

Supporting Families through Early Intervention¹

Roy McConkey

*Professor of Learning Disability , University of Ulster ,
Northern Ireland*

Introduction :

Internationally early intervention programmes for infants and preschoolers with disabilities have proved to be remarkably successful (Shonkoff and Meisels , 2000) .

In many countries , they began with teachers for visually impaired or hearing impaired children visiting the family home to teach parents how they could overcome the child's impairments. The logic of early intervention was irrefutable . For example , the sooner children with visual impairments learnt to be independently mobile , then the greater their potential to learn and to lead an ordinary life .

In time , this philosophy was extended to children with neurological and developmental delays, such as mental retardation , although success could be variable. In part , many different factors contributed to this variability : the form the interventions took , the extent of family involvement in the intervention and the lack of sensitivity of the measures used to assess a child's progress , to name but three .

Perhaps the most extensive and intensive early intervention schemes have been in the United States with their Head Start programmes . They were aimed at promoting the educational potential of preschoolers

from deprived socio - economic backgrounds . Although the first phase of programmes had varying success , those in the second phase yielded impressive results which were mainly attributed to a greater focus on parental participation and links forged with the school system .

Recently in developing countries , priority has been given to establishing early intervention as a means of creating new styles of family - based and community - based service in these countries in contrast to the hospital or institutional - services that were a legacy from a previous generation (McConkey , 1995) . Although formal evaluations are largely lacking , informal reports have been broadly enthusiastic .

In sum , early intervention is no longer a new approach to developmental disabilities . It is an approach of proven effectiveness with children who have different impairments ; and who come from different cultures and socio-economic circumstances.

Finally compared with specialist - led , clinic - based services they are cost - effective . Hence there can be little hesitation in recommending that government and non - government agencies invest in these services .

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The aims of early intervention

International experience has helped to define the essential aims of early intervention programmes . Initially the focus was solely on assessing the child's deficits and instigating teaching and therapy to overcome them . For maximum effectiveness it was felt that experienced and well trained specialists should provide these interventions and often parents expected this to happen .

However this overtly medical model of disability is now considered outmoded and the emphasis has shifted towards a bio - psycho - social model in which disability is recognised to be the outcome of social and environmental influences as well as bodily impairments and imperfections (WHO , 2002) .

Moreover , benefits to the child can accrue by optimising and adapting their environments and interactions with other people . This makes intuitive sense as it has long been recognised that the social , emotional and cognitive development of all infants is susceptible to family circumstances and parenting styles. Why would it be any different for children with impairments ?

Consequently early intervention programmes now generally have a three - fold aim .

- To promote the child's well - being and development
- To boost family morale and confidence through support and training
- To increase the child's social inclusion within families and communities .

Such aims necessitate new ways of working for specialists involved in designing and delivering early intervention

programmes. For instance, rarely are these services headed by medical doctors although there are notable exceptions but these tend to be paediatricians with a strong commitment to social and educational interventions alongside medical procedures .

In addition all specialists involved in early intervention need to work in partnerships with families and with community services .

Some of the main features of these new styles of service are as follows

- The focus of attention is not just the child with the disability but rather it is the family . Hence information needs to be gathered on family circumstances , beliefs and attitudes as well as making detailed assessments of the child . This is often best done by visiting the family home on at least one occasion .
- The emphasis is on supporting and empowering the family to help the child and to help themselves . This can mean enlisting the help of all family members - brothers and sisters , grandparents and aunts - as well as working with mothers .
- Instead of focussing only on specialist therapy , the goal is for the child to join in all aspects of family life and to take part in community events . Families may need guidance on how they might do this and encouragement to try. Play activities within the family are a primary means for helping children acquire new skills .
- Finally , early intervention programmes work to ensure that the child is placed in suitable kindergartens and later into appropriate schools . They will do this by visiting , training and advising the personnel in these settings who are working with the children graduating from the early inter-

vention programme .

Partnerships with families

Early intervention schemes can respond to the needs of families in different ways . A range of responses are needed given the inevitable variation found among families and among children with disabilities . The most common responses include the following .

Information for parents

Many services have produced information leaflets or booklets for families . These can be of two types . The first describe the various conditions that result in developmental problems . They describe the possible causes for the condition and try to dispel any myths associated with them .

The second type of leaflet gives advice on topics of common concern- for example : encouraging play activities ; self - feeding ; managing problem behaviours .

These leaflets should be written in simple words with plenty of illustrations . There are many examples from around the world and often they can be accessed on the internet .

Parent Groups

A second strategy for supporting families is by bringing them together for regular meetings over a period of time , lead by two specialists . These can especially helpful when parents are coming to terms with their child's disability . Groups offer several advantages to parents .

Emotional Support :

Many parents feel isolated and shunned by society if they have a child with a marked disability . Having the opportunity to meet with others shows them that they are not alone . As their sense of solidarity grows they will be able to face the future more hopefully .

Advice and Guidance :

Families can draw on their own experience when offering advice to others . Their recommendations may be more credible than those offered by professionals who lack the day - to - day experience of living with a child who is disabled .

Empowering parents :

In groups the specialists can focus on explaining how parents might manage the child at home rather than on delivering the therapy to the child . The expectation is then built that it is families not specialists who are responsible for ensuring the ' treatments ' are carried out .

Support for one another :

Groups enable parents to get to know one another and these friendships could lead to mutual support .For example , parents may take it in turns to look after one another's child so that they can have some free time ; they might borrow toys or equipment from one another .

Some services provide a parent's room in

their centres so that families can meet together and for meetings to be held during working hours or in evening times .

Involvement in assessment and therapy

A family member should always be present when a child is being assessed or receiving therapy and they should be encouraged to actively participate in the process . In this way they will develop a better understanding of how best to manage and encourage new behaviours . Indeed , specialists may spend more time observing and instructing family members than working ‘ hands - on ‘ with the child .

Many services have found that home visits provide extra benefits as the child and family tend to be more relaxed in these surroundings ; it is easier to integrate the advice they give into existing routines and resources; and other family members can be enlisted to help who otherwise would not attend clinics .

Training courses for parents

The need to provide training courses for service staff is well understood. It is all the more surprising then that parents rarely are given the same opportunities. However this need not be so . Parents can be invited to join staff on their training courses or else adapted courses are organised to address the particular needs of parents .

These should make full use of visual materials , such as video , as parents will find the content easier to follow . This approach has proved beneficial in developing countries when specialist staff are scarce but the fami-

ly's need for information is just as great(O'Toole and McConkey 1998).

Conclusions

Providing this range of services to families is not easy for organisations with limited resources . It has been possible to do so by a combination of redefining the roles of staff working in the service and enlisting the help of ‘volunteers ‘ - often mothers who have been through the service - to assist with these tasks . However the reluctance of disability specialists to change their ways of working is often harder to achieve .

Partnerships with communities

These partnerships can serve a number of purposes :

- They can assist with the early detection of infants with disabilities if links are made with community health workers whose job covers maternal and child health .
- Community volunteers can assist parents who have limited or no support available to them , perhaps because they have recently moved to a new area.
- Children can move from early intervention programmes into kindergartens and schools . This “ through - put ” is necessary to ensure that the service can take in new referrals .

Links with Primary Health Care

Information leaflets about the early intervention service should be made available to all health care workers in the localities served by the programme . Information

sessions could also be held as part of their inservice training courses . Special training courses could be devised by the early intervention service to train health workers in the screening for disabilities and giving advice to families that will promote the growth and development of all children (e.g. UNICEF , 2002) .

Kindergartens and schools

Parents should be encouraged to enrol their child in kindergarten - either one that serves all children or a special kindergarten for children with disabilities . Indeed many early interventions services have started kindergartens as part of their programmes .

It is important the specialists who have been working with the child in early intervention programmes visit the kindergarten to show the staff there the activities they have been doing with each child and to observe them undertaking this work . Equally the kindergarten staff can visit the clinic to see the work there . Contact phone numbers are given for kindergarten staff if they want any further guidance or help .

As children come to the age for school attendance , early intervention staff should form links with local schools or special schools that the child may attend . They should do this in partnership with parents . Also staff should be available to advise the child's teachers in the early months to ensure the child settles into school routines .

Early intervention services can organise training courses to develop the knowledge and skills of leaders and teachers in kindergartens and schools .

Another purpose can be served by early intervention services developing links with

kindergartens and schools in local communities . Their premises might be used to organise ' satellite ' clinics or meeting places for parents that are closer to the family home . Early intervention staff would travel to these clinics on perhaps a monthly basis to undertake reviews of the children .

Community helpers

Some families experience extra stress . Research has shown that they can benefit from informal supports provided by family and friends . If these are lacking or unavailable , services have tried to recruit volunteers who are prepared to befriend families . Often these are ' grandmother ' figures who assist in practical ways - looking after the child so the mother is free to undertake other tasks ; accompanying the parents to hospital visits or simply providing a listening ear .

In addition services have used such volunteers to provide additional help to kindergartens and schools when they take a child with a disability ; for example recruiting retired teachers to act as classroom assistants .

Conclusions

Early intervention services have to break away from a focus solely on health or disability services . They need to forge links with mainstream community facilities . One way of doing this , is to try and recruit staff from the areas in which the service is based as they are more likely to know , and to be known by , people in that community .

New roles for disability specialists

Early intervention services have encouraged disability specialists such as therapists, psychologists and social workers, to find new ways of working and to undertake new roles. Some of these have already been mentioned; namely:

- Providing information and training to families and to community workers;
- Leading parent support groups;
- Visiting families at home and also the kindergartens and schools which their children attend;
- Observing and involving parents and community staff in the assessment of children and the provision of therapy and learning activities.
- Recruiting and supporting volunteer helpers to work with families.

Often there are no ready-made training courses to prepare personnel for these new roles. Most learn 'on-the-job' although through time these pioneers can become the trainers for new staff joining the service. Even then, most of this learning is best done through mentorship: namely observing and emulating a skilled professional as they undertake these tasks.

However there are number of new organisational arrangements that can assist specialists to change their roles.

Key working

Instead of a child and family seeing a number of different specialists and provide a common plan for the family. This person is selected from the staff team whose experience and expertise best matches the needs of the child and the family. They become the

main point of contact for the parents and hopefully become a trusted ally of the family. In this way, transdisciplinary working can become more of a reality.

Common records

Services increasingly use a common record system in which all assessments and plans are noted. These records are held by the family and are contributed to by the various specialists involved with the child and family. However the key worker has the main responsibility for maintaining the records.

Individual Family Plan

For each family, an individual plan is prepared that brings together all the learning objectives identified for the child and family. This delineates who has responsibility for each objective. This plan is also a useful means of evaluating progress as it is reviewed regularly; at least once a year.

Conclusions

I suspect that historians of the future will look in puzzlement at our generation's efforts to assist young infants with disabilities. They will wonder why we thought that approaches which had been developed to rehabilitate adult persons would be suited to developing infants; namely specialists delivering therapy in clinics!

They will marvel at how we have ignored three simple truisms.

- Parents are involved in all children's development. We trust them to bring up children without disabilities, so why not do so when the child has disabilities?

◦ Nearly all children with disabilities live in families . Family members can spend much more time with the child than any therapists , hence we must support them in this .

◦ All children grow into the community by making use of local facilities. This is just as true for children with disabilities although initially there can be some resistance to this . We need to break down these barriers .

Hence the development of new styles of early intervention is not just a question of retraining staff , finding extra resources or garnering research evidence to see if it is effective . Rather it requires a change of mind - set primarily among professionals working in disability services . That may be the biggest challenge we face in creating effective early intervention service within countries .

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