

Have you seen any success in achieving the unmet needs from the Shared Plan so far?

A number of the children had unmet needs around manual handling, leisure activities, overnight care, housing issues, transport, schooling issues and child safety.

Four interviewees felt that these issues were now being addressed and one participant felt that changes were starting to happen to meet the needs of the child and that about 50% of this had now been achieved.

Two felt that most of the unmet needs were things that the carers needed to take forward themselves, one set of carers were unwilling to engage with other services.

One respondent believes that these issues are dealt with anyway within their current systems of working and feels that the ASPIRe impinges on this to no benefit.

One felt these issues were still at the stage of needing the meeting to address them as The ASPIRe process was not quite at that stage.

Is the ASPIRe easy to use? If no would you make any changes?

There was a range of views on the document and its structure.

In the main, it was considered to be too lengthy, time consuming and unwieldy with areas of duplication. Some participants felt it should be condensed and restructured to reflect only important information. It was felt by some that it was too intrusive in its questions and contained parts that were redundant for a number of families.

However, some interviewees felt it was easy to use but one felt the challenge was to make it person centred and not focussed on the negative aspects of the child.

It was felt by two participants that the documentation created another tier of information but did not really improve anything and merely caused extra work to achieve the same for the child. One of these participants felt that the whole ethos was not constructive to discussion and was not individual enough more of a tick box exercise.

The main changes suggested were around condensing the documentation and making it less time consuming to complete. Also ensuring that it was available in template form to make completion on computer simpler and less awkward.

Did being the Lead Person change the amount of time spent with the family?

Seven of those interviewed felt that the amount of time spent with the family had increased a little but most of them felt that the time spent information gathering and completing the ASPIRe documentation had definitely increased quite significantly the time they spent on the case. It was also felt by some of the Lead People that liaising with different agencies and attend meetings had increased the time spent as well.

One participant felt that as they would have had a high level of input into the case anyway it had not made much difference in the time spent with the family.

Opportunities/Challenges



What opportunities did being a lead person bring?

Four of the Lead People felt that the experience had afforded them opportunities.

One Lead Person felt it had opened up her understanding of other agencies and gave her the opportunity to call meetings with people she previously would not have accessed to look at problems experienced by the client

One felt that she had improved her communication skills with other professionals and also improved her time management between her own role and that of Lead Person due to having the opportunity to understand the ASPIRe working better.

One felt that he had had the opportunity to focus more on the child than the problems and diagnosis. She felt this had allowed her to become more personally focussed in the case.

The last Lead Person felt that she had the opportunity to find out more about services available and this would help all her clients.

Three participants felt that it had opened up no new opportunities to them and one felt that although it had raised no new opportunities it had been helpful to be involved in the case and would be able to take other cases forward.

What challenges did being a lead person bring?

Only one Lead Person did not feel that it brought any particular challenges.

The others identified a range of challenges:

- Getting information from other professionals was seen to be quite challenging as some were unsure how much badgering they should use to get it. It can be very challenging to get other professionals to understand the benefits of the pilot and to engage with it.
- Problems around identifying the people who need to take things forward and to attend meetings can be very difficult.
- There were also issues with most of the Lead People around the time it takes to update the information and complete the initial assessment documentation. They found this quite problematic, as was the nature of the document, in that it was not in template form and this led to challenges around their IT skills.
- Three participants felt that the documentation was quite intrusive for the carer around areas such as personal relationships and found it a challenge to use, as it did not sit comfortably with their existing model of working. This was made more challenging for them as they felt that it sits in isolation and does not feed into established systems or way of working.



General Comments

There was a range of comments, both positive and negative, made by participants about the ASPIRe pilot and these are reflected below.

Negative

Initially difficult to complete but this might have been due to complexity of case.

Lead People have to be aware of time commitment involved.

Awareness of the pilot needs to be raised, as communication is still a problem with other areas.

Confidentiality issues need to be addressed for example, does everyone involved need access to all parts of the documentation or could key issues only be shared? Parents should have a say about which people get which information.

Can be quite intrusive for the family as some questions quite sensitive.

Should not continue in current format – needs to take account of IEP and CSP – may need adapting or sharing. What already exists in other formats might be better.

Responsibility of ensuring document kept current and altered forms distributed to all involved areas.

Sometimes needs to be motivated to keep going and keep people involved or momentum can be lost.

Can be problematic balancing time depending on Lead Persons' profession – may not have the required knowledge.

Can be time consuming but template version of document would help with this.

Repeating information not an issue for some parents as retelling can be therapeutic.

Appropriateness of some professions as Lead People needs to be considered.

Positive

Family say they like the one document and the professionals involved also like it.

It is an easy way of introducing new professionals to the case although crossover time would be needed if a new Lead Person was taking over.

Saves family having to retell information.

Saves on duplication of information recorded.

It focuses on the child as a person and not just a diagnosis.

Raises awareness of unmet needs.

Overall document good and useful.

Process works reasonably well.

Document great if family engages with you and the process but some find it difficult to see how it can help meet their needs.

Network meetings are very useful

Helps flag up other agencies to get involved, for example, benefits- acts as a good prompting system.

Document easy to use.

Could work well but this depends on document being accepted in its current format by all other agencies as means of assessment and information recording.

Questions

Was baseline from literature or were clients consulted on the process?

Is it going to be compared with outcomes for those not involved with ASPIRe?

What is the view of managers and is there a shared commitment across agencies? This is needed to establish validity of process.

Could it be used in a different way to greater benefit using the education plan as the main structure?



Appendix 2

Definition from the Scottish Special Needs Group (Health.)

Complex needs require multi-professional interventions and support, such that no one agency or discipline has a monopoly.

Children have severe or profound impairment in at least:

3 of the following

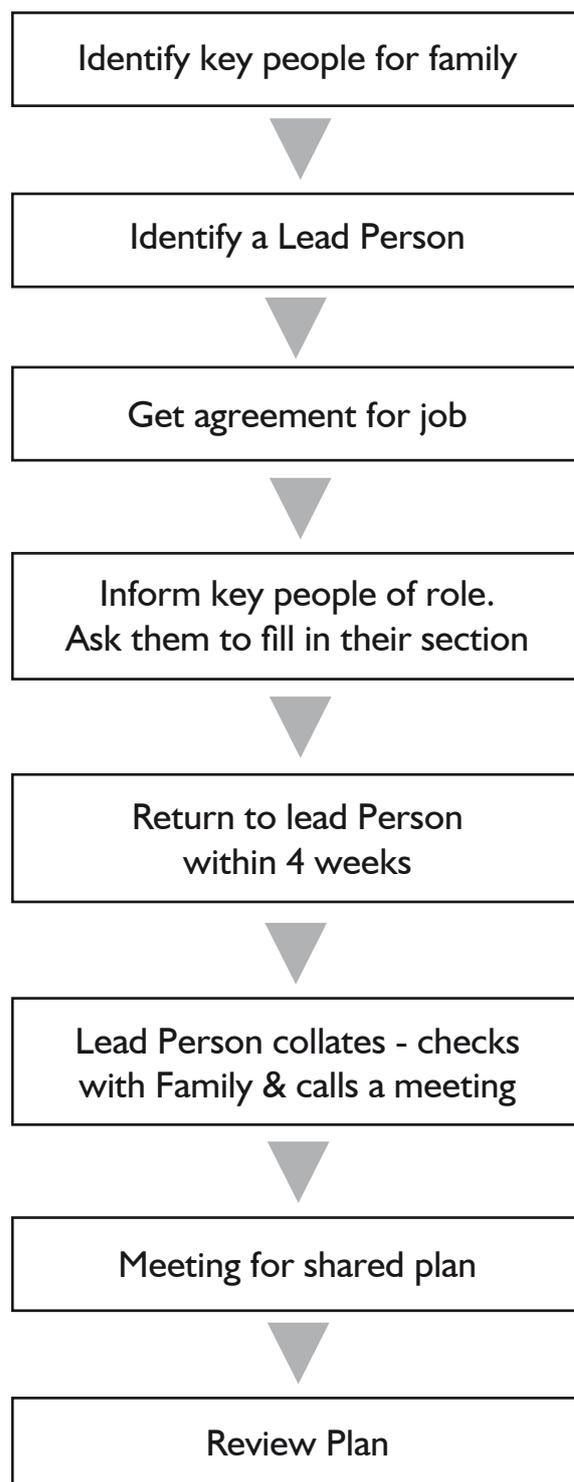
- motor
- speech and language
- vision
- hearing
- cognitive ability
- behaviour
- additional chronic health needs

need for at least 2 additional resources

- therapy services
- additional nursing care needs
- additional educational resources
- additional social care resources
- mental health services

The needs are sustained (more than 6 months and are on-going).

Care Co-ordination





ASPIRe
Unit 7
Nethergate centre
Dundee
DD1 4ER

t: 01382 435103
f: 01382 435103
e: aspire@dundeecity.gov.uk



ASPzRe

A SHARED PLANNING AND INFORMATION RECORD

Unit 7
Nethergate centre
Dundee
DD1 4ER

t: 01382 435103
f: 01382 435103
e: aspire@dundeecity.gov.uk