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Link-Up: A Parental Involvement Training Course

This structured programme is aimed at enabling parents to contribute to their child's education with regard to behaviour management and skills training using a five step plan. The programme, as well as providing a forum for parents to share with each other their experiences and needs, has opened up avenues of communication between service providers and the families of special needs children.

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BACKGROUND

The parents and family of a child with a mental handicap need on-going support throughout his/her life. The actual diagnosis of mental handicap is probably the most dreaded outcome for any parent. The inevitable stress for such parents is enormous.

Parents' ability to cope with their child's condition has been linked to various factors such as the circumstances in which they are told the diagnosis, the child's age when the diagnosis was made, parents' educational and social background, the type of support and information they receive, etc. In relation to this latter point, Hannam (1982) writes of wanting to know "too much at the same time." Hannam also outlines how the sympathy of family and friends, though welcome, did not help to "deal with the shock." Featherstone (1980) refers to the dual need for "concrete help and psychological support."

Since 1984 St. Michael's House has been addressing parents' need for practical information. They target the parents of children from two different age groups. They run an introductory course for parents of children up to three years. They also run a course for parents of four to six year olds to help them to prepare their children for school.

Within COPE Foundation's services a support group is run each year for the parents of the new pupils in Scoil Eanna. (Scoil Eanna is a junior school that

caters for children with a mild level of mental handicap). The focus of these groups has been to help parents to deal with their personal reactions to their children being admitted to special education.

St. Paul's School is a junior and senior school for children with a moderate level of mental handicap. Our work with parents in this school has highlighted a need for practical information to assist them in making a vital contribution to their child's training.

INTRODUCTION TO *LINK-UP*

As the psychologist and occupational therapist working in St. Paul's School, we found that we were both encouraging individual parents to become involved in their child's educational programme. We decided to amalgamate our work. We compiled a package of information that can be presented to groups of parents whose children are of a similar age.

The major objective of the *Link-Up* course is to enable parents to contribute to their children's education both as regards behaviour management and skills training. We stress the importance of home-school liaison from the onset. Our introduction to the course at the start of session one is as follows:

“School and home are the two areas that together make up your child's life. The two areas should not operate independently of one another. Your child's experience in one area should work to his benefit in the other. This course plans to link up the child's two worlds so that he can function better in each.”

AIMS OF THE PROGRAMME

The specific aims of the course as outlined to parents are as follows:

- to discuss the term mental handicap, its meaning, its consequences for your child's life and for your family's life.
- to offer a systematic approach to training your child.
- to discuss how to deal with aspects of your child's behaviour that pose problems.

- to give you as parents a chance to get to know one another, to exchange information and to learn from one another.

A major influence on the course content came from an excellent course "Children with Special Needs: A Workshop for Practitioners." The occupational therapist attended this course when working in Malaysia, where a shortage of trained personnel resulted in a huge need to train all those involved in the child's care.

OVERVIEW

We envisaged the *Link-Up* course primarily as a means of empowering parents to assume their educational role in their child's life. The course content was therefore geared to providing them with the background information and methodology needed to enable them to do so. The course is run over a series of four weekly meetings, each of which lasts approximately 1.5 hours. Both parents and/or other family representatives are encouraged to attend so that a uniform approach is applied at home. To this end each participant is provided with a file containing key points outlined in the course. Participants therefore have the relevant information on hand to discuss with other family members during the week.

COURSE CONTENT

We outline the rationale, aim and objectives of the course. A discussion of the terminology used historically and currently provides parents with an opportunity to vent their feelings on what terms are acceptable and unacceptable to them. A discussion about their preference for the term we will use to describe their child's condition then follows. On the issue of terminology the Report of the Review Group on Mental Handicap Services (1990, p.14) stated that "there is no widely accepted alternative to the term mental handicap at present." They stressed that any new term can be debased over time and that a simple change of label in itself will not have a long-lasting positive effect unless a concurrent effort is made to change professional and public attitudes. The debate continues. In the absence of a stated preference from the group we have opted to use the phrase "child with a mental handicap". It should always be kept in mind that people with a mental handicap are people first and people with a mental handicap second. Grunewald (1978) pointed out that the handicap is the person's condition of life and not his identity.

Once we have agreed upon a term to describe the children's condition, we then outline the different aspects of that condition. We separate the intellectual and social aspects of the condition. This allows us deal with inappropriate behaviours as distinct from the child's intellectual deficits. We discuss this point at a later stage. We also outline the features of the condition and the children's resulting needs. All of the above information is outlined for each parent on two separate handouts. The value of play as an important learning experience for children is highlighted using the "Let's Play" video from St. Michael's House.

Having explored some of the background issues, the next stage of the course identifies a basic approach to training which can be applied to any situation. The approach used in the *Link-Up* course is referred to as the 5 Step Plan which is a systematic approach for skills training.

THE 5-STEP PLAN

- 1. Find out what the child can do.**
- 2. Decide what to teach.**
- 3. Decide how to teach.**
- 4. Teach.**
- 5. Evaluate.**

STEP 1

We encourage parents to become effective observers of their child's everyday functioning.

STEP 2

Parents' observations will identify an attainable skill that the child needs to learn. This objective needs to be stated in terms of the child's behaviour i.e. what he will be able to do as a result of the teaching.

STEP 3

Some of the tasks selected will be simple enough to be taught as they are. However for the child who finds learning difficult, most of them will be too complicated and will have to be made simpler by breaking the task into small manageable steps:- task analysis, an extract from the video from the E.D.Y.

(Education of Developmentally Young) in-service training course, is shown to demonstrate this method. Parents are then given a practical session where they are asked to analyse a specific task. This proves to be a very valuable learning experience. Attention is also given to identifying and using appropriate resource materials that can make the learning easier for the child.

STEP 4

Now we look at the 'doing' stage: putting the plan into action and recording what the child does as a result. The training method used is based on the systematic and effective use of reinforcement. The importance of rewarding the child immediately and consistently during the training process is continually stressed. The training techniques used are prompting, fading and changing; video clips from the E.D.Y. course video and from the COPE self-care training video, "I Can Do That" are used to highlight these techniques. Parents are requested to apply the 5-Step Plan in teaching a task to their child. They are requested to fill in the standard work sheets provided. They will then be able to discuss their experiences and evaluate their progress at the next session.

STEP 5

The final step relates to evaluation. This is a vital step as it shows parents whether or not their teaching has been successful. Evaluation will highlight where the strengths and weaknesses lie in their programme planning and implementation and also where they need to make changes. Parents are encouraged to evaluate not only their child's progress but also their own teaching, the programme, and resources used.

DISCUSSIONS ON BEHAVIOUR DIFFICULTIES

Parent discussions regularly highlight the on-going behaviour difficulties their child poses within the family. We discuss how important it is that the child with a mental handicap fits into the family, rather than the family changing to suit the child. Our main aim is that the child will learn to control his behaviour from within and that he does not rely on external control in the guise of threats and promises. Young children who have a moderate level of mental handicap seem to have no difficulty whatsoever in tuning into the behavioural expectations of adults around them. In many instances the child lives up to his teacher's expectations and at the same time, he fulfils his parents' low expectations. In our discussions with parents we initially refer back to our original description of the child's condition in which we isolated the two component features - intellectual deficits and impaired social functioning. We then go on to stress that

inappropriate behaviours are not unavoidable aspects of a child's intellectual deficits. This point is outlined straight-forwardly to parents on a handout using one or a combination of the following type of statements - "a mental handicap is no excuse for bad behaviour", "slow is O.K., bold is not."

No one does anything without a reason. We discuss this point with parents firstly in relation to their own behaviour. The essential point here is for parents to realise that their child is not misbehaving haphazardly. His inappropriate behaviour leads to a worthwhile outcome for him. He will continue to misbehave as long as he achieves his desired outcome. We reiterate this point on one of the handouts we give to each parent.

BEHAVIOUR TRAINING TECHNIQUES

We encourage parents to be as systematic in their behaviour training as they are when skill training. In the same way that we stress the need to decide on a specific teaching objective we now encourage them to be equally specific when deciding what particular instance of misbehaviour they are going to tackle. We explain that a specific instance of misbehaviour (e.g. banging doors) is a lot easier to tackle than inappropriate behaviour in general (e.g. aggression).

Once they have isolated a specific misbehaviour, parents are then instructed on how to effectively observe it. We explain that certain events may trigger the child's misbehaviour e.g. time of day, visitors in the home, etc. We refer to these events as antecedents. When the child misbehaves (the behaviour the parents have decided to focus upon) certain consequences result. We stress the need to identify the consequences of a child's misbehaviour. Parents need to know what exactly happens as a result of the misbehaviour. If the behaviour has become routine then it is an effective means for the child to get what he wants. We provide parents with a basic record sheet to record their observations regarding their child's misbehaviour. We discuss their findings at the final session.

Also at the final session we ask parents to evaluate the course content and presentation. This is facilitated by each participant filling in a questionnaire. Questions cover the suitability of the time of the sessions and the impact of the course as regards their attitude to skill training and behaviour management. We also question parents as to the benefit they would see for themselves and other parents attending this or other similar courses in the future.

PARENTS' REACTION TO PROGRAMME

Responses to questionnaires highlighted the mutual support the groups afforded the participants. This comradery was evident in the way that individuals in the different groups often referred to the group as "we." Individuals often supported one another if someone became upset, was looking for information or was reluctant to ask a question. This reflects Kupfer's (1982) observation when she wrote that what "has helped me more than anything else has been talking to other women who have handicapped children, a cruel common denominator." One parent's response to the question on the effect of the course on him/her was, "now I don't feel so alone." This response typifies parents' general reactions to the course.

Studies have shown that systematic teaching is unlikely to be maintained once the intervention period is over. Parents' reports that the *Link-Up* course offered them insight into their child's learning are most encouraging. Hopefully this information will help them to set realistic goals for their children in the future. Many wrote of an acceptance that everything "would take time." This type of positive acceptance of the situation reflected an increased level of confidence on parents' part to become involved in their child's training on an equal partnership basis. If parents feel more in control of their situation this will hopefully help them to adjust to their child's condition. Junker (1964) pointed out that "the uncertainties of the early period inspire a special terror, the panic of acknowledged powerlessness."

ASSESSING BEHAVIOUR MANAGEMENT SKILLS

The impact of the course in the area of behaviour management is difficult to define. Parents found the 5-Step Plan a useful guide in helping their child acquire new skills. However, many found the entrenched habitual nature of many of the misbehaviours their child displayed much more difficult to tackle. It was evident that specific problem situations improved even over the short duration of the course. The question of whether or not parents would be able to generalise a specific behaviour management strategy to other problem situations remains an open question. Parents' responses to the questionnaire did indicate that they accepted the point that inappropriate behaviour is not an inevitable result of a moderate degree of mental handicap. However, the level of on-going behaviour problems that parents experience with their children, many of whom present no behaviour problems at school, would indicate the need for continuous parent support. When asked when they considered that they would need another course

such as *Link-Up*, several answers clearly reflected this need. "When the children leave school" and particularly "when they are approaching adolescence" were considered to be useful stages for similar courses in the future. There was unanimous agreement among parents that they would encourage other parents to attend the *Link-Up* course in the future.

Overall parents are clearly finding the area of behaviour management difficult (as are "professionals"). The impact of the *Link-Up* course to date has been to alleviate specific problem situations, and more importantly to highlight parents' awareness of the problem situations that remain. This awareness coupled with an understanding that these situations are not unavoidable will hopefully prevent the next generation of elderly parents or clients passively accepting habitually appalling behaviour from their son/daughter.

Responses from teachers in St. Paul's School echoed parents' sentiments. Teachers see real benefit in developing parents' confidence and teaching ability so that home and school can 'link-up' for the child's benefit.

THE FUTURE

Link-Up has helped to empower parents to make their unique contribution to their child's education. More importantly *Link-Up* has offered parents a forum to discuss their views and experiences of having a child with a mental handicap within a family. *Link-Up* and other similar undertakings throughout the child's life will offer service providers an opportunity to listen to parents. Service providers need to experience the reality of family life for parents whose child has a mental handicap. On-going avenues of communication between service providers on the one hand and the client and their family on the other is necessary for what Patrick McGinley (1992, p.338) recently referred to as "the area of engaging parents and family members in planning future policy for our services in Ireland." It is our hope that the *Link-Up* course will be a useful contribution to the mechanism and structures that will allow clients and their families to be heard and really listened to be the decision-makers in our services throughout the country.

REFERENCES

- Featherstone, H. (1980). *A Difference in Family Life with a Disabled Child*.
New York: Basic Books.

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- Featherstone, H. (1980). *A Difference in Family Life with a Disabled Child*. New York: Basic Books.
- Foxen, T. and McBrien, J. (1981). *The EDY In-Service Course for Mental Handicap Practitioners*. Manchester: Manchester University Press.
- Grossman, H. (1973). *A Manual on Terminology & Classification in Mental Retardation, Series 2*. Washington D.C.: American Association in Mental Deficiency
- Grunewald, K. (1978). The Guiding Environment: The Dynamics of Residential Living. in P.M. Boswell and J. Wingrove (Eds.), *The Handicapped Person in the Community*. London: Tavistock Publications in Association with the Open University.
- Hannam, C. (1982). *Parents & Mentally Handicapped Children*. London: Penguin.
- Junker, K. (1964). *The Child in the Glass Bell*. New York: Abingden Press.
- Kupfer, F. (1982). *Before and After Zacharial*. London: Victor Goldancy Ltd.
- McGinley, P. (1992). Our Learning Difficulties. *Irish Journal of Psychology*, 13.
- Report of the Review Group on Mental Handicap Services (1990). *Needs and Abilities: A Policy for the intellectually disabled*. Dublin: Stationery Office.