ANCE-BULLETIN NO. 89

SÉMINAIRE EUROPÉEN DE LA FICE Ã LUXEMBOURG DU 15 AU 16 MAI 1995

LE RÔLE DES PROFESSIONNELS INTERVENANT AU NIVEAU DE LA FAMILLE ET DE L'ÉCOLE POUR FAVORISER L'INTÉGRATION SCOLAIRE ET SOCIALE DES ENFANTS À BESOINS SPÉCIAUX

(SERVICES DE PRISE EN CHARGE PRÉCOCE ET SERVICES DE RÉÉDUCATION AMBULATOIRE)

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BULLETIN DE L'ANCE

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- *L'ANCE a été constituée le 9 juin 1978. Elle est la section luxembourgeoise de la Fédération Internationale des Communautés Educatives (FICE) qui a été créée en 1948 sous les auspices de l'UNESCO. La FICE est la seule organisation internationale qui s'occupe des questions de l'éducation en dehors du milieu familial. Comme organisation non-gouvernementale, elle est représentée auprès de l'UNESCO, de l'UNICEF, de l'ECOSOC et du Conseil de l'EUROPE.*

- *L'ANCE regroupe une cinquantaine de membres actifs (Centres d'accueil, centres d'éducation différenciée, institutions spécialisées, associations de parents et de professionnels du secteur médico-psycho-pédagogique et social ainsi que 150 membres individuels. Les principaux objectifs de l'ANCE sont les suivants:*

1. *Défendre les droits des enfants, surtout des enfants les plus démunis*
2. *promouvoir la coopération et le dialogue entre les différentes professions du secteur médico-psycho-pédagogique et social*
3. *soutenir les communautés éducatives dans les actions et projets visant une amélioration des conditions de vie des enfants*
4. *promouvoir la formation continue des professionnels du secteur*
5. *mettre en oeuvre des programmes de loisirs et de vacances destinés aux enfants des communautés éducatives*
6. *collaborer aux efforts d'intégration scolaire, professionnelle et sociale des enfants défavorisés*
7. *publier régulièrement un bulletin*
8. *collaborer activement aux travaux de la FICE*
9. *favoriser les échanges internationaux à tous les niveaux de l'action éducative*

Editorial

Du 15 au 16 mai 1995 avait lieu au Centre de Conférences à Luxembourg-Kirchberg un séminaire international de la FICE sur le thème du rôle des professionnels intervenant au niveau de la famille et de l'école pour favoriser l'intégration scolaire et sociale des enfants à besoins spéciaux (Services de prise en charge précoce et services de rééducation ambulatoire).

Le questionnaire qui a été distribué à la fin du séminaire montrait que la grande majorité des participants étaient très contents avec la qualité des interventions et souhaitaient une suite au séminaire (suite qui a d'ailleurs été annoncée dans le dernier bulletin de l'ANCE avec le cours de formation continue du Westminster College à Luxembourg).

Mais il y avait également des différences d'opinion, surtout en ce qui concerne le rôle de l'école luxembourgeoise par rapport à la politique d'intégration. A mon avis, la majorité des enseignants sont opposés ou du moins sceptiques par rapport à cette politique.

La politique des petits pas du ministère de l'éducation nationale est une politique à double tranchant: D'une part, les portes sont maintenant ouvertes pour l'intégration des enfants à besoins spéciaux dans notre système scolaire normal, d'autre part une intégration se heurte à des obstacles tels que les parents désireux d'intégrer un enfant sont vite découragés. Dans ces négociations, tous les coups sont permis. On cherche un coupable qui osé déranger la routine paisible du système scolaire caractérisé par une rigidité sans pareil, une orientation vers un type d'élève que l'on ne retrouve que dans les communes-dortoirs autour des quelques villes de notre pays. Tantôt c'est le ministre, qui, influencé par de mauvais conseillers a exigé en même temps l'augmentation des effectifs de classe et l'intégration d'enfants handicapés! Tantôt c'est le psychologue ou un autre farfelu qui fait de l'intégration une affaire d'idéologie. Tantôt ce sont les parents, qui, méconnaissant totalement la dure réalité du système scolaire luxembourgeois, veulent par l'intégration démontrer que le handicap de leur enfant n'est pas si grave que ça.

Il y a également les prudents, qui affirment le droit des enfants handicapés à l'intégration mais qui pensent que dans l'intérêt bien compris de l'enfant, il vaudrait mieux y renoncer. Ne sera-t-il pas chaque jour confronté avec ses déficiences? Les parents ne seront-ils pas déçus si après quelques années, e retard de l'enfant devient de plus en plus évident? Les autres enfants, ne seront-ils pas freinés dans leur élan vers les cimes de la connaissance par la présence d'un condisciple moins valide?

Le drame c'est que dans la situation actuelle au Luxembourg, il faut répondre à toutes ces questions par l'affirmative.

Tant que notre système scolaire fonctionnera comme il le fait aujourd'hui, une intégration d'un enfant handicapé n'est possible que dans des îlots de tolérance qui existent par ci et par là et qui deviendront stigmatisants à leur tour.

Même si j'apprécie le travail et l'engagement personnel des instituteurs et institutrices qui travaillent dans des classes d'intégration ou dans le service de rééducation ambulatoire, je suis convaincu qu'à la longue, ces structures doivent disparaître pour faire place à une école ouverte, moins dominée par les programmes et horaires rigides que par une pédagogie de la découverte, du jeu, de l'apprentissage par l'erreur, de la solidarité et de la stimulation mutuelle entre élèves « faibles » et « forts ». Aujourd'hui, l'école ne fait que refléter les inégalités de notre société et au lieu de servir d'endroit compensateur et égalisateur, elle s'efforce de les approfondir.

Dans ce contexte, le séminaire de mai 1995 a réuni des personnes désireuses d'apporter le changement et de s'investir pour réaliser une intégration sans conditions des enfants à besoins spéciaux. Pour réaliser ce but, il faut apprendre. Apprendre de nouvelles méthodes d'intervention, apprendre à connaître ce qui se passe de l'autre côté de nos frontières, apprendre à défendre une politique sans répéter les erreurs des autres. Je crois que le séminaire y a apporté une contribution valable.

Robert Soisson

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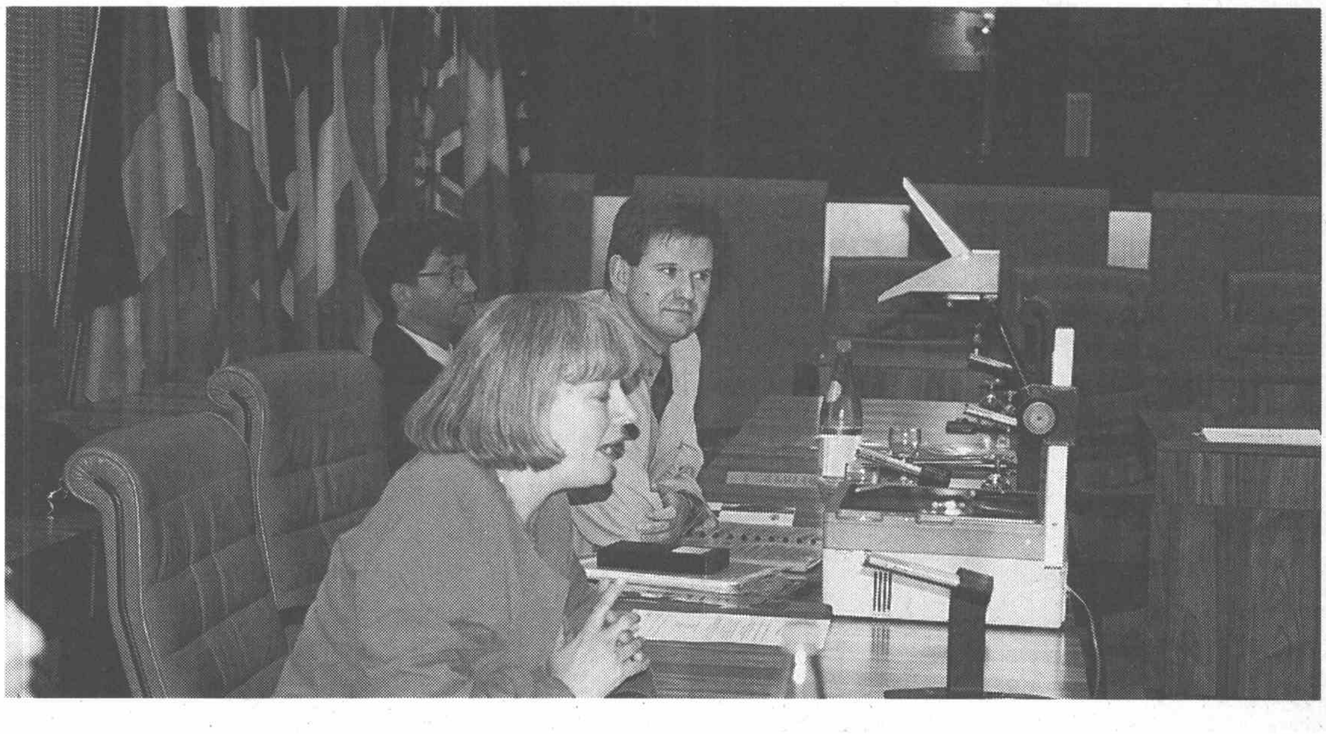

Allocution de Mme Marie-Josée Jacobs, Ministre de la Famille, des Handicapés et des Accidentés de la Vie

Monsieur le président,
mesdames, messieurs

C'est avec un grand plaisir que je participe aujourd'hui à l'ouverture de votre séminaire international sur le rôle des professionnels intervenant au niveau de la famille et de l'école pour favoriser l'intégration scolaire et sociale des enfants à besoins spéciaux

A tous les intervenants et aux participants, je souhaite dans notre pays une cordiale bienvenue ainsi qu'un séjour instructif et agréable. Je remercie l'Association Nationale des Communautés Educatives pour son inlassable engagement en faveur des enfants les plus démunis et les enfants à besoins spéciaux.

C'est avec plaisir que je contribue aux travaux de ce séminaire qui porte sur deux thèmes qui préoccupent mon ministère pour plusieurs raisons. Il faut savoir qu'après le remaniement ministériel de décembre 1994 suite au départ de Monsieur Jacques Santer à Bruxelles, j'ai eu pour mission la coordination des services en faveur des personnes handicapées.

Comme notre pays dispose d'un réseau social bien tissé et d'une multitude de services étatiques et privés qui s'adressent aux enfants et adultes handicapés, il est parfois difficile de se retrouver dans cet univers particulier. Il arrive que des services délivrant des prestations semblables soient conventionnés par des ministères différents provoquant ainsi des confusions chez les utilisateurs. De même, la collaboration entre différents services s'adressant à une même clientèle s'avère insuffisante ou fait totalement défaut. Il est donc important de coordonner ces services, de simplifier leur accès pour les personnes handicapées et d'éliminer les situations de double emploi.

Ceci est particulièrement vrai dans les domaines que vous discuterez lors de votre séminaire: l'intégration scolaire et la prise en charge précoce.

Il y a quelques années, l'ancien ministre de l'Education Nationale, M. Marc Fischbach, a demandé aux administrations communales et aux enseignants de faire des efforts pour stimuler l'intégration scolaire des enfants handicapés. Depuis, un certain nombre d'expériences ont été faites dans ce domaine, la loi sur nos services de l'Education Différenciée a été modifiée pour permettre aux parents de maintenir leur enfants - s'ils le désirent - dans les structures du système scolaire normal. Un service de rééducation ambulatoire a été créé pour encadrer ces mesures d'intégration et donner aux enseignants le support nécessaire pour alléger et compléter leur tâche difficile.

Mais ce système ne fonctionne pas encore d'une manière satisfaisante. Il subsiste des problèmes au niveau du dépistage et de la sélection des enfants intégrables, au niveau des mesures à prendre pour faciliter leur intégration et au niveau de la préparation des enseignants travaillant dans une classe d'intégration, de la formation des intervenants extérieurs et de l'évaluation des résultats de cette politique d'intégration.

Dans ce contexte, il est toujours important et utile de comparer notre politique avec ce qui se passe à l'étranger et d'apprendre pour essayer d'éviter des erreurs et d'ajuster nos mesures. Je suis donc très heureuse de souhaiter la bienvenue à des spécialistes anglais et français, des chercheurs et des praticiens, qui nous informeront des évolutions récentes dans leurs pays respectifs.

Depuis une dizaine d'années, les services de rééducation précoce ont développé leurs activités au Luxembourg. La période allant de la naissance à la scolarisation de l'enfant au préscolaire à quatre ans est d'une importance primordiale pour son développement futur. Toute mesure prise pendant ces années cruciales pour aider l'enfant affecté d'un handicap augmentera ses chances de mieux s'intégrer dans la vie scolaire, professionnelle et sociale. Les associations qui travaillent dans ce secteur ont des revendications que mon ministère va étudier; ainsi par exemple il mes semble important de créer une base légale pour leurs activités.

Quel sera le sort des enfants suivis par ces services lorsqu'ils auront dépassé l'âge de quatre ans? Qui prendra la relève? En écoutant les expériences faites par nos collègues anglais, j'espère que nous aurons des indications qui nous permettront de mieux définir nos propres projets dans un proche avenir.

Mesdames, messieurs,

Le travail des professionnels dans le secteur de l'éducation, de l'éducation différenciée et dans le domaine de la prise en charge précoce est sujet à des changements permanents. Sa qualité est un indicateur sensible pour l'humanisme et la justice sociale d'un pays comme le nôtre. Améliorer la qualité des services en faveur des personnes les plus démunies, les encourager à participer activement dans la vie scolaire, professionnelle et sociale de notre société, lutter contre l'exclusion sociale de ces concitoyens, tels sont les principes que mon ministère veut défendre.

Je vous souhaite deux journées de travail fructueuses et stimulantes.

Allocution du président de l'ANCE, Robert Soisson

Madame le Ministre de la Famille
Monsieur le Directeur de l'Education Différenciée
Mesdames, messieurs, chers collèges et amis,

C'est un grand plaisir pour moi de vous saluer si nombreux à ce séminaire et j'espère que vous passerez deux journées informatives et stimulantes.

Pourquoi ce séminaire?

L'Association Nationale des Communautés Educatives est la section luxembourgeoise de la FICE, une organisation internationale regroupant des sections dans 26 pays. La FICE défend les droits de l'enfant et s'intéresse plus particulièrement à la situation des enfants placés en dehors de leur milieu familial. La FICE a été créée en 1948 et les sections nationales qui se sont créées après ne se sont pas développées toutes selon le même schéma. Ainsi par exemple, les sections francophones étaient toujours très impliquées dans le travail avec les enfants handicapés, placés ou non. C'est ainsi que la FICE a rejoint - dans le cadre du programme Hélios - un groupe d'organisations européennes travaillant dans le secteur du handicap. Dans Hélios II, la FICE fait partie du secteur "Education" ensemble avec d'autres organisations comme par exemple "EIN" (European Inclusion Network), une organisation que préside notre ami et conférencier d'aujourd'hui Harry DANIELS. Le programme Hélios II prévoit la participation d'organisations non-gouvernementales dans le cadre du « Disability Forum » pour aider à mettre en oeuvre la politique européenne en faveur des personnes handicapées par l'échange *d'expériences, des visites d'études, des conférences et séminaires sur des thèmes d'actualité. En décembre 1994, la FICE avait organisé un premier séminaire international ici même pour mettre en place son "Professional Exchange Programme". Pour la conférence d'aujourd'hui, j'avais proposé une combinaison des thèmes de la prévention et prise en charge précoce et de l'intégration scolaire, parce qu'il me semble qu'il existe un vrai problème ici au Luxembourg au moment du passage de l'un vers l'autre.*

Le groupe de coordination du secteur éducation du programme Hélios II est un groupe très dynamique, animé par des personnages capables d'affronter les dures réalités de la vie professionnelle mais avec un penchant également pour les côtés agréables de la condition humaine. Vous n'avez certes pas de mal à croire qu'il s'y créent des amitiés à toute épreuve et le fait que Flo, Barry, Daniel et Harry ont consenti à accourir à Luxembourg pour ce séminaire en est un bel exemple.

En participant à un séminaire FICE/Hélios à Manchester en Décembre 1994, j'étais étonné de rencontrer une dame charmante, très british, qui m'a révélé qu'elle habite notre petit pays, dans un village qui fait toujours la une des journaux lorsqu'il pleut un peu plus que prévu et que nos amis du ministère de la famille et de la solidarité visitent toujours en bateau. Heureusement, ***Flo Longhorn*** *et sa famille habitent sur les hauteurs environnantes de sorte que notre conférencière peut entreprendre ses nombreux voyages sans devoir se faire trop de soucis au sujet de sa demeure. Flo travaille comme "consultant in Special Education"; elle est "associate tutor" au "Centre for the Study of Special Education" au Westminster College à Oxford, dont Barry Carpenter est le directeur.*

J'ai rencontré ***Barry Carpenter*** *lors du même séminaire à Manchester. Il était spontanément d'accord pour participer à ce séminaire. Barry est le père de deux enfants à besoins spéciaux et connaît donc la problématique du double point de vue des parents concernés et des professionnels. Il est professeur à l'université de Oxford et vient d'être chargé du poste de directeur du "Centre for the Study of Special Education", inauguré il y a quelques mois au Westminster College.*

Harry Daniels *est "senior lecturer" à l'"Institute of Education" de l'université de Londres où il travaille surtout dans le domaine de la pédagogie différenciée et où il lui arrive de travailler avec des étudiants luxembourgeois. Dans le contexte de l'intégration scolaire, il participe à des recherches sur le terrain comme celle dont il va nous parler aujourd'hui. Harry est également le président du "European Integration Network", une ONG qui regroupe des associations actives dans le domaine de l'intégration scolaire et qui vient récemment à Thessalonique de se rebaptiser "European Inclusion Network" pour bien montrer qu'il ne faut pas seulement lutter pour l'intégration mais contre l'exclusion.*

Enfin ***Daniel Vidaud****, le directeur de l'ANCE française, que je connais depuis de longues années par mes activités dans le cadre de la FICE. Daniel est un habitué de ce centre et un expert en matière de politique française à l'égard des personnes handicapées. L'ANCE française regroupe plus ou moins 1400 institutions et services actifs dans le secteur du handicap et a toujours adopté une attitude nuancée face à l'intégration scolaire des enfants à besoins spéciaux. Comme l'ANCE organise son congrès annuel à partir du mercredi à Brest, Daniel ne peut malheureusement pas rester avec nous demain, mais il doit repartir ce soir même à Paris.*

Jörgen Hansen *n'a malheureusement pas pu venir à Luxembourg. Je l'ai connu à Padoue lors d'un séminaire de l'"European Association for Special Education", l'association qui préside le groupe de coordination du secteur éducation de Hélios II. C'est à ce moment, que j'ai pris connaissance pour la première fois du document très important pour notre secteur que constitue l déclaration de Salamanque. Comme Jörgen Hansen était l'un des auteurs, il aurait pu nous donner des informations de première source sur la petite histoire de ce document. Il m'a bien indiqué quelques autres personnes susceptibles de le remplacer, mais aucune d'entre elles était libre ce jour-ci de sorte que j'ai décidé de vous présenter moi-même la déclaration.*

Avant cela, je tiens à remercier ***Madame le Ministre de la Famille, Marie-Josée Jacobs*** *d'avoir accepté le patronage de cette manifestation et sa présence parmi nous ce matin témoigne de l'intérêt qu'elle porte aux thèmes que nous discuterons. Je remercie également* ***Mme le Ministre de l'Education nationale Erna Hennicot-Schoepges*** *qui a* *également accordé son patronage à notre séminaire et je souhaite la bienvenue à* ***Monsieur John Pull, directeur de l'Education Différenciée,*** *qui la représente ici ce matin. Un merci également aux responsables du programme* ***Hélios II*** *de la Commission de l'Union Européenne, qui ont subsidié la présente manifestation.*

Vous n'ignorez pas que ***l'Association Nationale des Communautés Educatives*** *a depuis sa création en 1978 défendu l'idée de l'intégration scolaire, professionnelle et sociale des enfants, adolescents et adultes handicapés. En feuilletant les bulletins publiés par l'ANCE, on constate que notre organisation a régulièrement publié des articles, organisé des conférences et tables rondes sur ce thème et elle a soutenu toute initiative visant le même but. Cette politique s'inscrivait et s'inscrit toujours dans le contexte d'une lutte contre toute exclusion au niveau de l'école, de la vie professionnelle et de la société.*

Si on parle d'intégration, on doit bien sûr se poser toujours la question: intégration dans quoi? Est-ce que l'école comme elle se présente aujourd'hui dans la plupart des sociétés postindustrielles, le monde de l'emploi ou la société avec ses nombreuses injustices sont vraiment des endroits où il vaut la peine d'intégrer quelqu'un? Les personnes handicapées, n'ont-elles pas une chance inouïe de pouvoir vivre dans leurs cages dorées?

Effectivement, nous vivons dans une société qui traverse une ***triple crise du lien social, du sens et de l'emploi****, comme l'a constaté Jean-Baptiste DE FOUCAULD, commissaire au plan en France, lors de l'assemblée générale des Organisations Internationales Non Gouvernementales dotées du statut consultatif auprès du Conseil de l'Europe. Le sens que l'on donne à la vie, le lien social accepté et l'activité qui donne à l'homme sa place dans la société sont les trois critères essentiels de cohésion sociale. "La société n'est jamais un paradis radieux, mais il est rare d'avoir trois crises de cette ampleur en même temps." (P.5). Les exclus sont seuls; il n'y a pas de combat social qui s'organise spontanément autour d'eux. Les tentation de repli sont grandes. Si tout ça est vrai pour les personnes "normales", vous imaginez sans difficulté combien les personnes handicapées qui vivent quotidiennement cette situation ont de raisons pour essayer de sortir de leur ghetto.*

Jean-Baptiste DE FOUCAULT insiste sur la nécessité de réagir face à cette triple crise sur cinq niveaux différents et vous verrez sans doute le lien avec les deux sujets qui nous intéressent.

En premier lieu, il s'agit de ***réduire le champ de l'utilitarisme*** *dans nos représentations. L'éducation sert bien sûr à la formation professionnelle, mais elle a également la fonction de fournir à chacun des ressources de sens. Le temps est mal géré dans nos sociétés: il est la ressource du sens, du lien social et de l'emploi. Notre logique productiviste nous amène à produire toujours plus au lieu de travailler moins. Mais il y a de plus en plus de personnes qui sont prêtes à réduire leur temps de travail et leurs revenus. Il faut organiser tout ça, trouver un nouvel équilibre entre le collectif et l'individuel, reconstruire une vision globale de la société.*

En deuxième lieu, il faut ***chercher un nouvel équilibre entre marché libre et marché institutionnellement régulé****. Les sociétés postindustrielles créent l'exclusion au niveau mondial. Les marchés sont organisés autour de l'idée de la concurrence, pas assez autour de l'idée de la coopération. C'est d'ailleurs une des raisons, pourquoi les personnes handicapées et les marchandises qu'elles produisent ont tellement de difficultés pour trouver leur place dans les économies nationales.*

En troisième lieu, il faut ***trouver la bonne liaison entre développement économique et Etat providence****. La dépense publique ou sociale ne doit pas augmenter plus vite que le Produit Intérieur Brut. Il ne faut pas reporter sur les générations futures les charges actuelles. C'est un problème d'équité intergénérationnelle. Les vies de nos enfants seront plus mobiles: Des périodes de formation, de plein emploi, de chômage, de "temps choisi". DE FOUCAULT propose la création d'une "banque du temps", un genre de "caisse nationale d'aménagement du temps" qui permettrait entre autres aux actifs de prendre un congé sabbatique de temps en temps.*

En quatrième lieu, il faut ***régulariser autrement l'accès à l'emploi:*** *il ne faut pas laisser jouer seulement les mécanismes du* *marché. Une alternative serait de combiner les systèmes de régulation du marché connus avec les acteurs de la société, tels que entreprises, syndicats et ... les ONG.*

En effet, DE FOUCAULT donne un ***rôle important à jouer aux ONG dans le combat pour une société plus juste:*** *Le secteur des ONG est un secteur démocratique, qui ne refuse pas le progrès technique, ouvert et humain. Il est porteur de réenchantement et producteur de lien social. Il est complémentaire à l'Etat qui a du mal à réaliser les mêmes buts avec des subventions, des décrets et des circulaires et votre présence ici en témoigne.*

En tant que ONGs, nous avons donc notre place dans la lutte pour une société plus juste et dans le combat contre la triple crise qui secoue nos sociétés postindustrielles et qui se fait particulièrement remarquer chez les jeunes. Ce double combat est donc surtout un combat contre l'exclusion dans toutes ses formes.

Dans le contexte de ce séminaire, on peut affirmer que les enfants à besoins spéciaux sont les premières victimes de l'exclusion, surtout à partir du moment où ils quittent le cadre protecteur de leur famille. Dans un article publié récemment dans "Hélioscope", le professeur Peterander de l'université de Munich définit l'intervention précoce comme la première étape de l'intégration. "L'intervention précoce est destinée à prévenir les handicaps évitables, à aider et à encadrer l'enfant dès son plus jeune âge, à venir en aide à sa famille et à intégrer l'enfant handicapé à l'école et au jardin d'enfants."

Ici au Luxembourg, on constate un consensus assez large au niveau des services d'intervention précoce et des foyers de jour qui accueillent des enfants de moins de quatre ans en ce qui concerne la politique à mener face aux enfants à besoins spéciaux. Comme le décrit le Professeur Peterander, on essaye de renforcer la confiance des enfants handicapés en leurs propres capacités, d'accorder la priorité au bien-être de l'enfant, de s'intéresser à l'ensemble de la personne de l'enfant, de mieux assister la famille, de placer les centres le plus près possible des utilisateurs, d'améliorer la collaboration interdisciplinaire. En Allemagne s'ajoute la recherche au niveau universitaire et le développement des systèmes multimédias d'apprentissage à distance, comme le video-home-training, très populaire aux Pays-Bas actuellement.

Mais cette entente cordiale est brutalement mise en question lorsque l'enfant à besoins spéciaux entre le préscolaire à quatre ans. Les services d'intervention précoce essayent souvent de préparer le terrain en contactant directement ou indirectement des institutrices préscolaires susceptibles d'accepter un enfant à besoins spéciaux dans leur classe. Bien qu'ils ont parfois de la chance et réussissent à "placer" leur enfant, ils se heurtent dans la plupart des cas au refus ou à des attitudes revendicatives souvent exagérées. Il y a deux possibilités:

La voie inofficielle: On trouve une institutrice qui par conviction ou par pitié accepte l'enfant. Dans ce cas, l'institutrice n'a pas le droit de demander une aide supplémentaire: un intervenant extérieur, la réduction des effectifs de la classe ou l'achat de matériel didactique supplémentaire.

La deuxième possibilité est de passer par la "Commission Médio-Psycho-Pédagogique Nationale" en demandant une "intégration" de l'enfant dans une classe préscolaire ce qui donne droit théoriquement à quelques heures de présence d'un intervenant extérieur en classe en fonction des disponibilités du "Service rééducatif ambulatoire". Ensuite il faut quand même encore trouver une institutrice prête à accueillir cet enfant dans sa classe.

Cette procédure a plusieurs désavantages:

- *la procédure administrative entraîne une stigmatisation de l'enfant; c'est un "intégré"*
- *les investissements en temps de travail des professionnels (préparation du dossier, réunions, déplacements) sont parfois considérables*
- *les aides ne sont pas dispensées en fonction des besoins réels mais des disponibilités du SREA*
- *il se crée lentement une structure intermédiaire entre le système scolaire normal et l'Education différenciée avec son personnel, ses méthodes, ses habitudes qui ne va pas tarder à développer sa propre image professionnelle avec ses revendications et tout ce qui en découle*
- *la déresponsabilisation des enseignants de l'enseignement primaire s'accroît: il se créent des animosités entre enseignants*

qui reçoivent une aide et d'autres qui n'en reçoivent pas;
des enfants présentant des troubles d'apprentissage ou des troubles du comportement mineurs tombent en disgrâce dans leurs classes parce que leurs enseignants estiment avoir droit à une aide supplémentaire.

Dans deux communes, on discute la création de "filières intégratives", pour éviter que les parents d'enfants à besoins spéciaux ne doivent pas craindre à chaque fois l'approche de la fin de l'année scolaire parce qu'ils ne savent pas si et où leur enfant trouvera un enseignant daignant le prendre dans sa classe. Ceci facilite la tâche des institutions de placement mais crée le danger d'une structure à part qui sera certainement un "example of good practice" mais qui cimentera les exemples beaucoup plus nombreux de la "bad practice".

En tant que ANCE, nous défendons le concept de ***"l'école pour tous"*** *tel qu'il a été défini lors de la Conférence Mondiale du 5 au 9 mars 1990 à Jomitien en Thaïlande sur l'Education pour Tous et nous soutenons les "Règles des Nations Unies pour l'égalisation des chances des handicapés".*

Les ***"Standard Rules on the Equalisation of Opportunities for Persons with Disabilities"*** *est un texte qui a été longuement préparé sur le plan international. Il a largement influencé les auteurs de la Déclaration de Salamanque sur laquelle je parlerai plus tard.*

Les "SR" ne constituent pas un document contraignant mais elles peuvent servir de modèle aux Etats désireux d'adapter leur législation. Elles peuvent servir de base pour définir la politique des organisations défendant les intérêts des personnes handicapées. Leur but est d'assurer aux personnes handicapées l'exercice des mêmes droits que les personnes non-handicapées et d'inciter les Etats d'éliminer les obstacles qui s'opposent toujours à la réalisation de cette politique.

Les "SR" définissent les conditions préalables pour réaliser les chances égales: L'information du public; les soins médicaux, la réhabilitation et les services. Le document définit huit domaines critiques où doivent de réaliser les programmes pour promouvoir les chances égales: L'accessibilité, l'éducation, l'emploi, les revenus et la sécurité sociale, la vie familiale, la culture, les loisirs et les sports, la religion. Le document définit également dix secteurs susceptibles de faciliter la mise en oeuvre des "SR": L'information et la recherche, la politique, la législation, les politiques économiques, les comités de coordination au niveau national, les organisations des personnes handicapées, la formation du personnel, l'évaluation des politiques au niveau national, la coopération technique et économique, la coopération internationale.

J'ai mentionné ce texte important, car la déclaration de Slamanque est explicitement basée sur lui. D'ailleurs ce dernier document n'est pas seulement une déclaration, mais un programme complet comme son nom l'indique: ***« Déclaration de Salamanque et cadre d'action pour les besoins éducatifs spéciaux »****. La conférence de Salamanque se tenait du 7 au 10 juin 1994 et rassemblait 92 gouvernements (dont le nôtre) et 25 organisations internationales. Dans son préface, le directeur général de l'UNESCO, M.* ***Frederico Mayor*** *souligne que la déclaration et le cadre d'action sont inspirés par le principe de l'intégration et la création d' »écoles pour tous ». Il souligne l'appel lancé aux gouvernement d'une* ***réforme majeure des écoles ordinaires****.*

La déclaration proprement dite est constituée de cinq points, que je résume:

1. *Les représentants de 92 gouvernements et de 25 organisations internationales réaffirment leur engagement en faveur de l'éducation pour tous et demandent l'éducation des enfants à besoins spéciaux dans le système éducatif normal.*

2. *L'éducation est un droit fondamental, chaque enfant a des caractéristiques et des besoins propres et les programmes doivent tenir compte de cette diversité. Les personnes ayant des besoins éducatifs spéciaux doivent pouvoir accéder aux écoles ordinaires, ceci étant le moyen le plus efficace de combattre les attitudes discriminatoires, de créer des communautés accueillantes et d'édifier une société intégratrice.*

3. *Les gouvernements sont appelés à donner le rang de priorité le plus élevé dans leurs politiques et dans leurs budgets à l'amélioration de leurs systèmes éducatifs afin qu'ils puissent accueillir tous les*

enfants, d'adopter en tant que loi ou politique le principe de l'éducation intégrée, d'encourager des projets pilotes, d'assurer la participation des enfants et de leurs parents dans la mise en oeuvre de leur politique et de veiller à ce que la formation des enseignants traite des besoins éducatifs spéciaux dans les écoles intégratrices.

4. *Les participants font appel à la communauté internationale (UNESCO, UNICEF, OMS, OIT, etc.) de tout mettre en oeuvre avec les moyens qui leurs sont propres pour réaliser l'éducation pour tous*

5. *Ils remercient le gouvernement espagnol et l'UNESCO d'avoir organisé cette conférence et espèrent que le texte adopté soit porté à la connaissance des participants aux grandes conférences et sommets mondiaux de Copenhague et de Beijing en 1995.*

Le cadre d'action est composé de 85 points regroupés dans trois chapitres

« L'idée principale qui guide ce Cadre d'Action est que l'école devrait accueillir tous les enfants, quelles que soient leurs caractéristiques particulières d'ordre physique, intellectuel, social, affectif, linguistique ou autre. Elle devrait recevoir aussi bien les enfants handicapés que les surdoués, ...(p. 6) » « Une pédagogie centrée sur l'enfant est bénéfique pour tous les élèves et, donc, pour toute la société. L'expérience nous a montré qu'elle peut réduire sensiblement le nombre des échecs scolaires et des redoublements, qui caractérisent tant de systèmes éducatifs et assurer un niveau plus élevé de réussite scolaire.(p. 7) »

Ce document est d'une très grande importance pour la politique scolaire et l'ANCE se chargera de sa diffusion au Luxembourg. J'espère que les travaux de notre séminaire seront inspirés par l'esprit de cette déclaration et je vous souhaite un agréable séminaire.

Teacher Support Teams: School based peer group support for teachers' problem solving

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Background

The development of practices of integration of children with special educational needs (SEN) in ordinary schools has been associated with a gradual acceptance that assessment and intervention must focus not only on individual difficulties but also on factors within schools which can prevent or exacerbate problems (NCC 1989). The current emphasis in the Code of Practice on Individual Educational Plans (IEPS) and school development planning from an SEN perspective is a manifestation of this interactional orientation to SEN intervention. Support is available for institutional development and individual learning. Support for groups of teachers led by outside professionals rather than peers has been discussed and developed by Hanko (1989, 1990). Collegial support for teachers in their approach to SEN work has received relatively little attention despite recommendations for teacher peer support systems to be found in the Elton Report (DES, 1989, recommendation 6). One possible reason is the often found culture of schools, which encourages a conception of the teacher as isolated in the classroom with no established system of peer collaboration.

Many classroom teachers feel that they do not have sufficient training and support to meet many of the challenges presented by children with special educational needs (SEN) in their classes. They tend to lack confidence in their ability to provide programmes of study which are appropriately differentiated. Many teachers find themselves working in school situations where they regularly teach large classes with little or no internal special needs support and where external resources are rarely available. Facing the task of meeting a wide range of needs in isolation can lead to acute stress or disaffection. This can happen to capable teachers working in unfavourable circumstances. This briefing paper introduces a practical way of easing the difficulties experienced by many such teachers by transforming their work situation.

Teacher Support Teams: an outline

*Teacher Support Teams (TSTs) act as school based problem solving groups of teachers which function to support pupils indirectly through teacher collaboration. TSTs are novel in that they are an example of a school based development designed to give support and assistance to **individual teachers**. They may be seen to complement existing forms of SEN work within schools and existing patterns of informal mutual peer support as and when they exist. Individual teachers approach teams of their peers for collaborative support in understanding problems and designing appropriate forms of intervention related to learning and behaviour difficulties. These teams aim to enable staff to develop their confidence and competence in making provision for children with SEN in mainstream classes. As such the operation of TSTs would have some contribution to make in alleviating some of the stresses of teaching.*

Teacher support teams represent a significant way of establishing peer support which is compatible with professional autonomy. Professional autonomy would be well served by schools having a system of collegial assistance in response to voluntary requests for assistance. In providing a structured and accessible forum for encouraging an interchange between peers in connection with specific teaching difficulties, support teams can contribute to making schools more effective. In this way TSTs become an intermediary form of provision between individual child focused support arrangements and whole school policy initiatives.

What are TSTs ?

- *They may be seen to constitute a practical embodiment of a school's commitment to SEN by offering an indirect mechanism for* *supporting pupils , through supporting teachers in a setting in which knowledge and understanding may be shared and developed by professional peers.*

- *While other professional groups have been using systems of peer professional support and consultation, teachers who have considerable knowledge and skill rarely share this with colleagues. TSTs set up a forum for professional educators to share, manage and solve problems which arise from teachers' individual and immediate classroom concerns.*
- *In seeking assistance teachers make requests to the team who help them to define the problem/s, consider possible alternatives and try out practical strategies.*
- *In that TSTs develop structured approaches to collaborative problem solving with an emphasis on follow-up and review they differ from much of the informal peer support which is to be found in many schools. Teachers may often ask each other for advice. However these exchanges typically take place in the context of busy staff rooms in a very short space of time and rarely with any possibility of reviewing the effects of the advice. TSTs allocate a dedicated amount of time to a referring teacher, in a calm and peaceful setting in which issues may be discussed without interruption and in confidence.*
- *Crucially they embody the problem solving cycle in that teachers are offered the opportunity to monitor and review the, situation through follow up meetings.*

What are the advantages of TSTs

- *as a school resource for collegial assistance and support.*
- *as a forum for teachers to share expertise and understanding*
- *as a way of enabling teachers to develop their approaches to children with special educational needs.*
- *as a support for the implementation of stages 1 to 3 of the Code of Practice*
- *as a system for schools to offer more effective provision for children with special educational needs in the context of Local Management of Schools.*

In the context of devolved and perhaps dwindling resources for meeting SEN, questions of cost effectiveness spur the need for the development of services which make the best use of what is available. TSTs offer the possibility of intervention that is distinctive by dint of the focus on teachers rather than children or school policy. They utilise the sadly under used potential resource which consultation and collective problem solving can offer teachers. They also provide a way in which a school may structure and organise its response to the Code of Practice. In so doing they may well enhance and refine the role and effectiveness of the SEN Co-ordinator. TSTs may support the formulation and review of IEPs as part of the practice of offering more general support to teachers. They may help schools to establish priorities in their negotiation for external support services. Issues raised in TSTs may also feedback into the institutional and SEN policy development planning process.

How do TSTs work ?

- *Typically 3 teachers (the SEN co-ordinator, a senior teacher and another class teacher)'serve as the core team, who call on outside support and advisory staff and parents when needed.*

- *Teams meet weekly or fortnightly with the teacher making a request for support - meetings last about 30 minutes each (usually during lunch time or after school). A team member usually collects relevant information about the teacher's concern before the meeting.*

- *Typically one case is dealt with per meeting, either a new request or a follow-up. Unless a case is closed a follow-up date is always agreed at which the situation will be reviewed.*

- *Teams keep confidential notes about cases to enable follow-up work and a log of meetings.*

- *Teachers involved in meetings need to have some time release from other responsibilities.*

- *The principle and practical aspects of TSTs need staff and head teacher support.*

For TSTs to operate successfully it would seem that there needs to be a clear specification of the kinds of teaching problems which could be referred by teachers to the *teams. It is also vital that responsibility for referral is with class teachers, not the head teacher or TST teachers. One teacher needs to co-ordinate the work of the team using clear procedures for referral, conduct of meetings, analysis of the problems and design of interventions, implementation, records and follow up of interventions. In practice referrals are often concerned with behaviour problems, though many are also about learning difficulties. Not all referrals may be about individuals, some may be about groups or classes.*

Responses to TSTs in action

TST support can include providing emotional support and encouragement, specific approaches to managing behaviour, teaching strategies and consulting others, such as the headteacher, the educational psychologist and involving parents. On the basis of recent evaluations of TSTs, teachers appear to be supportive of the TST concept and its practice.

Setting up TSTs in Schools

The evaluations show that setting up TSTs depends on clear and detailed initial communications and negotiations between the schools and those with the development ideas and training resource. This involves the heads and the whole staff in understanding what is involved, considering what the TST arrangement has to offer the school and then deciding to commit the school and the resources to enable TSTs to work. In addition to these factors, evaluation indicates the importance of the whole staff and head-teacher needing to support the principle of TSTs . School staffs would therefore be given the choice to adopt the TST approach and to design it to fit the school's particular circumstances and needs.

Preparing a school for a TST should involve enabling participating teachers to:

- *be familiar with the concepts and principles of school based teacher support teams as providing peer support* ***and*** *meeting special educational needs*

- *understand the function, risks, constraints of designing and running teacher support teams*
- *have designed an appropriate teacher support team for their schools through consultation with colleagues.*
- *be aware of and sensitive to the needs and feelings of the teacher making requests for support.*

- *be proficient in*

- *receiving requests for support*
- *conducting meetings*
- *liaising with parents and support services*
- *making sense of teaching problems*
- *devising appropriate forms of advice*
- *assessing outcomes in the classroom*
- *reviewing and evaluating the overall TST arrangement*

Above all, team members need to be involved in simulations of the processes of analysing and conceptualising problems, deciding on intervention goals, planning and evaluating interventions. This involves consideration of issues common to many consultation settings such as active listening. If they are to function successfully TSTs need to be designed to fit the perceived needs of the schools by the TST team and their colleagues.

How do arrangements work ?

When a TST is being planned in a school there a number of issues which need to be resolved. The following list may serve as an aide-mémoire:

1. who is the target population?
2. who can refer to the team?
- *some schools may wish to extend the TST principle to all staff including classroom assistants.*

3. who serves on the team and who are they to be identified?
4. who co-ordinates the team?
5. receiving referrals.
- *how many referrals can be handled at one meeting*

6. conducting meetings
- *timing of meetings*

7. how to make use of others
- *parents, psychologists, advisory teacher*
- *support services*

8. how to co-ordinate and overlap with other support systems.
9. how to make recommendations and gain access to resources.

10. how to minimise the amount of recording in the design of recording sheets.
11. how to follow up recommendations.
12. how to support and encourage team use.
13. how to review and evaluate the team process (formative)

- *adapting team procedures*

On-going support for TSTs

TST members value the mutual support given by the regular meetings of, networks of other schools running TSTs. The guidance given in the recent circular on the organisation of special provision provides strong support for the notion of such cross school collaboration.

Given appropriate conditions within the school TSTs can make a significant difference to the quality of teaching and learning. Schools may become more actively engaged as organisations by not treating support as provided mainly by individual co-ordinators / support teachers to individual teachers. Difficulties may be dealt with more collectively and collaboratively. TSTs can also be seen to enable individual teachers to become more actively engaged with SENs in their class teaching through the systematic approach used by TSTs in analysing difficulties, making positive action suggestions and following up referrals. TSTs may make it possible for schools to be more actively engaged with SEN in that better use may be made of staff resources and individual teachers may have opportunities to discover and develop their own teaching knowledge and approaches.

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Support for the Teacher: A Report on an Evaluation

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First I would like to say, that it's a real delight to be here working with you; I hope that what I am going to say will be valuable, but I had also looked forward at this time to learning from you about the way you are developing your own system here in Luxembourg.

Firstly teaching is difficult. It presents people with very complex problems to solve; it presents them within complex problems often very rapidly in complex situations. Lots of people are making demands on usually one adult. The kind of problems that teaching presents to teachers are not easily solved individually .It may be much more powerful to solve problems with other adults. And certainly, in the UK teachers are terribly isolated. If you work as a doctor in the UK and somebody comes in and tells you something about their health and you don't understand it, you are trained to go and ask one of your colleagues straight away about what they think about this situation, how they will think they would act, what ideas they have. If you work as an architect you work in a problem solving team. If you work as an engineer you work in business. In all major professions people solve problems together. The problems teachers face in teaching in the staff-room, those problems enter the micropolitical life of schools, and they impact on the way the many teachers feel they have to present themselves, in their professional life, and that is essentially as someone who can cope on their own with the children, and already is very self sufficient.

So it's in that kind of context that the work I want to talk to you this morning has a reason. A context where many, many, teachers feel quite isolated; they don't feel that they can easily work together and solve problems together. So that's the kind of context. The other part of context which I'll go through very, very briefly is the broadest special needs context in the UK which is becoming a lot more complicated over the last few years, but in essence the argument that is taking place in the last fifteen years is that search for children who fit nicely into categories of special need is a misguided adventure. That we have to think about how a special need arises in terms of many factors contributing to children's difficulties in schools. That identifying children in terms of scales with administratively convenient cut of points, actually can create more problems then it solves. The will to start thinking about children experiencing difficulty of a quite a broad range: we have a politically convenient twenty percent figure. We've been trying to change attitudes and practice, so we stop the endless search for the ultimate cause of the difficulty, well, don't put so much emphasis on it any way. Except that any child any time in any situation will be performing in a way the reflects of a very complex interaction between who they are and where they are and how people are working with them.

And probably as teachers the one thing that we really we can make a difference to is the Curriculum. So the Curriculum becomes the focus of intervention for children who are experiencing difficulties in school. And that has caused us to do a lot more work in the analysis of teaching as a practice and in management to classrooms and in management of schools themselves as institutions, and we've started to talk in terms which have been devaluated a bit but all children having entitlements in terms of the Curriculum ,and of the job of teaching has a lot to do with ensuring the children have access to those Curriculum experiences which they are entitled to. It's a part of the move to think of special education work in human rights terms, and that is been rumbling on in one form or another for a long time. It has involved schools, working-at one time anyway- working together much more closely to think about how the

Curriculum can assume some form of continuity across different sides, so that what goes on in special schools in units and clinics and can have some degrees of compatibility. The children can move, they don't get locked into particular kinds of Curriculum which deny them the possibility of ever moving, and hopefully that schools will work together much more to develop patterns of provision where short and long term Curriculum requirements can become a corporate responsibility that schools can develop common Curriculum policies and that the common communication break down that often typified schooling can be eased. That's what's been going on roughly in the UK.

The introduction of some kind of transactional model of causation and the kind of intervention that has been largely meant to support children with special needs, in main stream and in special schools has been in two broad directions. We've been doing a lot of work with children as individuals and our recently introduced code of practice talks about individual education plans for children ,and we've been doing a lot of work in trying to make schools as institutions better places for all children but particularly for those with special needs through the development of special needs policies which talk about Curriculum, they talk about the general systems which apply in schools.

Now, that sounds great which in work it doesn't. Individual teaching is jolly expensive, unlike Luxembourg the UK is really a rather poor place. Individual teaching costs an awful lots of money . If you start to cost what a child having two or three hours a day, of individual support, comes to across a year you can demolish a special needs budget for even quite a large school with four or five children, you can't do it. There are significant problems in mounting special needs support systems particularly in main stream schools because while on a one hand we said we want to remove the social stigma attached to special education provision that's a nice thing to have it accurate but if somebody like me is operating as a special needs support teacher if I stood up and reveal the full horror of my bulk I don't sly it into classrooms I've noticed people tend to see that I'm there and if I just casually wander up next to some unfortunate twelve years old and sit down and say" how is your work going" ? The rest of the children seem to know what's going on they seem to know why I've come in there and that presents social problems particularly for other lessons. They may not feel always terribly comfortable about somebody shambling into a classroom and trying to be discretely supportive. There are many issues behind the social organisation of support work in schools as well as the financial implications. The other side of the work developing policies when schools take on policy development as parts and parcel of themselves being learning organisations they see themselves as organisations organised around the principle of learning that the children and the adults are there in schools to learn to develop. And school policy development really helps schools to walk (as Susan Rosenholz would say: to move), they develop, they change, they respond, they're flexible.

However, thanks largely to the wonders of technology I could let you have on desks so very nice policies which you can download into Apple Mac or IBM-PC form you could print out as your school policy which would be fine if an inspector said «Where is your policy? We've got one", but aren't really that much use in terms of making a difference to how children and adults feel about working together in a kind of complex support work in main stream schools. An awful lot of policy development has become entirely rhetorical. In the two lines of work, the individual child oriented work in a school policy work does lots of good work that's going on but it's not perfect.

When my colleague Brahm Norwich and I sat down about four or five years ago and have been approached by a local authority in the Northern part of London to give them some ideas about how we could help them develop their response to children in main stream schools particularly children with learning and emotional difficulties maybe particular emotional difficulties. We were looking at these kind of developments and it occurred to us, well, there are children in schools ,schools are institutions, but as there are people in schools, there are adults in schools and we are not offering them that much support. So the work I want to talk to you about is actually supporting teachers.

Supporting teachers to teach children? But nonetheless the work that we've been doing has *been very much about supporting teachers and it recognises that teachers are often faced with really complicated things to do and they can't go to somewhere else to do it. When we're doing the training for the work I am talking about I often present teachers a case of a child who was in a special school, he has now left, who was very much from a working class background, extremely lively child, whom the teachers said to me "I am really stuck, I don't know what to do with this child». But when presented with this would say" My dad said that when I came to this school it was because teachers in my last school picked on me and he said I was never to feel worried about being picked on the mane to do the work it was to hard for me to do again . And you will be making me do work that is too hard for me, you are not being fan . I will get my dad to came and to complain". And this child is really unhappy.*

And the teacher tried everything she knew to teach this child how to move from here to here and she had assertive ways of working. And she was completely stuck and I was coming in from the outside she felt she could talk to me but she found there was no way she could go because she tried everything she knew. The way that this child actually solved this problem and I think it is a lot to do with certainly in English classrooms ,that children may learn something like :"School are strange places that there are some pretty old adults who work in them. They tend to ask you really rather silly questions all over the time, and largely if you can give them an answer and a reason, if you are lucky they'll go away and the one thing you must never ever is tell them how you've got your answer and certainly often a lot of English school children spent a lot of time concealing how they understand the problems that they face.

Just to give an example from the fascinating work by Valery Walkerdme Two little girls sitting down with problems not all like this, with some match sticks and bundles of match sticks in tens, and hundreds, and single match sticks." And they have been told to solve the problems and one little girl said to the other: «what are we supposed to do with all these match sticks "? and the other little girl said:" I will do the songs then you will sort the match sticks out afterwards ,and they were completely messed the whole point, and they didn't' know what the game was. Now is that side of interpretation . This child:" I'll do this slowly," I have eventually, got from this child how he was solving this problem why something which I think will be adequately described in psychological terms as bullying. Let's say three from seven is four, nine from four is three and one, and two and one is thirty-three, thirty from seventy is forty, nine from forty is thirty-one, two and thirty-one is thirty three. That took me a while to get my head brown. My view is an awful lot of children do things like that in school and they spend a lot of time hiding how they have done it from teachers because they are well aware that is not the way their teachers do it but they don't understand the way their teachers and it but the teachers don't understand why they are doing it. Is that kind of problem the teachers are often faced with.

Quite apart from the emotional behaviour and complexities that they are faced with as well put the actual understanding how children make strategic approaches to Curriculum problems which teachers find themselves trying to solve on their own and they don't find many places to go. So in the light of that kind of issue we were interested in finding a way of giving support and assistance to individual teachers through a semiformal group of other teachers in the school who could work with individual colleagues when they request support on a voluntary basis and I have some notes here if anyone wishes to know what the nature of the system actually is. They are provided with support by peers for solving managing or easing teaching problems. This is a school based development, it is a organisation of development which requires some commitment from the school and it does express a whole school combatant to supporting teachers; it is supporting assistance for individual teachers ,it is teacher centred , it complements, it does not replace, it complements other forms of mutual support and many of other teachers we have been working with would say ":Well ,actually I have got a body, I have got a friend who gives me this kind of help I don't need but that is fine, we don't have a problem with that at all". We do feel it is a fairly thorough form of work it is collegial, it is collaborative it involves the sharing of expertise rather than people acting as experts and that is of people who request support about a class or about non-class matters, about individual children or about a group and particularly it is on a voluntary basis, teachers cannot be required in our view to seek assistance.

So in a sort of solving and managing and easing of teaching problems it is work problem focused, most of the problems around special needs matters but they may be of wider concern, they can be of learning or emotional behavioural nature and managing these problems may not always involve referring on to some other authority. It may not even actually involve solving the problem because one of the things that come out of our work is we use terms of tolerance and active engagement and our view is that a lot of the teachers in schools that we have been working with have been pushed beyond their level of tolerance for teaching. They are very stressed, a lot of them, it is as if you were not a terribly good swimmer and you get out of your depth and you panic then you do absolutely anything you can to get back within your depth again you splash around, you make a noise but you do anything.

The other side of that is the notion of actively engaging with problems actually feeling that you are making some progress, you are really involved in it , and our view is that when people have gone beyond their level of tolerance for the job they tend to cease or decrease their level of active engagement which makes the problem worse. They are not doing so much because they are almost retreating from it. Our view is that this kind of support can help people feel more tolerant about the very demanding situations they are working in and can help them to feel more like actively engaging with the problems they are confronted with.

I think it is important to mention as well that this system which is a forum for educated people to share knowledge and skills with each other, it is a resource for supporting teachers for the school, it is a practical embodiment of the whole school commitment and it is an opportunity for real development to take place. It differs significantly from a lot of the consultancy type of work that goes on in schools which are maybe typified by somebody coming to a special needs teacher and saying: «Oh, have you got a second, I really don't know what to do with X or, have you got any work sheets on geography or is there something else I can give this child in maths and it might be a break time when everybody is having a coffee it is a very busy conversation, somebody might shout from the other side of the room, it is your turn to be on duty outside, you have got the head teacher who is asking you to fill in a form and there is something in the corridor over there, try that, but they never follow it up.

One of the important characteristics of the piece of work that we've been doing is that it embodies a sort of follow up procedure whereby when a teacher comes to a teachers support team they actually have the opportunity of setting a time when they come back to that team and discuss the implications of what happened. So how does it work? In the schools that we've been working with, which are largely schools for children in the age range five to eleven, three people form a team in the school. Those three people are usually the persons who know most about special needs in a school, who understand the special needs system most clearly, somebody who if the support team raises matters of managerial significance can effect change within the scene of management team of the school. So somebody who has maybe the rank of deputy head or senior teacher within the school, somebody who has some significant influence within the management of the school and somebody who understands what is like to be an ordinary classroom teacher who lives with the demands and tries and tribulations of the difficult work that classroom teachers have before them, so those three people usually are elected to form a teacher support team.

They make arrangements within the school, so that's teachers can find a private way of saying they wish to come along to talk about the problem which concerns them. They want to talk to the rest of the staff as a whole group about how they are going to manage and organise a teacher support team working in school. We still feel it is very important significantly in the early days of this work that there is complete confidence in the staff that anything that anybody comes along to talk about is confidential.

We have systems of appraisal and systems of monitoring of teachers in which actually some schools find it very difficult to admit they are having problem because it could have an impact on your own professional career, they could actually be used at a time when maybe the school is losing staff and has to identify people who they think ought to be going. Is therefore important in our mind that this work is entirely *confidential to the members of the team and the teacher concerned.*

These three people, the members of the team, will organise a time which everyone knows about during the week, when they will meet in a pleasant place, a pleasant part of the school in which the meeting will not be interrupted by anyone marching through looking for the photocopier or the biscuits or the work sheets or their homework or whatever else it is, so it is a quiet place , a place where people can sit down in comfort, have a cup of coffee or tee and a cake. A relaxed environment where teachers can sit for about half an hour, during which time the problems the teacher is concerned about will be discussed in the nature of the problem refined and defined.

Sometimes prior to this meeting the special needs teachers in school would have talked to the referring teacher and say: «Look, would you like me to come into your classrooms so I can have a closer look at what is going on and we can talk about my view and your view about what's happening so we get extra data which can inform the situation or if it's as it often typically is it's an issue of a group of children behaving badly when they are coming from lunch time into the school when we can watch these children and watch what happens, so that we can talk about this problem with some depths of data, some richness of observation.

So part of the meeting which is managed in a way that it has been thought through very carefully and is thought through in the training that we provide for these teams and the teams adopt their own roles, they have thought through the business of active listening so they are not to talking across people so they are being supportive, they know how to be empathetic and there will be a sort of brain storming session where lots of ideas are buzzed around the group and at the end of the meeting the group will decide that four people in the room will decide on a strategy.

This strategy may actually be saying something like well, we ought to involve the parents in this and maybe we ought to bring an educational psychologist in maybe we ought to think about involving speech therapist maybe involving all sorts of other people and maybe say why don't you try this out and why don't you come back to us in two weeks time and we can talk about how it's gone. So this working body is an evaluation cycle, it's saying we've looked to the issue we've come to understanding what the issue really is as far as we can within the intellectual resources of our own group. We've made a suggestion about what seems to be a sensible and feasible way of working and we've sat a time when we'll come back and we'll talk about the work.

So that's what these teacher support teams are, we've been training teachers using three days of in service training to do this work. At the central of that work is really stimulating the process of taking requests and managing meetings. Does this lovely problems solving model in a lot of the special needs books where you go identify the problem, analyse it, plan the action, evaluate and you have a feeling a little bit of guilt sometimes that if you are not moving in a nice circular way where you go to identify it, now the next thing I've got to do is actually analyse it. Our view is that might be fine in a machine model of problem solving and human beings aren't machines and they tend to sort of move backwards and forwards in various stages of problem solving and we keep that very strongly in our mind that as your working out what's going on you might analyse it a bit and then even if that's wrong I have to go back and rethink it, that's very typical of what's going on in these support teams. I don't want to say it's messy but we hang on to the notion that the analysis and intervention can be at the individual level, can be at the group level or class level maybe at the whole school level and it is significant in the work that we've been doing that many of the actions that have come out of this work have been at the whole school level. The two most powerful examples which we are pleased to notice in independent inspections of the school have been noted by both local authority and national inspectors have been about the improvements that have been brought about in the general management of the school as a result of teaching to the support team activity.

So that's the kind of problems solving cycle that we induct people into, the training is very much with the school. We present teachers with the list like that. We say:" right in this training you've got to sort out a number of things, you've got to sort out who can request support from you, is it just teachers or is it just classrooms assistance, is it parents. What's sort of problems we can try *and solve together, who's going to work on the team, does the team rotate in its membership, how we are going to manage the requests for support, when are the meetings going to take place, who's going to co-ordinate them, how are they to be conducted, how we are actually going to make the recommendations, how they get to be recorded, how are we going to manage to follow our meetings and making use of other people, how do we co-ordinate with other support services, how do we make records of what goes on, how do we publicise this and how do we evaluate it.*

Now, our work in the training is very much saying: «If this is going to work in your school you as an institution have to find your own ways of answering those questions, we don't have a sat formula for doing that, this is a development of your own, we'll offer you advice, we can talk about our experience with other schools but really is going to be something that works in your school, it is going to be something you feel comfortable with and colleagues feel comfortable with that is going to make a difference and actually happen in your school.

What happened was that this local authority gave us some money to develop this work in their schools and is now local authority policy in those schools and all the junior schools in that are doing this that now. It was one of the very interesting things came about this part of the work, the message went to this local authority that Brahm Norwich. and I would come into the local authority to help them do something about emotional behaviour difficulties and I think they thought we were a couple of gorillas that were kept in the basement of the University of London that were let out into local authority schools to tell of naughty children so they wouldn't behave badly.

Actually communicating the nature of this kind of work is really quite difficult, we've had to pay quite a lot of attention to getting the message across that is not somebody coming in telling you how to solve your problems, it is a system which you make your own minds about what's the best thing to try in your school. So we had quite an amusing time when we actually declined the offer of sorting out Erica who was being particularly annoying. Following the work that we did in these north London schools. We were given a government ground to look at, to evaluate the impact of these teams over two year period and the work that goes on in the States does actually suggest that two years is a minimum to really get the feeling of the impact of this kind of work because it is in a sense introducing a bit of a cultural change into the school, that takes time and you really do need to leave things for a while. And fortunately long term evaluation studies are expensive so you only got two years worth of money to do this.

We did it in two rounds using for those of you who are psychologists of single case study design, two rounds of four schools some in North London, some in East London, some in a very rural local authority. We took base line data before we did any work in the schools on factors about the schools as institutions, factors about the teachers within them. We monitored the workings of and the setting up of the teacher support teams in these schools and our search officer monitored our own training, we may regularly support visits to the schools and we evaluated logs of the teacher support team meeting themselves. We followed up their work nine to twelve months after the teams have become fully established and looked at the impact on the schools as institutions on teachers as individuals and particularly the passive usefulness of the intervention on the part of all people involved including parents in the schools.

We have two schools where it didn't work. One school had a very great difficulty in managing any kind of implementation whatsoever . One of the interesting data points we had on this was that it was almost impossible to phone the school, we couldn't get through to the school, one example was an issue that rose about a major conflict between the non teaching in the school and the teaching staff and the head said "Well, we have a policy on this"; and the members of staff said" Do we ?"and the head said "Yes, we wrote that two years ago" ," Are you sure? "the staff said "Yes, I'll go and find it" and the head couldn't find the policy, was a lot of rummaging around in the room, and two weeks later we've got a phone call and she said »Oh, I found the policy"; and that notion of having a policy which is something which is filed away and nobody knew about it ,but it was there would typify the school . That school did not find it possible to organise teacher support team work.

The other school where the intervention failed was one in which the senior member of the team decided that this was therapy for teachers and advertised it within the school as if you were feeling stressed come to a teacher support team meeting and it will help you cease your stress. We have some fascinating interview data from the teachers in that school who fairly firmly pointed out to us that if they wanted therapy they were not going to go for it from their own colleagues. It was significant in our interview with teachers in these schools and in many others with which we subsequently worked. The proportion of teachers who without us trying to illicitate told us that they were in therapy because of the problems they felt they were presented with in school; because of the stresses of their professional life a significant proportion of the teachers that we interviewed spoke to us about the fact that they were actually seeing a councillor or going to some kind of group support meeting for personal support outside of school because of the problems they were having. However when it was advertised as a direct therapy for teachers they said" No, thank you very much, I would very much support them in that, but that is not what this intervention is for». Although having said that teachers do report therapeutic effects of having been. The intervention is not designed to do that is designed to help and solve problems.

The referring teachers, the teachers who used the teams, all felt encouraged to ask support and really very few of the people who didn't use the team did not feel encouraged to. There was very, very low level of disaffection from the idea in the school that we worked in and in the schools we've looked at subsequent to this, The main reason given by teachers who did not refer to the teams was that they've already got support from somebody else or they didn't have any particular problems at that time when the team was running.

The meetings themselves typically lasted thirty to forty five minutes usually during lunch time or after school. In a few of the schools the schools made time available during the afternoon and in the secondary schools they were about to start work in September, it looks as though that's going to happen there.

Typically one case was dealt with per meeting and that was either a new request or a follow up to a previous request and there are about six to seven meetings a term typically in each school. All the schools kept confidential notes of proceedings sometimes these were held by the team, sometimes by the individual teachers themselves.
Most of the referrals were about behaviour problems although these were often linked with learning difficulties not always referrals were about individuals some were about groups and classes. In the early days of working in team support work in the school typically teachers would talk about something that wasn't desperately personal, It would be about something that was sort of outside the class most typically about the movement of children around the school when fights or disruptions were occurring and they were fed up with the consequences coming back into their classrooms afterwards. So, it was only after the schools' confidence seemed to grow that they would talk about things that had very much to do with them in their classrooms.

The sort of support that was provided, teachers reported feeling emotionally supported and encouraged, they came out with specific approaches to managing behaviour and teaching strategies and sometimes they were consulting with others. I think one of the most important aspects of this work is the consistent report , was when asked about the nature of the advice that they were given. Most teachers said: «Yes, it wasn't new, I've heard it before, I've used it before, I've done it before, I just didn't' think of doing it in a situation or I've forgotten about it and in computer language it was almost like this: "This understanding was on long term memory it was on back- up store" and they haven't access to it, they haven't thought about using a strategy which they knew about in this particular situation. And it's part of our view that this work can be seen to be using a massively underused resource in schools and that teachers' own experience and understanding and energising that and bringing it to bear, making best use of it, because all of them said "It's funny but I've really forgotten about that and of course it makes perfect sense to use it and I can go and using it and I can't see why I didn't do that"

So it was that level of reaction it was also the level of reaction which said:" It made a bit of a difference but it has not really solved the problem and certainly our view within existing *resource levels in the UK at the moment it is going to be impossible to solve all the teaching problems that children present teachers with. What we did find, our observation of teacher behaviour, our interview data with teachers themselves, this was that they had significantly switched from being beyond the level of tolerance to be much more likely to be actively engaging with the problem and feeling better about it. There are two very important issues for us; one is the use of an under used resource and that's teachers' history, that kind of collective understanding which wasn't being fully utilised and secondly that it helps them to feel better about the situation to make their life a bit easier.*

There were changes we noted in the Curriculum and behaviour management policies in the in quite a number of schools. In two of the schools children's parliaments came out of them as a result of concerns over bullying and they were major school developments which came into being directly as a result of conversations that took place in teacher support team meetings spilled out into wider school movements and fascinating data from interviews with head teachers who said:" I can get always the work I'm being able to get to, I don't have queues of children being placed outside my door to be reprimanded for dreadful behaviour".

The behaviour management systems in the school seem to be working now, that's the kind of report we have from high teachers. We found that special needs co-ordinators in the schools that we worked with found their role was significantly enhanced, they reported they could work much more effectively, they knew much more about what the problems were in the school, they knew much more about how to deploy their own resources more effectively, they thought that they could target the use of external support much more efficiently and effectively. We also had some sign the policy implementation generally improved in the school.

So the referring teachers felt more confidence, we noted improvements in natural children all but one of the teachers referred to the teams so they would refer again and they reported tremendously strongly they perceive benefits from having a chance to heir problems in a symphathetic setting which enable them to distance themselves from the problems to an extent, to look beyond themselves and to re-examine what they were doing

The teacher support team members themselves gained tremendous benefits, they said they learned a lot about the importance of listening and how they felt in the past they had not listened to people terribly well in schools, they felt they learned themselves a lot about new teaching strategies and they felt they've gained a new amount of confidence themselves. It was undoubtedly a very powerful form of staff development for those team members themselves

The schools as institutions, very interesting, not all the schools told parents what they were doing; in those schools that did tell parents what they were doing the parents were really delighted that this was happening. In schools that involved governors of the schools these governors were very pleased, several of the schools actually built the teacher support team into their publicity for attracting new members of staff because they felt it was a very powerful incentive to offer to new teachers coming to the school, the idea that if they came to the school there was a system in place whereby teachers themselves were being supported and new teachers joining in the schools reported.

We brought members of different teacher support teams from different schools together on one monthly basis ant that in itself was a formal mutual support for those people. It was very important that they learned from others who were trying the same system --- --- to keep going when times felt a bit difficult, how to think of other ways round when they had problems of time, or resistance, or whatever. That was a very important factor. One of the most frequently reported --- in the early days of this work was that the schools, the heads, the teachers reported that they said they just couldn't possibly find the time to do this. « We've got meetings for this, we've got meetings for that, we don't want anymore meetings ». A rather nice headline came out when a report on maths was issued a few years ago that said: « Let's do less better ». I'm a very strong advocate of that, I can't teach children in detail because I've got to teach them all these things and so they learn nothing very much about the awful lot of things that seem to be going on.

At the end of our two years working with these schools, not one of the schools reported time as an issue. They all found the time to do it once they've affiliated to the notion, once they have felt that it was important time did not become a problem. We also feel that for our work there is much more to be done in understanding the relationship between tolerance and active engagement. We feel that a very powerful thing and particularly we feel that the understanding of how to activate prior knowledge on the part of teachers, how to bring the wealth of their understanding an experience to bear at the right time, as a very crucial part of the work. And we think the teacher support teams can do that. I'll just finish with a few things that teachers said to us. This is a classroom teacher: « For goodness sake you've actually seen wonderful with this child. I've got some pats on the back and also some practical suggestions of help which didn't mean extra work for me; just gave me support in dealing with it. » We've got a lot of comments like that: « Give me support in dealing with it ». They felt that somebody understood what was happening and they felt more like carrying on. For us, that's a terrible important one. « I felt that I was allowed to feel frustrated as I was feeling that it was quite understandable ». So it was a sort of expression of frustration, quite chatarsing, that was in there. And now they expressed it, felt more like carrying on doing something else.

I think that the teacher support team is a great idea. It was OK to have the feelings I had and still is. It has been very supportive, it's an opportunity to talk and clarify what's going on. It doesn't make you think « Oh dear, tomorrow is just another day » or that sort of things and you feel all pushed and stressed. But now you know you've got a follow up day and something has been done, some ideas have, and yes, it's good, it does give you some help.

So, those are sorts of statements teachers gave to us two years ago. They fall into the kind of categories that I've talked about because we use a rather complex qualitative data analysis system. It's a consistent finding, we are very clear in our view that they can make a significant impact and I think above all we've come out of this piece of work saying: « It is worth trying to support teachers in their problem solving as well as improving policy development and working with individual children in the school ».

Problèmes actuels de la politique d'intégration des enfants handicapés en France

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Avant d'aborder les problèmes actuels de la politique d'intégration en France, je crois utile de rappeler le cadre législatif et réglementaire, ainsi que les structures existantes spécialisés en intégrations.

I - Le cadre législatif et réglementaire

La France est un pays de droit, très attaché aux textes officiels...

Depuis 1975, le texte de base est la loi d'orientation des "personnes handicapées" du 30 juin 1975 qui prévoit que leur éducation est à la charge de l'état, cette loi intéresse tous les ministres concernés.

Le 10 juillet 1989, la loi sur l'éducation prévoit dans son article 1er que l'éducation nationale favorise l'intégration des enfants handicapés et apporte son concours à la scolarité de ceux qui sont dans des établissements spécialisés relevant d'autres ministères.

Le décret du 22 avril 1988 prévoit les modalités de prise en charge en établissements spécialisés et en intégration des enfants handicapés auditifs (Annexe 24 quater) et handicapés visuels (Annexe 24 quinques).

Le décret du 27 octobre 1989 concerne, les handicapés mentaux et inadaptés (annexe 24) les handicapés moteurs (annexe 24 bis) et les polyhandicapés (annexe 24 ter).

Ainsi au travers de ces cinq annexes de décrets, nous avons la description des modalités de prise en charge de tous les enfants porteurs de handicap - à la fois dans les établissements et en soutien à l'intégration scolaire.

A ces textes s'ajoutent plusieurs circulaires interministérielles éducation nationale et affaires sociales, qui sont plus particulièrement consacrées à l'intégration scolaire : les circulaires des 29 janvier 1982 et 29 janvier 1983.

Lorsqu'elles sont parues au journal officiel, elles ont provoqué un certain remue ménage.

Jusqu'ici la tendance générale était d'orienter systématiquement les enfants vers les établissements spécialisés dont la construction s'était développée durant la période de fort développement économique : instituts médico-pédagogiques, médico-professionnels, d'éducation sensorielle ou d'éducation motrice etc. ...

La parution de ces deux circulaires a donné l'impression aux associations gestionnaires et à leurs personnels qu'ils allaient perdre leur clientèle, que leurs structures étaient obsolètes.

Des réactions diversifiées se sont produites, positives parfois mais aussi des oppositions.

A noter que des associations de personnes handicapés, des familles concernées se sont engagées à fond dans la politique d'intégration scolaire.

Cette intégration s'est mise en place, parfois de façon anarchique, parfois avec pragmatisme.

La difficulté venait de l'obligation de créer des services d'accompagnement pour aider ces enfants, mais leurs normes, leur financement et leur fonctionnement restaient imprécis. La sécurité sociale qui est, en France l'organisme financier restait en retrait, une circulaire n'étant pas en effet un texte réglementaire.

Certaines intégrations non préparées ont abouti dans les années suivantes à des échecs ; des enfants et adolescents ont du être réorientés vers des établissements spécialisés, car ils n'auraient pas bénéficié d'un soutien suffisant ou parce que leur *handicap ne permettait pas à ce moment là leur intégration.*

Il a fallu attendre les deux décrets du 22 avril 1988 et du 17 octobre 1989, présentés plus haut, pour qu'apparaisse une politique cohérente reposant sur une complémentarité établissements spécialisées apportant le soutien directement ou de façon autonome.

La sécurité sociale s'est alors engagée dans le financement des services d'accompagnement à l'intégration scolaire individualisée.

Le 18 septembre 1991 paraissait une circulaire de l'éducation nationale sur l'intégration non pas seulement individuelle mais par groupe de handicap : les classes d'intégration scolaire (CLIS dans notre jargon de sigles !).

Jusqu'alors, dans une classe ordinaire, il pouvait y avoir un enfant handicapé moteur, sensoriel ou autre. La circulaire va prévoir, pour certains, un regroupement au sein de l'école dans des classes spéciales.

Depuis plusieurs années, les travaux du Plan HELIOS l'ont montré dans plusieurs pays européens, ces regroupements étaient pratiqués au nom de l'intégration.

En France, cela restait l'exception bien que depuis 1907, il existait des « classes de perfectionnement » pour enfants en difficulté dans le cadre de l'obligation scolaire.

Le texte évoqué répartit en :

- *CLIS 1 les enfants déficients intellectuels,*
- *CLIS 2 les handicapés moteurs,*
- *CLIS 3 les déficients auditifs,*
- *CLIS 4 les déficients visuels.*

Dans l'ensemble, les classes d'intégration scolaire 2, 3 et 4 ne posaient pas trop de problèmes pour leur mise en place. Par contre une difficulté existe pour les classes d'intégration scolaire 1 qui dans l'enseignement primaire accueillent les enfants avec déficience intellectuelle.

II - Fonctionnement des structures éducation nationale et services d'aide à l'intégration (cf. tableau p. 27)

Jusqu'ici deux systèmes existaient

- *l'un, ordinaire, de l'éducation nationale, avec des intégrations scolaires individuelles,*

- *l'autre, spécialisé des affaires sociales.*

Actuellement un troisième, intermédiaire, sous la responsabilité de l'éducation nationale est mis en place, permettent une intégration scolaire par classes spécialisées.

Les services d'aide à l'intégration scolaire relèvent des affaires sociales et interviennent dans les écoles, collèges et/ou dans les familles.

III - Commentaires rapides sur le tableau

En France, la scolarité obligatoire va de 6 à 16 ans.

- En fait, l'école maternelle reçoit des enfants de 3 à 6 ans, même dans les zones urbaines à partir de 2 ans.

- De 6 à 11 ans, fonctionne l'école primaire. En parallèle dans ces écoles peuvent exister des classes d'intégration scolaire spécifiques mais aussi des enfants handicapés en intégration individuelle.

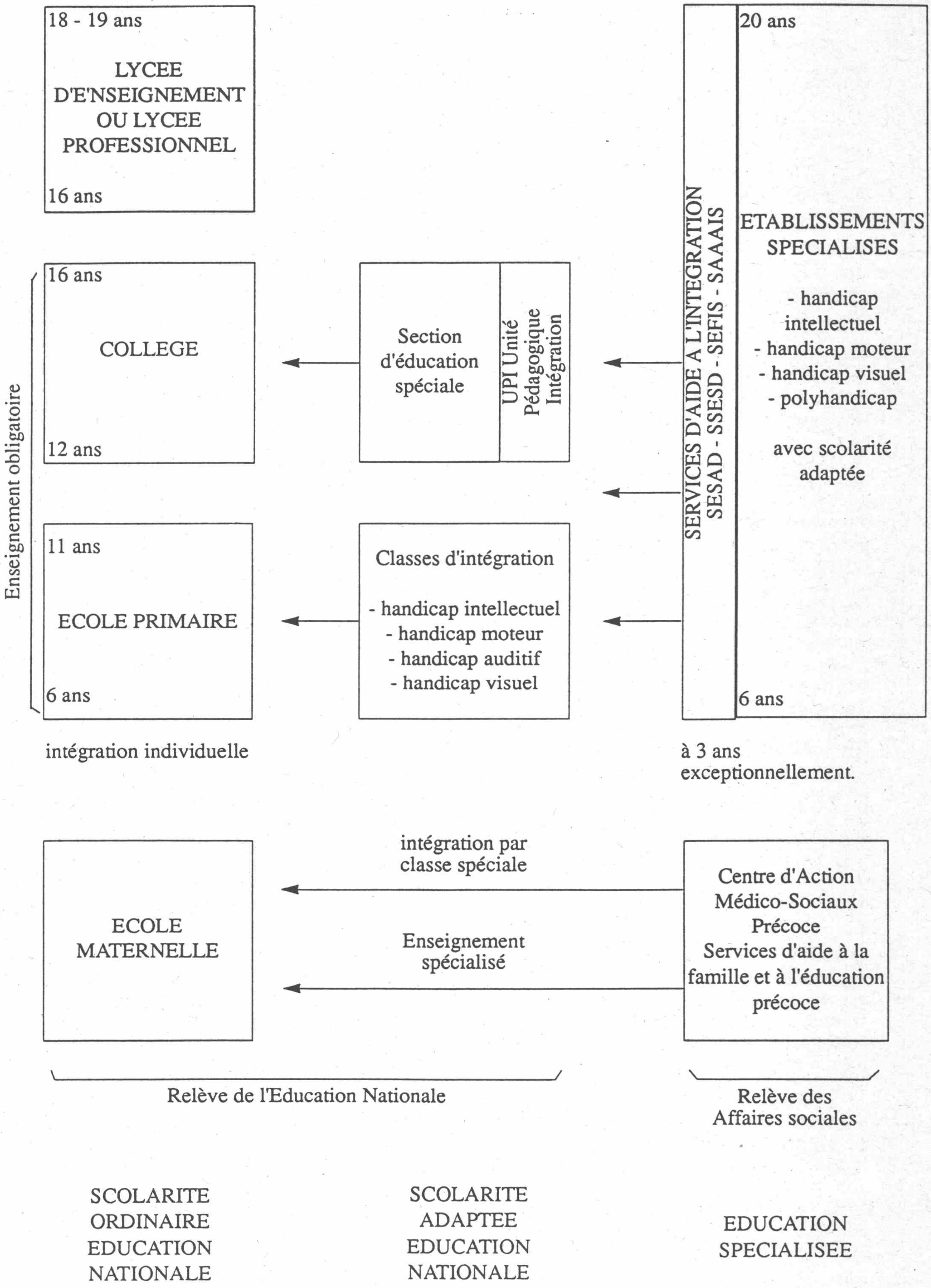
- De 12 à 16 ans, fonctionne le collège où l'intégration individuelle peut se poursuivre, l'intégration en classe se fait dans les sections d'éducation spécialisées (SES appelées aussi section d'enseignement général professionnel adapté SEGPA) ou, dans les unités pédagogiques d'insertion pour les adolescents handicapés individuels.

- A partir de 16 ans, après le collège, fonctionne le lycée d'enseignement ou le lycée professionnel - à ce niveau il n'y a que des intégrations individuelles possibles.

- A l'université qui suit le lycée, il n'y a que des intégrations individuelles.

Rappelons que ce sont les comissions départementales d'éducation spéciale (CDES) qui déterminent, avec les parents, les orientations.

Toute classe doit intégrer des enfants handicapés, dans la mesure où ils peuvent suivre une scolarité ordinaire - c'est aux enseignants, après essai, de prouver que ce n'est pas possible.


18 - 19 ans
LYCEE D'E'NSEIGNEMENT OU LYCEE PROFESSIONNEL
16 ans
16 ans
COLLEGE
12 ans
11 ans
ECOLE PRIMAIRE
6 ans
Enseignement obligatoire
intégration individuelle
Section d'éducation spéciale
UPI Unité Pédagogique Intégration
Classes d'intégration
- handicap intellectuel
- handicap moteur
- handicap auditif
- handicap visuel
SERVICES D'AIDE A L'INTEGRATION
SESAD - SSESD - SEFIS - SAAAIS
20 ans
ETABLISSEMENTS SPECIALISES
- handicap intellectuel
- handicap moteur
- handicap visuel
- polyhandicap
avec scolarité adaptée
6 ans
à 3 ans exceptionnellement.
ECOLE MATERNELLE
intégration par classe spéciale
Enseignement spécialisé
Centre d'Action Médico-Sociaux Précoce
Services d'aide à la famille et à l'éducation précoce
Relève de l'Education Nationale
Relève des Affaires sociales
SCOLARITE ORDINAIRE EDUCATION NATIONALE
SCOLARITE ADAPTEE EDUCATION NATIONALE
EDUCATION SPECIALISEE

Dans la pratique, le CDES a déjà tenu compte des potentialités de l'enfant pour son intégration scolaire éventuelle.

N'oublions pas que dans l'éducation spécialisée (établissements des affaires sociales), l'éducation a ouvert plusieurs milliers de classes spécialisées avec des enseignants ayant reçu un complément de formation.

Dans le tableau joint, des flèches indiquent qu'il est toujours possible de passer d'un établissement spécialisé à une classe d'intégration ou à une section d'éducation spécialisée, de même de ces structures spécialisées de l'éducation nationale aux structures ordinaires : écoles, collèges, lycées, si l'enfant en a les potentialités scolaires et intellectuelles.

IV - Les structures d'accompagnement et de soins à domicile

Elles sont spécialisées par nature de handicap (intellectuel, moteur, auditif, visuel) et relèvent d'annexes d'établissements spécialisés ou de services complètements autonomes sous la tutelle du ministère des affaires sociales e avec un financement par la sécurité sociale. ,

Rappelons que pour les jeunes enfants de moins de 6 ans, en famille ou en école maternelle, les centres d'actions médico-sociale précoce (CAMPS) aident à la rééducation, de même que les services d'accompagnement familial et d'éducation précoce (SAFEP) pour les tous petits aux déficiences auditives ou visuelles et les services d'éducation et de soin à domicile pour les handicapés intellectuels et moteurs.

Entre ces différents services spécialisés pour les tout petit, il y a parfois une concurrence.

Rappelons également que pour les enfants de 6 à 16 ans et au delà il y a les centres médico-psycho-pédagogiques (CMPP) (pour les troubles du comportement et/ou l'échec scolaire), les services d'aide à domicile (SSESD) et pour les déficients auditifs en intégration, les services d'éducation familiale et à l'intégration scolaire (SFFIS) pour les déficients visuels, les services d'aide à l'acquisition de l'autonomie et à l'intégration scolaire (SAAAIS).

Pour les jeunes adultes handicapés à l'université, il y a intervention d'autres services, en particulier pour les problèmes psychologiques les bureaux d'aide psychologique universitaires (BAPU).

Cette organisation a été longue a mettre en place, mais peu à peu les structures se créent, les équipes travaillent, la complémentarité entre le secteur ordinaire, spécialisé de l'éducation nationale et les établissements spécialisés apparaît.

V - Composition des services d'aide à l'intégration scolaire

Ces services peuvent être rattachés a un établissement spécialisé ou être autonomes.

Les personnels de direction peuvent être des médecins, en particuliers pour les centres d'action médico-sociaux précoce (CAMPS) et pour les centres médico-psycho-pédagogiques, mais le plus souvent leurs responsables sont des rééducateurs, éducateurs ou enseignants.

Chaque service comprendra selon le type de handicap pris en charge du personnel à temps partiel ou a temps plein : orthophonistes, kinésithérapeutes, ergothérapeutes, éducateurs, psychologues, assistants sociaux mais aussi souvent, des enseignants spécialisés mis à dispositions par l'éducation nationale pour aider l'intégration scolaire.

VI - Les modalités de l'intervention

En premier lieu pour les enfants handicapés qui doivent être orientés vers l'intégration scolaire, il doit y avoir une décision de la Commission Départementale d'Education Spécialisée, la CDES. Cette commission existe dans chaque département, elle est parfois subdivisée en mini-commissions (des commissions de circonscription ; des écoles) les CCPE ou pour secondaire les CCSD (qui sont des commissions pour l'enseignement du second degré). Il est important de noter que cette décision de la Commission de l'éducation spécialisée entraîne le prise en charge par la sécurité sociale des frais.

Le service d'aide à l'intégration va avoir un financement par la sécurité sociale qui permettra de payer l'ensemble des personnels à statut privé, les enseignants spécialisés étant payés par l'éducation nationale, et puis de prendre en charge les frais de *déplacement, les frais d'organisation, de réunion etc. ...*

Autre point important : la convention avec l'éducation nationale. Les circulaires sur l'intégration scolaire ont obligé ces conventions qui permettent de déterminer qui fait quoi. En effet il y a eu parfois, il y a encore dans un certain nombre d'endroits quelques difficultés pour que l'équipe du service entre et intervienne dans l'école primaire, dans le collège ou dans le lycée, donc il faut que les choses soient réglementées. Qui est le responsable de quoi et de qui ? Il est évident que lorsque l'enfant est dans une classe primaire ou secondaire, il relève de l'école ou du collège, lorsque l'enfant est pris en charge au moment d'une rééducation le service a sa propre assurance, c'est lui qui est responsable de l'enfant.

Lorsqu'il est nécessaire d'avoir des orientations, cela va se faire avec la famille bien sûr, selon l'âge de l'enfant, et également avec l'équipe d'enseignants. Il y aura à ce moment-là une réunion de synthèse qui permettra de réfléchir et de déterminer l'orientation et les prises en charge. Tout ceci est pris en compte à travers un projet, que nous appelons chez nous « Le projet pédagogique éducatif et thérapeutique individuel ».

Tous les établissements spécialisés doivent avoir un projet définissant comment ils fonctionnent, comment ils sont organisés et comment sont assurées les prises en charge.

A l'intérieur de ce projet pédagogique éducatif et thérapeutique d'établissement il y a un projet pour chaque enfant. Il est évident qu'à la sortie d'un établissement spécialisé, le service d'aide à l'intégration, va compléter ou déterminer des objectifs nouveaux à travers un nouveau projet individuel. Il comprend à la fois les séances de rééducation qui ont la priorité et les autres besoins de l'enfant, pour des activités socialisantes par exemple. Dans ce cas, c'est l'éducateur du service qui assumera en partie avec la famille ou totalement la prise en charge.

Il peut y avoir aussi des activités complémentaires faites par l'enseignant spécialisé pour rattraper du retard scolaire.

Ce projet doit être souple, il peut évoluer, et déterminer ce que l'équipe aura comme objectif pour l'enfant.

Les interventions se feront soit dans l'école, soit dans la famille ou dans un lieu annexe.

L'intervention dans l'école ou le collège n'est pas toujours très facile, certains enseignants y voient un empiétement d'une équipe extérieure.

L'enseignant spécialisé du service d'aide peut jouer un rôle efficace pour que tout se passe bien.

Il est parfois nécessaire d'avoir un local adapté, en particulier pour les séances de kinésithérapie.

Mais l'intervention peut se faire aussi dans la famille de l'enfant.

Dans ce cas, il y a des précautions à prendre, car, professionnellement, seuls les assistants sociaux sont préparés à ce travail avec les familles.

Cela, d'autant plus que dans notre pays, il y a une migration importante de familles originaires des pays de l'Asie, d'Afrique noire ou du Maghreb.

Il est donc nécessaire d'informer, de sensibiliser les équipes des services d'aides à l'intégration à l'ensemble de ces problèmes.

Notre organisme ANCE-FORMATION, assure une formation continue sur les aspects culturels, ethniques, pour les aider à bien entrer en contact avec les familles.

Vous devez sans doute connaître, ici au Luxembourg, les mêmes difficultés.

En complément je voudrais quand même attirer votre attention sur quelques notions. La notion d'intervention à domicile ou même au niveau de l'école doit faire l'objet pour ces équipes-là, d'une description et d'une analyse suffisamment fine pour que le professionnel qui s'y aventure trouve, construise une place dans un espace. En effet auprès de la famille il y a l'espace famille-enfant, auprès de l'école il y a l'espace enseigant-enfant et les personnes de l'équipe de l'aide à l'intégration vont devoir entrer dans cet espace : c'est un espace dans lequel se manifestent d'autres *acteurs avec leurs rôles et leurs responsabilités. Cette notion d'espace ouvert est particulièrement importante, il faut aussi veiller à ce qu'on ne reproduise pas à l'intérieur de l'école ou du collège, un établissement spécialisé, c'est pourquoi l'intervention - qui est à la fois indispensable - doit être aussi assez souple, assez limitée à fin de bien montrer que le plus important c'est l'école et non pas l'intervention, les services d'aide à l'intégration. Le service d'aide à l'intégration est là pour aider à la scolarité.*

D'autre part, comme dans tous lieux d'éducation, l'enfant va peu à peu se constituer sa propre personnalité, acquérir son autonomie. Il faut donc veiller à respecter le lieu où se fera l'intervention. La philosophie du travail de ces services, c'est un travail de proximité caractérisé essentiellement par l'individualisation du contact avec les jeunes, mais aussi avec les familles.

A l'entreprise de l'équipe du service, chaque enfant doit avoir un référent, ce dernier sera aussi en relation avec sa famille, et pour cela, il est important d'avoir des gens solides, proches de l'enfant qui leur est confié, mais capable aussi de maintenir des distances pour ne pas affecter ses activités professionnelles.

Dans les établissements spécialisés, c'est beaucoup plus facile pour les personnels car il y a un travail d'équipe, dans un lieu commun, d'où l'importance des réunions institutionnelles.

L'action menée par chaque membre des services d'aide à l'intégration se situe en grande partie auprès des enfants, mais comprend aussi un rôle de conseiller auprès de la famille, de l'enseignant, parfois même auprès du directeur de l'école ou du principal du collège.

Il est nécessaire d'accompagner les familles, d'approfondir le diagnostic, d'aider au développement psycho-moteur, à la préparation des orientations collectives ultérieures, de soutenir l'intégration scolaire avec l'acquisition de l'autonomie, avec des moyens adaptés médicaux, paramédicaux, psycho-sociaux éducatifs, pédagogiques etc.

Selon le type de handicap, l'accent sera mis sur des aspects prioritaires et spécifiques. Ainsi les services pour enfants handicapés moteur, handicapés sensoriels, ont tendance à être très spécialisés, avec des intervenants nombreux, ce qui peut gêner le fonctionnement de l'école.

Le directeur d'école de son côté et le directeur du service doivent avoir le souci de l'unicité de l'enfant, ils en sont les garants dans le cadre du projet pédagogique éducatif et thérapeutique, en respectant la déontologie de chacune des professions.

L'organisation prévue au travers des textes réglementaires peut paraître parfaite, mais, dans la pratique, ce n'est pas aussi simple.

La dynamique mise en place repose beaucoup sur les qualités humaines de tous les intervenants et nécessite par l'enfant des efforts importants, ce que l'on oublie parfois.

VII - Quelques chiffres pour conclure

Dans l'éducation nationale, école, collège, lycée, il y a 80.000 enfants et adolescents handicapés, là dessus, 48 462 sont dans des classes d'intégration scolaire ou en section d'éducation spécialisées de collège.

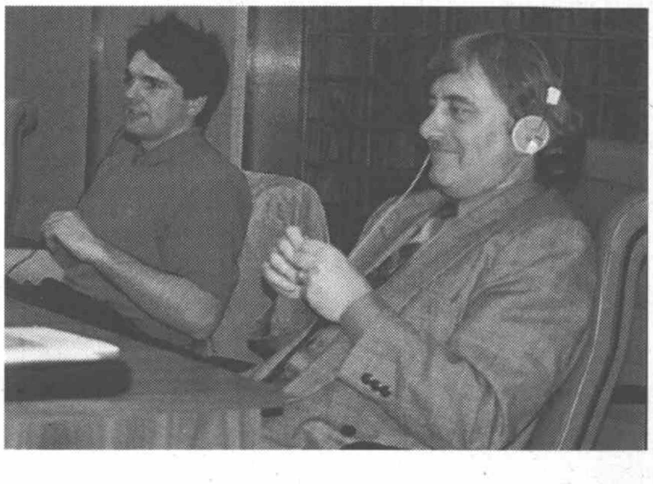
Il y a plus de 100.020 enfants et adolescents handicapés, certains dans les établissements spécialisés.

Pour l'année 1994/1995, il existait 4.579 classes d'intégration, pour 48.62 élèves.

Il y a de plus, 280 classes d'initiation pour 2 479 élèves de l'immigration et 1.318 classes d'adaptation pour enfants en difficulté.

En conclusion, le système d'intégration existe et se développe normalement en complémentarité avec les établissements spécialisés, mais il reste beaucoup à faire.

Je vous remercie de votre attention.



Family Support
The Contribution of Early Intervention Services

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Robert and Louise eagerly anticipated the arrival of their first child, and when Clare was born they were elated. Their joy lasted for only a few short moments. Clare's physical disability was obvious - only one ear, her chin depressed into her neck. The paediatrician advised an emergency tracheotomy.

Numbed with shock, Robert and Louise agreed to the operation. During the operation, Clare lost consciousness for 15 minutes. In spite of this she survived. As feeding was clearly going to be a problem, a nasogastric tube was fitted.

During the next week, Clare began to gain weight. Louise noticed that Clare's tongue was exceptionally small. The paediatrician confirmed this and told her that the implication was that Clare would never feed properly. No one counselled Robert and Louise at all during this week. Doctors engaged them in conversations around medical issues; nurses were kind in their ministrations to Clare, and talked to Robert and Louise, but only on care matters.

When Clare was three weeks old Louise noticed that the baby startled whenever she approached her and that Clare did not visually track her face even when she was very close to her. Louise reported this to the nurses, and tests were carried out. She was told (without her husband present) that Clare had a significant visual impairment. Louise asked where she could get help and advice about her child. The doctors shook their heads; they did not know.

Both extended families visited Robert, Louise and Clare frequently. From an initial poor prognosis, it became evident during Clare's first month of life that she was beginning to thrive. Robert and Louise were desperate to talk to someone about Clare and to discover what they could do constructively to aid her development.

Robert's sister happened to know of someone working in special education. Perhaps he could help. Indeed he could; he had a friend working in a regional service for Multi-Sensorily Impaired (MSI) children. He contacted this friend. Within a day the head of the MSI service had visited Clare and her parents in the hospital. She has kept in regular contact and has taken the parents to visit a Family Centre specialising in the care and support of children and their families with Multi-Sensory Impairments.

After three months in hospital, Clare was finally allowed home for a one-day visit. Prior to this no professional had visited the home; no one accompanied the parents on this occasion. Within two hours of being at home, the portable machine the parents had been given to keep Clare's air passages clear failed to work. The family made an emergency dash back to the hospital.

This story is true. It is the sort of saga one would have expected to hear before Early Intervention programmes became standard practice from the late 1960s onwards. If only it were; this story happened this year in the second largest city in the United Kingdom. To this day, those parents have not been given any counselling to help them to come to terms with the shock, grief and despair they have endured in these last few months. The words of Wyman (1986) ring out from this situation : '...our child is still a child, a child with special needs for whom no miracle cures can be awaited: just herself, just himself, with potential to be explored, love to be given or awakened and a dignity and life to be safeguarded.'

The services this family received, outside the hospital environment, have come via a friend of a friend. This is 1994: have we not progressed beyond this hand-to-mouth existence? In March this year, a conference on Early Intervention in Oxford asked : 'Where are we now? Clare was born in September. Does her case not make you want to cry with shame: 'Where are we now?' At that conference a statement was made that: 'the underlying premise that the very young child with special needs should receive support as early as possible seems to be universally accepted' (Carpenter, 1994). Can that statement now be refuted in the light of Clare's plight? If so, what would enable us to rebuild our Early Intervention services? This paper will endeavour to answer some of those questions.

Where Are We Now?

Following the growth of Early Intervention programmes for very young children with special educational needs and their families in the 1960s and 1970s there came a reflective period during which the efficacy of Early Intervention was questioned (Marfo and Kyseta, 1985). Buckley (1994) challenged some of the narrow interpretation of effectiveness. She sought to encourage a more holistic analysis of the benefits of intervention programmes for the whole family, not just in terms of direct quantifiable learning gains for the child with special educational needs.

In the United Kingdom, it would be difficult to assert that Early Intervention is currently seen as a priority. So many other pressures seem to be reformulating the agenda for all of the major service providers that Early Intervention at times appears to be lost in the morass. Whilst it used to be a key feature of special education, Early Intervention has found itself reshaped, redefined and recontextualised through a variety of social as well as educational factors.

Early Intervention service delivery in the field of education, where it has retained a high profile, has also been subjected to revisions and updates even. Researchers such as Michael Gurainick (1991) have pointed out that services in the past tended to focus upon helping the child to progress, particularly in areas of motor, language and cognitive development, and that perhaps more attention should be given to the quality of relationships being established between the child and family members. Families themselves have begun to assert this (Fitton, 1994; Hebden, 1985). Buckley (1994) has reinforced Gurainick's points and has stressed the danger that the emphasis placed on teaching skills in many Early Intervention programmes could actually have an adverse effect on parent/child relationships unless they are handled with care and sensitivity. The demands of therapy might have a disruptive effect on families, preventing them from having undirected quality time to spend playing with their children and limiting their contact with friends.

We must give attention to the context in which we deliver Early Intervention programmes. Whilst the home may be a suitable setting it is at times isolating. Conversely, the large group situation may prevent us from giving the specific attention that some very young children with special educational needs and their carers require. Although Portage has its critics, it has certainly made a major contribution in formulating thinking about home-based learning programmes, particularly with its focus upon involving the parents' knowledge about their child. Such programmes have often laid the foundations for the much talked of 'partnership with parents'. Similarly other schemes have been reported which work with families in settings outside their home (Carpenter and Carpenter, 1989).

Russell (1994) has drawn our attention to the fact that the successful delivery of home teaching programmes, as a strategy for meeting individual needs in very young children, must acknowledge the interdependence of children's educational, social care and health needs, and the importance of offering services which reflect the children's and families' culture, lifestyle and other family commitments. The various changes in legislation in the United Kingdom have impacted upon how services can provide for very young children with special educational needs and their families. In every sector concerned with the empowerment of these children health, education and social services - the changes in legislation have underlined the need for strong interdisciplinary approaches to meet the diversity of special educational needs that exist in our child population.

We are being faced with children with increasingly complex learning disabilities.

These children challenge special educators to devise new and innovative methods of teaching, as well as demanding of professionals in other services new strategies for sustaining and upholding families. More than ever we need dynamic Early Intervention services that can enable families to work in an active dialogue with professionals towards meeting the needs of their children.

For many years, a variety of professionals have encouraged families in the acceptance of their child with special educational needs, and the fact that some parents have been slow or reluctant to do this has been attributed to a bereavement response in those parents. At times their irrational behaviour has been likened to grief. Whilst one may endorse many of the similarities that there are between grief and parenting a child with special educational needs, the reality is that the sadness of having a child with disabilities is constantly renewed, regardless of the pleasures gained from each hard-grafted development. The reality for the family of a child with special educational needs is that they face recurrent and unpredictable challenges. Not only do they require appropriate Early Intervention, but they require access to ongoing support at points when they need to push the button.

The families of children with special educational needs do not seek sympathy, do not want to be patronised. They do want to be valued and treated as equals. They are not interested in being converted to particular educational ideologies or medical or therapeutic doctrines. They desire recognition of the individuality of their child and the uniqueness of their families. If we are to meet these expectations in families, and deliver services to very young children with special educational needs, then we need to achieve a co-ordinated and coherent approach. What indicators do we know of that would enable us to structure our services in such a way that they can achieve some of the expectations of families and some of the rights of children ?

Early Intervention: Principles for Good Practice

Recently I have undertaken an international comparative study of three Early Intervention programmes in New Zealand, Australia and the United Kingdom. Through observation and analysis of these programmes certain key principles emerged. However, the unifying factor which provided the context for practice in all cases was that, within an interdisciplinary team, there was a recognition of the parent as an implicit and fundamental member of that team. The following features were the markers of good practice within this context.

*1. **Family focused service delivery**. Parents were integral to the whole operation. Not only were they the recipients of services but also were seen as service deliverers themselves. There was a recognition of their unique and invaluable contribution. Siblings were also included in family-based activities. The context for service delivery was balanced between the home, as the environment where parent and child were most comfortable and confident, and community-based settings, such as playgroups or Early Intervention centres.*

*2. **Parents and professionals mutually valued**. This was apparent in the levels of respect and dignity each afforded the other. Whilst the focus of the programme was the child, the context of the programme was the home and other key environments in which the child functioned. The key agents for implementing the programme in a sustained and meaningful fashion were the family. As such, there was a trans-disciplinary approach which endeavoured to achieve a seamless and unbroken circle of support for the child.*

*3. **Shared agenda: shared goals**. An open and frank exchange of information existed between parents and professionals. Sensitivity to needs and skills was evident, with parental choice embodied as a feature of programme development. The quality of interaction between parent and child was seen to be of paramount importance. There was an acceptance that this at times might take priority over specified goals for development. The approach is well summarised in the words of Roy McConkey (1994) who said : 'It's farewell to authoritarian experts prescribing similar treatments to « patients », and a welcome to professionals who meet people as people, striving to share their community and valuing the worth and dignity of each as they seek to overcome the adversities of life.'*

*4. **Collaborative working**. Programme implementation was a joint venture which recognised the capabilities and limitations of all concerned. Jargon-free communication and flexibility of programme delivery were positive features of the parent-professional* *relationship. Programmes were enskilling for all concerned - child, parent and professional - acknowledging that we can all learn so much from each other. We never know it all.*

*5. **Effective evaluation**. Whilst the programme review meeting had its place, evaluation in these programmes was an ongoing feature. Adjustment to programme goals, contexts and resources were made where the shared feeling was that this was in the child's best interests. Implementation was a shared responsibility and no longer the onerous task of parents who had been dumped with a programme so intensive that it was disorientating to the life of the family. In these programmes there was no place for the precious professional domain; only for skilful, resourceful contributions that would benefit the child and empower the family.*

Clearly, in these principles, the quality of partnership between parents and professionals is explicit. In reviewing research in the field of Early Intervention McConkey (1994) stated that whilst there was at present a greater emphasis on families and their role in Early Intervention, the implications of this new emphasis might not have been worked through adequately in professional practice. He challenged researchers and practitioners to develop, and adapt Early Intervention strategies for use in family homes as well as in clinics and schools, and criticised the continued dominance of research literature by laboratory-style investigation. He also mentioned the need for the focus of professional training to shift from the treatment of individuals to working with families in the provision of teaching and therapy.

Pugh (1994) summarised the aspirations of many authors in expressing the need for a 'developmentally appropriate' curriculum which would provide a quality curriculum for very young children. She further emphasised that 'quality is a dynamic rather than a static concept' (p. 111).

In countries such as New Zealand, Early Intervention training is offered to teachers on a one-year secondment basis. In the UK there is no such equivalent available, again reflecting the low status of pre-school Early Intervention-type services. What is very much needed is a trans-disciplinary training. Apart from specific training in our respective individual disciplines when do we ever have the opportunity to study interactively with colleagues from other professions on a long-term accredited basis ? (Westminster College, Oxford, is currently in the process of developing a research-based programme of training in Early Intervention which will be open to professionals from all disciplines.)

McConachie (1994) in reviewing the implications of stress for families with young disabled children also criticised current professional practice, and argued that the organisational model might owe more to habit than to clear rationale based on the varying needs of the population it serves. The well-supported family might be better equipped to dissipate the stress which has traditionally been associated with the care of a child with a disability (McConachie, 1994; Wilton and Renaut, 1986). In order to achieve this, however, those professions working in Early Intervention must reconcile their differences and find a truly trans-disciplinary model for service delivery where they, with parents, are sincere co-partners.

Fathers - the Peripheral Parent?

McConkey has identified fathers of children with disabilities as so-called 'hard-to reach parents'. Their role as key members in any family needs to be elaborated if we are to appreciate and develop their contribution.

A recent study by Herbert and Carpenter (1994) has focused upon fathers and their role in Early Intervention. Their study explored the recollections of seven fathers at the time of the birth of their children with Down's Syndrome. It discussed the disclosures of diagnosis and subsequent contacts the fathers made both professionally and socially during the period following, both in the hospital and at home. Myer (1986) suggest that amid the explosion of research into the role of the father in society as a whole and the family in particular, the fathers of children with special needs were relatively ignored. The literature on the subject is sparse (Hornby, 1991; Roddgue et al., 1992). From a review of 24 studies in America, it was found such fathers were rarely consulted and that discussion papers 'allot a page or so to fathers as an aside' (McConachie, 1986, p. 43).

The study reported by Herbert and Carpenter (1994) looks at factors such as how the news is broken, parental responses, the content of information and the way in which it is given, *professional perceptions of fathers, professional prediction, information-seeking and sources of support. This research aimed to not only analyse the issues identified by the seven fathers, but to retain the emotion of the stories they were telling. Often research, in adopting an analytical stance, divorces itself from emotion. Situations such as the disclosure of a baby's disability is an emotion-ridden experience, and as such we should give credence to the emotions people express and use these to illuminate the situation and improve our knowledge. For example, in this research, professionals had given gloomy forecasts of the effects the child with a disability would have on family life. One general practitioner warned that 'the mother may become mentally unstable and may attempt suicide or harm the baby': another warned that a marriage might fail. The words of one father illustrated his actual feelings when given such news:*

'This must all be a dream - this thought runs through my mind again and again. This cannot happen to us! In this turmoil, I was conscious of the supportive attitude of the hospital staff, that every effort they made was an endeavour to uphold us, to help us to endure the pain and distress that fell upon us as the reality of our baby's disability dawned upon us.' (Herbert and Carpenter, 1994, p. 50)

The fathers in this study described situations such as 'the calm after the storm' when, once the family had returned home from the hospital, the fathers received no specific help from the professionals. All help was focused on the mother and the baby. The fathers' needs were not addressed or, perhaps, even noticed. They were seen as the 'supporters' and as such adopted the role society expects - that of being competent in a crisis (Tolston, 1977). All seven fathers talked of returning to work and trying to search for normality and keep a sense of reality in their lives. One father explicitly said:
'I returned to work, but in a fog. The feelings of disorientation were enormous and even simple tasks took considerable effort to complete. This only served to disempower me even further.' (Herbert and Carpenter, 1994, p. 53)

In this study, the extended families were found to be a major source of support to the fathers. It could be conjectured that the existing familiarity at the emotional level with other family members generated a climate of openness in which fathers could reveal their true feelings. In some societies they have a concept of what, in Maori culture, is known as 'whănau'. A whănau is a Maori social structure incorporating all age ranges, interests and experience. it is a form of extended family (see further Ballard, K., 1994). Current social trends cry out for the emphasis to be not only on the family but also on the extended family; surely a message we should carry forward from this International Year of the Family.

In a further debate about the role of fathers in Early Intervention, Carpenter and Herbert (1994) challenged the traditional model of professional support. Fathers became particularly distressed that once they had returned to work many appointments were made with professionals for their wives and children during the time when they were at work. Having to constantly receive anxiety-raising information through their wives was not always a positive factor in the relationship, and caused some fathers to feel that they were, inevitably, the secondary partner.

Innovations considered essential for good practice arising from this study were :

*1. **Training**. Training should be available to ensure that the professional support workers (of whatever discipline):*

- *has appropriate listening skills*
- *has up-to-date information about the dynamics of the family*
- *uses a vocabulary which conveys a positive image about the child whilst being realistic about the true nature of the disability.*

*2. **Co-ordination of services**. It is important the information is not held in pockets. Amongst the professionals there should be:*
- *clearly established procedures for information exchange in order that the family feel supported and do not perceive each service to be working in isolation*
- *clear acknowledgement of the key worker/lead professional who may be tackling the more sensitive issues.*

*3. **Accessibility**. Parents need to be able to access both information and personnel easily. They may need help with questions such as : 'Where do I go?' and 'What are the key sources of information I need and want?'*

Booklets giving clear explanation of roles and telephone numbers would help with this.

4. ***Networking.***

- *Professionals need a detailed knowledge of the support network within their area in order that they can make it available to parents who should not be expected to undertake the search alone.*
- *Sensitive networking of families is crucial. They have a tremendous capacity for self-support.*

5. ***The issue of consumer needs.*** *Services should be tailored to meet individual consumer needs, not pre-packaged. This would entail flexibility and adaptability by all professional support workers.*

6. ***The needs within the family.*** *Professional support workers should look at the needs of every individual within each family and should not neglect or forget those who may be absent during the day.*

Fathers, like Early Intervention itself, can find themselves marginalised, on the periphery of activity, secondary to the key carer who inevitably seems to be the mother.

Conclusion

Can Early Intervention 'Come in from the margins'? Can it re-emerge as a key strategy for supporting families, empowering parents and meeting the highly specific development needs of infants with disabilities?

A reconceptualisation of Early Intervention is needed if it is to gain credibility with families. Already there are reports of parents rejecting the reliance the Early Intervention programmes of the 1970s placed on professionals (Brown, 1994) and stressing the need for normality (Wills, 1994). Philip Ferguson (a parent) and Addenne Asch (who is disabled) say that:

'The most important thing that happens when a child is born with disabilities is that a child is born. The most important thing that happens when a couple become parents of a child with disabilities is that the couple become parents' (Wills, 1994, p. 248)

The days of professionals as experts have gone ; what are needed now are informed supporters. McConkey (1994) rightly points out that in the previous three decades many Early Intervention programmes 'floundered in simplistic notions about intervention and a failure to appreciate the difficulty of changing human behaviour patterns' (p. 7). Where these programmes were successful was in the positive approaches they engendered in parents. They gave a basis for meaningful transaction between (often) mother and child.

We must move our focus of support from the dyad of mother and baby alone to the triad - mother, father and baby (Herbert and Carpenter, 1994). This is a message to carry forward, but also on which to elaborate. Indeed, mindful of the need to regenerate the extended family ought we to be giving time to other members of this family structure, grandparents in particular? Peter Mittler (1994) has pointed out that since grandparents now live a much longer active life, and since transport and telephone can bring families together across longer distances, then perhaps we should take their potential contribution into account in professional assessments of family resources and influences.

To achieve closer collaboration with parents, professionals must acknowledge the uniqueness of each family. We may be asking professionals to operate in new ways, and as such we have to recognise that there is a training need. Previously many packages attempted to train parents as teachers or therapists (often with limited success) (Basil, 1994; McConachie, 1986). Has the time now come for parents to offer training to professionals ? If we genuinely have an equal partnership, each valuing the contribution of the other, then there are messages to share about our philosophy and practice. Such information is not necessarily for the conference hall or even seminar room. Rather it is an ongoing training process, encapsulated in the dialogue of support and interaction between parent and professional.

Early Intervention is coming in from the margins. It is reasserting its role as the first means of support to families of children with disabilities, and it will prove its efficacy based on their evaluation, not on qualitative clinical research data. Through holistic approaches to family support differentiated intervention strategies will emerge that enable the child with a disability to be seen as a contributing family member; there will be an expectation of *success for the child and celebration of its achievements.*

Such approaches will ensure that no family member is marginalised (i.e. Fathers) and that they have a right to direct involvement in the parent-professional dialogue (Carpenter, 1995). This will challenge some professionals and demand a radical reappraisal of the structure of their role and their style of delivery, but, if we want quality Early Intervention, such a review is fundamental to re-establishing the place of Early Intervention as a valid and valuable resource to families.

Early Intervention is not an optional activity; it is a crucial contribution. The facilitating foundations of Early Intervention can ensure quality of life for the child with a disability and its family. Do you wonder as I do what opportunities have already been missed for Clare? What irrevocable damage has been wreaked on her family? For the sake of present and future generations, we must ensure that families are in focus.

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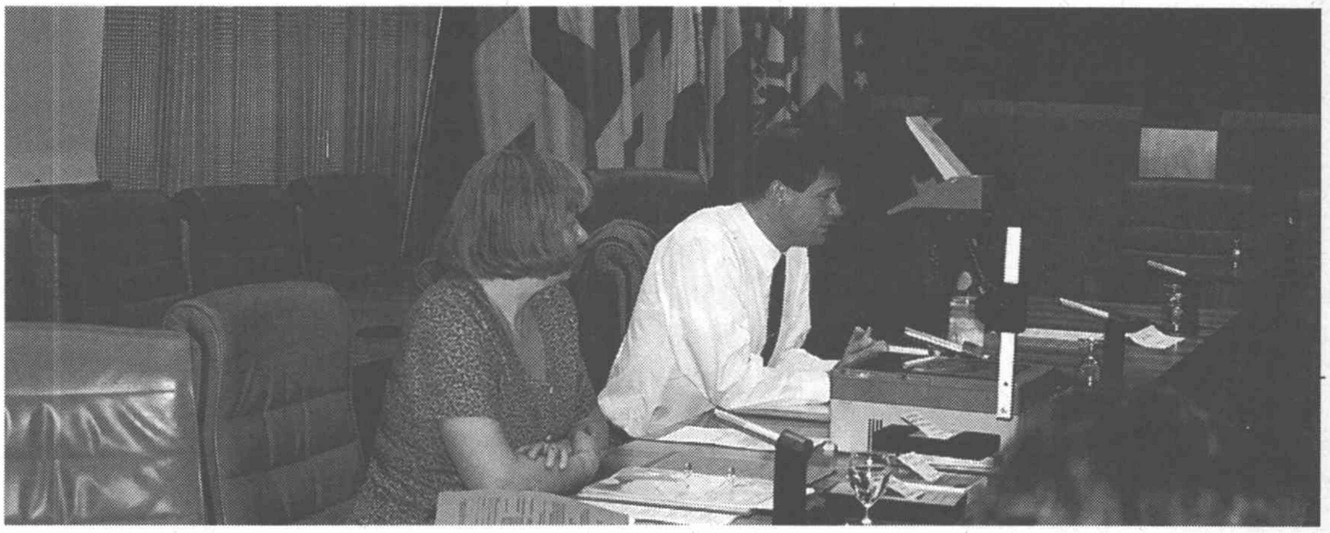

Smelling, Tasting, Looking, Moving, Touching and Feeling, Listening: Families and Professionals Sensing Together

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In the beginning...

Before we are born, our main senses are alert and beginning to respond to the enclosed world around. Our biggest sensory organ, the skin, is continuously massaged and caressed within the womb. As we develop physically, we are subjected to a range of bodily movement sensations including our own involuntary movements, rotation and our mother's movements. About three months before birth, ears begin to listen and react to sounds made both inside and outside the womb. Taste buds and five million smell receptors are awakening to prepare for the smell and taste of nourishment outside the womb.

At birth, we are ready to show a preference for smells and a liking for particular tastes banana smells and milky tastes. As we are born, we tumble into a blinding world of visual confusion, although within eight weeks we are already differentiating between shapes, forms and colour with a preference for red and then blue. Soon we learn how to put two or three senses together for better effect - we snuggle into secure, warm arms, turning our heads to an interesting voice nearby and staring into a friendly face. We relate and bond to another human using a sensory platform which holds the five main senses taste, smell, sound, vision and touch - but also holds as many as 15 additional senses, such as weight, body position, balance, fatigue, etc.

However, when a baby with any sort of special need is born, their senses may be incomplete. They may have a physical disability, sensory impairment, intellectual delay or a combination of all three. They may just have a temporary special need because of premature birth, through to a baby with permanent profound and multiple learning difficulties. Carpenter states (1994) that forty percent of all 1 to 2 lb. (450-900 g) babies are now surviving, with half requiring special education and one in five having profound multiple learning difficulties. Some of these babies with special needs may have, for example, a visual or hearing impairment shutting down on particularly areas of sensory learning.

A baby with a severe intellectual delay may not be able to use their senses to explore the world around them because they have not 'learned' to use their primary senses. It is difficult to be motivated to reach, grasp, and explore a bright, noisy rattle if you have no sense of the satisfaction of using the skills of looking, listening and consciously moving. Fraiberg (1975) conducted many studies on mothers with blind babies and made it clear that inhibition in cuddling (i.e. bodily sense), touching (i.e. tactile sense) and talking (i.e. sound sense) to babies has a significant negative effect on the normal bonding process between parents and their baby.

First steps...

Members and friends of any family, with a new baby in the midst, instinctively approach them in sensory ways. They, with varying shades of enthusiasm, or expertise, approach babies and:

- *cuddle, rock, hold them close*
- *pat and stroke, bounce, bring their face close to the baby's face*
- *move faces in exaggerated motions*
- *emphasise lips in sounds and repeat sounds back*
- *wave a bottle under a nose to smell*
- *make funny noises, blow raspberries*
- *stroke lips to encourage feeding*
- *provide peek-a-boos and stimulating toys, play silly games and, in short,*
- *provide a rich sensory background in which to grow and progress.*

Indeed, Lewis & Coates (1980) give evidence that babies who experience such a responsive environment make faster social and cognitive progress.

However, families and friends with a baby with special needs may also use these intuitive sensory strategies but are met with an apparent blank wall of response. They[may think twice about interacting after these rebuffs. Jones (1994) states that « sensory deprivation is common amongst sensory impaired children firstly because of reduced handling and because of the difficulty some parents have in intervening physically and relating emotionally with their child ».

This reduction in interaction may also happen with the many - or few, as the case may be ~ professionals surrounding the family - eager to help and perhaps be the 'expert' in a particular area. They may feel that their 'expert' help is being rejected at source - the unresponsive baby. As Featherstone (1980) says: « It often looks to parents as though outsiders hold the child's future in their hands. For their part, professionals often feel less powerful than they appear to clients ».

Even the educationalist, with specialist training in teaching strategies and an understanding of early sensory and learning processes, may respond to a child with profound multiple learning difficulties in a different way than normal. Ware (1994) describes a number of studies on staff-pupil interactions, including one which found most classroom interactions were extremely brief (less than a minute each), time between interactions averaged 12 to 13 minutes and pupils with more severe disability were less likely to receive initiations that expected a response.

An instance confirming reduced intervention was seen in my own family, five years ago. Alexander, a surviving triplet, was born weighing 1 lb. 10 oz. (700 g) and spent the first months of her life in an incubator. Her physical and medical needs were very well met but there was little interaction with the nursing staff as she was 'a good baby'. Her dad felt that even if she was a good baby, she needed something more in life than a humming, white incubator. Every day that he visited, he gathered her from the incubator (tubes and wires and all) and balanced her on his hand. He massaged her with his little finger as he sang nursery rhymes to her, blew raspberries on her feet and finished with 'peek-a-boo' using a little handkerchief. It was a much *needed sensory input for both of them to interact and to awaken Alexander's senses.*

Sensing together

Taking the above circumstances, how can families, friends and professionals intervene together and help the baby with special needs with early learning and positive interactions? How can they find a common baseline without feeling threatened or being put in a pass/fail situation? How can they overcome the initial barrier, seen as an unresponsive baby who does not appear to want to interact or form any sort of relationship?

The simplest way is for everyone to start on the first level of learning - using their senses alongside the baby. This means that everyone thinks and works with the baby using the senses as tools of stimulation and learning. Everyone needs to be aware of what the senses are - touch, smell, taste, vision, sound and bodily movement. They need to know of their importance in developing learning and how they can nudge other senses into useful interactions. For example,

- *if I give an unusual smell to try, then the baby might crinkle a nose and move their head away on purpose,*
- *if I shine a bright torch near the baby's face, they might focus on it and track the beam as it moves slowly by,*
- *if I massage toes, the baby may feel they have toes and wriggle them.*

There also needs to be a realisation that it is perfectly acceptable for ***all*** *babies to receive a lot of extra sensory stimulation. All that is happening is that the normal intuitive sensory approaches to babies are heightened, intensified and repeated many times On one level, some babies will receive it as an added bonus to their normal pattern of development. On another level, babies with severe impairment will begin to receive an early intervention that may break through their barriers of disability at a crucial early stage. It will ensure an increase in handling and more opportunity to relate to others. It will also provide a realistic baseline for everyone as they grow older - each sensory step can be carefully linked to the framework of learning. It is not a baseline of remote, unachievable goals set by a checklist or unthinking adult. The important sensory input will provide opportunities for the special baby to begin to respond, initiate some reciprocal response and ultimately take the ownership of leading their own sensory learning.*

Sensing - the multi-disciplinary team...

A multi-sensory or multi-professional team covers all those involved with the family health, social services, voluntary agencies and pre-school educators. The concept of a multi-disciplinary approach can be enhanced through a common training for all in the significance and use of the senses in early intervention work. ***Sensory networking*** *could establish common sensory approaches in all the disciplines. As Lambe (1994) says « schools and paediatric services have for some acknowledged [that] the effectiveness of their own work with a child will be diminished if they do not support and empower the child's parents ».*

One step further is to include social services and voluntary organisations in this 'enablement' and empower not only parents, but the whole family through sensory intervention with the special baby.

The way forward...

There are two significant ways in which this sensory approach to early intervention can be developed. These are through sensory training programmes and use of a sensory kit by the family.

Sensory training *for professionals should be offered in initial training for anyone who will be working with children - regardless of the age or disability range they will be working with in their profession. Ideally, the training should be with all the professions . together. For example, it is important for*

- *the nurse in a baby unit to take time to massage a baby or place different textures and fluorescent colours within the incubator,*
- *the social worker, when visiting, to have a box of attractive sensory materials so that they can interact with the child and the family in a non-threatening way,*
- *the physiotherapist to 'brush' body parts with a paint brush or play lively 'boom boom' music to make movement more fun,*
- *the parent to play with torch beams at night time and enjoy a music and movement*

mobile together with the child, as suggested by the orthoptist,

- *the paediatrician to dangle a fuzzy koosh ball on the end of his stethoscope and explain the importance of sensory stimulation and learning to parents,*
- *the health visitor to introduce sensory ideas into routines, changing the colour of bath water, putting a nice smell on the warm towel to enfold the baby,*
- *the voluntary worker bringing help with benefits could also bring information about attractive sensory environments in the neighbourhood, the local school 'lite' room, the herb garden at the garden centre, etc.*

This initial training should be updated and revised through in-service training. Sensory workshops not only educate the professional in the senses; they provide a practical and simple method of intervention that is enjoyable and non-threatening to anyone involved.

The second way forward with sensory intervention is the most crucial as it involves the most important and essential part of the special baby's life - their family. This includes extended family members and friends - usually at a loss on how to help but nevertheless wanting to help in a practical way. This need to help could be acknowledged and supported with a ***sensory kit.***

A sensory kit could contain a range of sensory materials, simple information on stimulating the senses and how to do this within the normal family routine. It could form part of the hospital or surgery 'welcome baby' pack. Families do not need checklists, training sessions, etc. at a time when emotions are overflowing, time schedules are disrupted and life is on hold. The kit would enable families to have simple sensory interactions in daily routines despite the enormous complex issues in their thoughts such as - the future, how can I cope?

While there is no easy answer to the future, there may be some sense of achievement in stimulating their baby to respond. Sensory kits for patients who are in a coma are in use in some hospitals. They try to stimulate the patient ***back*** *to consciousness. A sensory baby kit could stimulate them* ***on*** *to consciousness of the world around them.*

In conclusion ...

As the special baby grows older, they will receive more formal sensory training and education as they enter pre-school or school provision. It is nevertheless important that work with the senses continues in settings other than school. The link to the next steps of beaming will he made at this stage and again the crucial role of the family and its rich contribution should be clearly acknowledged. The prerequisites to beaming needed for progression in beaming are:

- *beginning to look and attend,*
- *beginning to communicate,*
- *beginning to relate,*
- *beginning to play,*
- *beginning to co-ordinate the body, and*
- *overcoming behavioural barriers*

These all need a sound sensory base and familiarity with the senses for everyone to succeed - ***families and professionals sensing together.***

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Fathers: The Secondary Partners

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Abstract

The following is an account of a research project exploring the recollections of seven fathers at the time of the birth of their children with Down's syndrome. It discusses the disclosure of diagnosis and subsequent contacts the fathers made both professionally and socially during the period following, both in the hospital and at home.

This is combined with the personal recollections of one father, not part of the original study, whose child was born with special needs. The implications for both professional practice and fathers are highlighted.

Whilst there is an acknowledgement that the project was small scale, the conclusions will raise challenging issues for further discussion both among professionals and individual members of families.

Introduction

In 1990 a small-scale investigation was carried out into the reactions of nine families to the fact that their new-born babies had been born with Down's syndrome and into their feelings and reactions in the weeks immediately following the births. Down's syndrome is a genetic condition which can be diagnosed within the first few days of life, therefore, it is usual that the disclosure of diagnosis is made before the mother and baby leave the maternity hospital.

The children and their families were known to the researcher through her work as a member of a team of teachers devising programmes for pre-school children with possible special educational needs. This work takes place in the home setting and aims to enhance the skills of both parents and children.

The nine children in this study were born in 1986-87 and were the only children with Down's syndrome born and nurtured by their natural parents within the Local District Health Authority during the period. (Since all the children with possible special needs are referred to the Pre-School Service, all children with Down's syndrome born in the area are therefore known to that Service.) The paediatrician at the local maternity hospital stated that during the last five years, seven children with Down's syndrome have been rejected at birth by their parents. However, this was not the case with the cohort that formed this research sample.

The size of the research sample was determined by two criteria. Firstly, the demographic focus of the group and the need for the results of the research to be relevant to the development of the researcher's service.

Secondly, the size of the group had to be manageable within the working caseload of the researcher. As such, this was a practitioner-led research enquiry, carried out in the spirit engendered by Lawrence Stenhouse who argued that practitioner research was vital but also that small-scale studies contribute to an accumulated body of knowledge (Stenhouse 1975).

it was decided to carry out the study using face-to-face interviews, and arrangements were made during the course of the researcher's routine home visits to speak to the parents of these nine children. An assumption had been made by the researcher that both partners would be present but, in the event, only the mothers took part although in some cases the fathers were in the house. The interviews lasted for up to three hours.

Despite the growing research into the optimum method of disclosure (Cunningham 1984, Cunningham and Davis 1985, Byrne et al 1988, Hornby 1991, Jupp 1992) and the availability of support services (Lacey and Lomas 1993) the project concluded that there was little co-ordination between professionals *working with families. The mothers felt isolated and that their needs were rarely met within the community, and that their reactions to the births had been different from their partners. Because the project had involved only interviews with the mothers, it reflected their feelings and their perceptions of the fathers' responses.*

An increasing awareness developed of how little was known of the reactions of the fathers in these circumstances particularly in the very early days following the birth.

It was found that when research was conducted (Blacher 1984), the findings were based on clinical observations of small samples and interviews with the mothers. Meyer (1 986) suggests that amid the explosion of research into the role of the father in society as a whole and the family in particular, the fathers of children with special needs have been relatively ignored. An assumption was made that what was good for the mother was good for the father (Meyer 1986). McConachie (1986), is aware that the roles of separate members of the family are liable to be obscured unless each is interviewed separately and few researchers have interviewed the fathers of children with special needs on their own. Collins (cited Meyer 1986) suggests that a major reason for this is that fathers are inaccessible during the day and in order to observe fathers, researchers would have to work unsocial hours during the evening and at weekends.

Literature on the subject is sparse (McConachie 1986, Hornby 1991, Rodrigue, Morgan and Geffken 1992). From a review of 24 studies in America, it was found such fathers were rarely consulted and discussion papers 'allot a page or so to fathers as an aside' (McConachie 1986, page 43). One can understand why fathers must feel second-class parents (Lewis 1986).

Consequently in 1991, the researcher set out to redress the balance a little and to investigate the feelings of the fathers of these same children at the time of their birth.

Early considerations

A major consideration when planning the enquiry was the restricted size and constitution of the study group. Of the nine families originally contacted, it was only possible to interview seven fathers. (One family had left the area and in another, only the mother remained.) Having acknowledged that the sample was small and located within a unitary authority, it was still felt that the interviews would provide information directly from the actual evidence source of this research, i. e. the fathers, and that first-hand responses would provide the possibility to formulate hypotheses based on their personal reflections and recollections.

Before embarking on this in-depth study, careful thought was given to the method of approaching the fathers and indeed, whether the approach would intrude into areas of their lives which were wholly private. This concern arose because during the interviews with the mothers, some became very distressed when discussing the events of the early weeks and it was felt that fathers may exhibit similar feelings and become embarrassed. Secondly, many of the mothers commented on the father's inability to discuss the child with them. One mother stated, "'He was very upset, and he's never said much since. "

*Several approaches to making the initial contact were considered, e. g. telephone calls, visits, informal notes, but it was decided to approach the fathers formally **by** letter - the wording of which would emphasise the academic aspect of the study and the lack of information on the subject. It was hoped that as the researcher was known to the families, she would not be perceived as 'a prying individual interested in research for its own sake' (A father 1991). The letter included a tear-off slip which the fathers were asked to return only if they were prepared to talk. Despite the initial fears, all seven were returned but in five cases the fathers stressed that they would speak to the researcher only because they knew her.*

As the fathers were not accessible during the day, the interviews were arranged for the evening (at around 8. 00 p. m.). The interviews took place in the home and the responses were recorded in note form as it was felt that the presence of a tape recorder could have been intrusive. Both the length of the interviews (between two and three hours) and the apparent ease with which the fathers spoke, surprised and moved the researcher. This could be attributed to the fact that at last they felt that someone was listening to them (Cunningham and Davis 1985).

Whilst it must be remembered that balk of past emotions is distorted through selective perceptions and selective memories' (Murgatroyd 1985, page 87), their recollections of the events surrounding the birth seemed particularly clear and mirrored almost exactly those of the mothers.

When the research report regarding fathers was read by the father of a disabled child (not concerned with that study), he found parts of it deeply motivating. Key findings in the study not only reinforced his own experiences and feelings, but enabled him to reflect and refine his personal experience.

it was decided to combine with the researcher to compile this joint paper, which would explore a professional's perceptions and a father's reflections of the issues surrounding a father's role in the early stages of parenting a child with a disability. For however thorough researchers are investigating topics such as these, they can never articulate the depth of emotion and the life shattering experience as it truly is for the parents of the disabled child. The authors thus aspired to give an holistic overview of the experience from the professional and parent vantage points.

It is only through an analysis such as this that we can hope to assess the implications for the parent/professional partnership and reappraise how working practices can be redesigned to actively include fathers.

Breaking the news

The diagnosis will be the most disturbing crisis the parents will face during the child's life (Wikler 1984), and in all seven cases it was the hospital paediatrician who gave the news. Although there can be no optimum time to do this there must be an optimum method (Erikson cited in McConachie 1986, Hannam 1988). Cunningham and colleagues (1984), at the Hester Adrian Centre, have attempted to explore this and to formulate a preferred way of imparting the news.

How were we told?

When the news was broken by the paediatricians, the style of delivery varied from the 'abrupt' to the 'sympathetic and understanding':

Within minutes, the Paediatrician was by our side. His eyes were full of sympathy, his voice soft and understanding; before he uttered a word we knew something was wrong. He told us in clear, unambiguous terms; 'I think there is something wrong with your baby's back and lower limbs. I am sending her for further tests. " His calmness contrasted the inner turmoil we began to feel. Helplessness descended upon us: my wife lying on the operating table following the Caesarean Section: me garbed in medical gowns.

The responses

Similarly, the responses portrayed 'anger', 'shock', 'disbelief', 'numbness':

> *Shock was an inevitable response, but my male protector role came to the fore - "We can cope; this is fine. She is our baby,' we have the experience" My next recollection was of some nurse reviving me on the operating room floor - I had fainted!. At this point we were too numb to cry, we had to have hope. His (the paediatrician's) diagnosis was incorrect,. he was mistaken - he* ***must*** *be mistaken.*

Too much too soon

The issue of "how much' information and 'when' was a recurring theme in all seven fathers interviewed for this study. The most unwanted information was often that of further complications, such as a heart defect.

> *Inevitably we asked for more information than his initial bald description of the bare facts of our baby's disability. Was it Spina Bifida?. "No" was his response. If anything, he thought it was Sacralagenesis. What was that?. We had never heard of it. "And there are some complications with the baby's heart too. ' But I don't think I heard that comment at the time, I was still stuck on Sacra-whatever-it-is!*

Content of information

The professionals suggested a range of strategies through their advice. Some suggested adoption, surgical intervention, or even putting the cot behind the bed "so you don't have to look at her". The fathers who felt *the news had been given badly or were unhappy with these contacts, were deterred from complaining because The medical fraternity stick together', and were concerned that any action might have an effect on future contacts with the doctors on whom they might be dependent for ongoing care.*

At every step we were kept informed. They told us when they were carrying out tests, and what the test results were as soon as they were known. But it seemed like an eternity between the two. We were so anxious, and all the time the feeling of helplessness persisted, disabling us from answering even the simplest of questions like "Would you like a cup of tea?" When we did summon up the mental energies to ask questions, we were given honest answers. I say 'we', in fact I would creep out of the side ward we had been placed in to find a passing nurse or doctor who might have some more news. I did not want them to tell my wife, to increase her distress, I wanted to bear it all.

Professional perception of fathers

The fathers felt that because they were regarded as 'different', the hospital staff were not trained to deal with them. They were constantly watching for others' reactions conveyed by words and body language.

A nurse constantly attended my wife, and gave me kindly glances. Any medic who came anywhere near our room must know something, and I pounced upon each of them. When there was news to give, they told us together, but all the time you expected more. Were they withholding information?

Professional prediction

Many contacts, medical and social, offered gloomy forecasts of the effects the child would have on family life. A General Practitioner warned that 'the mother may become mentally unstable and may attempt suicide or harm the baby". Another was warned that his marriage would fail.

This must all be a dream - this thought ran through my mind again and again. This cannot happen to us!. In this turmoil, I was conscious of the supportive attitude of the hospital staff, and that every effort they made was an endeavour to uphold us, to help us to endure the pain and distress that fell upon us as the reality of our baby's disability dawned upon us.

Information seeking

In all cases, fathers sought additional information initially from books, but later from other families and professionals.

In spite of what we had been told by the Paediatrician, it was not enough. A thirst for a greater and a deeper knowledge became all consuming. This search became a driving passion. I wrote to anyone and everyone who might be able to throw more light on our baby's disability. When I finally made contact with an appropriate Parent support group, I scoured their membership lists for other parents nearby who had similar children. Once I realised that we were not the only family in the area with this type of child, I accepted with a degree of peace, the knowledge I had gained.

Hornby (1991) recommends networking amongst families. Various practical examples of this exist (Carpenter and Carpenter, 1989). In the context of this small-scale research, the sensitivity of this process was highlighted. Whilst acknowledging its implicit value, it was found that families needed more than 'one feature in common' (Byrne, -Cunningham and Sloper 1988) in order to make the contact positive and effective.

As in any set of personal relationships there are those that are richer and more rewarding than others. With some families our only point in common was that our children had the same disability, and this led to a fairly factual exchange of information; but even that was helpful. With other families there were interests in common other than with our children and time spent with these families was for the same reasons one might spend time with any set of friends. What is unique about friendship with other families is the depth of understanding: they are more than the sincere, empathetic professional. They have been there too - through the endless hospital appointments, the perplexing behaviour patterns, the unanswered questions. This in no way diminishes the invaluable contribution of professionals, but to live with a child with a disability twenty-hour hours a day, brings lessons that no professional course of training can ever hope to teach.

Source of support

Extended families were found to be a major source of support to the fathers.

It could be conjectured that the existing familiarity at an emotional level with other family members generated a climate of openness in which fathers could reveal their true feelings.

Is It the child that remains in each of us that causes us to turn to our own parents in times of despair?. Certainly, the unquestioning support of members of our extended family helped greatly with establishing the valued place of our disabled child in our family. Their capacity for support is endless. It is duty?. Is it love?. Whatever the reason, the emotional dialogue we have with our extended family has at times been our salvation.

The calm after the storm

When the family returned from the hospital, the fathers reported that no help was offered specifically to them by the professionals. All help was focused on the wife and baby. The fathers' needs were not addressed or, perhaps, even noticed, all being seen as The supporter' and adopting the role society expects - that of being competent in a crisis (Tolston 1977).

Having been on hand at the hospital to receive all of the necessary information first hand, my frustration began to mount at having to receive all information via my wife, as I had returned to work. The telephone would ring and the professional would ask to speak to my wife; all appointments were made for my wife to attend (although the offer was occasionally made that I should attend, it was often impractical to do so). I accepted much of this, but just once in a while it would have been wonderful if one of the many professionals we were dealing with had offered to call one evening so that I could have actively engaged in the dialogue of care for our child. What gradually happened was that 1, as the father, became in some ways 'disabled' also in the supportive role I was expected to fulfil. Although my wife recalled conversations with professionals as accurately as possible, there was inevitably something that she had omitted to ask, or that they had not explained fully enough. But it is hard with a struggling baby on your lap to totally concentrate, and articulate your thoughts. My frustration grew at never being part of the interaction with professionals who were playing such a major part in my child's life, and to some degree influencing the direction and shape of our family life.

Searching for normality

All seven talked of returning to work and of trying to keep a 'sense of realityin our lives'.

I returned to work, but in a fog. The feelings of disorientation were enormous and even simple tasks took considerable effort to complete. This only served to disempower me even further.

Planning for the future

Although this may be seen as a need for 'normality', it can be viewed as an escape from the situation at home. Perhaps if more effort was directed towards the fathers in these early days, it would enable them to explore and formulate strategies to cope with future crises. They were aware of their need to talk to someone and perhaps for a third party to help out with their wives, but no one fulfilled, or fulfils, this role.

At the end of the day only you, as the parents, can make the ultimate decisions. But in those early days, this was a mammoth task. With levels of concern about our child so high, combined with tiredness and the routines of caring for other family members, the quality of decision-making was far from what it ought to have been. In spite of the care of family and friends, the support of various professionals, the experience of having a disabled child can, in the early days, be very isolating. All either partner wants is the other. This child was created out of your love for each other, a product of your union. That same love must now help to reformulate what you had anticipated for your family whilst absorbing the pain and the grief. What the family unit needs most during its phase of readjustment is to feel safe and secure; that there are people around - friends, family, professionals, holding you together, enabling you to exist. And at times it is existence not living.

Professional access

one reason for this issue may be that the majority of support services work only during the day when many fathers are at work, and after the first few days all such contacts took place during the day and, therefore, all information reached them second-hand with the changes inherent in the retelling and giving the mothers' construction of events.

"What did they say?" To this day, following every appointment, that is the question I ask my wife. Always it is tinged with anxiety; always anticipating the worst. And I expect an immediate answer, a full blow-by-blow account. It doesn't matter if the evening meal is just ready for serving; now it must be! I have tried saying this question in various ways - calmly, with a smile, from another room in a casual, semi-interested way - but inevitably my deep-rooted anxiety comes through! Invariably, I will follow up my wife's account with "And did you ask about...?' Either she did, and the answer was unsatisfactory, or she did not - in which case she feels guilty because she failed in her imposed role as our envoy. Is this really a healthy state of affairs? Does it act in a supportive way to the family of a child with a disability? Does it not create tension, disempower the father, cause the mother to feel inadequate? What was the overall value to that family of the professional interview? Has it really acted as a catalyst for strengthening that family's resolve to care more effectively for their child? Was it a growth point? As yet, my answers to these questions would tilt towards the negative. But then I am only the father, the secondary partner.

Conclusion

An overwhelming question throughout this study has been that of professional accessibility in the journey parents make following the birth of their child with a disability. For fathers this is an unresolved issue because it is assumed by the professionals that the ongoing dialogue can be sustained in the main through the mother.

Is this fair to fathers? Are we meeting their needs? Are we being professional in our response to them?

Implications for practice

There are several implications for practice arising from this research and this parent-professional analysis of its findings:

1. Training

Training should be available to ensure that the professional support worker (of whatever discipline):

- *has appropriate listening skills.*
- *has up-to-date information about the dynamics of the family.*
- *uses vocabulary which conveys a positive image about the childwhilst being realistic about the true nature of the disability.*

2. Co-ordination of services

it is important that information is not held in pockets. Amongst the professionals there should be:

- *clearly established procedures for information exchange in order that the families feel supported and do not perceive each service to be working in isolation.*
- *clear acknowledgement of the key worker/lead professional who may be tackling the more sensitive issues.*

3. Accessibility

Parents need to be able to access both information and personnel easily. They may need help with questions such as 'Where do I go?' and 'What are the key sources of information I need and want?' Booklets giving clear explanations of roles and telephone numbers would help with this.

4. Networking

- *Professionals need to know the network within their area in order that they can make it available to parents who should not be expected to undertake this search alone.*
- *Sensitive networking of families is crucial. They have a tremendous capacity for self-support.*

5. To address the issue of consumer needs

Services should be tailored to meet individual consumer needs not pre-packaged. This will entail flexibility and adaptability by all professional support workers.

6. To address the needs within the family

Professional support workers should look at the needs of every individual within each family and should not neglect or forget those who may be absent during the day.

Whilst professionals like researchers prefer not to work unsocial hours, we must look at the triad

Baby

Mother *Father*

and not solely at the dyad of mother and baby and must adapt our support services to fit the needs of the whole family, for at present fathers are, unfortunately, the secondary partners.

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